International Handbook of Health Literacy

Research, practice and policy across the lifespan

Edited by
Orkan Okan, Ullrich Bauer, Diane Levin-Zamir,
Paulo Pinheiro and Kristine Sørensen

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First published in Great Britain in 2019 by

Policy Press
University of Bristol
1-9 Old Park Hill
Bristol
BS2 8BB
UK
t: +44 (0)117 954 5940
pp-info@bristol.ac.uk
www.policypress.co.uk

North America office:
Policy Press
c/o The University of Chicago Press
1427 East 60th Street
Chicago, IL 60637, USA
t: +1 773 702 7700
f: +1 773-702-9756
sales@press.uchicago.edu
www.press.uchicago.edu

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British Library Cataloguing in Publication Data
A catalogue record for this book is available from the British Library

Library of Congress Cataloging-in-Publication Data
A catalog record for this book has been requested

978-1-4473-4451-3 hardback
978-1-4473-4452-0 OA pdf
978-1-4473-4453-7 ePub

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Cover design by Hayes Design
Front cover image: istock
Printed and bound in Great Britain by CPI Group (UK) Ltd, Croydon, CR0 4YY
Policy Press uses environmentally responsible print partners

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Introduction

Health literacy has recently become a topic of relevance among researchers, practitioners and policy-makers across various disciplines. One major driver of this obvious increase in importance is the potential that has been attributed to health literacy in order to understand, explain and tackle individual as well as group differences in various health outcomes. Empirical findings such as the results from the European Health Literacy Project have supported such perspectives as they have consistently been highlighting the need for action. The emergence of the topic of health literacy in various research and policy agendas has also been promoted by the zeitgeist prevailing in Western societies that is also rising in other parts of the world.

Concepts of health literacy basically address the use of health information in all forms and thus fit well as an approach to cope with the various challenges that Western societies have recently been faced with. The rise of digital technologies, for example, has been associated with a sharp increase in the multimodal availability of, and a simplified access to, information and data. Citizens and consumers are therefore challenged by the overwhelming supply of information in various ways. Other key words such as 'shared/informed decision-making' or 'patient empowerment' point to the ongoing transition in the notion of the bond between the doctor and the patient. The questioning of interaction patterns and power relationships between experts and laypeople, as well as the shift in the assignment of responsibilities to laypeople, is not only restricted to healthcare but also applies to other areas of life – or, in other words, to everyday life where people live, work, study and play. People are increasingly assumed to act as consumers and to make choices on health and information, both of which are increasingly viewed as services or goods. This shift complements the increasing emphasis that is generally put on the self for the shaping of individual and collective lifestyles. Concepts such as self-management of chronic diseases or everyday self-optimisation not only serve as examples but also give indications on the effects of macro-level conditions, such as the ongoing market liberal transformation of welfare economies. This sketchy outline of the multifaceted societal developments and challenges illustrates that they offer favourable conditions to advocate and call for the topic of health literacy as a promising approach.

The revived interest in health literacy has not only been noticeable in public health and medical care. This is well documented, such as with the growing number of published scientific papers and the introduction of health literacy as a major subject in various policy agendas (most recently and notably in 2016, with the World Health Organization's Shanghai Declaration on health promotion). Findings from an exploratory bibliometric analysis confirm the growing attribution of relevance to health literacy as a subject of research as they highlight that there was an almost ten-fold increase in the number of articles that were published about health literacy from 1997 to 2007. There are good reasons to assume that the numbers have continued to skyrocket since them. The multidisciplinary nature of health literacy is reflected by the fact that information on health literacy can be found in health-related databases as well as in education, library and information sciences, nursing, pharmacy, communication and sociology databases. The large interest in health literacy and its international uptake are also well documented on the policy level with governmental and non-governmental organisations (NGOs) addressing health literacy promotion in their national policy strategies and health goals. For instance, the United Nations' (UN) Economic and Social Affairs Council (ECOSOC) released a ministerial declaration in 2010 to strengthen health literacy on the policy level. Since then, health literacy has been included in strategic plans, with health literacy-related policy programmes, white papers, recommendations, alliances, health goals and action plans developed and implemented in several countries. Beyond health policies, in some countries health literacy is also part of educational policies, placing health literacy at the core curriculum of teaching and learning in schools starting early on in the life course.

With the proliferation of health literacy research and policy measures, it has also become clear that there is no unanimously accepted overall definition of the concept, although available definitions are predominantly overlapping while also highlighting subtly different aspects. They coexist and may be linked to different vocabularies and conceptual backgrounds from different academic fields, and it becomes obvious that they share more commonalities than differences. In spite of many similarities, the differences influence attempts to operationalise the concept that varies widely in scope, method and quality. The currently dominant views of health literacy have mainly been nurtured by perspectives from healthcare and public health that started to evolve three decades ago.

From the healthcare perspective, in the early 1990s health literacy was defined as a set of skills that enables the individual to act as a competent patient within the patient–provider interaction. Health literacy in this context primarily focuses on functional skills such as reading, writing and numeracy, and can be broadened to skills, such as understanding for better health communication, self-management and caring skills, better adherence and navigation of the health system.

By the end of the 1990s, the public health approach took a shift to people's everyday life settings, and views health literacy as a multidimensional concept that is closely associated with health promotion. Besides cognitive skills, public health highlights the social and cultural components and connects health literacy with a Freirean perspective on education, literacy and empowerment in order to improve health behaviour and to act on the political and social determinants of health and wellbeing. Thereby it focuses on a social justice approach, taking into account environmental factors and sociocultural context conditions, the wider social determinants of health, participation in society and health and personal agency.

Today there is common sense across disciplines that health literacy is a broad concept. Thus, the field of health literacy has advanced from a concept that focused on functional skills in a medical and healthcare context, to an interdisciplinary and multidimensional construct that entails people's knowledge, motivation and competences to access, understand, appraise and apply health information in order to make judgements and take decisions in everyday life to maintain or improve quality of life. There is also a consensus that health literacy evolves and develops throughout life, 'from the womb to the tomb'. Therefore, efforts to comprehensively embrace and discuss the topic benefit most from a life course perspective. Health literacy plays an important role for healthcare, prevention and health promotion, and in this context, it is a major influence on the capacity of the individual, throughout his/her lifespan, to make sound health decisions at home, in the community, in social media settings, at the workplace, in the healthcare system, in the marketplace and in the political arena.

For many years, the individual's health literacy skills and related health knowledge have been the predominant focus of interest, while the environment with which the individual interacts in the context of health issues received less attention, although research streams have continuously highlighted that health literacy is context-specific and affected by a social and relational dimension as well. Attention towards collective health literacy and distributed health literacy increased substantially, especially since the individual is always embedded into a social, cultural, economic and political context. Besides the health literacy of individuals and groups on the micro- and meso-levels, also addressing macro-level systems and policies was moved up on the health literacy agenda. It became obvious that health literacy is a systems issue demanding a systems perspective and systems-wide approach across the whole spectrum, addressing individuals, professionals, organisations and policy-makers. Addressing health literacy in its depths and in the long run requires a systematic approach, and to issue it within an advanced cooperation and network framework for strengthening health literacy at local, regional, national and global levels, including aiming at (inter)national level change. In this context, the health-literate healthcare organisation first introduced a concept to overcome barriers between the individual and population's health literacy skills and the complex demands of healthcare settings. This concept has been transferred to settings beyond healthcare, with various approaches available addressing the improvement of the physical and social infrastructure of a system and facilitating the creation of health literacy-friendly settings, including its responsiveness and training for healthcare professionals and other professional groups working with people in a health context. However, as of today, social care organisations remain the only other setting besides various healthcare settings that have included the health-literate organisations' approach, but especially regarding health promotion and prevention, defining and demarcating actions and action areas in relation to health literacy-friendly settings must encompass further everyday life settings, such as kindergartens, schools, universities, workplaces and beyond. Addressing systems and settings, and therefore the structures into which individuals are embedded, is an important target in order to increase equity and reduce health inequalities and health literacy disparities.

This handbook, therefore, draws on a new narrative and should be seen as a frontrunner for new thinking that aims to provide an overview of the multifaceted and multidimensional nature of health literacy by adopting a lifespan perspective, while addressing research, practice and policy. Hence, the book is intended for health literacy experts, as well as researchers, practitioners and policy-makers who are interested in, but less familiar with, the topic. The various chapters offer a wide range of major findings, outline the current discourse in health literacy, and provide updates about the latest developments and future prospects. The breadth and depth of the book's chapters present cutting-edge research and future prospects for research, policy and practice in the health literacy field.

Comprised of 45 chapters and divided into four thematic parts, the book addresses different populations, such as children, adolescents, adults and older people, in different settings, and with a wide range of concepts, methodologies, programmes and interventions to improve health literacy and governmental, community and institutional policies. The book further aims to share research results, to provide insights into new approaches and theoretical considerations, including making theoretical and practical connections between health literacy and fields and disciplines such as education, sociology, health promotion, social epidemiology, public health, healthcare, medicine, nursing or pharmacy. The aim is to promote future research, practice and policy dialogue among academics, health and educational professionals, and policy- and decision-makers from multiple disciplines and sectors, and to engage and support students interested in learning more about health literacy.

Finally, the book draws on practical experience on a global scope from leading health literacy projects and organisations: the Health Literacy in Childhood and Adolescence (HLCA) Research Consortium, the Health Literacy Europe project (HLS-EU), the Global Working Group on Health Literacy of the International Union for Health Promotion and Education (IUHPE), the International Health Literacy Association (IHLA), the Asian Health Literacy Association (AHLA) and more.

We would like to acknowledge the concerted investment of the 100 authors from 19 different countries who contributed so significantly to the book, and we also thank Mona Corsmeier, Baris Ertugrul, Alexandra Fretian, Anna Goedecke, Elena Hannah Groß, Juri Kreuz and Vanessa Ohm who all supported the formatting process of this book and never lost motivation. A special thanks is dedicated to the German Federal Ministry of Education and Research (BMBF) that funded this book to be available as Open Access (#01EL1824A; Health Literacy in Childhood and Adolescence, HLCA).

Part 1

RESEARCH INTO HEALTH LITERACY: AN OVERVIEW OF RECENT DEVELOPMENTS

One of the first lessons learned from initial efforts aimed at getting acquainted with the topic of health literacy is the insight that it is challenging to readily grasp its scope and permeate its depth, in order to develop a deeper understanding of the concept. There are several reasons for this that can be connected to the theoretical, methodological and empirical approaches to health literacy. Part 1 of this handbook therefore serves to address these three topics by introducing: the many facets of health literacy and scoping the current research of theories, concepts and models; different methods and methodologies on measuring health literacy; and empirical findings on health literacy, associated outcomes and health inequalities.

The many facets of health literacy: Scoping the current research of theories, concepts and models

The first section in this part has four chapters offering insights into different conceptual approaches to health literacy. Albeit there is a common reference to the processing of health-related information in almost every definition of health literacy, there is little overlap of common theoretical frameworks, as reflected by a wide range of very different and contested definitions and models. The diversity and proliferation of definitions can be partly attributed to the fact that the development of health literacy has been informed by different disciplines and guided by different purposes.

The first set of chapters in this section therefore addresses some of the major theoretical challenges in the field of health literacy, aiming to contribute to the guidance and clarification on the topic of health literacy. Kristine Sørensen's contribution provides a general overview of the theoretical framework by highlighting commonalities and differences among definitions and concepts of health literacy. Chapter 2 by Orkan Okan complements the focus on the present with a historical review, and offers a reconstruction of the various historical streams that have shaped the current understanding of health literacy. In Chapter 3, Janine Bröder and Graça S. Carvalho focus on a tailored approach to the health literacy of children and adolescents, which is informed by developmental differences and synthesises available definitions and models for these populations. In Chapter 4, Anthony F. Jorm focuses on the concept of mental health literacy, which he developed in the aftermath of the 1993 published public health goals for Australia, and which is best described as an approach towards knowledge that a person can use to take practical action to benefit their own mental health or that of others.

Measuring health literacy: What, why and how?

In the next section, the conceptual chapters are followed by a series of contributions focusing on methodological issues and basically addressing questions related to the collection and interpretation of data. Chapter 5 by Andrew Pleasant and colleagues provides an overview of the tools that are currently in use to measure health literacy in adults. In order to improve the field of health literacy measurement, they ask why research seems to continually struggle with measurement-related issues, also looking at definitions and providing implications as to how to move the field forward. Torsten Michael Bollweg and Orkan Okan, in Chapter 6, extend considerations about the measurement of health literacy with a contribution that focuses on children aged 13 and younger, and build on earlier work. Their chapter provides both an overview of available tools and discusses challenges and potentials in this field of research. In Chapter 7, on how they developed and validated a health literacy tool to assess adolescents' health literacy in Germany, Christiane Firnges and colleagues share their experiences during the various research steps involved. In particular they provide key results from their qualitative research, introduce how those findings were used in the methodological design of their questionnaire, and highlight the conceptual framework of the tool. Finally, Chapter 8 by Jürgen M. Pelikan and colleagues introduces the Health Literacy Europe Questionnaire (HLS-EU-Q) and discusses the impact of the survey for health literacy policy, research and practice. It exemplifies the general methodological considerations they have taken into account when developing and using the tool, including the variations and adaptations of their tool. In addition, they summarise the many follow-up studies they have conducted in various countries across the world and in different populations.

Health literacy, health outcomes and health inequalities: Some empirical findings

Part 1 is complemented with a set of chapters that focus on empirical health literacy data. Interestingly, the screening of literature reveals that most of the findings outline consistent patterns of health literacy. This covers prevalence data of health literacy in high-income countries, a social gradient of health literacy, as well as indicators on health outcomes such as the uptake of preventive services, engagement in health-promoting behaviours and in communicating with health professionals, or data on mortality and morbidity. The empirical consistency, however, contrasts with the diversity of the theoretical approaches and also calls for a careful and critical interpretation when the issue of causality is addressed. The series of contributions focusing on empirical data covers some of the major issues and provides valuable information for further readings.

In Chapter 9, Sarah Mantwill and Nicola Diviani raise the issue of health literacy and health disparities, and provide an overview of the current research. In doing so, they discuss three interrelated challenges that they stress not only to have influenced current research but that should be considered accordingly when investigating the association between health literacy and health disparities in future work. Taking a closer look at health literacy in older people in Germany and internationally, Dominique Vogt and colleagues, in Chapter 10, present and discuss findings on health literacy in later phases of life. Their view focuses on the prevalence of limited health literacy among older people, determinants associated with limited health literacy in older people, and associated consequences. Based on the Freirean approach to education and literacy, critical health literacy has often been mentioned as the most important dimension of health literacy as it empowers people to take greater control over their lives and enables them to take action on the social and political determinants of health. In Chapter 11 Susie Sykes and Jane Wills place an empirical focus on the critical health literacy for marginalised people, and report on the available evidence about strategies to improve critical health literacy. The next chapter explores the associations between chronic conditions and health literacy. Gill Rowlands and colleagues thereby focus on the perspective of patients and citizens and people's life journeys from childhood through to adulthood and old age, considering such important aspects as culture and healthy lifestyles. Kristine Sørensen and Josefin Wångdahl's contribution, Chapter 13, on research in the European Nordic countries, summarises empirical findings from Denmark, Finland, Iceland, Norway and Sweden, and also provides an overview of how the Nordic health literacy network was established. They introduce numerous projects and thereby discuss the scope and scale of how health literacy is addressed in the Nordic region and what future opportunities lie ahead.

Part 1 should allow the reader to enter some well-chosen historical, conceptual, methodological and empirical discussions around health literacy, and be a guide for the other parts of this handbook.

1

Defining health literacy: Exploring differences and commonalities

Kristine Sørensen

Introduction

Health literacy has become a priority for health in the 21st century. It is vital for people's ability to manage health and to navigate the health system. Health literacy is also a foundation for health organisations' capacity to serve patients and clients, and for society to ensure the health and wellbeing of its citizens. Health literacy develops during the life course through formal capacity building and education as well as informal learning. It is influenced by personal, situational and societal determinants and has, in turn, an impact on healthcare use and costs, health behaviour and status, participation and empowerment as well as sustainability and equity (Sørensen et al, 2012).

Building on numerous overlapping definitions, there is a growing acceptance of several core aspects of how to define health literacy. Hence, this chapter aims to provide an overview of existing health literacy definitions; to explore their differences and commonalities; and to discuss why they are important for application in policy, research, education and practice. This chapter is relevant for researchers, policy-makers, decision-makers, educators and practitioners to help them understand how their interpretation of health literacy influences their work and its wider impact.

Why is it important to define health literacy?

Definitions, by their very nature, establish a shared understanding of words and concepts but also set parameters for inquiry and measures (Rudd, 2017). Research has shown that the concept of health literacy has been used in different ways in different contexts. It is attributed with value that means it is relative – when we talk about patients, it depends what is meant by having, for example, 'low health literacy'. As an emerging term, it has gained interest from a wide range of stakeholders. It was first cited in 1974 by Simonds with regards to health education in schools. However, academically, the first scientific article appeared in the 1980s, the second at the beginning of the 1990s and in 2006 more than 100 articles were issued. A decade later, more than 1,000 scientific publications yearly addressed health literacy, according to PubMed, and this exponential growth has resulted in more than 7,000 records to date (PubMed, 15 February 2018).

While the lack of one commonly accepted definition has, at times, been a barrier for action, especially political action in the field of health literacy, it has become clear through recent research that the definitions that exist are much more overlapping and similar than often presented. Previously, the disputes about the uncertainties dominated the health literacy discourse, but increasingly common grounds are being established, indicating more unifying than dividing factors. Importantly, this chapter attempts to demonstrate that the definitions refer to health literacy as one multidimensional, complex and heterogeneous concept, and may themselves often describe different aspects of the concept (Sørensen and Pleasant, 2017).

An outline of health literacy definitions

In spite of the vast amount of health literacy-related publications, only a few specifically focus on the analysis of definitions (Zarcadoolas et al, 2005; Massey et al, 2012; Sørensen et al, 2012; Malloy-Weir et al, 2016; Bröder et al, 2017; Cadman, 2017). The first systematic literature review on health literacy definitions and models was conducted by Sørensen et al in 2012. The second focused on health literacy definitions and their interpretations, and implications for policy initiatives (Malloy-Weir et al, 2016), and last, a recent study entailed an analysis of health literacy definitions with relevance for children and adolescents (Bröder et al, 2017). Table 1.1 outlines some health literacy definitions that are commonly used. The list is not intended to be either exhaustive or exclusive. It draws on the wide range of disciplines from which health literacy has been applied.

Exploring health literacy definitions

In the last two decades the conceptual approach has moved beyond an individual approach to an approach considering health literacy embedded in a societal context, influencing the relationship and interaction between individuals and the societal services to maintain and improve health (Parker and Ratzan, 2010). The outline of definitions included in this book shows how the definitions have evolved. The first clear definition is from 1995, which states that 'health literacy is the capacity of individuals to obtain, interpret, and understand basic health information and services and the competence to use such information and services in ways which enhance health' (Joint Committee on National Health Education Standards, 1995). In 1998, the World Health Organization (WHO) defined health literacy as 'the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health' (Nutbeam, 1998, p 10), whereas since 1999, the American Medical Association Ad Hoc Committee on Health Literacy has defined health literacy as a constellation of

Table 1.1: Definitions of health literacy

No	Source	Definition
1	Joint Committee on National Health Education Standards (1995)	'Health literacy is the capacity of individuals to obtain, interpret, and understand basic health information and services and the competence to use such information and services in ways which enhance health.'
2	Nutbeam (1998)	'The cognitive and social skills which determine the motivation and ability of individuals to gain access to understand and use information in ways which promote and maintain good health.'
3	American Medical Association (1999)	'The constellation of skills, including the ability to perform basic reading and numeral tasks required to function in the healthcare environment.'
4	Nutbeam (2000)	'The personal, cognitive and social skills which determine the ability of individuals to gain access to, understand, and use information to promote and maintain good health.'
5	USDHHS (2000)	'The degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.'
6	Fok and Wong (2002)	'To understand and act upon physical and psycho-social activities with appropriate standards, being able to interact with people and cope with necessary changes and; demands reasonable autonomy so as to achieve complete physical, mental and social well-being.'
7	Nielsen-Bohlman et al (2004)	'The individuals' capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.'
8	Kickbusch et al (2005)	'The ability to make sound health decision(s) in the context of everyday life – at home, in the community, at the workplace, the healthcare system, the market place and the political arena. It is a critical empowerment strategy to increase people's control over their health, their ability to seek out information and their ability to take responsibility.'
9	Zarcadoolas et al (2005)	'The wide range of skills, and competencies that people develop to seek out, comprehend, evaluate and use health information and concepts to make informed choices, reduce health risks and increase quality of life.'
10	Paasche-Orlow and Wolf (2007)	'An individual's possession of requisite skills for making health-related decisions, which means that health literacy must always be examined in the context of the specific tasks that need to be accomplished. The importance of a contextual appreciation of health literacy must be underscored.'
11	Kwan et al (2006)	'… [P]eople's ability to find, understand, appraise and communicate information to engage with the demands of different health contexts to promote health across the lifecourse.'

(continued)

Table 1.1: Definitions of health literacy (continued)

No	Source	Definition
12	European Commission (2007)	'The ability to read, filter and understand health information to form sound judgments.'
13	Pavlekovic (2008)	'The capacity to obtain, interpret and understand basic health information and services and the competence to use such information to enhance health.'
14	Rootman and Gordon-El-Bihbety (2008)	'The ability to access, understand, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across the life course.'
15	Ishikawa and Yano (2008)	'The knowledge, skills and abilities that pertain to interactions with the healthcare system.'
16	Mancuso (2008)	'A process that evolves over one's lifetime and encompasses the attributes of capacity, comprehension, and communication. The attributes of health literacy are integrated within and preceded by the skills, strategies, and abilities embedded within the competencies needed to attain health literacy.'
17	ABS (2008)	'The knowledge and skills required to understand and use information relating to health issues such as drugs and alcohol, disease prevention and treatment, safety and accident prevention, first aid, emergencies, and staying healthy.'
18	Yost et al (2009)	'The degree to which individuals have the capacity to read and comprehend health-related print material, identify and interpret information presented in graphical format (charts, graphs and tables), and perform arithmetic operations in order to make appropriate health and care decisions.'
19	Adams et al (2009)	'The ability to understand and interpret the meaning of health information in written, spoken or digital form and how this motivates people to embrace or disregard actions relating to health.'
20	Adkins and Corus (2009)	'The ability to derive meaning from different forms of communication by using a variety of skills to accomplish health-related objectives.'
21	Freedman et al (2009)	'The degree to which individuals and groups can obtain process, understand, evaluate, and act upon information needed to make public health decisions that benefit the community.'
22	Massey et al (2012)	'A set of skills used to organise and apply health knowledge, attitudes and practices relevant when managing one's health environment.'

(continued)

Table 1.1: Definitions of health literacy (continued)

No	Source	Definition
23	Paakkari and Paakkari (2012)	'Health literacy comprises a broad range of knowledge and competencies that people seek to encompass, evaluate, construct and use. Through health literacy competencies people become able to understand themselves, others and the world in a way that will enable them to make sound health decisions, and to work on and change the factors that constitute their own and others' health chances.'
24	Wu et al (2010)	'Health literate individuals are able to understand and apply health information in ways that allow them to take more control over their health through, for example, appraising the credibility, accuracy, and relevance of information and action on that information to change their health behaviours or living conditions.'
25	Sørensen et al (2012)	'Health literacy is linked to literacy and entails people's knowledge, motivation and competencies to access, understand, appraise and apply information to make judgements and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain and improve quality of life during the life course.'
26	Dodson et al (2015)	'The personal characteristics and social resources needed for individuals and communities to access, understand, appraise and use information and services to make decisions about health. Health literacy includes the capacity to communicate, assert and enact these decisions.'

skills, including the ability to perform basic reading and numerical tasks required to function in the healthcare environment. Along these lines, *Healthy people 2010* in the US defined health literacy as the degree to which individuals have the capacity to obtain, process and understand the basic health information and services needed to make appropriate health decisions (USDHHS, 2000). In 2002, Fok and Wong highlighted the importance of autonomy in their definition, defining health literacy as 'to understand and act upon physical and psycho-social activities with appropriate standards, being able to interact with people and cope with necessary changes and; demands reasonable autonomy so as to achieve complete physical, mental and social well-being' (Fok and Wong, 2002, p 249). The Institute of Medicine alluded that health literacy is a shared function of social and individual factors emerging from the interaction of the skills of individuals and the demands of social systems Nielsen-Bohlman et al, 2004). In this regard, Kickbusch and colleagues (2005) proposed a context-driven definition of health literacy as:

> the ability to make sound health decision[s] in the context of everyday life – at home, in the community, at the workplace, the

> healthcare system, the market place and the political arena. It is a critical empowerment strategy to increase people's control over their health, their ability to seek out information and their ability to take responsibility. (Kickbusch et al, 2005, p 4)

Similarly, Kwan et al (2006) from Canada have offered a health literacy definition that refers to 'people's ability to find, understand, appraise and communicate information to engage with the demands of different health contexts to promote health across the life-course' (Kwan et al, 2006, p 80). Kwan et al (2006) furthermore highlight the importance of engaging and equipping *all* parties involved in communication and decisions about health, including patients, providers, health educators and lay people. Similarly, in the definition proposed by Zarcadoolas and colleagues (2005), a health-literate person is able to apply health concepts and information to novel situations, and to participate in ongoing public and private dialogues about health, medicine, scientific knowledge and cultural beliefs, hence defining health literacy as 'the wide range of skills and competencies that people develop to seek out, comprehend, evaluate, and use health information and concepts to make informed choices, reduce health risks, and increase quality of life' (Zarcadoolas et al, 2005, p 196).

Freedman et al (2009) argued that the medical perspective on factors influencing people's health should be viewed at a societal level, and that a distinction must be made between public and individual health literacy. Public health literacy, according to Freedman et al (2009), can be found when health literacy is in place in a group or community. Bridging the gap between the individual and the societal approach, the European Health Literacy Consortium proposed an all-inclusive definition, stating that 'health literacy is closely linked to literacy and entails people's knowledge, motivation and competencies to access, understand, appraise and apply information to form judgements and to make decisions in everyday life concerning healthcare, disease prevention and health promotion, to maintain and improve quality of life during the life course' (Sørensen et al, 2012, p 3). Similarly, in 2015, Dodson et al highlighted the community aspect of health literacy, defining it as the personal characteristics and social resources needed for individuals and communities to access, understand, appraise and use information to make decisions about health. Health literacy includes the capacity to communicate, assert and enact these decisions (Dodson et al, 2015).

Health literacy: a multidimensional, complex and heterogeneous concept

Most research on health literacy has previously regarded it as a one-dimensional concept primarily focused on reading ability or functional health literacy. However, with the evolvement of the health literacy field, it has become clear that health literacy encompasses multiple dimensions, and that it is a rather complex and heterogeneous construct.

A multidimensional concept

While recognising that the range of definitions is largely overlapping, each particular definition also highlight specific aspects of health literacy that help to expand the understanding of health literacy. Health literacy is a skill-based process that individuals can use to identify and transform information into knowledge and action. Hence, it is not only about the knowledge that people pursue, but much more importantly, how the knowledge enables them to act to maintain and promote their health and the health of others, and to become aware of the role of communities and society at large. Indeed, recent discussions have highlighted the importance of moving beyond an individual focus, and of considering health literacy as an interaction between the demands of health systems and the skills of individuals (Sørensen et al, 2012). In this regard Nutbeam (2008) distinguishes between functional, interactive and critical health literacy. *Functional health literacy* refers to the basic skills in reading and writing that are necessary to function effectively in everyday situations, broadly comparable with the content of 'medical' health literacy referred to above; *interactive health literacy* refers to more advanced cognitive and literacy skills, which, together with social skills, can be used to actively participate in everyday situations, extract information and derive meaning from different forms of communication, and apply this to changing circumstances; and *critical health literacy* refers to more advanced cognitive skills, which, together with social skills, can be applied to critically analyse information and use this to exert greater control over life events and situations (Nutbeam, 2008; see also Chapters 11 and 14, this volume). According to Kickbusch (2004), health literacy is about rights, access and transparency. It is about a new form of health citizenship, in which citizens take both personal responsibility for health and become involved as citizens in social and political processes that address the root causes of health inequalities as well as inequalities in access to care.

A complex concept

Health literacy is a complex concept because it is content- and context-specific. In fact, more and more definitions are appearing that specify particular aspects, areas, or target groups related to health literacy. A recent study revealed more than 100 types of specified health literacy (Sørensen, 2017). These developments reveal an amplifying effect of the evolvement of health literacy which, at first sight, may blur the discourse regarding the definition of health literacy; however, on the other hand, it may help us to clarify the complex concept in a way where we can much more easily understand how specific aspects, contexts and target groups can benefit from the application of the health literacy lens. Examples of health literacy types include diabetes (health) literacy (Van den Broucke et al, 2014), eHealth literacy (Norman and Skinner, 2006; see also Chapters 18, 39 and 43, this volume) and maternal health literacy (Mobley et al, 2014).

Notably, Mackert et al (2015) identified four streams in health literacy research focusing on health domains (for example, various conditions and diseases), populations (for example, by role or age), in specific channels and contexts (for example, eHealth), and languages. First, various studies exemplified the role of health literacy in relation to specific illnesses and conditions such as, for example, AIDS (Kalichman et al, 2000), diabetes (Perrenoud et al, 2015), cancer (Friedman and Hoffman-Goetz, 2008) and mental health (Jorm, 2000). For more information on mental health literacy see Chapters 4, 17, 19 and 25, this volume. A second direction focused on specific patient populations (Pignone et al, 2005) as well as specific individual roles, such as caregivers (Hironaka and Paasche-Orlow, 2008), mothers (Porr et al, 2006) and parents (Yin et al, 2009). The life course perspective is also often used, for example, in terms of children (Borzekowski, 2009), adolescents (Abel et al, 2014), adults (Kutner et al, 2006) and older people (Tiller et al, 2015). Potential gender issues associated with health literacy have been explored as they relate to both men (Peerson and Saunders, 2009) and women (Shieh et al, 2010). A third stream of research focused on the various channels by which people might receive health information, for example, media health literacy (Levin-Zamir et al, 2011) and eHealth literacy (Norman and Skinner, 2006). Finally, a fourth path included research in languages other than English, which often included a focus on translations and adaptations of health literacy instruments and tools into, for example, Asian (Duong et al, 2016) and European languages (Sørensen et al, 2013).

Domain and population-specific studies on health literacy can contribute to a deeper understanding of health literacy and its impact on health outcomes. The continuous effort to study health literacy in different contexts, and developing improved tools and measurements to be used in research, is a crucial element of advancing the health literacy field and eventually, the development of more focused health literacies build productively on the more general construct of health literacy (Mackert et al, 2015). A recent example in this regard is the systematic literature review conducted on the definitions regarding children and adolescents' health literacy (Bröder et al, 2017).

A heterogeneous concept

Health literacy is a heterogeneous phenomenon that has significance for both the individual and society (Mårtensson and Hensing, 2012). According to Mårtensson and Hensing, health literacy is characterised as a polarised phenomenon, focusing on the extremes of low and high health literacy. The health literacy definitions in this approach are associated with a functional understanding, highlighting certain basic skills needed to understand health information. The other approach represents a complex understanding of health literacy, which acknowledges a wide range of skills in interaction with the social and cultural contexts (Mårtensson and Hensing, 2012). Pleasant and Kuruvilla (2008) explain the two approaches as a tale of two health literacies based on the clinical and public health approaches to health literacy. Baker argues from a clinical perspective that knowledge is a resource in individuals that 'facilitates health literacy but does not in itself constitute health literacy' (Baker, 2006, p 879), and Abel describes health literacy as a knowledge-based competency for health promoting behaviours (Abel, 2008). Zarcadoolas and her colleagues (2005) expand this approach to health literacy by identifying the fundamental scientific, civic and cultural domains of health literacy and defining the acquisition, understanding, evaluation and use of knowledge as an integral component of health literacy.

Although health literacy remains subject to varying definitions and conceptual approaches, both clinical and public health approaches tend to find common grounds insofar as they focus on people's ability to find, understand, evaluate and use information to improve their health and quality of life during the life course. Furthermore, many definitions incorporate the contextualisation of health literacy by including a focus on interaction and participation in the wider community and society (Sørensen and Pleasant, 2017). Notably, the Australian Commission on Quality and Safety in Healthcare (2013) in Australia highlights the health literacy of the individual as well as the role of the health literacy environment:

- Individual health literacy is the knowledge, motivation and competencies of a consumer to access, understand, appraise and apply health information to make effective decisions and take appropriate action for their health and healthcare.
- The health literacy environment is the infrastructure, policies, processes, materials and relationships that exist within the health system that make it easier or more difficult for consumers to navigate, understand and use health information and services to make effective decisions and take appropriate action about health and healthcare.

Lost in translation

When discussing how to define health literacy, it is important to also reflect on the challenge of translating the concept. The definitions of the two words 'health' and 'literacy' have various origins and are applied differently in various settings (UNESCO, 2005). Hence, in practice, the English term 'health literacy' has proven difficult to translate into other languages (Sørensen and Brand, 2013). The polarisation seen with regard to the conceptualisation of health literacy is often mirrored in its translations where the two words are translated as two separate words, reflecting a broad understanding of health and a narrow understanding of literacy focusing on 'functional health literacy'. However, 'health literacy' can also be translated into interrelated words such as 'health competencies', 'abilities', 'capabilities', 'skills', 'capacities', 'knowledge' and 'awareness'. According to the thesaurus for these terms, they are closely associated. They represent nuances of the same term, and the different translations even overlap in some respects (Sørensen and Brand, 2013):

- Competence can be understood as 'the ability to do something successfully or efficiently' or as 'the scope of a person's or group's knowledge or ability', thus it can also mean 'skill or ability'.
- Skill means 'the ability to do something well; expertise' and has its origin in late Old English 'scele', knowledge.
- Ability means 'the capacity to do something' and 'talent that enables someone to achieve a great deal'.
- Capacity means 'the ability or power to do, experience or understand something'.
- Knowledge means 'facts, information and skills acquired by a person through experience and education; the theoretical or practical understanding of a subject as well as awareness or familiarity gained by experience of a fact or a situation'.
- Awareness refers 'to having knowledge or perception of a situation or a fact'.

The findings from the analysis of translations support the broad overlap of definitions and the view that we need to understand that the glass is half full rather than half empty when we compare and discuss differences and commonalities. In other words, we are in the same forest while we may study in detail the different trees (Mackert et al, 2015).

Implications of applying health literacy definition(s) in policy, research and practice

As the definition of health literacy expands, so, too, does the scope and depth of health literacy research, practice implementation and public policy (Rudd, 2017). Therefore, it is important to pay attention to:

- the definition(s) of health literacy adopted in practice;
- the differing and potentially problematic ways in which definitions may be interpreted;
- the way(s) in which differing interpretations may affect the delivery of health literacy-related policy initiatives (Malloy-Weir et al, 2016).

The various interpretations of health literacy can be perceived as problematic for policy-makers, researchers and practitioners. First, it is not clear which definition of health literacy is best in any given context or by which criteria this should be judged. Second, if policy-makers understand definitions differently than others who are implementing and evaluating health literacy-related initiatives, this may generate confusion and misunderstandings. Third, if policy-makers act on assumptions that are not fully supported by empirical research, it may lead to unintended or unwanted consequences (Malloy-Weir et al, 2016). Linguistically, the term itself implies multiple interpretations building on the understanding of the two individual words 'health' and 'literacy'. Nevertheless, it has become clear that the two parts are more than their sum, and 'health literacy' is an emerging field in its own right (Sørensen and Brand, 2013). It is important to recognise that the translations of health literacy are potential carriers of the latent meaning of literacy and as such, may enhance efforts in certain areas and less in other areas, depending on the particular interpretation of the notion. Eventually, the loaded meaning of the translated literacy component may generate a certain agenda and guide an action framework in research, policy and practice, for instance, if health literacy is understood primarily as functional health literacy or in its wider sense of critical health literacy (Sørensen and Brand, 2013).

Definitions by their very nature are restrictive, representing summaries of complex ideas and actions (Nutbeam, 1998). The exponential developments in terms of health literacy research, policy and practice keep opening new avenues on how health literacy can be defined in more detail. The multiple aspects each provide a piece to the puzzle that can help us define what health literacy is and why it is important (Sørensen and Pleasant, 2017). Definitions identify the focus of concern, provide variables for analysis, set parameters for inquiry and shape measurement tools. With an understanding of health literacy as multidimensional, researchers will be better able to investigate the array of contributing factors that may further explain the link between literacy and health. Furthermore, practitioners, researchers and others will be better able to generate and test effective actions at multiple levels. Therefore, when considering the appraisal and usefulness of the various health literacy definitions, Pleasant et al (2016) recommend considering four components:

- Focus on system demands and complexities as well as individual skills and abilities.
- Include measurable components, processes and outcomes.
- Recognise the potential for an analysis of change.
- Demonstrate the linkage between informed decisions and action.

The final word is not said with regards to the definitions of health literacy. As experience grows and ideas evolve further, the term will need to be regularly assessed for its meaning and relevance (Nutbeam, 1998). The use of the term will often be situation-specific and moulded by prevailing social, cultural and economic conditions that may influence its interpretation. This is particularly the case when discussing health literacy in high-, middle- and low-income countries (Dodson et al, 2015). Furthermore, health literacy is a key component of the trend in increasing people-centred health, which implies strong participation from both experts and patients and lay people, which may, in turn, have an impact on how we define health literacy in the future.

Conclusion

The field is expanding, and so is the understanding of how we can define health literacy. With the growing evidence on health literacy, stakeholders may be more likely to understand the phenomenon in light of its multidimensionality. The differences are in the details in relation to specific aspects of health literacy, rather than profound differences among the definitions. The similarities are greater than the differentiating factors, as explained in this chapter.

The health literacy deficit is a public health challenge we cannot neglect. The discussions concerning differences and commonalities, strengths and weaknesses should not overshadow the important task ahead to bridge the health literacy divide. Health literacy in all its facets needs to be recognised by the world community to develop health for all across the lifespan.

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2

From Saranac Lake to Shanghai: A brief history of health literacy

Orkan Okan

Introduction

In the early 21st century, health literacy has evolved into a broadly discussed and widely researched topic in health research and beyond. In the past 40 years, health literacy has become an object of interdisciplinary interest, and today, almost all health-related sciences are engaged in research on the matter. Health literacy has also attracted the attention of many governments, government-related organisations and national and international non-governmental organisations (NGOs), such as the World Health Organization (WHO) and UNESCO. These organisations have prioritised health literacy and included it in their programmes and agendas. Although health literacy was mostly developed in Western countries, it has become a global phenomenon that, as of today, has been researched in thousands of studies worldwide and used in countless health education programmes, and has led politicians to implement national policies to promote health literacy in their populations and organisations. While the attention given to contemporary health literacy is continuously growing, a look at the concept's past and its roots might help to clarify where health literacy comes from, which disciplines were the main drivers of the increased focus on health literacy in research, practice and policy, and what has influenced its development throughout the past decades. This may also help in understanding and unravelling why the field of health literacy research is so heterogeneous in relation to conceptual and methodological approaches, as described throughout this handbook.

This chapter addresses the entire lifespan, and introduces the four main roots of health literacy: school health education, adult education, healthcare research and public health. It describes the historical pathway that began in 1974 at Saranac Lake, New York, USA, and reached its preliminary climax in 2016 at the WHO Shanghai Conference on health promotion in China. Each of the four roots is introduced by specifically describing the research, practice and policy interest that enabled people decades ago to address health literacy in their specialised fields. These sections show how these roots significantly influenced the pathway of health literacy and the types of health-related developments that made it necessary to create and address health literacy at that time. After describing the four roots, their inherent intricacies and how they contributed to the field of health literacy, their commonalities, differences and intersections as well as future implications for moving the field forward are discussed.

School health education

The origin of the term ‘health literacy’ can be associated with a particular event and date in the USA. In 1973, during the interdisciplinary Will Rogers Conference on Health Education at Saranac Lake, a small village in the state of New York, the future of health education for the US public was discussed (Simonds, 1974). With the goal of determining how education may be advanced most effectively to prevent illnesses, experts from education, health, communication and the entertainment industry came together and addressed various research, practice and policy issues related to new directions in health education and public health communication. The proceedings of the conference show that it was Scott K. Simonds (1974) who understood that health education must be considered an important social policy topic. He highlighted three dimensions deeply associated with better health education:

- social responsibility of the healthcare sector to adopt modern health education principles, to provide health insurance to all citizens and to engage in health promotion, education and maintenance in all their settings;
- responsibility of education systems to implement health education for children and young people;
- responsibility of the communication and entertainment industry to commit to public health education throughout their media channels, and to support the creation of active and health-responsive citizens by using social marketing and reinforcing healthy practices.

It was in this context that he coined the term *health literacy*, which he understood to be the outcome of health education, and recommended establishing quality health instruction by highly qualified health education teachers in kindergartens and schools to develop citizens who could meet these health education goals. Although this model represented a top-down approach that redistributed the responsibility for good health to individuals, the social justice aspect of these policy goals became clear: Simonds emphasised that efforts should also be dedicated to creating a better and more just healthcare system that helped citizens protect and maintain their health.

However, there is almost no scientific documentation on health literacy in relation to school-based health education until 1995, when the Joint Committee on National Health Education Standards (1995) defined the achievement of health literacy as the major goal of school health education. This was also the first time that health literacy was clearly defined in the health education context as the health knowledge and skills ‘to obtain, interpret, and understand basic health information and services and the competence to use such information and services in ways which enhance health' (Joint Committee on National Health Education Standards, 1995, p 5).

Whereas health literacy was understood to be the outcome of health education, the outcome of health literacy was being literate in the context of health. A health-literate person was defined as a critical thinker and problem solver, a responsible and productive citizen, a self-directed learner and an effective communicator. These dimensions are very much interconnected with Simonds' recommendation from the 1970s; he understood that being health-literate has two dimensions: individual health responsibility and public responsibility for creating a health-supportive environment for the benefit of all citizens. Although health literacy was highlighted a second time, most prominently in the context of school health education, it has largely been ignored; it was not considered in curriculum development, and no assessment or monitoring system for students was implemented. By the time the Institute of Medicine (Nielsen-Bohlman et al, 2004) indicated that the education system was among the major areas for health literacy-promoting interventions, 30 years had passed since Saranac Lake, with almost no health literacy activities in schools. Although the curriculum for health literacy was renewed in 2007 (Joint Committee on National Health Education Standards, 2007), today only 75 per cent of the states in the US have adopted these kinds of health education standards; furthermore, the implementation of health education standards is very heterogeneous, and programmes are not well evaluated (Ormshaw et al, 2013).

While for many years health literacy was a school education matter only in the US, albeit only in rhetorical terms and as a tool that was not really practised, Australian educators have been constantly highlighting the role of schools in promoting health literacy, beginning in 1993 with the report on the new Australian public health goals (Nutbeam et al, 1993). They especially discussed how schools could facilitate the achievement of health literacy, the necessary organisational and professional structures and the future challenges associated with the promotion of health literacy in schools (St Leger, 2001). However, this approach is not linked to the approach used in the US, and nor does it follow the US model. Instead, the Australian approach is informed by a public health approach to health literacy and the WHO-invented health-promoting school approach (Nutbeam, 1992) (introduced later in this chapter). Nevertheless, it took another 10 years before the Australian government adopted a curriculum that addressed the promotion of health literacy competencies in all Australian schools (ACARA, 2012).

While many countries lack a health literacy component in their school health education curriculum, Finland proves how health literacy can be promoted and successfully accomplished through schools (Finnish National Board of Education, 2014). Similar to the US approach both conceptually and structurally, the Finnish health education curriculum views health literacy as the primary health education outcome and uses a multidimensional health literacy framework (Paakkari and

Paakkari, 2012). The curriculum is mandatory for the entire education system. The health literacy curriculum is based on a previously developed model, and its core components encompass theoretical and practical knowledge, self-awareness, critical thinking and citizenship. This understanding is close to how health literacy is conceptualised in the US curriculum. (The Finnish approach is described in greater detail in Chapter 34, this volume.)

Many scholars and practitioners highlight the importance of including health literacy in school health education as schools are viewed as a key arena for promoting health literacy early in the life course (Nutbeam, 2000; St Leger, 2001; Benham-Deal and Hodges, 2009). In this context, two books on health literacy, school health education and adolescent health learning have been published recently, highlighting available methods, conceptual considerations and future directions related to this field (Begoray and Banister, 2012; Marks, 2012). The books conclude that to address health literacy promotion, there is a need for better classroom-based practices, whole-setting approaches, collaboration across sectors, parent involvement and better professional development, especially in terms of teacher education. In this context, the WHO Regional Office Europe recently published a policy brief on improving school health literacy promotion in European countries (McDaid, 2016). In conclusion, one important root of health literacy is health education, but at present, few countries have adopted a health literacy curriculum, and those that have focus more on school practices than on conducting studies to produce evidence.

Adult education and literacy learning

The previously mentioned Saranac Lake conference was also a platform for discussing the health education of adults. Although health literacy was not directly mentioned as a learning goal for adults, the overall health education goals were clearly defined to address adult learners as well as children (Simonds, 1974). Although adult education was discussed at this event, it was not the factor that made adult education a root of health literacy. In fact, adult and continuing education and literacy learning have a long tradition around the world (Coben, 2013). Both aim to equip adults with basic reading and writing skills, functional literacy and knowledge (Kerka, 2003), and other approaches are based on the idea of increasing individual empowerment (Kickbusch, 2001).

Unlike school health education, adult education did not provide a particular definition of health literacy; instead, it drew from traditional literacy and functional literacy (the ability to use reading and writing and computation skills to meet everyday life situations and to develop knowledge and potential) (Andrus and Roth, 2002), and emphasised health-related knowledge and health communication. Health literacy for adults was based on these sorts of literacy concepts.

In adult education, the connection between literacy and health was recognised long before the term 'health literacy' was coined. Literacy research in this field began early to investigate the effects of poor education and literacy on health (Segall and Roberts, 1980). During the 1970s, a broad array of research on adult literacy in the US found that a significant number of adults experienced reading difficulties (Rudd et al, 2000), and that illiteracy has a direct effect on health and on interactions with the healthcare sector (Holt et al, 1992). Literacy was especially important when adults interacted with the healthcare system as patients. It was known that for adult patients, literacy is an important determinant of effective health communication with the health sector and health professionals, and of acquiring and understanding health-related knowledge and information.

Although there was no mandatory health curriculum in adult classes, health became a fundamental component of adult education. The inclusion of health projects in adult classrooms was a bottom-up approach driven mainly by adult educators as they recognised that health is in adult learners' personal interest. Educators used this method to motivate adult learners to engage with and better learn reading, writing, oral expression and maths skills (Rudd et al, 2000). In the mid-1980s, the book *Teaching patients with low literacy* (Doak et al, 1996) specifically linked adult and health education principles to address the promotion of patient literacy. During this period, professionals from adult education and healthcare collaborated to provide health-related print materials that corresponded to the reading abilities of patients (Plimpton and Root, 1994). Poorly educated and low-literate adults also have poor health status, including the highest rates of morbidity and mortality (Plimpton and Root, 1994), and this link has been proven in studies throughout the world (Zarcadoolas et al, 2005, 2006). Therefore, by the time the second edition of the book by Doak, Doak and Root was published in 1996 (Doak et al, 1996), the healthcare sector had already begun to investigate the health literacy of patients by using literacy screening tools during routine visits and studies (Berkman et al, 2011). When the National Adult Literacy Survey (NALS) found that 90 million American adults had limited functional literacy skills (Kirsch et al, 1993) that affected their healthcare interactions in terms of adherence, compliance and communication, it provided a starting point for health literacy in the healthcare and medicine context that dramatically changed the path, measurement and political uptake of health literacy. A clear distinction of where adult education ends and healthcare starts cannot be made within the context of health literacy. Moreover, those fields intersect, with the healthcare sector producing rapid screening tools and empirical studies and the adult education field providing interventions to increase adult patients' literacy skills. However, healthcare used the functional literacy concept taught in adult education as the foundation of healthcare-based health literacy understanding (see Chapter 26, this volume).

Healthcare: an uprising of health literacy

As mentioned earlier, the healthcare areas dedicated to research on health literacy are linked to adult education, but are subtly distinct. The roots can be traced backed to the 1960s and subsequent decades in the US, where researchers, mostly physicians in healthcare settings, but also nurses and pharmacists, investigated patient–provider communication, patient knowledge and comprehension of health information, and medical adherence and compliance (Segall and Roberts, 1980; Davis et al, 1990; Rudd et al, 2000). During this time, the health system was changing and becoming more complex, and healthcare providers and health professionals began to expect patients to assume a more active role in their care and greater responsibility for their own health (Parker, 2000), if not to say that in relation to health literacy this was and still is a desire in order to lower healthcare costs and liability.

The significantly negative results of the NALS and the International Adult Literacy Survey (IALS) (Statistics Canada, 1995) increased health researchers and practitioners' interest in exploring the relationship between patient literacy and healthcare interaction more deeply than they had throughout the 1970s and 1980s. That said, the NALS findings triggered a significant uptake of health literacy in healthcare, and literacy and functional literacy became the core units of observation throughout the 1990s and 2000s. By that time, US-based and international studies of health research were clearly showing that limited patient literacy levels were associated with poor health status and had an impact on several intermediate factors known to influence health outcomes (Rudd et al, 2000). In extensive studies in this field, limited patient health literacy was identified as having negative effects on various health actions and health outcomes. Healthcare professionals understood that deficiencies in patient literacy could threaten effective patient–provider communication, medical adherence, treatment, self-management, utilisation of care and information, and have an overall negative effect, and that they needed instruments to analyse patient strengths and weaknesses during medical care procedures to provide better healthcare tailored to patients' needs and capabilities.

To address and better identify these problems, fast screeners were developed (see Chapters 5 and 6, this volume), such as the Rapid Estimate of Adult Literacy in Medicine (REALM) (Davis et al, 1993) and the Test of Functional Health Literacy in Adults (TOFHLA) (Parker et al, 1995). These fast screeners were used in routine testing in healthcare practice and in many studies. They were meant to identify certain patient needs in relation to education and literacy levels, and although they were developed more than two decades ago, these tools are still in use in the US and internationally. Most of the work performed in this era was dedicated to measuring health literacy and exploring its association with health outcomes. Defining health literacy was also a matter of discussion in the 1990s and the early 2000s. As a result, the most prominent and frequently cited definition of health literacy emerged (Malloy-Weir et al, 2016); it described health literacy as 'the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions' (Ratzan and Parker, 2000, p iv).

Several health-related organisations in the US began to prioritise the health literacy of patients, including the US Department of Health and Human Services, in their *Healthy people* reports (USDHHS, 2000), the American Medical Association, through their Ad Hoc Committee on Health Literacy (1999) and the National Institutes of Health and the National Library of Medicine (NLM) with several networking, knowledge, database and online resources (NLM, 2000). Among the most prominent evidence of this prioritisation is the report on health literacy published by the Institute of Medicine in 2004, *Health literacy: A prescription to end confusion* (Nielsen-Bohlman et al, 2004), which is still echoed in the field of health literacy. The report summarised contemporary evidence, provided possible interventions and solutions, broadened the concept of health literacy, presented several areas for intervention (namely, culture and society, the education and the health system), and facilitated the uptake of health literacy by many sectors and settings. Since the Institute of Medicine, which is now called the National Academy of Medicine, started engaging with health literacy, they have been instrumental in developing and organising working groups, meetings, networks and discussions to improve health literacy research, practice and policy, and to make it a high priority in the national political agenda (Parker and Ratzan, 2010).

While health literacy has almost always taken a bottom-up approach in healthcare and medicine, the rise of these policy-related reports led to the National Health Literacy Act, the National Action Plan on Health Literacy and finally, to the Patient Protection and Affordable Care Act signed by Barack Obama (Parker and Ratzan, 2010). That was when health literacy efforts shifted from a bottom-up approach to a top-down approach, ensuring the support and promotion of health literacy initiatives backed by law. However, it can also be stated that those regulations have no enforcement mechanism in regard to health literacy aspects, and are largely ignored by many in the US.

This healthcare stream also brought the idea behind the health literacy communication framework into existence, highlighting that health literacy involves a complex process of communication and interaction between patients and healthcare providers (Parker and Ratzan, 2010). In this context, health literacy became known as a two-sided concept in which individual abilities and system demands and complexities must meet to promote health literacy and sustain effective health practices. This was clearly a shift towards considering the environment and addressing health system change, as suggested by Simonds in 1974. In the long run, this has also led to the concept of the health-literate healthcare organisation, one that addresses the improvement of the physical and social infrastructure of the health system to better fit patient needs and demands (Brach et al, 2012). Highlighting the embeddedness of individuals in their context, the public health literacy concept, which addressed the health literacy of both individuals and groups, was introduced in 2009 (Freedman et al, 2009). However, this concept is not related to the public health approach to health literacy; instead, *public* highlights that there is a dimension to health literacy beyond individual abilities.

Given the number of research studies, measurement tools, interventions and health education programmes and policies that were produced by this stream, healthcare research is among the main devices that have advanced the health literacy revolution in health sciences and practice. The development in this field continues, and most recently, researchers and practitioners who have been involved with health literacy for many years have published a brief report on how to improve health literacy, the concept of health literacy, and its measurement, interventions and policies (Pleasant et al, 2016).

Public health: the second coming

In public health, the development of health literacy is closely related to the health promotion movement that began with the WHO's Ottawa Charter in 1986 and was mainly driven from within Europe (WHO, 1986). In fact, the bedrock of health literacy was formed much earlier, in 1974, when the so-called Lalonde report in Canada introduced the term 'health promotion' to broader audiences and health policy (Lalonde, 1974). Although the term itself was coined in the 1940s by Swiss medical historian Henry E. Sigerist and subsequently led to advances and new perspectives in epidemiologic research throughout the following decades (Breslow, 1999), it was the Lalonde report that is believed to have paved the path for health promotion as it is being discussed today (Hancock, 1985). Unlike traditional medical approaches to health, a public health framework for strengthening the population's health was proposed; this framework was labelled the *health field concept*. Although it still comprised the biomedical dimension of health, the framework specifically addressed the environment, lifestyle and health decisions, individual responsibility and health behaviour, social determinants of health and populations at risk in an effort to reduce health inequalities; additionally, it introduced responsive health systems and health policies to support the accomplishment of these goals. These ground-breaking ideas were then adopted in the Ottawa Charter.

While the Charter defined the development of personal skills as one of its five strategies for promoting health, health literacy was not specifically mentioned. That changed during the 1990s, when, in the context of developing Australia's new public health goals, health literacy and health skills were interconnected with education, and the WHO's health-promoting schools approach (Nutbeam, 1993) and health learning became more important components of health throughout the lifespan (Kickbusch, 2001). Finally, during the WHO's Jakarta Conference, health literacy was introduced to expand and summarise the personal skills strategy presented in the Ottawa Charta (see Chapter 42, this volume). Health literacy was then understood to be an indicator of personal skills, namely, health knowledge, self-confidence, self-efficacy, self-empowerment, attitudes, behaviour, future orientation, participation, coping, caring and health sector navigation (Kickbusch, 2001).

A year later, in 1998, the new WHO health promotion glossary defined health literacy as the 'cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health' (Nutbeam, 1998 p 357). Another difference to the healthcare approach is the fact that health literacy is not just restricted to health information, but also to information in general. It was emphasised that health literacy is a distinct and independent concept rather than a derivate of literacy (Nutbeam, 2008), and that health literacy goes beyond the healthcare sector and also addresses everyday life settings.

By highlighting that health literacy goes beyond the ability to read pamphlets and make appointments, in contrast with the functional literacy take on health literacy described earlier in this chapter, the public health approach made clear its differences from the narrow healthcare approach. Shortly after, by adopting the idea that literacy is a set of social practices that enables practical abilities in everyday life (Nutbeam, 1999; see also Chapter 36, this volume), Nutbeam (2000) highlighted health literacy as an essential skill for the 21st century, and further introduced a three-tier model of health literacy that comprised *functional health literacy*, *interactive health literacy* and *critical health literacy* (see Chapter 14, this volume). This approach is informed by interaction, participation and critical appraisal, and linked to Paulo Freire's education for critical consciousness, which sought to empower citizens in general but the most deprived one specifically. In this context, health literacy was labelled an important health- and wellbeing-related life skill required for participation in society and an active, empowering and dynamic concept (Kickbusch et al, 2005; Kickbusch, 2006) that was understood to be an important driver in the determinants-based health promotion approach (Kickbusch, 1997). Although health literacy was already characterised as a content- and context-specific concept, during the Mexico Conference on health promotion, the WHO Health Literacy Working Group recommended broadening the concept by including relational and dynamic aspects as well as the dimensions of health-related life skills and community development (Kickbusch, 2001). Moreover, this recommendation led to a definition of health literacy as an important determinant of population health (Kickbusch, 2001). Many of the WHO's follow-up conferences have confirmed their interest in promoting health literacy and have endorsed new approaches throughout the years. In 2008, the critical role of health literacy for empowerment was highlighted again, and it was recommended that health education programmes link health literacy development with actions to address the social determinants of health; furthermore, the 'Nairobi call to action for closing the implementation gap in health promotion' identified health literacy as a key strategy and action for improving quality of life and health outcomes and for reducing health inequities on a large scale (Kanj and Mitic, 2009).

Health literacy was significantly strengthened when health promotion and disease prevention were highlighted as important approaches for addressing the increase in the burden of disease in many developed countries (Kickbusch, 2001).

At the same time, the citizenship concept, including the capacity and self-efficacy to manage health and wellbeing, was associated with health literacy. Therefore, health literacy became an even more important target for public health policies and for addressing the social determinants of health. Consequently, individual responsibility was emphasised as a target for improving individuals' capacities to address modifiable risk factors and prevent diseases (Peerson and Saunders, 2009). In this context, culture is another indicator influencing health literacy, as Levin-Zamir and Wills (2012) have highlighted before suggesting that culture should be considered an important determinant of health literacy, especially in the context of the increasing migrant and refugee populations moving to Western countries. While community members and health systems, including health professionals and further staff, should be culturally competent in order to meet cultural demands of individuals and populations, culture in this context refers 'to the shared values, beliefs, and practices to find meaningful, structured modes of social interactions interpersonally and institutionally to support the well-being of its members' (Levin-Zamir and Wills, 2012, p 6). It is worth mentioning that culture has likewise become important to health literacy approaches in school and adult education as well as for healthcare.

When European-based public health researchers conducted the first health literacy survey in eight European member states (Sørensen et al, 2015), it was a global catalyst for health literacy research, practice and policy around the world, and many follow-up studies have been conducted since. This widely acknowledged study and its associated results also led the WHO to report on health literacy in their 'Solid Facts' series, which aimed to present best evidence and identify the policy and action implications of converting research into practice (WHO, 2013). The report highlighted the importance of delivering health literacy action as part of the settings approach, how policy interventions could be implemented at European and national levels, and the need to invest in and strengthen health literacy research and practice. A subsequent policy brief supported these recommendations, particularly those related to investing in health literacy in the education sector (McDaid, 2016). Similarly, health literacy has been placed high on the agenda in the WHO Southeast Asia Region via the introduction of a health literacy toolkit for low- and middle-income countries to help communities to develop their own solutions (Dodson et al, 2015). Furthermore, it informs governments and organisations about health literacy, and introduces ways to provide action for health promotion, disease prevention and management and to address inequities in health. Complementing these developments, and in line with the tradition of discussing health literacy during the WHO's health promotion conferences, the Shanghai Declaration on health promotion prioritised health literacy development as an important health promotion and sustainable development goal; in doing so, the WHO defined the development of health literacy as one of three central pillars of its agenda, and identified it as the key to empowerment and increased equity (WHO, 2017).

In public health, the development of health literacy is ongoing at all levels. This continued development is best expressed by several national policies in Europe (Heijmans et al, 2015), and by the WHO's recent launch of its first Health Literacy Collaboration Centre with Director Richard Osborne, located in Australia (Deakin University, 2017). Besides the ongoing and tremendous public health efforts addressing health literacy in Europe, North America and the Australasian region, there is only little to no work still in Africa, very little in the Middle East, India and South America, and also very little in Russia and the Slavic countries in Europe (Pleasant, 2013a, b).

Discussion and future directions

This chapter sought to chronicle the development of health literacy and introduce major milestones in the evolution of health literacy in different disciplines. Despite many commonalities, each of the four main roots provides a heterogeneous pathway for health literacy, and the concept and its community remain in a state of constant change, both conceptually and practically.

There is some common ground among the four roots of health literacy. For example, all the approaches define health literacy as the outcome of health education and associated health learning in schools or educational settings. All the approaches understand that health literacy is an individual responsibility; however, they also consider the interrelationship between individuals and their environment, including social factors and cultural sensibility. While public health and school health education show that social policy, including citizenship, just health systems and societies, participation and empowerment, were part of the early agendas in the 1970s and 1980s, the systems and professional perspectives that emerged in the 2000s prompted healthcare to emphasise that health literacy goes beyond individual abilities. Although health literacy initially began as an upstream approach in adult education and healthcare and a top-down approach in school health education and public health, today, both top-down and bottom-up actions can be found in all these disciplines. While the number of countries developing national policies to ensure health literacy promotion is constantly increasing, on the other end of the spectrum, school teachers, health educators and health practitioners are providing programmes at individual and community levels. The most important understanding that all of the approaches share is that health literacy must be regarded as a whole-of-society approach involving research, practice, industry and policy. In this context, including health literacy in the 'Health in All Policies' (HiAP) approach is becoming a critical public policy goal at national and international levels, and governments in many countries as well as NGOs have already begun addressing health literacy on their HiAP agendas.

The adult education and healthcare streams naturally merged very early in the US in the 1990s – the former provided teaching methods and educational content and the latter provided extensive studies. However, school health education has never connected with these other approaches. In fact, even newer approaches such as the Finnish health literacy curriculum do not relate to the healthcare and public health approaches; instead, they are very similar to the school education approach developed in the US. Regarding public health, although there are some intersections with the healthcare approach that primarily evolved after the Institute of Medicine's 'Prescription' report in 2004 (Nielsen-Bohlman et al, 2004), the two fields seem to coexist mostly independently. Nevertheless, since Australia adopted a health literacy curriculum for their national school health education programme that is implemented within the health-promoting schools approach, there is at least that intersection between public health and school health education.

Health literacy itself, however, is defined differently within both. In contrast to public and school health education, healthcare's approach to health literacy still focuses primarily on the use of medical services and adherence, adjusting health systems to meet patients' demands, and patient–provider interaction. Public health is based on a health promotion approach that is much broader and emphasises the health and wellbeing of individuals in their everyday life, including how they can improve their living conditions and address the social determinants of health. The school health education and public health approaches share an understanding of health literacy that is based on developing socially responsible citizens and critical thinkers. While in the health education approach these are components of health literacy itself, in public health, these are greater health promotion goals to be sustained by addressing health literacy.

However, critical health literacy as introduced in public health is very similar to the critical thinker approach used in school health education. Especially in the context of modifiable health risks, health literacy addresses the individual's responsibility to prevent those kinds of health threats. Responsibility is also meant to address the social determinants of health and to encourage patients to change them in ways that promote their personal health and the health of others, including encouraging citizens to take on leadership positions and to make the health system more just and equitable system for all. Approaches in school health and adult education have conceptually and practically focused more on improving the 'literacy' aspect of health literacy by teaching skills, knowledge and further cognitive and social abilities, while public health and healthcare prioritised the 'health' aspect as well, by keeping the focus on improving health outcomes. Decision-making as a product of health literacy seems integral to all perspectives, but from a medical and healthcare perspective, it is about an appropriate decision, whereas in public health and education, it is more about an informed decision. Finally, the WHO-based public health approach highlights 'information' (Nutbeam, 2000, p 264) rather than health information, which, however, is the term of choice in most of the other definitions and approaches.

On a large scale, the main driver of the healthcare approach has always been US-based healthcare and medical organisations, health professionals, and recently, health policy-makers, while the WHO has always been the main driver of the public health approach. In addition to the vast number of studies conducted through healthcare research, a main contributor to this stream has been the inclusion of the health literacy of health professionals, the health-literate organisations approach and the introduction of health literacy as a two-sided concept involving individual abilities and systemic complexities. In comparison, public health has mainly contributed by providing a much broader notion of health literacy that addresses everyday life settings and is both content- and context-related, introducing a determinants approach, and emphasising the critical judgement of information that can be used in health and wellbeing contexts. Moreover, public health has led to the uptake of health literacy around the world, and to the first and only international, population-based survey using a self-report questionnaire. In turn, that study has revived and re-initiated European health literacy research, practice and policy as well as the uptake of the public health approach in many countries across the world (see Chapter 8, this volume).

There is still a sharp contrast among these approaches in their understanding of health literacy, but there are also some commonalities and intersections. From a lifespan perspective, it is important to have one understanding of health literacy that, if needed and based on purpose, can be shaped to serve different populations (based on age, gender, culture, professions, roles), different settings (healthcare, everyday life, schools, workplaces), different health approaches (physical health, mental health, wellbeing, digital health), and different conceptual needs (based on needed personal or environmental skills). For the future of health literacy development, it will be particularly important that the approaches intersect and are unified, starting with early years and school education and proceeding to adult and continuing education, both of which are based on the principle of lifelong learning for health, and that this approach combines the values and characteristics of both healthcare and public health, as introduced in this chapter.

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3

Health literacy of children and adolescents: Conceptual approaches and developmental considerations

Janine Bröder and Graça S. Carvalho

Introduction

The interest in children and adolescents' health literacy has strongly increased in recent years (Ormshaw et al, 2013; Bröder et al, 2017). Childhood and adolescence are life phases in which major physical, cognitive and emotional development processes take place. Likewise, health-promoting attitudes, beliefs and behaviours surface in these life phases, and can be supported by meeting children and adolescents' information needs and fostering their active involvement in their own health. Therefore, addressing health literacy from an early age onwards is argued to be a promising investment in children's health and wellbeing now and throughout their adolescence and adult lives (Borzekowski, 2009; Sanders et al, 2009; Velardo and Drummond, 2016).

The health literacy concept is multifaceted, with diverse conceptual understandings. Sørensen and colleagues (2012, p 3) define health literacy as 'being linked to literacy and entail[ing] people's knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention, and health promotion to maintain or improve quality of life during the life course.'

As for adults, there are various health literacy conceptualisations and definitions addressed to children and adolescents, prominently addressed as outcomes of school health education (Joint Committee on National Health Education Standards, 1995; Paakkari and Paakkari, 2012) or through the focus on their parents or care takers' health literacy (DeWalt and Hink, 2009; Connelly and Turner, 2017). Moreover, there is limited evidence available regarding their fit and appropriateness for the target group, given their life phase-specific particularities and needs (Bröder et al, 2017). Indeed, Fairbrother and colleagues (2016) have revealed gaps in understanding not only 'what' health literacy (skills) children and adolescents have and develop in the different life phases, but also 'how' they actually interact with health-related information in their everyday lives. Similarly, Velardo and Drummond (2016) stress the need to bring forward a child-centred health literacy understanding that integrates children's understanding, attitudes and choices related to health and health-related information.

The purpose of this chapter is, therefore, to highlight life phase particularities for health literacy by exploring children and adolescents' health literacy from development-focused perspectives. Thus, this chapter focuses on:

- synthesising the available definitions, models and research discourse on children and adolescents' health literacy;
- describing and discussing considerations of developmental processes and life phase particularities, for children and adolescents' health literacy available in the literature.

Current conceptual approaches for health literacy in childhood and adolescence

Health literacy is a highly diverse construct, with over 100 different definitions for the general population (Malloy-Weir et al, 2016) and at least 12 definitions and 20 models addressing children and adolescents (Bröder et al, 2017). The major perspectives in the conceptual discussion of children and adolescents' health literacy are synthesised in this section.

Most commonly, it has been described as an individual attribute that addresses how children and adolescents access, comprehend, evaluate and communicate health information and messages, and how these are used for health-related decision-making and behaviours (Bröder et al, 2017). Within most of the conceptualisations there is a focus on the acquisition and utilisation of individual competencies, skills and knowledge that comprise health literacy. Most frequently, there is an emphasis on individual cognitive abilities, such as reading, writing, critical thinking or information-processing skills (Wolf et al, 2009). Nevertheless, it has also been argued to be an umbrella concept, containing, in addition to cognitive attributes, affective attributes (for instance, self-reflection, self-efficacy, motivation), operational or behavioural attributes (such as communicative and social skills) or specific technical skills (such as navigating the healthcare setting or system, technological information-searching skills; see Bröder et al, 2017). An example for a skill-centred concept is provided by Paakkari and Paakkari (2012), who define health literacy as a learning outcome of school health education, and assess students' abilities in a testing situation. Therefore, health literacy is clearly detached from the actual actions or behaviour in a given environment. This skill assessment is common within many performance-based measurement tools of health literacy in school (Ormshaw et al, 2013).

Another common approach concerns areas of action related to health literacy by focusing on how health information is used and applied in different health-related life settings (Sørensen et al, 2012) and the 'context of everyday life', that is, in the family and social environment (Kickbusch, 2008). Hence, health literacy is argued to be a personal and societal asset and a resource for one's own health and the health of others (Nutbeam, 2008). Moreover, health literacy can be regarded as a tool for personal empowerment (Crondahl and Eklund Karlsson, 2016).

At the outcome level, many concepts define broad levels of purposes and effects of health literacy, such as healthy behaviours and increased personal health and wellbeing. Often, models and definitions imply a sequential association effect between health information on the one hand, and 'healthier' decision-making, reducing risks and promoting personal health on the other, being mediated by personal health literacy. This implies the underlying assumption of a rational acting subject, engaging in deliberate health-related choices and actions. By stressing the active role of the individual, these concepts presume a high degree of personal agency – the capacity of acting independent of structural factors (Stones, 2015). Moreover, these assumptions fall short in considering the complexity and broader set of factors affecting behaviour and behavioural change. These are, for example, interdependencies between the subject and their life contexts, cultural factors, social support as well as affective and emotional aspects, such as self-efficacy, self-determination, habits and belief systems (Malloy-Weir et al, 2016; Bröder et al, 2017). As some abilities may be helpful for some children and adolescents in a specific context, other situations and contexts may require the adaptation of such abilities or even totally different abilities. Moreover, children and adolescents' personal abilities as well as their opportunities for applying their health literacy are determined by the demands posed on them in a given situation as well as by their socio-ecological and cultural environments.

The importance of considering health literacy as being linked to a given environment, social contexts (Kickbusch et al, 2013) or as a product of the person's attributes and situational demands (Nutbeam, 2017) has been widely emphasised within the health literacy discourse. For child and adolescent health literacy, Bröder and colleagues (2017) have identified different conceptual approaches in models for addressing the relation of contextual factors and health literacy, but only very few definitions referring to it. Most frequently, contextual factors are addressed as antecedents of health literacy: (a) the interpersonal context, for example parental socioeconomic status and the home environment; (b) situational determinants, such as the degree of social support, and influences from family and peers, the school and community setting, media etc; and (c) the broader social and cultural environment, for example, characteristics of the health and education system, as well as political and demographic variables. Some models address the contextual relationship of health literacy through sociological perspectives, proposing a health literacy socialisation model (Paek et al, 2011), or socio-ecological model of health literacy for adolescents (Wharf Higgins et al, 2009). Within the definitions found in the literature, the relevance of contextual factors is only vaguely considered through the recognition of different health contexts and life settings, for example, in the domains of healthcare, disease prevention and health promotion (Bröder et al, 2017). As a result, the interdependency of sociocultural and socioeconomic factors is recognised, but far less understood than the prevailing focus on individual attributes (Sentell et al, 2017).

Regarding the focus of health literacy in children and adolescents, many studies have addressed the health literacy of people close to the child, such as caregivers, mothers, parents and teachers' health literacy (Mackert et al, 2015). As these people are certainly important contributors to children or adolescents' health and health literacy, researchers have proposed that child and adolescent health literacy be regarded as the sum result of the health literacy skills *and* resources available in the proximal social context, namely, adults, peers or institutions the adolescents trust in. Among others, this is referred to as 'collective' (Sanders et al, 2009), 'distributed' (Edwards et al, 2015) or 'public' health literacy (Freedman et al, 2009).

However, it is equally important to recognise children and adolescents' health literacy potential from a very young age onwards (Borzekowski, 2009). Nevertheless, most conceptualisations have not included these target groups, not even indirectly, so that children and adolescents are just assumed as having similar health literacy needs and skills sets as their close adults (Bröder et al, 2017). Hence, there are still shortfalls in the recognition of children and adolescents' subjective perspectives on health, their informational needs and the adequate levels of participation in health decision-making (Brady et al, 2015; Velardo and Drummond, 2016; Bröder et al, 2017). As a result, this target group particularities and voices remain underrepresented in health literacy literature. To address this gap, together with the purpose of discussing approaches for targeting health literacy in children and adolescents, Okan and colleagues (2016), by building on the existing 4D model (Forrest et al, 1997), proposed a 5D model that highlights five dimensions of particularities in children and adolescents: differential epidemiology and health patterns; demographic patterns and inequalities; developmental processes; dependency within intergenerational relationships and power structures; and democracy through participation and citizenship.

Besides general health literacy, numerous topic-specific (for example, oral, mental or diabetes), area- and context-specific (for example, science, media, technology, information) literacies are defined for the target group or general population (Mackert et al, 2015). The outlined conceptual heterogeneity as well as the occurrence of many specific forms of health literacies – or related literacies – has resulted in a high internal differentiation or even fragmentation of the health literacy concept. Consequently, this conceptual heterogeneity poses challenges for health literacy measurements (see Chapters 5, 6 and 8, this volume), and influences how health literacy for children and adolescents is operationalised and promoted in practice and policy.

Particularities of children and adolescents' development for health literacy

Given the conceptual heterogeneity and gaps in life phase-specific understandings for health literacy of children and adolescents, this section explores and discusses children and adolescents' particularities for health literacy through a development perspective. Developmental aspects are important for better understanding of

(a) how individual health literacy develops during these early life phases, and (b) how general developmental processes and changes interact and affect a child or adolescent's health literacy. Hence, this section outlines current approaches of how developmental aspects are being considered within current child and adolescent health literacy literature and research. It is structured into psychological and sociological perspectives, and then discussed and complemented with insights from the respective theories and research fields.

Psychological perspective on health literacy and development

A common approach for a psychological perspective on health literacy and development is to focus on cognitive abilities – for example, development-depending health literacy levels with three successive developmental stages (Borzekowski, 2009; Sanders et al, 2009; Lambert and Keogh, 2014). The development perspective from Sanders and colleagues (2009) is presented in Table 3.1 for children up to the ages of 4, 10, 14 and 18. In this model, health literacy is conceptualised within four skill areas (prose/document literacy, oral literacy, numeracy and systems-navigation skills), and examples of activities are provided for each age and development stage. A more extensive classification of such an approach can be found within the US National Health Education Standards (Joint Committee on National Health Education Standards, 1995) that provides a detailed overview of the health literacy skills that students of a certain school grade should achieve.

Advocates of these stage models argue that they may provide an overview or a guideline of what health literacy skills can be expected of children and adolescents at each specific stage, and hence may enable comparisons at the population level. Nevertheless, stage models on child and adolescent development have in common that they set normative standards that a child should be able to reach at a certain age. In other words, such a development perspective is strongly 'top-down' as it limits health literacy to a predefined set of abilities: if a child develops such abilities, he/she is considered health literate; if not, he/she is left to a low score, as, for example, with the widely used measurement tools that typically measure only distinctive skills, such as reading abilities (TOFHLA, Test of Functional Health Literacy in Adults) or word recognition (for example, the REALM measurement tool, Rapid Estimate of Adult Literacy in Medicine) (see Chapters 5 and 6, this volume).

Moreover, stage models offer an idealistic, one-size-fits-all approach, implying that all children develop at the same speed and reach certain levels at a particular age, not taking into account individual–environmental interaction. Hence, they build on the questionable assumption that it is possible to determine how children's understanding of health and illness and their health literacy skills typically evolve, regardless of the environment or the culture in which a child lives. In contrast, Gossen and Nürnberger (2013) have argued that children gain computer skills at an increasingly younger age, and that nowadays, 'age' is not a very good indicator of children's abilities.

Table 3.1: Examples of health literacy levels according to age groups

	Prose/ document literacy skills	**Verbal/expression skills (oral literacy)**	**Numeracy skills**	**Systems-navigation skills**
By age 4, a child should be able to…	N/A	Communicate with an adult, caregiver or health provider about health behaviours (eg, tooth brushing, physical activity)	Recognise the relative value of health choices (eg, food portion sizes)	N/A
By age 10, a child should be able to…	Understand the content of a child-oriented handout about bike helmet use	Describe ways to prevent common childhood injuries and health problems	Identify the characteristics of healthy versus non-healthy foods on the basis of sugar or fat content in nutrition labels	Describe how the media can influence health behaviours
By age 14, a child should be able to…	Develop a written plan to attain a personal health goal that addresses personal strengths, needs and risks	Demonstrate refusal, negotiation and collaboration skills to enhance peer and family influence on health behaviours	Analyse personal susceptibility to injury, illness or death if engaging in unhealthy behaviours	Evaluate the validity of health information, products and services and access valid health information and counselling services
By age 18, a child should be able to…	Complete a document with a child's medical history and health needs and read and understand the patient's bill of rights	Identify a child or family's health behaviours and establish personal health goals for a family or child	Understand and use simple forms of medication and understand results of child health screening tests (eg, new-born screening results, growth chart)	Complete the enrolment process for child health insurance and obtain school-based health services

Source: Sanders et al (2009)

Sociological perspectives on health literacy and development

Health literacy scholars have also stressed the interrelatedness of personal skills with structural and situational factors in a given setting. Therefore, it is critical to review and discuss considerations of sociological perspectives of children's development for the health literacy of children and adolescents by focusing on four prominent sociological approaches: sociocultural aspects of the development; socio-ecological approaches; childhood socialisation: a modern perspective; and the new sociology of childhood: the concept of intergenerational order.

Sociocultural aspects of the development

Health literacy researchers have applied Vygotsky's (1978) theory of sociocultural development to health literacy (Borzekowski, 2009) for highlighting the fundamental role of social interactions with regards to health literacy and development. Vygotsky challenged the concept of development taking place in distinct stages. Rather, he stressed the importance of social interaction, viewing children's learning as taking place in a social context. A central aspect in his approach is the assumption that one's development potential is limited to a 'zone of proximal development', the distance between the child's actual development level and the level it can potentially achieve through guidance and support. Hence, through 'scaffolding', the health literacy abilities a child can develop through temporary adult guidance or peer collaboration would exceed the health literacy a child could attain by him/herself. Vygotsky's interest in how cognitive processes are directly impacted by the specific culture in a child's surrounding results in the concept of the 'inter-subjectivity of social meanings'. It refers to the shared understanding of social meanings that occur within social groups through negotiation and communication (Smith et al, 2015). As health information is loaded with cultural meaning as well, Okan and colleagues (2016) argue for the crucial importance of children's participation within a cultural community to observe how their peers and adults seek and derive meaning from information and engage in health decision-making. Promoting children and adolescents' health literacy may benefit from the concept of 'guided participation', proposed by Paradise and Rogoff (2009), who draw on the idea of scaffolding by Vygotsky (1978). It entails that 'children actively engage in cultural practices' when 'adult models guide and regulate performance while creating temporary scaffolds that offer a form of bridge between old patterns and new' (Ansell, 2017, p 562). Hence, it allows children to receive appropriate levels of guidance as they encounter and master new activities.

Socio-ecological approaches

Wharf Higgins and colleagues (2009) and Okan and colleagues (2017) proposed a socio-ecological approach to health literacy for children and adolescents that includes internal and external factors affecting their health literacy. This socio-ecological perspective on development was originally introduced by Bronfenbrenner (1979), and represents a prominent approach for highlighting the relationships between people and their social world within health literacy research. As such, the relationship between individuals and their social world are structured in dynamic micro-, meso- and macro-layers, while taking into account a life course perspective on the chronologic dimension. Wharf Higgins and colleagues (2009) locate: (a) internal influences on children and adolescents' health literacy at the micro context, including factors such as age, gender, beliefs, values, experiences and socioeconomic status; (b) intrapersonal influences at the meso context, bridging between the micro and the macro context, and include factors such as 'social support and influences, the quality and nature of human interactions, peers, family' (Wharf Higgins et al, 2009, p 352); and (c) external influences, namely, environmental and structural factors in society, the community and neighbourhood affecting people's health at the macro context. They concluded that any approach that aims to promote health literacy effectively needs to consider the structure of adolescent's social worlds, and the reciprocal interaction between individuals and their social environment (Wharf Higgins et al, 2009; Okan et al, 2017).

Childhood socialisation: a modern perspective

Paek and colleagues (2011) proposed a health socialisation model for health literacy that focuses on the direct, relative and mediating role of interpersonal (that is, parents, peers, schools) and medial socialisation agents for adolescent health literacy. The study revealed that interpersonal and media socialisation agents have 'similar important roles' in the development of adolescents' health literacy skills (Paek et al, 2011, p 143). They concluded that the recent developments in online social media and social networks blurred the line between 'traditional' media and interpersonal channels by 'building new types of relationships and may serve as a proxy for interpersonal health information sources' (Paek et al, 2011, p 143). Indeed, modern types of media, including prominent social media channels such as YouTube, Facebook and Twitter, apply multimodal designs, such as text-based, visual, audio and image (Tse et al, 2015). Hence, utilising multimodal social media designs in health literacy interventions and assessments seems promising and requires students to develop multimodal literacies instead of learning how to use single modes, such as print-based media, as advocated by multi-literacies researchers (Cope and Kalantzis, 2005; Kress, 2010).

By focusing on the (one-directional) impact of social and media structures on the individual's health literacy, Paek and colleagues' research (2011) is in line with traditional structure-centred approaches to socialisation. Nevertheless, modern socialisation researchers have emphasised the mutual dependency and continuous interaction between personal agency and structures (Bauer et al, 2012; Richter and Hurrelmann, 2016). Hence, socialisation is defined as the process of emergence, formation and lifelong development of human personality, entailing the reciprocal adjustment of individuals and society (Bauer et al, 2012). Richter and Hurrelmann (2016, p 270) proposed the concept of 'the individual as a productive processor of internal and external reality' that has been popular in German-speaking countries, with limited consideration in English publications. It assumes that personality development is largely constructed and self-directed through coping with developmental tasks, and a person's constant interaction with their 'outer reality', that is, the social and material environment, and the 'inner reality', that is, their biophysical and psychological structures of human personality (Richter and Hurrelmann, 2016). This process takes place as 'the individual assimilates environmental factors and reconciles them with his/her existing views and potentials, and at the same time he/she endeavours to achieve equilibrium between environmental demands and his/her own needs, interests and abilities' (2016, p 269). Hence, the emphasis on the child as the central agent of socialisation can help to understand the active role that is attributed to the person's health literacy. As such, common health literacy concepts presume that children and adolescents possess adequate degrees of agency and capacity to act in a given environment. Nevertheless, it has not been investigated what degree of active agency children and adolescents possess with regards to health literacy at a certain age and developmental stage, and how this agency is acquired. In addition to the need of making children's active role for health literacy visible, Richter and Hurrelmann's concept (2016) emphasises the person's needs and interests, and the importance of voicing, hearing and understanding children and adolescents' own perspectives, beliefs and needs. Therefore, it is impossible to observe and understand how children and young people are socialised with regards to their health and health information by using health literacy approaches that focus on predefined skill areas and standardised testing.

New sociology of childhood: the concept of intergenerational order

Next to modern socialisation models, health literacy researchers, including Fairbrother and colleagues (2016) and Velardo and Drummond (2016), have stressed the relevance of the 'new' childhood sociology (NCS) paradigms (Bühler-Niederberger, 2010; James and Prout, 2015) for a child-centred approach to health literacy. NCS stresses children's role as active social actors and embodied beings in their social worlds. It therefore overcomes the traditional sociological perspective on childhood, rooted within the structural functionalist paradigm, where the child is regarded as future becoming, waiting to be moulded by adults (Bühler-Niederberger, 2010). Also, NCS researchers Alanen (2009) and Mayall (2009) introduced the concept of (inter-)generational order, which Okan and colleagues (2016) considered to be a helpful approach for understanding the social dimensions of health literacy. While traditional views distinguish adults and children into two categories with specific duties and rights that vary with age, development stage and context, the new concept of intergenerational order stresses the dynamics of adult–child relations as unequal power structures. As such, an adolescent's health literacy agency – referring to their actual options for engaging with health information and decision-making in a given environment – is 'bounded by and in intergenerational relations as well as in wider socioeconomic contexts and bodily, social and material resources' (Brady et al, 2015, p 174). Through an extensive ethnographic study, Lareau (2011) showed that an unequal distribution of resources, mainly caused by inequality from social class, manifest in patterns of unequal intergenerational relations and educational approaches (see Chapter 37, this volume). These observations revealed the robustness of the social conditions that children are born into, their manifestation and reproduction in children's life trajectories though unequal power structures and parenting strategies. The latter are characterised by the degree of parental intervention in their child's institutional career, the degree of free-time activities being structured/scheduled and promoted, and the culture of verbal interaction (Lareau, 2011). In summary, viewing children as being positioned in intergenerational relations sheds light on unequal power structures and the way children and adolescents, as their own social groups, are viewed, listened to and involved in health literacy in different health-related settings, such as their home, school context or healthcare setting.

Conclusion

The purpose of this chapter was to highlight life phase particularities for health literacy by exploring children and adolescents' health literacy from a development-focused perspective. First, the chapter highlighted that health literacy is commonly considered as a combination of predefined individual attributes with a strong focus on cognitive skills. Within this approach, the focus is on 'what' – mostly cognitive – prerequisites children and adolescents need for understanding and dealing with health information and engaging in health decision-making. Indeed, specific skills are rather easy to promote through individual focused intervention, which is in line with traditional health education paradigms that focus on the provision of information. Nevertheless, children and adolescents' knowledge acquisition is embedded in contextualised narratives, for instance, conversations, personal interpretation, stories, gossip, carrying norms, morals and ideas of sociocultural practices. Learning and developing health literacy-relevant skills and knowledge can take place in highly variable and specific ways that are unique to the child and their family's specific situation and needs. Hence, health literacy must be recognised as a personal asset that can take on many forms and dimensions as one's life trajectory is shaped by one's experiences, social condition and choices, among others. Understanding health literacy as a personal asset of children and adolescents requires approaches that depart from a person-centred point of view, with the aim of observing and understanding the person's strategies for encountering and dealing with information, their personal mix of resources and belief systems. A child-centred health literacy understanding would therefore consider children and adolescents as active and reflective members of the society, acknowledging their individual perspectives, beliefs, expertise, personal resources and embodied understandings. Hence, future research should address how children and adolescents actually mobilise their resources and capabilities to practice healthy decisions in the context of their everyday life. This implies a shift away from judging/classifying individuals by their health literacy skill levels towards observing how these skills are practised and developed by the child within a given environment. This relates to the sociocultural research paradigms on literacy, which focus on how literacy is being practised, viewing it as culturally and historically embedded and situated in everyday practice (Barton et al, 2000).

Second, health literacy researchers (for example, Nutbeam, 2017) have stressed the need to focus on health literacy not as an individual attribute, but as the product of the interaction between social conditions and individual skills related to health information-seeking and health-related decision-making. Hence, what and how well a person is able to use their skills largely depends on the situation or task at hand, and interrelations with environmental factors. Considering insights from childhood socialisation and childhood sociology enables a differentiated understanding of this individual–contextual interaction. This can be referred to as the social embeddedness of health literacy, which has remained under-explored in current conceptual and empirical research. As intergenerational relationships and an unequal distribution of power are manifest inequalities, they influence children and adolescent's health literacy development and their opportunities for participating in health-related decision-making. Future research should therefore address how the health literacy of children and adolescents is promoted or hindered through the intergenerational transfer of abilities, values, habits and norms as well as the internalisation of societal ideologies.

It is important to understand the relationship between the social and material structures of the environment and personal agency, including one's biological and psychological factors, for health literacy. Hence, it is proposed to shift the focus away from individual skills and to consider it as the interaction between (a) resources at the personal, interpersonal and societal level and (b) the situation demands in a given environmental setting. This highlights that, in addition to promoting skills, health literacy research needs to address questions of how children and adolescents encountering health information have opportunities and alternatives for their action in a given environment. If personal health literacy agency is best developed through continuous and hands-on practice in everyday health-related life situations, it is crucial that there are protected spaces and responsive structures available for children and adolescents to do so. Hence, future health literacy research, policy and practice needs to focus on making children's health literacy abilities visible, by insisting on their meaningful participation with issues that concern their health, and by voicing their perspectives with regards to health and health information.

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4

The concept of mental health literacy

Anthony F. Jorm

Introduction

In a 1993 Australian government report, *Goals and targets for Australia's health in the year 2000 and beyond*, Nutbeam and colleagues defined health literacy as 'the ability to gain access to, understand, and use information in ways which promote and maintain good health' (Nutbeam et al, 1993, p 151). They then proposed a range of goals and targets concerning literacy for various physical diseases. Curiously, they omitted any mention of health literacy for promoting and maintaining good mental health. Spurred on by this omission, Jorm and colleagues (1997a) subsequently proposed the concept of 'mental health literacy' that they defined as 'knowledge and beliefs about mental disorders which aid their recognition, management and prevention' (1997a, p 182). They further proposed that mental health literacy includes 'the ability to recognise specific disorders; knowing how to seek mental health information; knowledge of risk factors and causes, of self-treatments, and of professional help available; and attitudes that promote recognition and appropriate help-seeking' (1997a, p 182).

More recently, Jorm (2012) distinguished a number of components of mental health literacy, including:

> (a) knowledge of how to prevent mental disorders, (b) recognition of when a disorder is developing, (c) knowledge of help-seeking options and treatments available, (d) knowledge of effective self-help strategies for milder problems, and (e) first aid skills to support others who are developing a mental disorder or are in a mental health crisis. (2012, p 231)

A notable feature of how this concept has been defined is that it is not simply knowledge of mental disorders or mental health, but rather knowledge that a person can use to take practical action to benefit their own mental health or that of others. For example, knowledge of the genetics of schizophrenia or the distinction between bipolar I and bipolar II disorders would not constitute mental health literacy under this definition, because this knowledge does not underpin any potentially beneficial action.

The intention in proposing the concept of 'mental health literacy' was to draw attention to an area neglected by both health literacy researchers and by the mental health sector. At the time the concept was defined (the mid-1990s), the notion that members of the general public needed an understanding of mental disorders that could empower them to take action was novel. The emphasis within the mental health sector was very much on extending professional training, particularly of the mental healthcare skills of primary care professionals such as GPs. Members of the public with mental disorders were very much seen as passive recipients of professional actions (Goldberg and Huxley, 1992). The introduction of the concept of 'mental health literacy', by contrast, portrayed the person affected as the primary agent managing their own symptoms, with seeking professional help being one of a range of strategies they might try (Jorm, 2000).

While the concept of 'mental health literacy' was originally developed for adults, it has since been extended to adolescents, as this is an important phase of life for first onset of mental disorders. For more information on the mental health literacy of adolescents, see Chapter 19, this volume. Less attention has been given to the mental health literacy of children.

This chapter looks at what community surveys have shown about these components of mental health literacy, and examines the measurement of mental health literacy at both the population and individual level. It argues for the necessity of having a concept of 'mental health literacy', which is additional to the broader concept of 'health literacy', and considers proposals to extend the concept to include non-stigmatising attitudes and wellbeing literacy.

What community surveys reveal about mental health literacy

The concept of 'mental health literacy' led to an initial Australian national survey of adults in 1995 (Jorm et al, 1997a). Similar surveys were carried out independently in Germany and Austria in the mid-1990s, although unknown to each other at the time (Jorm et al, 2000a). These surveys involved presenting a vignette describing a person with symptoms of a mental disorder (see Table 4.1 for examples), and then asking the respondent a series of questions about the person. The vignette-based method has become the standard for studying mental health literacy in community surveys in many countries.

When studying the mental health literacy of the public, it is helpful to have a standard of ideal responses against which to compare. Various methods have been used to do this. In some cases it is possible to judge responses against the published evidence or against existing professional guidelines. However, another method that has been used is to ask similar questions to various groups of mental health professionals and to examine discrepancies between public and professional beliefs, for example, about what treatments are likely to be helpful (Lauber et al, 2005; Jorm et al, 2008; Morgan et al, 2014). The Delphi method has also been used to reach a professional consensus on appropriate public actions, for example, to develop guidelines on appropriate mental health first aid strategies (Kelly

Table 4.1: Examples of vignettes used in community surveys of mental health literacy

Type of problem	Vignette
Depression	John is 30 years old. He has been feeling unusually sad and miserable for the last few weeks. Even though he is tired all the time, he has trouble sleeping nearly every night. John doesn't feel like eating and has lost weight. He can't keep his mind on his work and puts off making decisions. Even day-to-day tasks seem too much for him. This has come to the attention of John's boss who is concerned about his lowered productivity.
Schizophrenia	John is 24 and lives at home with his parents. He has had a few temporary jobs since finishing school but is now unemployed. Over the last six months he has stopped seeing his friends and has begun locking himself in his bedroom and refusing to eat with the family or to have a bath. His parents also hear him walking about his bedroom at night while they are in bed. Even though they know he is alone, they have heard him shouting and arguing as if someone else is there. When they try to encourage him to do more things, he whispers that he won't leave home because the neighbour is spying on him. They realise he is not taking drugs because he never sees anyone or goes anywhere.

Source: Jorm et al (1997a)

et al, 2008a, b, 2009, 2010; Hart et al, 2009; Kingston et al, 2009, 2011; Ross et al, 2014). Some results from community surveys of adolescents and adults are reported below to illustrate the various components of mental health literacy, particularly where there are commonly deficiencies.

Knowledge of how to prevent mental disorders

While some important risk factors, such as traumatic life events, may be outside of an individual's control, there are other lifestyle factors that can be modified to reduce risk. For example, to determine what adolescents can do to reduce their risk of depression, Cairns and colleagues (2014, 2015) carried out a systematic review of longitudinal risk and protection factors and a Delphi study to establish expert consensus on preventive strategies. The found a large number of strategies to have preventive potential, including strategies to develop mental fitness and life skills, fostering healthy relationships and adopting healthy lifestyles.

A survey of Australian young people aged 12–25 assessed their beliefs about a number of prevention strategies for depression, psychosis, social phobia and post-traumatic stress disorder (PTSD) (Yap et al, 2012). There was a high level of agreement by the young people that physical activity, regular contact with family and friends and relaxing activities were protective, which is consistent with both the available evidence and professional consensus. However, a major discrepancy between the young people and professionals' beliefs occurred for the strategy of avoiding stressful situations. Whereas most of the young people endorsed this strategy, few professionals did. The professionals' views are consistent with the evidence that avoidance is associated with the maintenance of anxiety disorders, and that dealing with stressful situations provides an opportunity to learn effective coping strategies.

Because some risk factors for mental disorders occur early in life, preventive action needs to be taken by parents or other carers. In order to guide what parents can do, a number of systematic reviews have been carried out on longitudinal studies of parenting factors associated with depression and anxiety and in children or adolescents (Yap et al, 2014a; Yap and Jorm, 2015) and alcohol misuse in adolescents (Yap et al, 2017). Delphi expert consensus studies have also been carried out on preventive strategies that parents can use for reducing the risk of these problems (Yap et al, 2014b, 2015b). However, parents often do not know what to do or how to act optimally in these areas. For example, when parental beliefs about reducing the risk of alcohol misuse were examined in an online survey, many parents had deficiencies in their knowledge and actions about modelling responsible alcohol use and in setting appropriate family rules (Yap et al, 2015a).

Recognition of when a disorder is developing

It can be useful for members of the public to be able to recognise when mental health problems are reaching the threshold that warrants intervention, and to conceptualise what they are experiencing in ways that facilitate appropriate help-seeking. Lack of recognition of a person's problem as a mental disorder may contribute to the long delays that often occur between reaching the threshold for a mental disorder and seeking help (P.S. Wang et al, 2007). Community surveys of mental disorders in many countries have found that many people do not seek professional help, and even those who do eventually seek help may delay for many years. Longer delays between onset and professional help-seeking are associated with worse outcomes, so it is important that these delays be reduced. While there are many factors that can lead to these delays, an important one is that the person does not conceptualise what they are experiencing as a mental disorder. This can be seen in an Australian study of people who sought professional help for anxiety or mood disorders. The average delay was 8.2 years, but most of this was the delay between onset and recognition (average of 6.9 years), with a much shorter delay between recognition and help-seeking (average 1.3 years) (Thompson et al, 2004).

In community surveys of mental health literacy, recognition can be assessed by presenting vignettes like those in Table 4.1, and asking the respondent what, if anything, they think is wrong with the person. For example, in the first Australian national survey of mental health literacy carried out in 1995, it was found that while most adults could recognise some sort of mental health problem, some categorised the problem as a physical disorder or saw it as a personal or employment issue. For the depression vignette, 39 per cent used the label 'depression', while for the schizophrenia vignette, 27 per cent used the labels 'schizophrenia' or 'psychosis'. Recognition of the problem typically varies between vignettes, and there is variation between countries. Studies of non-Western countries often find that recognition is poorer than in Western ones (Jorm et al, 2005b; Atilola, 2015). Recognition has also varied over time in some countries (Reavley and Jorm, 2012; Schomerus et al, 2012).

A contributing factor in failure of recognition is that mental disorders often have first onset early in life and young people may have less knowledge in this area. It has been found that young people who can give a psychiatric label for the problem in a vignette have more appropriate help-seeking preferences, while those who used lay labels such as 'stress' and 'shy' are less likely to see professional help as warranted (Wright et al, 2007, 2012). It may be that the use of psychiatric labels activates a schema about appropriate action to take (Wright et al, 2007).

Knowledge of help-seeking options and treatments available

When the threshold for a mental disorder is reached, the person affected needs to know about sources of professional help and effective treatments that are available. However, community surveys of mental health literacy show that many members of the public lack adequate knowledge in these areas. For example, in the 1995 Australian national survey of mental health literacy some major differences were found between public and professional beliefs. Counsellors (who are not a registered profession in Australia) were more often seen as likely to be helpful than psychologists and psychiatrists, while vitamins were more often seen as likely to be helpful than antidepressants (Jorm et al, 1997a). More recent surveys of mental health literacy in Australia have shown considerable changes in these areas, with public views moving to be much closer to those of mental health professionals (Reavley et al, 2013; Morgan et al, 2014). However, there are still some major gaps, with the public more likely than professionals to believe in the helpfulness of close family or friends, a counsellor, vitamins and minerals, a special diet or avoiding certain foods, and having an occasional alcoholic drink to relax. By contrast, professionals showed a greater belief than the public in psychotherapy and cognitive behaviour therapy for depression and anxiety, and antipsychotics for schizophrenia.

Negative views of mental health services have been found to be common in many other countries. For example, a survey of the public in six European countries found that around one in three people believed that professional care for mental health problems was worse than or equal to no help (Ten Have et al, 2010).

Given that beliefs about services and treatments are often less than optimal, it is not surprising that many people with mental disorders in the community remain untreated. While there is no single cause of the low rates of treatment for mental disorders, attitudinal factors are important. An analysis of data from the 24 countries participating in the World Mental Health surveys found that a desire to handle the problem on one's own was the most commonly reported barrier to not receiving treatment (Andrade et al, 2014). Even when treatment is sought, a person's beliefs and attitudes to treatments are an important factor in whether they are continued (Acosta et al, 2013).

Knowledge of effective self-help strategies for milder problems

Surveys of mental health literacy in a number of countries have found that members of the public often believe in the helpfulness of self-help strategies (Jorm et al, 1997a, 2005b; J. Wang et al, 2007), and there is evidence that they commonly use them (Jorm et al, 2000b). Some of these self-help strategies have evidence of effectiveness (for example, physical activity), whereas others are more likely to be ineffective (for example, vitamins) or even harmful (for example, use of alcohol to relax).

Self-help strategies are most often used for milder mental health problems. Jorm et al (2004) have proposed an 'overlapping waves of action model' to account for the role of self-help. According to this model, a person can use a range of strategies to deal with mental health problems, including increasing the use of self-help strategies already in their repertoire (for example, seeking more social support or engaging in more physical activity), taking up new self-help strategies (for example, learning meditation or taking a herbal remedy), or seeking professional help. At the individual level, the person can use these strategies in any order or can use them simultaneously. However, when looking at the population as a whole, existing self-help strategies show peak use with milder problems; this is the first wave of action. New self-help strategies show peak use with more moderate problems; this is the second wave of action. The third wave of action is professional help, which increases in frequency as mental health problems become more severe.

Given that members of the public are often positive about self-help strategies, there is a need to promote those that are most likely to be helpful. Delphi studies have been carried out to find out which self-help strategies experts think would be most likely to be effective for milder levels of depression (Morgan and Jorm, 2009) and anxiety (Morgan et al, 2016).

Mental health first aid knowledge

Mental health literacy is not only important to protect one's own mental health, but also for the capacity to support others with mental health problems. The term 'mental health first aid' has been used to refer to 'the help offered to a person developing a mental health problem, experiencing the worsening of an existing mental health problem or in a mental health crisis' (Kitchener et al, 2015, p 12). To find out what are appropriate actions to take for mental health first aid, a number of Delphi studies have been carried out with professionals, consumers and carers to develop guidelines on how to assist people with various mental health problems (for example, psychosis, depression, eating disorders), and experiencing a range of mental health crises (for example, suicidal, self-harming, experiencing a traumatic event) (Kelly et al, 2008a, b, 2009, 2010; Langlands, 2008a, b; Hart et al, 2009; Kingston et al, 2009, 2011; Ross et al, 2014).

Mental health first aid knowledge has been assessed in a number of mental health literacy surveys by asking respondents what, if anything, they would do to assist a person in a vignette if it was someone they knew and cared about. Expert-consensus guidelines have been used as a standard to judge the adequacy of public responses. In Australian surveys of adults, the quality of responses overall has been found to be poor (Rossetto et al, 2014). While respondents often say that they would listen to the person, provide support and information, and encourage the person to seek appropriate professional help, other actions, such as assessing and assisting with any crisis, are rarely mentioned, even when the person portrayed in the vignette is suicidal. This lack of knowledge can have an impact on actions actually taken to provide mental health first aid in the community. Longitudinal studies show that intentions to provide help to a person in a vignette are a predictor of later providing mental health first aid to someone who has a mental health problem (Yap and Jorm, 2012; Rossetto et al, 2016).

Measurement of mental health literacy

The term 'mental health literacy' was originally proposed as a convenient label to draw attention to a neglected area. It was not intended to define a psychological construct. Much of the research that has been carried out on mental health literacy has involved community surveys aimed at describing various components of mental health literacy at the population level rather than to provide an assessment of individuals. However, some researchers have been interested in scale score measures to quantify mental health literacy, or some aspect of mental health literacy, at the individual level. O'Connor and colleagues (2014) carried out a review of scale-based measures and identified 13 relevant studies. They concluded that there was limited psychometric data on these scales and that most measured some component of mental health literacy rather than all of those proposed by Jorm et al (1997a).

Another 'scoping review' of mental health literacy measures has been carried out by Wei and colleagues (2015). They broadened the concept of mental health literacy for their review to cover mental health knowledge (including knowledge of positive mental health), knowledge of mental illness and treatments, and stigma/attitudes towards mental illness and help-seeking. In adopting such a broad definition, they found 401 studies, which included 14 knowledge measures, 65 stigma/attitude measures and 10 help-seeking measures that had some validation.

Kutcher and colleagues (2016) have argued for the virtues of measuring the much broader concept of mental health literacy that was used in the Wei et al (2015) review. They further argued that measures used in evaluation studies of mental health literacy interventions should simultaneously address all the components of this broader definition and be relevant to a wide range of mental disorders. However, it is not clear how practical such a measure would be, given the number of items that would be required to cover the knowledge, attitudinal and behavioural components of each mental health literacy dimension and the complexity of the scoring. Stigma alone is quite complex and multidimensional. Cross-cultural portability may also be difficult to achieve for an omnibus measure, given differences in health systems. An alternative approach is to base measurement on the specific aims of an intervention rather than try to measure a wide range of outcomes that are not necessarily the target of intervention.

If 'mental health literacy' were a psychological construct, one might expect to find a broad general factor reflecting correlations between a wide range of items tapping into the definitions of Jorm et al (1997a) or Wei et al (2015). At one extreme of this dimension might be mental health professionals, while at the other end might be children who are completely ignorant of the area. On the other hand, if 'mental health literacy' is simply a term to draw attention to an important area, one would not necessarily expect any underlying factor.

This issue has been investigated in relation to treatment beliefs in factor analytic studies of data from three Australian community surveys. In these surveys, respondents were asked to rate the likely helpfulness or harmfulness of a wide range of potential interventions for a person in a vignette. These studies found three factors of treatment beliefs: medical (with high loadings on medications, psychiatric ward and ECT), psychological (with high loadings on counsellor, social worker, phone counselling, psychiatrist, psychologist, psychotherapy and hypnosis), and lifestyle (with high loadings on close friends, close family, naturopath, vitamins, physical activity and getting out more) (Jorm et al, 1997b, 2000c, 2005). These same factors are found in relation to a range of different vignettes. One of these studies also found a fourth factor labelled 'information-seeking', which covered getting information from the web, a book, health educator or consulting an expert by email (Jorm et al, 2005). It is notable that the interventions that load on a factor do not reflect greater mental health literacy, as judged by what professionals rate as likely to be helpful. Rather, they include both interventions that have evidence of effectiveness and others that do not. This is seen most clearly in the medical factor, which includes beliefs in psychotropic medications, like antidepressants and antipsychotics, but also in analgesics and antibiotics, which are not indicated for mental disorders. Rather than the ratings reflecting knowledge, or lack thereof, they appear to be based on overarching attitudes to general classes of treatment, which might be applied to any health problem. Members of the public do not appear to be 'empty vessels' waiting to be filled with knowledge provided by experts. Rather, they have pre-existing general attitudes in favour of or against certain broad classes of interventions. These broad general attitudes can be viewed as a type of mental scaffold on which more specific evidence-based knowledge is grafted. Thus, a person with a strong predisposition towards lifestyle interventions might learn to favour physical activity over vitamins for depression, while still retaining the general commitment to that class of interventions.

Challenges and extensions to the concept

While the concept of 'mental health literacy' grew out of the concept of 'health literacy', it has since taken an independent path. Mackert and colleagues (2015) have expressed concern about the fragmentation of the area of health literacy, including by health domains. They argue that domain-specific health literacy measurements make it difficult to compare findings across domains and to advance the area more broadly. In a commentary on Mackert et al (2015), Jorm (2015) argued that both a broad concept of health literacy and a domain-specific concept of mental health literacy are needed, depending on the purpose. For example, a broad concept would be useful for a community survey investigating health literacy across a number of domains, whereas a domain-specific concept would be appropriate for evaluating an intervention targeting a specific aspect, such as mental health first aid knowledge. Jorm (2015) argued that the concept of mental health literacy has been useful in drawing attention to a neglected field that was being ignored by both mental health and health literacy researchers, that the introduction of the concept had had the desired impact on government mental health policies, that it has led to the development of specific interventions targeting mental health literacy and also to the development of measures that meet the aims of specific interventions. These advances may have been slower to occur without the concept of mental health literacy.

Others have argued that the concept of mental health literacy is too narrow or have proposed extensions (see Chapter 25, this volume). Kusan (2013, p 14) has stated that the original definition of mental health literacy 'effectively translates to knowledge of the contents of the DSM and reflects the dominant biomedical orientation of the mental health field.' He has redefined mental health literacy as 'the self-generated and acquired knowledge with which people negotiate their mental health' (2013, p 14), and included such topics as resilience, salutogenesis and mindfulness, which have been associated with positive psychology. In a similar vein, Bjørnsen et al (2017) have noted that mental health literacy and its measures have focused on knowledge and beliefs about mental ill health rather than on mental health, and have proposed the term 'positive mental health literacy' to refer to the latter. On the other hand, the knowledge proposed by these concepts of positive mental health literacy overlaps considerably with knowledge required for the prevention of depression (Cairns et al, 2015) and for dealing with mild anxiety (Morgan et al, 2016), as proposed in more traditional approaches to mental health literacy that conceptualise mental health as a continuum and call for action at all points on this continuum.

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5

Measuring health literacy in adults: An overview and discussion of current tools

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Introduction

Why does the field of health literacy seem to continually struggle with issues related to measurement and – by extension – definition? Definition should be the basis of measurement, but of course, measurement should continually inform definition (Baker, 2006; National Academy of Medicine, 2009; Pleasant, 2009; Pleasant et al, 2011, 2015; Pleasant and McKinney, 2011; Sørensen and Pleasant, 2017). The field of health literacy has not always proceeded following the scientific method of: develop a hypothesis, test that hypothesis and, if warranted, revise and re-test. The hypothesis, in this case, is the definition of health literacy.

As Enrico Fermi, creator of the world's first nuclear reactor, is attributed to having said, 'There are two possible outcomes: if the result confirms the hypothesis, then you've made a measurement. If the result is contrary to the hypothesis, then you've made a discovery' (Jevremovic, 2005, p 397). Bill Gates, co-founder of the Microsoft Corporation, is reported to have said, 'I have been struck again and again by how important measurement is to improving the human condition' (Gates Foundation, 2013). In today's policy world, it is quite commonly stated that it requires numbers (and thus measurement) to get into the policy conversation – and it is equally often proposed that we measure what matters – but stories win the hearts and minds of policy-makers.

Health literacy deserves a central role in policy discussions and decisions, not to mention daily clinical and public health practice, theory development, programme evaluation and research, and the entire range of activities related to health and wellness. There is a long way to go before health literacy reaches that level of influence. At least part of that long road exists because the field has not coalesced around a theoretical construct that is measurable and transferable across contexts.

Thus, the field of health literacy faces a choice. Do we continue to follow the dominant paradigm that seems to have situated us along a too well-travelled road to scientific paralysis caused by reductionism – the tendency to ask smaller and smaller questions in the face of complexity? Or do we attempt to embrace, rather than ignore, the true, deep and meaningful complexity of health literacy in action? Do we strive to build more and more measures for smaller and smaller areas of interest requiring fewer and fewer items in each measurement tool? Or do we build larger and larger questions that help people who are struggling with or who are already successfully using their health literacy in their own lives to fully inform us about the complex pathways they are taking and the difficult choices they are making?

The latter path toward embracing complexity requires a mixed-method approach of applying both quantitative and qualitative methods, but in order to get to that level of complex understanding we need to develop new and better valid and reliable tools for both discovering new knowledge and testing what we think we already know (Hawkins et al, 2018). While all that matters about health literacy in people's lives can't yet be counted or fully understood – and may never fully be so – we are most definitely not yet counting or fully understanding all that we should or could. Simply put, there is not yet a widely adopted method of measuring all that we could measure with our current understanding. This leads to even greater challenges for the field, including making systematic reviews unnecessarily difficult, if not impossible, to conduct due to the incomparable data produced by conflicting approaches to measurement. (Okan et al, 2015, 2018; Bröder et al, 2017). Therefore, a continuing discussion about the measurement of health literacy seems fully warranted.

Health literacy measures and screeners

Beyond considerations of reliability and validity, approaches to quantifying health literacy are largely considered either a screener or a measure (National Academy of Medicine, 2009). In this chapter, both approaches will generally be lumped into a single category of 'tools'. Certainly there are key differences between items developed as quick screeners and more complete measures of health literacy, but that distinction is not central to the discussion in this chapter.

Currently, the largest freely available collection of tools associated with the measurement or screening of health literacy exists at the 'Health Literacy Tool Shed' (nd), a resource created by Michael Paasche-Orlowe of Boston University in the US. As of this writing (late 2017), the Toolshed includes 134 tools – a good number of which are variations on a common approach. For example, the Cancer Message Literacy Test (CMLT) makes three appearances – two listings for a listening tool and one for a reading tool. Similarly, there are five different versions of the Rapid Estimate of Adult Literacy in Medicine (REALM). Additionally, there are six variations on the basic REALM approach that range from focusing on genetics to dentistry and on to vascular surgery (for the entire list, see https://healthliteracy.bu.edu).

According to the Health Literacy Tool Shed website, its current approach and goals are to include measures that match the following criteria:

1. Are published in peer-reviewed journals, which describe the measure and its development process.
2. Were published prior to January 2014, with plans to add more over time.
3. Measure an individual's health literacy. Some of the health literacy tools that are not included assess the complexity of the healthcare system, provider communication skills or other facets of organisations or materials.

An overview of the most used of the health literacy tools

While this is most definitely not an indicator of quality, to determine which of these tools were most mentioned or cited within the text of peer-reviewed journal articles, we conducted a search on PubMed using the keyword phrase 'health literacy' and the acronym or key identifier of each tool. In terms of total number of mentions or citations, TOFHLA (Test of Functional Health Literacy in Adults) (Parker et al, 1995) and REALM (Rapid Estimate of Adult Literacy in Medicine) (Davis et al, 1991) appeared most frequently. In declining order, others are NVS (Newest Vital Sign) (Weiss et al, 2005); Chew (Chew et al, 2008) or BHLS (Brief Health Literacy Screen) or SILS (Single Item Literacy Screener); eHEALS (eHealth Literacy Scale) (van der Vaart et al, 2011); HLS-EU (European Health Literacy Survey) (HLS-EU Consortium, 2012); and HLQ (Health Literacy Questionnaire) (Osborne et al, 2013). In another level of analysis, number of mentions or citations per year, the order from most to least is TOFHLA, HLS-EU, NVS, REALM, HLQ, eHEALS and Chew or BHLS or SILS versions (see Table 5.1).

We did not limit this analysis to citations only. Any mention of any of the tools would appear in the PubMed findings given the search strategy. Further, we combined all versions of tools with multiple iterations into a single category for analysis. We also combined Chew's original three items and other studies which have reduced the number of items reflecting the exact same or similar constructs

Table 5.1: Most mentioned or cited health literacy measurement tools (listed by total)

Health literacy measurement tool	Year range of PubMed mentions or citations	Total number of mentions or citations	Average mentions or citations per year
TOFHLA	1995-2017	185	8.4
REALM	1991-2017	167	6.4
NVS	2005-17	86	7.2
Chew or BHLS or SILS	2004-17	53	4.1
eHEALS	2006-17	45	4.1
HLS-EU	2012-17	39	7.8
HLQ	2013-17	22	5.5

Others: SAHLSA (Short Assessment of Health Literacy for Spanish-speaking Adults) – 6; HALS (Health Activities Literacy Scale) – 3; NUMi (Numeracy Understanding in Medicine Instrument) – 3; HLSI (Health Literacy Skills Instrument) – 2.

into a single item for this analysis. We report findings only on the seven most commonly mentioned or cited tools.

As shown in Table 5.2, the most used measures vary considerable in their size and the definition of health literacy they are based on. We determined which definition was used by examining text in the original reporting article. Largely, this was as simple as identifying which definition of health literacy was cited. At times, the HLQ is the perfect example of this – the authors would cite a historically

Table 5.2: Supporting definitions and size of existing health literacy tools

Health literacy measurement tool	No of items	Health literacy definition cited as basis in original article	If relevant, do items reflect every attribute of the definition?
TOFHLA	36-67	None	N/A
REALM	7-66	None	N/A
NVS	6	Institute of Medicine et al (2004)	No
eHEALS	8	eHealth literacy is comprised of six core skills or literacies: traditional literacy; health literacy; information literacy; scientific literacy; media literacy; and computer literacy. The foundations of the eHealth literacy concept are based in part on social cognitive theory and self-efficacy theory, which promote competencies and confidence as precursors to behaviour change and skill development, and are described in detail elsewhere	No
HLS-EU	47	As an outcome of health education and communication activities, health literacy represents the cognitive and social skills that determine the motivation and ability of individuals to gain access to, understand and use information in ways that promote and maintain good health	Yes
Chew or BHLS	1-3	Health literacy is the ability to perform basic reading and numerical tasks required to function in the healthcare environment (American Medical Association, 1999)	No; for example, no assessment or self-report of numeracy skills
HLQ	44 in 9 scales	The World Health Organization (WHO) describes health literacy as 'the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health' (quoted in Nutbeam, 1998, p 10)	Developed own construct map of health literacy as part of the measure development process

common definition yet in their work forge an entirely new conceptual model/definition of health literacy for use as the basis for their approach to measurement.

The number of items in a tool to measure health literacy has long been an issue in the field. The initial and continuing heavy push toward applying health literacy in clinical contexts in the US has clearly had an effect on the shorter tools such as the REALM and NVS. However, more recent and internationally developed tools like the HLS-EU (see Chapter 8, this volume) and HLQ are clearly seeking to identify more complex understandings of health literacy based on the number of items each tool contains.

Finally, we turn our attention to the nature of these most frequently mentioned or cited health literacy tools in terms of whether they are self-report or more objective measures, how the original sample for validation was selected, whether they are freely available, and note a few limitations of each tool from our perspective.

A near majority of these tools are based on self-reports, while the three older tools – TOFHLA, REALM and NVS – attempt a more objective approach to measurement: TOFHLA assesses health knowledge and some numeracy skills; REALM assesses the ability to correctly pronounce a written word aloud; and NVS is based on a nutrition label for ice cream. We leave it to readers to decide for themselves if those measurement topics are objective measures that are truly reflective of health literacy. Self-report measures, such as HLS-EU and HLQ, in our opinion, can lend themselves to better pre-post testing and lower the possibility of stigma as well.

The only initial validation with a random sample of the adult population of interest was performed with the HLS-EU (HLS-EU Consortium, 2012). Other tools were initially tested with convenience samples of various types. We encourage those considering using these tools to assess whether the tool has been proven valid and reliable with a population reflective of the one you plan to assess.

An interesting development in the field of health literacy has been the move toward privatisation and competition versus open access and creating public goods. One of the implications of this, is simply whether a tool is freely and easily accessible to those with limited resources. In regard to the tools that seem to be most mentioned or cited (and again, we caution that popularity is not necessarily an indicator of quality), many, but not all, are freely available for use.

Finally, in Table 5.3, we briefly list some (but this is not an exhaustive list) selected limitations for each tool. We do so hoping this perspective is useful to other researchers and practitioners as they consider which tool(s) might best fit their needs. Thematically, it seems that the most common nature of a limitation is a reflection of a limited focus of many of the tools. While definitions of health literacy, like the Calgary Charter on health literacy (Coleman et al, 2009), have started moving toward highlighting not only individual abilities but also recognising barriers created by health systems and professionals, the measures of health literacy are largely limited to the idea that health literacy is an individual level factor and overlooks system dynamics (Paasche-Orlowe et al, 2005). If we

Table 5.3: Attributes and limitations of existing health literacy tools

Health literacy measurement tool	**Self-report or objective measures?**	**Original validation based on random sample of population?**	**Freely available?**	**Selected limitations**
TOFHLA	Objective tests of knowledge and numeracy	No	No – long version Yes – short version	Solely focused on clinical context. Singular reliance on Cloze methodology. Some disagreement on how to define groups in literature. Difficult to imagine giving as a pre/post
REALM	Objective, but limited to ability to pronounce words	No	Yes	Word pronunciation only, no measurement of understanding
NVS	Objective	No	Yes	Limited in context to a nutrition label
eHEALS	Self-report	No; random but within youth only	Yes	Limited solely to context of internet use for health
HSL-EU	Self-report	Yes; following Eurobarometer methodology	Yes	Limited to self-report. Largely focused on healthcare context, less on health promotion
Chew or BHLS	Self-report	No	Yes	Solely focused on clinical context. Limited to reading and numeracy skills
HLQ	Self-report	No	No	Limited to self-report. Could be considered weak on numeracy

only measure an individual's health literacy, does that not then take us back a step? The field needs to move toward balancing the need to understand individual health literacy while not giving credence to the 'deficit model' that has been historically prevalent in the field.

Discussion

There have been long-running discussions in the field of health literacy not only about how to measure, but also whether to measure or not. There are many reasons why efforts to address health literacy might choose to not include a tool to evaluate health literacy (Pleasant et al, 2011; Pleasant and McKinney, 2011). These include, but are not limited to, the following:

- There is not a widely accepted measure or screener of health literacy, thus limiting comparability of findings and the viability of systematic reviews.
- Only a few measures of health literacy are built in such a way to successfully measure change in health literacy.
- Many have seen success, given the state of the available measures, by treating health literacy as an input and hypothesising change in other measures (such as health status) as a result.
- Funding to implement the measurement or screening of health literacy is often limited.
- Some argue that a universal precautions approach can preclude measurement.

However, we must note that measurement is a core tool of science. Developing a stronger, deeper, richer – as well as valid and reliable – understanding of health literacy is the best pathway toward successfully eliminating unnecessarily poor health and high costs caused by either/both low health literacy in individuals or health literacy barriers created by health systems and professionals (Pleasant, 2011; Iraj et al, 2016; Pleasant et al, 2016). From that perspective, a risk/benefit analysis to measuring or screening for health literacy should be fairly straightforward and demonstrate a clear benefit to measurement. That assessment depends, importantly, on what will actually be done with the information collected and knowledge hopefully gained as a result of measuring the presence, absence or barriers to the use and development of health literacy.

There is little to gain and certainly some risk in spending resources to conduct yet another research programme producing a hard-to-access peer-reviewed journal article demonstrating that some people have lower health literacy than others, and there may be a correlation to some metric of health status. Even with the faults of existing measures, we feel this point has been well proven and replication can do little to further advance the field. While citations may drive successful careers, we are less sanguine that replicating the least publishable unit advances the field. Thus, we suggest that use of even the best screeners or measures of health literacy is unwarranted if there is not a plan in place for how to make a difference with that information. From this perspective, it seems to make sense to not only measure health literacy but to also always include hypothesised outcomes of improved health literacy and a plan to address any issues causing preventable poor health and/or high costs. At the very minimum, this requires several elements to the design of data collection:

1. A pre-post design at minimum in order to assess change in health literacy and in any of the hypothesised outcomes.
2. A screener or measure that can effectively assess change.
3. An intervention to create that change.

Ultimately, from a perspective that values adding knowledge and effective evidence-based practices to the human arsenal of approaches to improving health at a lower cost, we can almost always see justification to measuring or screening health literacy when the achievable goal of the effort is to identify what elements of health literacy in which people affect objective health status in what manner and further, what approach can alleviate that challenge.

A greater and predictable problem has also emerged. Studies are beginning to show that the various measures of health literacy do not come to any solid agreement (Haun, 2012; Kiechle et al, 2015). This is predictable given the lack of a shared theoretical basis, including, at times, a lack of any clear theoretical basis used to support the creation and testing of various tools that have produced widely varying approaches to measurement, as noted above. Thus, in an oddly self-sustaining way, researchers have created a new generation of research questions. The need for the oft-requested 'further research' in this case largely arises because of less than high-quality research in the first place. Overall, we see three further challenging areas for the measurement or screening of health literacy. These are: the context of the measurement, the level of detail in the measurement, and the overall maturity of the field.

Context of the measurement

There seems to be great and continually growing interest in developing a health literacy measurement/screening tool for every possible context. Currently, as you can see from the table in the Appendix, tools have been developed for multiple languages (for example, Spanish, Portuguese and Dutch) as well as multiple medical contexts (for example, dentistry, diabetes and breast cancer) and linguistic/communication contexts (for example, numeracy, touchscreen, 'functional' word recognition and graphs). Most of these follow different approaches to measurement and, when explicated – which is not as often as one would hope – are based on different conceptual models of health literacy.

One could argue that the diversity of tools indicates a growing level of interest in health literacy emerging from multiple perspectives – which seems to be true. One could also argue that the diversity of approaches reflects a continual lack of consensus on just what exactly health literacy is, what it means and how it functions – which also seems to be true.

Often this dichotomy is treated as a blessing and a curse. But perhaps there is a third way. Would it not be at least theoretically possible to develop a broadly shared consensus understanding of the construct of interest – health literacy – and study that construct in many different contexts using the same, or at least comparable, theoretical constructs as the basis for measurement? For example, could there not be an approach to measuring health literacy that can be applied in multiple contexts or even via multiple methodological approaches in such a way as to allow comparison across those contexts? We suggest an organisation like the National Academy of Medicine in the US could be the convenor of such an effort.

Level of detail of the measurement

The tools listed in the Health Literacy Tool Shed are comprised of between 1 and 127 items. In plain language, there are tools that consist of only one question while other tools consist of 127. Over the 56-year history (from 1961 to 2017) of building those tools, there has been a strong emphasis on brevity (the reductionist impulse). That emphasis is due to much of the work being focused on developing a quick screener designed to be useful in clinical contexts. This movement toward smaller and quicker tools can be considered a dominant paradigm within the history of developing health literacy measurement tools and applications.

However, there are multiple arguments that suggest this albeit productive paradigm in terms of producing new tools is also counter-productive in many ways. In sum, we suggest that the field simply doesn't yet understand health literacy well enough to take a fully reductionist approach. That is, we don't know enough about the object of our interest – health literacy – in order to make a valid and reliable selection of a small number of items in a tool to fully reflect a very complex issue. Yes, the field has and can again easily hypothesise and test the use of a single item to screen for low health literacy in a clinical context, but in our opinion there is not currently a sufficient evidence base to select a single-item screener that can fully and accurately inform clinicians how they should respond beyond the oft-heard call for universal precautions. Statistical analysis to arrive at a single-item screener is certainly feasible; what we are concerned about is the conceptual knowledge base not being strong enough to support that vast reduction to a single item.

Proceed with caution given the lack of maturity of the field

There is another much less often discussed issue that can potentially arise from reductionist approaches to measurement and screening. This is when a tool – albeit shown statistically to be valid and reliable – does not adequately inform the potential users of that information where and how each person's health literacy is lacking and what should be done to address that need.

At the group and population level, universal precautions – which is another way to describe a standardised protocol – can be marvellously effective. For example, a great move is to make all signage in a clinical facility such as a hospital not only easy to read but effective for all users. Equally, when conducted correctly, the 'teach-back' technique also appears to be effective for all users (Kripalani et al, 2008). However, these types of standardised protocols, like universal precautions, can fail when we move from the population level to the individual level. The evidence for standardised protocols is almost universally drawn from large population-based data sets – hopefully (but clearly not always) longitudinally collected with random sampling strategies and comparison/control groups. The challenge at the individual level is that the average (or norm) derived from such data sets may not be relevant to or effective for each specific individual.

For example, imagine a person who was deemed to have low health literacy from a single-item screener. What exactly, with that information, should an intervention target in order to support that individual and improve their health literacy? Is it simply reading skills that are lacking (given that the screener was most likely in print format), or is this a person who possesses many facts and information about health and healthcare but who is not able to apply that information to their own health very well? Perhaps this is a physician who is not fluent in the language of the single-item screener? Thus, while universal precautions in health literacy can be very helpful in avoiding shame and stigma – as well as informing system design at the population level – over-reliance on that approach could possibly work counter to the best practice of personalising and tailoring responses.

What a complete measure of health literacy might look like

A full discussion of the desirable attributes that a complete measure of health literacy might want to possess can be found in previous work, but to quickly summarise that effort, we point out these desirable features below (Pleasant et al, 2011). Measures of health literacy:

- need to be explicitly based on a testable theory;
- need to be able to measure all sides of the health literacy equation – the health literacy of individuals, of health systems and of health professionals;
- must allow comparison across contexts including, but not limited to, culture, life course, population group, health issue and research setting;
- should be able to assess change in health literacy over time, including as a response to interventions.

Clearly, reaching those goals will require a well-funded robust research programme, not a one-off study. This will require a multistage process that will begin with full concept explication process, so the effort can be based on – and test – sound theory. Then the effort would need to build possible items to test each component of that theory of health literacy. Those items would need to undergo rigorous testing with diverse audiences. Continuously throughout that process would be feedback loops to improve the underlying theory and then modify the development effort to match the adjustments in the underlying theoretical construct.

Such an effort would, of course, require a longitudinal research programme with the capacity for large-scale random sampling and ideally, the capacity to develop and test the measure simultaneously in several languages. Ideally, such an effort would also engage in developing add-on modules for specific contextual areas such as various chronic diseases, foci of medicine (for example, dentistry) and, for example, different healthcare and system environments. Such a methodology would ultimately develop a family of well-tested valid and reliable tools that could be applied to a diverse range of situations and populations, and yet still be comparable.

The beginning of a theory-based approach

This chapter would be remiss to not include a brief section highlighting one example of a newer tool to assess health literacy in individuals and communities that seems to meet the criteria for a complete measure of health literacy, as delineated above – the Calgary Charter on Health Literacy Scale. This is not currently listed in the Health Literacy Tool Shed as the initial peer-reviewed academic journal article is currently in review (Pleasant et al, 2018). Briefly, the Calgary Charter on Health Literacy Scale consists of five self-report statements. These are exactly and explicitly based on the definition of health literacy that is the basis for the Calgary Charter on health literacy (Coleman et al, 2009).

Responses are on a commonly used frequency-based Likert scale with four responses – never, sometimes, often and always. An even number of response categories inherently prevents individuals from settling on the middle – or average – response. The stem question read to participants is, 'Please tell me on the following scale from "never" to "always" how often you engage in the following tasks.' Ideally, participants are shown a large font size print-out of the scale's four responses. The individual items read to participants are:

- Find or look for health information
- Understand information about your health
- Evaluate how health information relates to your life
- Communicate about your health to others
- Act on information about your health.

In Spanish, the scale is read to participants as:

- Buscar información sobre salud
- Comprender información sobre su salud
- Evaluar cómo se relaciona la información sobre salud con su vida
- Comunicarse con otros sobre su salud
- Actuar en función de la información sobre su salud.

The Likert-scale responses in Spanish are nunca, a veces, frecuentemente, and siempre. The stem question is read as, 'Por favor indique en la siguiente escala desde "nunca" a "siempre" qué tan frecuentemente realiza las siguientes tareas.' In both languages, a brief definition of 'evaluate' is provided if a participant asks for further explanation.

The effort to develop and test a self-report measure of health literacy based on the Calgary Charter on health literacy is simply the first step toward a goal of an objective measure at a greater level of detail. First, however, this approach was an economically viable method to learn if the fundamental conceptual framework was valid and reliable. In initial testing, Cronbach's alpha for the scale is at a very acceptable level of 0.80. The five-scale items consistently and significantly correlate with each other and the total scale score, which has a variance of 10.9. Thus, we can say that the scale appears to be reliable. Validity is demonstrated by hypothesised statistically significant correlations between the change in health literacy and participants' changes in knowledge, attitudes, beliefs, behaviours, as well as numerous objective health status indicators.

Factor analysis employing varimax rotation using an Eigen value of 1.0 as criteria identified only one component that accounted for over 56 per cent of the variance in responses. Thus, we have confidence that it is a coherent scale measuring much, but not all, the details of a single domain – health literacy. In this expanding pathway of our work, we have also started testing the viability and evidence-gathering strength of the new Calgary Charter on Health Literacy Scale through regression analysis. The goal is to take a first small step toward building evidence on the theorised causative yet complex and interrelated pathways to informed health behaviour changes through improved health literacy. We offer an early example of this work with a simple linear regression analysis based on pre- and post-differences – that is, the amount of change – using change in body mass index (BMI) as the health indicator of interest (and thus, the dependent variable in the regression equation). This regression equation takes into account the multiple sites of a health literacy intervention at which the tool was tested, number of children, age, gender, years of education, race, ethnicity, language spoken, having no health insurance, ethnicity, number of diagnoses of chronic diagnoses, pre-post change in number of push-ups accomplished, pre-post change in PHQ-9 depression score, pre-post change in self-reported amount of exercise and pre-post change in Calgary Charter on Health Literacy Scale score. The results indicate a significant relationship exists between change in BMI and change in health literacy with other factors accounted for (R-squared 0.585; Adjusted R-squared 0.523, $p<0.000$). An initial hypotheses being tested is that improving health literacy will produce improvements in health status.

Conclusion

The true promise of the study and application of health literacy is not to simply screen people and then group them according to their level of health literacy, but should be to advance their health literacy and then to prove that increasing health literacy leads to tangible improvements in people's objective health status – ideally at a lower cost. Health literacy will begin to fulfil its potential of contributing to a healthier, happier, more productive and efficient world only when such practices are widespread and common. At this point in time (late 2017), we must conclude that the state of measurement in health literacy is such that we can't precisely or confidently conclude where health literacy currently lies on the spectrum from an emerging idea to a testable hypothesis to a validated theory or on to a scientific law.

From a social constructionist perspective, there are certainly many labouring away at constructing knowledge in such a way to 'prove' the hypothesis of health literacy as a strong determinant of health. Nonetheless, in science we must strive to maintain objectivity – a strong critique of the field of health literacy is very possible in this regard. The field crosses back and forth between advocacy and observation and profit-seeking. In and of itself that movement is not inherently unwelcome, but it does seem to occur with perhaps too much ease and certainly with too little transparency.

An underlying driver of that issue is the focus on discovery by the individual in academics. Largely, academic success is merited by publication in peer-reviewed journal articles. The role of first author is most valued – with some exceptions, of course. While individual achievement is wonderful, an idea like health literacy by predicting complex interactions within society almost demands cooperation among the many rather than the success of the few. If you accept that health literacy is a social construct, how better for that construct to be organised than as a public good?

What, we wonder, in closing this chapter, would be the truly 'health-literate' manner to conduct ourselves within the field of health literacy? In what fashion, we ask, can we all work to advance the field most effectively and efficiently – through the focus on the success of an individual or individual research group, or by emphasising a broadly shared goal of advancing health literacy as a priority for all?

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6

Measuring children's health literacy: Current approaches and challenges

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Introduction

Starting at an early age, children are confronted with a plethora of health information in their everyday lives. This information might be communicated by their parents regarding healthy food, physical activity, preventing illness or general health risks. It may also be taught in school, provided by various media channels or discussed with friends and peers. While there is evidence that a vast proportion of the adult population have difficulty understanding or effectively using health-related information (Sørensen et al, 2015), there is barely any research on questions such as:

- How difficult is it for children to access health information?
- Can children understand what they learn about health?
- To what extent do children critically appraise health-related information?
- What opportunities do children have to apply health information in their daily lives?

Health literacy and appropriate tools for its measurement can provide answers to questions like these. However, for the last few decades, research on health literacy has paid little attention to younger age groups, and children younger than 13 years of age in particular (Ormshaw et al, 2013; Okan et al, 2018). For adult populations, various health literacy models, definitions and approaches have emerged over the years (Sørensen et al, 2012; see also Chapter 1, this volume). Simultaneously, a wide range of measures have been developed and used in different contexts (Haun et al, 2014), some of which have been criticised for not being based on existing models or definitions (Pleasant, 2014). For more information, see Chapter 5, this volume.

A multitude of studies has documented the adverse effects of limited health literacy on health-related outcomes. For example, a low level of functional health literacy (see Chapter 14, this volume) has been linked with an increased risk of hospitalisation, worse medication knowledge and skills, and a higher risk of misunderstanding medication and food labels (Berkman et al, 2011). Thus, health literacy is recognised as a critical determinant of health, and an important driver of empowerment and equity that should be promoted starting in school age (WHO, 2017). While the potential to foster health literacy through school health education was already considered more than 40 years ago (Simonds, 1974, p 9), it has been neglected until recently (Ormshaw et al, 2013; see also Chapters 2 and 34, this volume). Nowadays, there is growing consensus that the early promotion of health literacy could be foundational for good health literacy and positive health outcomes later in later life (Manganello, 2008, p 840; WHO, 2017). However, there is hardly any evidence on children's health literacy to inform innovations in health education curricula, interventions or health literacy programmes. Still, a solid evidence base is imperative to address these issues and to sustainably promote the health literacy of coming generations.

The lack of evidence is directly related to the scarcity of measurement tools, which can be observed for younger populations in general, but even more so for children. Although two systematic reviews have identified a total of 25 health literacy tools for children and adolescents (Ormshaw et al, 2013; Okan et al, 2018), the majority of these were developed for adolescents rather than for younger children. Therefore, little is known about the proportion of children with limited health literacy, or about how children interpret and use health information in their everyday lives. Accordingly, a targeted and evidence-based approach to the promotion of children's health literacy is inhibited by a lack of evidence. Thus, the development of child-specific measures is needed, as well as the implementation of high-quality surveys that assess the various components of health literacy.

This chapter aims to provide an overview of current approaches towards the measurement of health literacy in populations younger than 13 years of age, as well as a discussion of challenges and potentials in this field of research. While the selection of an age limit to distinguish children from adolescents can be somewhat arbitrary, a maximum age of 12 was chosen to exclude teenagers, and to bring into focus younger age groups.

Available tools and challenges

As reported earlier, only two systematic literature reviews have analysed health literacy tools for children and adolescents. Ormshaw and colleagues (2013) reviewed the literature until 2011 and found 16 tools, including measures of generic health literacy as well as mental and media health literacy. Okan and colleagues (2018) included only measures of generic health literacy instruments, and identified 15 different tools. Together, the reviews report on a total of 13 instruments that have been used to measure *children's* health literacy, that is, of participants younger than 13. In the following, findings of both reviews have been compiled to provide a broad, systematic overview of these measures. Particular attention is drawn to: target groups; health topics; components of health literacy; measurement design; and methodological rigour.

Target groups

Examining the age groups (see Figure 6.1), it becomes apparent that the number of studies primarily targeting children is limited, with only six tools found (Brown et al, 2007; Naito et al, 2007; Schmidt et al, 2010; Yu et al, 2012; Benham Deal et al, 2013; Driessnack et al, 2014). Another seven studies report on instruments that have been used primarily among adolescents or adults, but also include children (Davis et al, 2006; Hubbard and Rainey, 2007; Vardavas et al, 2009; Leighton, 2010; Olsson and Kennedy, 2010; Sharif and Blank, 2010; Wallmann et al, 2012).

Remarkably, the youngest age groups (6–7) were included in two studies that used adult instruments (nos 1 and 10; see Figure 6.1). Also, vast differences are visible with respect to the age range: while Benham Deal and colleagues (2013) and Naito and colleagues (2007) focused on samples with an age range of just one year (8–9 and 11–12), ranges of up to 9 or even 13 years can be found in the studies conducted by Davis and colleagues (2006) and Sharif and Blank (2010), respectively.

Of 13 instruments, 10 were newly developed for the purpose of the study. Two of the instruments, namely, the Newest Vital Sign (NVS, no 13) and the Short Test of Functional Health Literacy in Adults (S-TOFHLA, no 10) were originally developed for adults and were validated for use in younger populations without making any age-related adjustments to the instruments. In contrast, one

Figure 6.1: Age of participants in the studies

Notes: Sorted by year of publication, then alphabetical order.
* Age not reported in article: estimated based on grade levels.

study sought to validate an age-adapted version of the Rapid Estimate of Adult Literacy in Medicine, namely, the REALM-Teen (no 1).

In their review, Okan and colleagues (2018) also assessed whether children participated in the development of the respective instruments, and found that this was the case in only two studies. In these studies, qualitative interviews were conducted to verify the comprehension of questionnaire items (nos 2 and 3). Apart from that, they have not identified studies that implemented further child participation. While Ormshaw and colleagues (2013) did not investigate target group participation, brief screening of the articles shows that only one study applied pilot testing with the respective age group (no 7).

Challenges

First, it can be stated that 'the paradox of the missing child' (Darbyshire et al, 2016) is prevalent in this field of research. While all of the authors aimed to conduct research *on* children, most of the authors neither included children for feedback nor aimed to learn about their perspectives and experience (research *with* children). For future research, child participation is desirable and necessary to ensure the quality of measures and to enhance researchers' learning on children's health literacy.

Second, while the majority of measures have been developed for younger populations, measures were identified, too, that have been developed for adults (nos 10 and 13). The use of adult instruments among children has to be questioned, even when the respective measures have previously proven to be reliable and valid. For example, Sharif and Blank state that the S-TOFHLA is 'feasible for use in children' (2010, p 46), but also express 'uncertainty' regarding the use of their tool in order to measure children's health literacy (2010, p 46). Similarly, the NVS is described as 'a feasible, useful, and valid tool for children as young as 7 years of age' (Driessnack et al, 2014, p 169), but Warsh and colleagues (2014, p 143) recommend the use of the NVS with children no younger than 10. Hence, thorough discussion and replication of results is commanded when developing tools, even more so when adult measures are applied. Furthermore, the development of age-specific tools is advised, in contrast to the re-utilisation of measures for adults.

Health topics

Health literacy is contextual (Nutbeam, 2000). Thus, the ability of an individual to use health information effectively depends on situational demands, and the respective area of health. While some instruments apply a narrow focus on just one health topic (nos 1, 2, 4, 7, 8, 10 and 13), a broad range of health domains are addressed in other instruments (nos 3, 5, 6, 9, 11 and 12). It can be observed that instruments addressing health literacy in healthcare contexts (nos 1, 10 and 13) tend to focus on one single aspect and not include other health domains, which also applies to instruments focusing on mental health (nos 7 and 8). In contrast, there are also instruments that focus on up to seven health topics (nos 9, 11 and 12).

Challenges

The research streams on functional health literacy in medicine (nos 1, 10 and 13), as well as on mental health literacy (nos 7 and 8), are fairly distinct – methodologically and regarding content – from more comprehensive approaches. Thus, researchers are faced with a choice between measures of generic health literacy, which simultaneously assess multiple health topics, and domain-specific measures, which focus on a single health topic.

One the one hand, there is merit in measuring health literacy with respect to a single health topic. A child's level of health literacy with regard to oral health might not be comparable to that child's health literacy with respect to mental health. To that end, the application of specialised measures seems appropriate, and more practical with respect to informing specific interventions. However, findings from such specialised studies ought to be communicated and discussed very cautiously. For example, the 13 identified studies do not provide evidence on the general health literacy of children, but rather, fragmented information on children's health literacy regarding a variety of specific health topics. Hence, the emergence of different terminological concepts, such as media health literacy, mental health literacy, and so on, seems consequential.

On the other hand, measures of *generic* health literacy seek to assess the overall level of health literacy across multiple health topics and contexts. Such general measures can be useful, for example, to provide data on the efficacy of school health education, or on the ability of a population to use health information effectively, regardless of health topics. The aim of measuring health literacy comprehensively, however, translates to a broader scope of measurement, which is why measures of generic health literacy could prove impractical for the quick screening of patients.

Eventually, there is growing consensus 'that health literacy is too broadly defined to realistically allow a single, all-encompassing measure that could be used by researchers and clinicians alike' (van der Ploeg, 2010, p 145), which is why there is a need for both specific and general tools.

Components of health literacy

While some recurring themes in the measurement of children's health literacy can be identified, there are hardly any overlaps between the different operationalisations (see Table 6.1). For example, health-related theoretical knowledge is measured by five measures (nos 3, 6, 9, 11 and 12), and understanding of health information (nos 2, 3 and 5), as well as attitudes (nos 2, 9 and 12) are each assessed by three approaches. However, each other component is assessed by a maximum of two measures.

Table 6.1: Measures of children's health literacy

#	Authors	Measure	Design	Health topics	Components of health literacy	Age
1	Davis et al (2006)	REALM-Teen	p	Medicine	Word recognition, pronunciation	10-19
2	Brown et al (2007)	Kids-Health KidsPoll	s	General health	Understand, access, apply health information, interest, belief, attitude	9-13
3	Hubbard and Rainey (2007)	HEAP items[a]	p	Physical activity, nutrition/diet, smoking	(Theoretical) knowledge, understand, access health information, communication, self-management	11-18+
4	Naito et al (2007)	Questionnaire	p	Oral health	Critical thinking/evaluation	11-12
5	Vardavas et al (2009)	Questionnaire	s	Oral health, STDs, physical activity, smoking, nutrition	Access to and sources of health information, satisfaction with health-related interactions	12-18
6	Benham Deal et al (2010)	HEAP items	p	Personal safety and injury prevention	(Theoretical) knowledge, service navigation	8-9
7	Leighton (2010)	Vignettes	p	Mental health	Recognition, practical knowledge (treatment options)	12-15
8	Olsson and Kennedy (2010)	Vignettes	p/s	Mental health	Recognition, practical knowledge (treatment options), help-seeking behaviour	11-17+
9	Schmidt et al (2010)	GeKoKids questionnaire	p/s	Physical activity, nutrition, smoking, vaccination, oral health, general health	(Theoretical) knowledge, attitudes, communication, self-efficacy, behaviour	9-13
10	Sharif and Blank (2010)	S-TOFHLA	p	Medicine	Reading comprehension	6-19
11	Wallmann et al (2011)[b]	Health quiz	p	Nutrition, smoking, body weight, blood pressure, media use, physical activity, human body	(Theoretical) knowledge	12-15

(continued)

Table 6.1: Measures of children's health literacy (continued)

#	Authors	Measure	Design	Health topics	Components of health literacy	Age
12	Yu et al (2012)	Health Literacy Questionnaire	p	Nutrition, disease prevention, substance abuse, injury prevention, physical activity, growth and development	(Theoretical) knowledge, attitude, behaviour (health practice)	8-10, 13-14
13	Driessnack et al (2013)	NVS	p	Nutrition	Reading comprehension, numeracy	7-11

Notes: p = performance-based test; s = self-report measure; [a] Items from the proprietary Health Education Assessment Project (HEAP) database; [b] Study published in German only.

Source: Based on literature reviews conducted by Ormshaw et al (2013) and Okan et al (2018)

Although health literacy is increasingly being regarded as relational and context-specific (Sørensen et al, 2012), the contextuality of health literacy is barely recognised by the different instruments. For example, Okan and colleagues (2018) found that only two measures of children's health literacy take into account contextual factors or situational determinants (nos 6 and 10).

Challenges

First, there is neither an agreed upon theory of health literacy, nor are there commonly accepted models or definitions for children and adolescents' health literacy. Instead, there are a number of conflicting as well as complementing models and concepts that express specific understandings of what are the constituent elements of health literacy, its antecedents and its outcomes (Bröder et al, 2017). Both reviews find that not all studies are built on definitions of health literacy. This further exacerbates the lack of comparability, and the question can be raised 'if the available instruments are actually measures of the same construct' (Baker, 2006, p 878). It can be stated that measures of functional (nos 1, 10 and 13) and mental health literacy (nos 7 and 8) do indeed not measure the same construct or components of health literacy, also when compared to the other measures. For future research, it will be increasingly necessary to state the underlying definition of health literacy and to clarify which of the components of the definition are measured, and how they are operationalised. The latter is especially relevant, as a number of studies use the definition of health literacy by Nutbeam (2000) as a general framework, but chose vastly different approaches to measure children's health literacy (for example, nos 5, 9 and 11).

Second, the question can be raised to what extent the identified measures actually assess health literacy. In particular, it is disputed that measures of functional health literacy are appropriate measures of today's broad understanding of health literacy (Ormshaw et al, 2013, p 435). However, it has to be acknowledged that these measures were never intended to measure general, comprehensive health literacy (Baker et al, 1999; Weiss et al, 2005, p 521; Davis et al, 2006, p 1710). Thus, it needs to be understood that measures of functional health literacy are as different from comprehensive measures as are measures of mental or digital health literacy. Additionally, functional health literacy has been criticised due to its proximity to basic cognitive abilities that are not health-specific (Reeve and Basalik, 2014). It is probable that other dimensions of health literacy, such as the ability to access, understand or appraise health information, will be scrutinised in a similar manner. It remains a challenge to define what is genuinely health-specific about these components of health literacy.

Third, there have been calls for a significant advancement of the scope of measurement of (children's) health literacy. Among the possible advancements are, for instance, 'language, context, culture, communication, or technology' (Mancuso, 2009, p 87), or the 'ever-present or underlying stress or fear factor' inherent in health contexts (Institute of Medicine, 2004, p 41). Additionally, health literacy is increasingly being regarded as two-sided, relational or contextual. For example, adequate health literacy might not be determined by a static level of knowledge, or the proficiency of using health information, but rather, by the relationship of the knowledge and skills a child *has*, and the knowledge and skills a child *needs* to cope with health-related challenges. The other side of the 'health literacy equation' is increasingly being investigated, for example, through approaches on the *health literacy responsiveness* of health services (Trezona et al, 2017), or the related concept of *health-literate organisations* (Brach, 2017). Approaches like these contribute significantly to the advancement of health literacy research, as they shift the focus on health literacy away from individual skills and responsibility, towards the system level contexts of health literacy. However, further advancements are necessary, which might include measures that also assess 'the health literacy demands on individuals within different health contexts' (Institute of Medicine, 2004, p 51). Thus, future measures of children's health literacy are faced with ever-increased demands in terms of complexity.

Measurement design

A range of approaches for measuring children's health literacy can be identified. While almost all of the measures applied a questionnaire-based approach, only two instruments were administered as face-to-face interviews (nos 1 and 13). Notably, both measures of mental health literacy (nos 7 and 8) apply case vignettes, which are a common tool in the field of mental health literacy (Leighton, 2010, p 232). Five instruments apply a combination of closed-ended and open-ended items (nos 4, 6, 7, 8 and 12), and another five use closed-ended items only (nos 2, 5, 9, 11 and 12). Two instruments are conducted as interviews, in which no choice of possible answers is provided (nos 1 and 13), and one study does not report on the response format (no 3). Nine measures apply performance tests (nos 1, 3, 4, 6, 7, 9, 10, 12 and 13), three instruments apply self-report only (nos 2, 5 and 12), and one instrument applies both (no 8).

Challenges

First, it is difficult to make generalised recommendations about how health literacy should be measured, as the appropriateness of measurement designs depends on the measured component of health literacy. While it seems obvious that health-related knowledge is best measured by a performance test, it is not entirely clear how health-related skills should and could be measured. While performance tests to assess children's ability to access, understand, appraise and apply health information would certainly be the most valid approach, such tests are yet to be developed. Furthermore, approaches towards the measurement of the perceived difficulty of accessing, understanding, appraising and applying health information (*subjective* health literacy; see Sørensen et al, 2012) could be fruitful to assess children's health literacy as a truly relational concept, that is, as the relationship between perceived skills and health-related challenges. Currently, it seems plausible that 'objective' (knowledge and skills) and 'subjective' health literacy could independently provide insights into different aspects of health literacy. Eventually, further research is necessary to investigate the efficacy of the different approaches and their potential to predict health-related outcomes.

Second, no qualitative approaches on measuring children's health literacy have been identified by the reviews. However, interviews, focus groups or field research into children's health practices could contribute significantly to researchers' understanding of children's health literacy. The work by Fairbrother et al (2016) can be named as an example for research 'beyond *what* children know' towards research on '*how* children actively construct meaning from health information' (2016, p 476). Future research will need to adopt such perspectives to improve the measurement of children's health literacy, but also to accelerate the development of a definition of children's health literacy.

Methodological rigour

While all identified studies contribute to the knowledge base on children's health literacy, differences can be observed regarding the quality of evidence. Ormshaw and colleagues (2013, p 451) conclude that 'each of the studies followed sound research methods and principles', but also note that 'it is hard to assess the reliability … of the studies.' Regarding sampling procedure and sample size, for example, a convenience sample with 47 parent–child dyads (no 13) and a multi-stage cluster-stratified sampling survey with 8,008 participates (no 12) mark the end points of a spectrum.

Cronbach's α is the most frequently reported indicator of internal consistence/reliability (nos 1, 3, 9, 12 and 13), and two studies use additional indicators of reliability, namely, re-test reliability (no 1) and split-half reliability (no 12). Eight studies report no indicator of reliability (nos 2, 4 to 8, 10 and 11). Both studies that use HEAP items refer to them as having previously been tested for reliability (nos 3 and 6). Indicators of validity are reported in five studies, whereby two studies rely on face validity, as established by experts (nos 2 and 6). Concurrent validity is reported for two instruments (nos 1 and 13), and one instrument seeks to establish validity by developing the instrument based on the literature, receiving expert feedback and piloting the measure (no 7). Five studies report neither indicators of validity nor reliability (nos 4, 5, 8, 10 and 11).

Challenges

First, the small number of studies reporting on indicators of validity and reliability highlights the need for more transparent reporting and methodological rigour. However, there is also potential for improvement where such indicators are reported. For example, face validity cannot be verified where items are not reported. Also, due to the scarcity of measures of children's health literacy, concurrent validity cannot be established in many cases until similar measures are available. Additionally, future research should acknowledge that Cronbach's α can be inflated by a high number of items, and thus it is not necessarily a good indicator of the unidimensionality of a scale (Streiner, 2003, pp 101-2), although more costly, repeated testing and the assessment of re-test reliability might be helpful to investigate the reliability of future measures. Furthermore, even more thorough testing and reporting can be expected from those measures that are designed to inform professionals in clinical settings (REALM, TOFHLA and NVS). However, indicators of sensitivity and specificity have only been reported for the NVS (Driessnack et al, 2014, p 167).

Second, future research should aim to test measures of children's health literacy in representative samples to allow for an estimate of psychometric properties in the general population or a specific subgroup. The use of small convenience samples might be useful for the initial stages of instrument development, but inferences about the feasibility and quality of a measure may be limited.

Latest developments

Ormshaw et al (2013) and Okan et al (2018) have provided a systematic overview of available measurement tools for children and adolescents. However, the reviews are limited to studies published until April 2011 and July 2015, respectively. Therefore, in this section, some of the latest developments are briefly presented:

- Mulvaney et al (2013) adapted the Diabetes Numeracy Test (DNT) for type 1 diabetes among adolescents aged 12-17. Versions with 14 (DNT-14) and 39 performance test items (DNT-39) are available that have been used to assess numeracy with respect to the self-management of diabetes in a sample of 133 participants.

- The Health Literacy Assessment Scale for Adolescents (HAS-A) aged 12–19 has been developed by Manganello et al (2015). HAS-A is a 15-item self-report measure that was used to assess health literacy in the areas 'oral communication' (5 items), 'confusion' about health information (4 items) and 'functional health literacy' (6 items) among 272 adolescents.
- The Taiwan Children's Health Literacy Test (TCHL) was developed by Liu et al (2014) for children aged 11–12. In a survey among 162,209 children, knowledge, attitudes and behaviour were assessed. The final test consists of 32 items, and four items provided by Liu et al (2014) indicate that the test is a performance test.
- Okan and Bollweg (2018) have developed an adaptation of the European Health Literacy Survey Questionnaire (HLS-EU-Q) for children aged 9–10. There were 26 items assessing subjective health literacy with respect to healthcare, disease prevention and health promotion tested among 907 children. Psychometric analysis is ongoing.

Conclusion

In this chapter, an overview and critical discussion of current approaches towards the measurement of children's health literacy was provided. There is a limited, but growing, number of measurement tools available that can be used to assess different components of children's health literacy. Still, less than half of the instruments (8 of 17) were developed specifically for children, and children were rarely involved in the development process. Therefore, it remains debatable to what extent the available tools adequately capture the facets that characterise children's health literacy. Further research is needed, with a particular focus on participatory and qualitative approaches. Additionally, there is a need for more transparent reporting regarding psychometric properties, the instrument development process and the respective items, to allow for quality assessment, enable advancement of the measures and to increase methodological rigour in this field of research.

More generally, a fragmentation of research approaches on children's health literacy can be identified, expressed as a divide between measures of general health literacy and measures focusing on specific health topics. Although this variety of approaches increases complexity in the field of health literacy research, there are good reasons to regard these different approaches as complementary instead of mutually exclusive. Further complexity can be outlined with respect to the very essence of health literacy, that is, its constituent parts as assessed by the different measures. The lack of a universal theory of health literacy in childhood as well as particular research interests for specific components of health literacy manifest in a number of measures that don't share any commonalities at all. It cannot be expected that this problem will be solved in the near future, as the conceptual expansion of health literacy has not yet reached an end point. Instead, calls for even more sophisticated measures of health literacy will likely lead to greater segmentation in this field of research, but probably also to a better understanding of the processes related to the development of health literacy (in childhood). It will be increasingly relevant for researchers to provide systematic overviews of and to mediate between the different research streams on (children's) health literacy. Already today there seems to be misunderstanding or even a lack of awareness of the multiple approaches, such as general health literacy, media health literacy, mental health literacy, diabetes health literacy or health information literacy.

Last, however, researchers' efforts to measure children's health literacy in multiple ways are acknowledged as a significant contribution to a better understanding of this determinant of health and the pathways to its equitable promotion, to the improvement of effective school health promotion and to the health-related empowerment of younger generations.

Acknowledgements

This work has been prepared within the frame of the Health Literacy in Childhood and Adolescence (HLCA) Consortium (see www.hlca-consortium.com), funded by the German Federal Ministry of Education and Research (BMBF; Grant No 01EL1424A-E).

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7

Developing an instrument for measuring the health literacy of adolescents: Lessons learned

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Measuring and improving the health literacy of adolescents: a lifespan perspective

From the perspective of lifespan developmental psychology, behaviour change processes occur from conception to death, as development is regarded as a lifelong process, not assuming a special state of maturity. Childhood and adolescence are stages in which development and behaviour change are strongly influenced by biological maturation. Young people are undergoing cognitive, emotional, social and somatic change. Besides the influence of biological maturation on development, life events, for example, the death of family members, and history-graded influences, such as social change, also play a major role in influencing development. Hence, behaviour change does not necessarily persist into adulthood, as early life experiences are not presumed to prepare the individual for all situations of later life (Baltes et al, 1980). Still, health-related attitudes and health-promoting behaviour patterns are established and stabilised in childhood and adolescence, which can have a protective effect on later and more critical stages of the lifespan (Erhart et al, 2008; Voelcker-Rehage, 2012). Health literacy skills should therefore be enhanced in childhood and adolescence, as young people are increasingly managing their own healthcare, interacting with healthcare professionals and are exposed to health messages. Adolescents also have to manage developmental tasks and deal with health risks in their everyday life.

A commonly accepted definition determines adolescence as the lifespan ranging from 12 to 19 years of age. For health research, the cognitive development in this period is of particular interest, as it affects abilities connected with health literacy. During adolescence, cognitive development becomes apparent by the improvement of psychometric intelligence, logical thinking, autonomous regulation of decision-making processes and the processing of information (Silbereisen and Weichold, 2012). These cognitive abilities are of some importance, as they impact on the extent to which adolescents autonomously gain access, understand, appraise and apply health information. These abilities are defined as the core dimensions of health literacy (Sørensen et al, 2012).

Besides the cognitive development, Forrest et al (1997) conceptualised three further distinguishing characteristics that justify a separate focus in health research with young people: differential epidemiology, dependency and specific demographic patterns:

- Children and adolescents represent a relatively healthy population group. They are affected by a pattern of diseases that has a unique epidemiological profile.
- Parents play an important role for children and adolescents' health education, health decision-making, disease management and entry into the health system.
- Country-specific demographic patterns must be considered, as adolescents might be affected by financial deprivation and social exclusion. Compared with adults and the elderly, children (aged 0-17 years) were the age group at the highest risk of poverty or social exclusion in Europe in 2015 (Eurostat, 2018).

Previous health literacy research has almost entirely addressed adults. Consequently, reliable data on the origin and characteristics of young people's health literacy is lacking (Okan et al, 2015). Studies investigating the health literacy of children and adolescents have so far largely focused on specific health topics, such as nutrition (Ormshaw et al, 2013). Recently, more instruments measuring the generic health literacy of young people have been developed, varying widely by their underlying definitions and research purposes, considering different participant characteristics. However, a large part of these instruments use task performance-oriented measures (Okan et al, 2018, Guo et al, 2018). It is agreed that task performance-oriented methods neither adequately measure health literacy in different contexts and settings and nor do they capture the complexity of health literacy. Moreover, there is consensus that comprehensive validated measurement tools for diverse populations are required (Nutbeam, 2000; Wharf Higgins et al, 2009; Pleasant et al, 2011; see also Chapters 5 and 6, this volume).

For German-speaking countries, instruments measuring the generic health literacy of young people have either addressed 9- to 13-year-olds (Schmidt et al, 2010), 15-year-olds (Röthlin et al, 2013), young adults aged 18-25 (Abel et al, 2015), or specific populations, such as educationally alienated young people (Quenzel et al, 2015), or only assessed certain aspects, such as critical health literacy (Steckelberg et al, 2009) or health knowledge (Wallmann et al, 2011). Consequently, the development of an instrument measuring *generic* health literacy in adolescents in Germany appears to be necessary.

This chapter describes the process of developing and validating an instrument measuring generic health literacy in adolescents using qualitative methods as part of the project 'MOHLAA – Measurement of Health Literacy Among Adolescents'. The next section focuses on the methodological approach, depicting methods and results of the qualitative approach. Results of empirical data are analysed and discussed afterwards, followed by the conceptual framework of the MOHLAA questionnaire. The final section summarises implications for measurement instruments deriving from the empirical results, and the theoretical concepts of adolescent health literacy.

Development and validation of the MOHLAA questionnaire using a qualitative approach

The MOHLAA project was conducted at the Robert Koch Institute as part of the Health Literacy in Childhood and Adolescence (HLCA) Consortium, aimed at developing and validating an instrument for measuring generic health literacy in adolescents. The project encompassed two project stages – the development and validation of the first instrument draft using qualitative methods, and the quantitative validation of the finalised draft; the latter is not addressed in this chapter. The MOHLAA questionnaire (MOHLAA-Q) was developed for adolescents aged 14 to 17. As developmental stages differ greatly within the complete age range of adolescence from 12 to 19, the development of a single instrument adequate for all age groups might not be feasible. Hence, the instrument was designed for young people of mid-adolescence.

The development process of the MOHLAA-Q encompassed the design of a preliminary theoretical framework. Components of this framework were identified, based on theoretical concepts and expert knowledge, defined as a top-down strategy of instrument development (Bühner, 2011). Accordingly, the development process encompassed a literature review to identify the components of adolescent health literacy. Two focus groups with adolescents were conducted, as they can be viewed as lay experts concerning their experiences in navigating the healthcare system, managing diseases and staying healthy. A second strategy developing the instrument consisted of the use of the European Health Literacy Survey Questionnaire, German long version with 47 items (HLS-EU-Q47) (Sørensen et al, 2013), as a blueprint for the MOHLAA-Q.

The HLS-EU-Q47 encompasses the four dimensions of accessing, understanding, appraising and applying health information related to the domains of healthcare, disease prevention and health promotion. It was chosen as a blueprint, owing to its holistic approach, also covering the aspect of determinants of health in the social and physical environment. Developing the HLS-EU-Q47 in the European Consortium, adolescents did not participate in the validation process, except for the pre-test conducted in two countries. Due to feasibility reasons, the German survey was limited to the region of North Rhine-Westphalia (Sørensen et al, 2013). In an Austrian survey the applicability of the HLS-EU-Q16 short version has been proven adequate for 15-year-olds in a quantitative validation process (Röthlin et al, 2013). However, as the HLS-EU-Q47 was not pre-tested in Germany, and adolescents only participated in the validation process of other language versions, the applicability of the long version to adolescent age groups should be tested.

Cognitive interviewing of the HLS-EU-Q47 items

Cognitive interviews are particularly used in social sciences in order to conduct 'qualitative pre-testing' of items and to evaluate sources of response errors in questionnaires (Beatty, 2004). The technique of cognitive interviews is based on theoretical models of the question–answering process. The most general model was developed by Tourangeau (1984), conceptualising four processes: comprehension of the question, retrieval of relevant information from memory, estimation process and response process (Willis, 2015).

Using a snowballing technique, a purposive sample of 20 adolescents aged 14–17 was drawn, a sample size assumed adequate for cognitive interviews (Prüfer and Rexroth, 2005). Interviews were conducted between December 2015 and March 2016, lasting approximately 55 to 110 minutes. Adolescents were quoted in terms of gender, age and levels of secondary education. Two trained interviewers conducted the interviews, using a semi-structured interview guide. Interviews were recorded and partially transcribed. Fifteen out of 47 items of the HLS-EU-Q47 were selected for testing, based on results of a pre-test of one HLS-EU-Q subscale (Jordan et al, 2014) and on the results of the Austrian survey, indicating difficult items (Röthlin et al, 2013). The questionnaire provides a four-point scale (very easy, easy, rather difficult, very difficult): 'On a scale from "very easy" to "very difficult", how easy would you say it is to….'

The cognitive interviewing techniques of 'verbal probing' and 'retrospective think-aloud' were used in order to investigate whether items were understood in the intended way, and whether adolescents had experience with the described health-related situations in different settings.

Transcripts, interview protocols and notes on observation were analysed , based on a cognitive model of the survey response process (Tourangeau, 1984). The framework approach was applied, a method used in health research to facilitate the categorisation of qualitative data (Gale et al, 2013). A small part of the data was independently categorised and coded by two researchers in order to satisfy criteria of reliability.

Data analysis revealed three dominant themes:

- comprehensibility of items
- motifs of choosing a response option
- experiences with specific health-related situations.

These themes will be exemplified by crucial interview statements from adolescents; for more examples, compare Domanska et al (2018).

Comprehensibility of items

Not all items of the HLS-EU-Q47 were well understood by the adolescents. The following two examples illustrate this. Adolescents were asked to rate their competencies: '… how easy would you say it is to…' for item 11 '… judge when you may need to get a second opinion from another doctor?' Some adolescents did not understand the term '*zweite Meinung*' ('second opinion'). For item 35, '… find out about political changes that may affect health?', the German questionnaire provides the following hints: 'Hint: legislation, new preventive programmes, change of government, healthcare reform etc.' Some adolescents stated that they did not understand what was meant by 'political changes' or by the example 'legislation'. They did not understand the impact of laws on their individual health. In summary, results seem to indicate that adolescents do not understand the specific terms or complex issues described by those items that require a higher level of abstraction.

Motifs of choosing a response option

In case an item or term was not well understood, some adolescents chose the response option 'very difficult'. For example, in terms of item 11 (see above), one adolescent stated that he did not understand the term 'second opinion' but chose the response option 'very difficult' instead of not responding. This appears to indicate that the response reflects the difficulty of understanding the item rather than the difficulty of the assessed competence. Despite not knowing specific terms used in the questions or not understanding the issues covered by the items, some adolescents chose a response option rather than not responding. As only a few missing data could be observed, these results suggest biased data.

Experiences with specific health-related situations

Adolescents have no experiences with some of the described health-related situations in different settings. The following two examples illustrate this. Adolescents were asked to rate their competencies: 'how easy would you say it is to…' with item 6, 'understand the leaflets that come with your medicine?' One adolescent stated that he did not read the leaflets that came with the medicine, but was of the opinion that he would understand them if he did read them. Accordingly, he chose the response option 'easy'. For item 47, 'take part in activities that improve health and wellbeing in your community?', most adolescents had difficulty understanding this, because they could not imagine how an activity could have an impact on an individual's health and wellbeing. They also chose the response option 'easy'. These results suggest that adolescents who lack experiences with health-related situations in different settings overestimate their health literacy.

Focus groups

Focus groups represent a qualitative, explorative method, also deemed appropriate to investigate people's experiences of managing diseases and navigating health services (Kitzinger, 1995). This method has also been used with young people in health research and can specifically be used to generate items for inclusion in questionnaires (Detmar et al, 2006).

A purposive sample of 12 adolescents aged 14 to 17 was drawn, quoted in terms of gender, age and education level. Two focus groups were carried out in January and February 2016, lasting approximately 60 minutes. One was conducted with adolescents aged 14 to 15 (*n*=5), the other with adolescents aged 16 to 17 (*n*=7). Focus group discussions were conducted and analysed by the first author, partially protocolled by a student assistant and audio taped. The guided focus groups investigated adolescents' knowledge and experiences regarding healthcare, disease prevention and health promotion, corresponding to the domains of the HLS-EU-Q. As vignettes have proven to be a feasible method to obtain data in mental health literacy research (Leighton, 2010; Olsson and Kennedy, 2010), three vignettes were included in the discussion guide, focusing on the following scenarios: bullying at school; hepatitis B vaccination/piercing; attention deficit hyperactivity disorder/decision-making. The third vignette is presented here as an example:

> Paul suffers from hyperactivity. He went to see a doctor with his parents and has taken Ritalin for three months. Paul wants to stop taking the pills because he doesn't like how it feels. He doesn't like playing the drums any more. His parents would like him to continue taking the pills so that he is able to better concentrate in school. What would you advise him to do?

Data was analysed with the method content analysis (Mayring, 2015) using the data analysis software MAXQDA 12. Analysis and categorisation of the focus group data revealed the issues of:

- adolescents' experiences navigating the healthcare system or managing diseases;
- parents providing health information and advice;
- health decision-making in the family context;
- comprehending complex issues and joining the dots.

Adolescents' experiences navigating the healthcare system or managing diseases

Focus group participants stated that they did not often visit a doctor. One adolescent reported not having a family doctor: "I do not have a doctor – at the moment…. But I do not get ill…. I had a sore throat once during the last two years". Furthermore, adolescents were invited to discuss the third vignette (see above), and were asked to give advice on how to deal with the presented dilemma. Several adolescents indicated this as the most difficult question of the focus groups, as they had no experience with the regular intake of medication, and thus no experience with such dilemmas.

Parents providing health information and advice

Adolescents reported that the first source of health information was (in most cases) their parents. Adolescents turned to them for information about health and for advice. They stated seeking advice from them in case of unknown signs of illness, decisions about medication or the necessity of seeing a physician. Depending on the health topic, they also named other sources of information: friends, teachers and healthcare professionals.

Health decision-making in the family context

Adolescents were asked how they knew that their parents' advice concerning health decisions was correct. One adolescent responded spontaneously: "*Eltern wissen alles*" ["Parents know everything"]. Another adolescent reported that he had been vaccinated before going on holiday. He stated that he did not know against which disease, and that he had simply acted on his parents' advice. Furthermore, some adolescents explained that certain health decisions, for example, changing to a vegetarian diet, required discussion and agreement with family members – they stated that they would need to explain this decision to their family. Some believed that their parents would not agree to such a change.

Comprehending complex issues and joining the dots

In terms of health promotion and the determinants of health – staying healthy – adolescents reported that they had difficulty imagining how they could influence their living conditions in such a way as to improve their health. It appeared to be a challenge for them to join the dots between living conditions and their health status. Discussing media use, adolescents stated using the internet frequently. However, it became evident that they were not aware of criteria they might need for appraising the reliability of web pages. Adolescents believed that they would easily find reliable information on the internet, and consequently overestimated their media competencies.

Analysis and discussion of empirical results

The results of the cognitive interviews and focus groups reveal different issues relevant for the development of questionnaires aiming to measure the health literacy of adolescents. One issue area addresses the comprehensibility of questions and the stability of responses, while a second focuses on the relevance of interaction for adolescent health literacy.

Comprehensibility of questions and stability of responses

The comprehensibility of survey questions for children and adolescents has been investigated in the area of childhood studies and survey research. Results indicate that the higher the cognitive abilities of the children, the less problems with an adequate response (Emde and Fuchs, 2012). Moreover, the type and difficulty of a question influences data quality, since questions related to attitudes, behaviour or estimation demand higher levels of abstraction than questions related to facts. As the difficulty of a question appears to be a crucial factor for data quality, rules for the development of clearly understandable questions and answers in questionnaires (compare, for example, Payne, 1951; Krosnick, 1999; Faulbaum et al, 2009) are even more important for young people's measurement instruments. Owing to their further developed cognitive abilities, self-reports of adolescents are regarded as more stable compared with self-reports of children (Reynolds, 1993). Although the study by Borgers et al (2000) indicates that adolescents aged 15 and over can be treated as adults in surveys, the results of the MOHLAA study contradict this statement. Findings suggest that adolescents seem not to be aware of the complexity of issues and the demands of specific health-related situations. This observation can be interpreted in two ways: adolescents either lack knowledge about complex issues, for example, the knowledge necessary to understand the impact of laws on health; or their cognitive abilities are not fully developed, so that these items are still too complex to be understood. To summarise, data quality in surveys of young people is affected by adolescents' knowledge and cognitive abilities and the difficulty of items. Difficult items, requiring well-marked abilities of abstraction and comprehension of complex issues, might, in the best case, cause missing values or alternatively biased data.

The stability of children and adolescents' responses has been investigated in survey research. In case the context of a survey question refers to personal experiences and the living environment of children and adolescents, there are far fewer biases than in abstract knowledge domains (Lipski, 2000; Diersch and Walther, 2010). Since adolescents represent a relatively healthy population, they have limited experience with navigating the healthcare system or managing diseases. According to the results of the MOHLAA study, adolescents respond to questions despite not having the relevant experience, with some of them overestimating their competencies. Biases in young people's surveys might thus be founded in a lack of experiences with specific health-related situations.

The assumption that some adolescents overestimate their health literacy might be grounded in their competence-oriented self-concept. During adolescence, the ability of young people to describe their performance enhances and comparisons with others gains in importance. Adolescents learn to describe their performance in situation-specific contexts (Filipp and Mayer, 2005). Studies investigating self-concepts demonstrate that results often tend to the positive pole. Information relevant for self-esteem is often not objectively processed but rather motivated by the acquisition of a stable, positive self-concept (Dauenheimer et al, 2002), representing a self-serving bias.

In summary, the lack of experiences with specific health-related situations and the lack of knowledge about complex issues, such as, for example, health policy, has an impact on the comprehensibility of a survey question and might cause biased data. Adolescents' possible overestimation of health literacy might, on the one hand, be grounded in this lack of experiences or knowledge and, on the other, in the need for a positive self-representation.

Relevance of interaction for adolescent health literacy

Studies on the health information seeking of adolescents demonstrate that parents are the most important sources of information (Ackard and Neumark-Sztainer, 2001; Baheiraei et al, 2014). Moreover, parents and significant others are defined as interpersonal socialisation agents. Adolescents' health literacy is strongly connected with the amount of health information provided, and should be understood as a complex interplay among interpersonal and media socialisation agents and multiple factors (Paek et al, 2011).

However, findings of the MOHLAA study indicate that adolescents not only seek information from their parents; they also seek advice in order to make health decisions and to get support in terms of the management of diseases. Adolescents also state that they trust their parents concerning these issues. Some stated that in the case of using a health measure (for example, a vaccination), they simply acted on their parents' advice, because they trust them. These findings are in line with the results of a qualitative study investigating health decision-making in young people with a disability or who are chronically ill (Mitchell, 2014). Mitchell emphasises that adolescents need communication and emotional support from their parents before they arrive at a health decision. Young people stated that they value their parents' opinions and knowledge, and trust them to understand their feelings. Apparently, the described interactions between adolescents and parents seem to be characterised by a certain relationship quality. As adolescents state they trust their parents, this quality might be characterised as connectedness, defined by Beyers et al (2003) as the property of a relationship system encompassing the dimensions of 'mutual reciprocity, trust and dependency' (2003, p 360). As such it is regarded as a protective factor for adolescent health (Sieving et al, 2017).

At the same time, results of the MOHLAA focus group indicate the dependency of adolescents on their parents in terms of decision-making and behaviour change. In case the adolescents' decisions are not supported by their parents, behaviour change might not be realised, regardless of whether the decision reflects high or low health literacy. To summarise, interaction with family and significant others is crucial for adolescents' abilities to evaluate information in order to make sound health decisions and to manage diseases. However, as adolescents represent a relatively healthy population group, most of them do not have experiences with health decisions in terms of significant medical interventions. Furthermore, the quality of the child–parent relationship shapes this interaction and can have a protective effect on adolescent health.

Limitations

Analysis of qualitative data was limited due to the sample sizes of both focus groups and cognitive interviews. As they were not provided for in the study design, only two focus groups were conducted. Consequently, an achievement of redundancy in information or theoretical saturation of data cannot be claimed (Bowling, 2014). The sample size of 20 cognitive interviews is assumed adequate to satisfactory obtain information on the research questions, but was insufficient for sub-group analysis by educational level, age and gender. Furthermore, migrant background was not considered as a sample characteristic, though language proficiency or bilingualism might have affected the understanding of the questionnaire (Jacobson et al, 2016). Composition of focus groups only considered similar age-ranges, though health topics like sexual health would have required same-sex groups to facilitate free discussions on a gender-sensitive issue. Qualitative data should be categorised and coded by two researchers to discuss discrepancies and agree on final categorisation (Bowling, 2014). This procedure was only carried out for small parts of the data, due to its very time-consuming nature.

Framework concept of the MOHLAA questionnaire

Constructs of children and adolescents' health literacy are highly diverse, with 20 different models depicting the health literacy of young people. Children and adolescents' health literacy is mostly defined as a multidimensional construct with a focus on the acquisition of individual competencies and knowledge (see Chapter 3, this volume). Definitions of health literacy also acknowledge the interdependency of health literacy with social context (Sentell et al, 2017). The systematic literature review by Bröder et al (2017) has identified the diverse models of health literacy and categorised the components according to cognitive, behavioural or operational, and affective and conative competencies. The conceptual framework of the MOHLAA-Q is based on this categorisation, and thus comprises behavioural and operational components, covering, for example, the dimensions of finding or evaluating health-related information, affective and conative components, covering, for example, health consciousness and health motivation. The instrument is complemented by an objective measure, assessing health knowledge. This objective measure facilitates investigating how adolescents' self-reported competencies and their health knowledge correspond. Finally, adolescents' perceived conditions to act in a health-literate way are assessed in order to consider the interrelatedness with contextual factors. This component covers, for example, how adolescents perceive health-related communication with physicians or family.

Implications for the development of instruments measuring adolescent health literacy

Data quality in surveys of young people is affected by adolescents' knowledge and cognitive abilities and the difficulty of items. Instruments measuring the health literacy of adolescents should therefore be adapted to adolescents' development-dependent knowledge and state of cognitive development to ensure the comprehensibility of questions and response options in questionnaires. Complex items that require higher levels of abstraction need to be adapted. This may involve the adaptation of wording, the addition of concrete examples or the reduction of the complexity of the issues covered by the items. Furthermore, questions should refer to personal experiences and the living environment of children and adolescents, considering their limited knowledge and experiences with health-related situations in different settings. In addition, since the findings of the MOHLAA study suggest that parents and significant others play an important part in adolescents' health decision-making and the management of diseases, instruments should incorporate this interaction. To summarise, results suggest that the use of qualitative methods is necessary to verify the practicability of an instrument for adolescent age groups.

As the results also suggest that some adolescents' overestimate their subjective health literacy competencies, representing a phenomenon of subjective measurement, assessment approaches should be complemented by objective measurement tools. Provided that these mixed methods are based on coherent underlying constructs, the correlation of adolescents' self-reported and objective competencies could be investigated (Altin et al, 2014). Finally, since health literacy is interrelated with social and contextual determinants, instruments measuring adolescent health literacy should aim to capture contextual factors. Depending on the perspectives of the intersection between health literacy and social context, approaches may focus on the individual level or measure social context as independent property (Sentell et al, 2017).

Owing to adolescents' developmental abilities, dependency on adults and differential epidemiology, a separate focus on health research is highly recommended to prevent biased data in adolescents' surveys. Sound empirical data on the characteristics of adolescents' health literacy is required in order to tailor measures to their specific needs. Promoting health literacy effectively at an early age might contribute to the enhancement of present and future health behaviour and the health status of young people.

Acknowledgements

This research was funded by the Federal Ministry of Education and Research, Germany (Code 01EL1424D).

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8

Measuring health literacy in Europe: Introducing the European Health Literacy Survey Questionnaire (HLS-EU-Q)

Jürgen M. Pelikan, Kristin Ganahl,
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Introduction

At the beginning of the millennium, the growing interest and concerns regarding the impact of limited health literacy in North America was recognised, and health literacy was brought up among European politicians and researchers as being of relevance for active health citizenship and patient participation in contrast to the more prevailing paternalistic views. However, no European population data on health literacy existed, and it became evident that more information was needed to inform the policy discussions (Sørensen and Brand, 2017). Compared to the US, Canada and Australia, measuring health literacy not only came to Europe rather late, but measurement also followed quite a different approach. While in the US, after few studies in the tradition of population literacy measurement – using, for example, the Health and Literacy Scale (HALS) – the bulk of health literacy studies focused on the consequences of the low clinical health literacy of patient populations, using for measurement (rather short) instruments of functional health literacy (Rudd, 2017), in Europe, measurement started with a rather broad concept of health literacy in general populations (Sørensen et al, 2012; Wang et al, 2012; Pelikan and Ganahl, 2017a, b).

Crucial for the European developments were Ilona Kickbusch (Kickbusch, 2001, 2002; Kickbusch et al, 2006; Kickbusch and Maag, 2008) and Don Nutbeam (Nutbeam, 2000; Nutbeam and Kickbusch, 2000), who had recognised the potential of health literacy for health promotion and public health, besides its importance for healthcare (see Chapter 2, this volume). From 2004 onwards, Ilona Kickbusch advocated for health literacy within the European Health Forum Gastein (Kickbusch, 2004), and initiated the HLS-CH study in Switzerland in 2006 (Wang et al, 2012). At the European Public Health Conference (EUPHA) in Montreux in 2006, a representative from the European Commission was convinced of the relevance of health literacy for the European health agenda, and a group was initiated by Ilona Kickbusch, Jürgen Pelikan and Helmut Brandt to form a consortium, develop a proposal and ensure funding for a European health literacy study.

This chapter introduces the European Health Literacy Survey Questionnaire (HLS-EU-Q), and discusses its impact for health literacy policy, research and practice. From a life course perspective, the HLS-EU study included participants aged 15+, hence the survey results regard youth, adulthood and ageing, but not childhood.

The HLS-EU study

The HLS-EU was supported by the Executive Agency for Health and Consumers (EAHC) of the European Union (EU). The project had five objectives:

- Adapt a model instrument for measuring health literacy in Europe.
- Generate first-time data on health literacy in European countries, providing indicators for national and EU monitoring.
- Make comparative assessment of health literacy in European countries.
- Create National Advisory Bodies in countries participating in the survey and document different valorisation strategies following national structures and priorities.
- Establish a European Health Literacy Network.

The HLS-EU Consortium, including academic institutions from Austria, Bulgaria, Germany, Greece, Ireland, the Netherlands, Poland and Spain conducted the project.

The HLS-EU concept and definition of health literacy

To explore and define health literacy, a literature review was undertaken. The review identified 17 definitions and 12 models from which a content analysis yielded a comprehensive, 'all-inclusive' consensus definition and conceptual model (Sørensen et al, 2012; see Chapter 1). The resulting conceptual model and definition adequately mirror the evolution of the broadening understanding of health literacy in research, practice and policy within the last two decades (Pelikan and Ganahl, 2017a, b). According to the HLS-EU Consortium,

> Health literacy is linked to literacy and entails people's knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course. (Sørensen et al, 2012, p 3)

The definition and conceptual model covers the continuum of health when being ill, at risk and healthy from a personal view and from a systemic view in terms of healthcare, disease prevention and health promotion. It covers various aspects of health literacy (Nutbeam, 2008) in the modern 'health society' (Kickbusch, 2007), including clinical (Pleasant and Kuruvilla, 2008), medical (Peerson and Saunders, 2009), patient (Ishikawa and Yano, 2008), and public health aspects (Freedman et al, 2009) of health literacy. The definition relates not only to reactively understanding information offered by experts, but also to proactively finding/accessing, evaluating/appraising and personally using/applying information, that is, to the comprehensive competencies of information management necessary in the modern 'information society', 'knowledge society' or 'multi-option society'. The four steps of information management addressed in the definition and model adequately fulfil in an analytical fashion what Nutbeam (2008, p 2076) demanded for health literacy measures,

> to include assessment of a person's ability to
> - gain access to age and context specific information from a variety of different sources,
> - discriminate between sources of information,
> - understand and personalise health information that has been obtained,
> - appropriately apply relevant health information for personal benefit.

In addition, it relates to the typology of functional, interactive and critical health literacy (Nutbeam, 2000), where functional health literacy refers to understanding, interactive health literacy to finding/accessing and critical health literacy to evaluating/appraising information to form decisions for maintaining and improving health and quality of life. Health literacy is not seen just as knowledge, which has a very short half-time in late modernity, and cognitive skills, but also as an emotional resource for motivating health-relevant action. Thus, health literacy is not narrowly understood as relevant for adequately fulfilling a compliant or adherent patient's role in healthcare, but as a resource for enacting in a healthy way in all roles in all settings and systems in everyday life in late modern society. It reflects the World Health Organization's (WHO) Ottawa Charter for health promotion: 'Health is created and lived by people within the settings of their everyday life; where they learn, work, play and love' (WHO, 1986). Although, the HLS-EU definition only implicitly relates to the interactive, dual relational character of health literacy, as the fit of personal competencies to the complexity of situational demands (Parker, 2009; Brach et al, 2012; Kickbusch et al, 2013; Pelikan and Ganahl, 2017a, b), when stating the competencies related to accessing, understanding, appraising and applying information concerning healthcare, disease prevention and health promotion, the operationalisation of the definition into an instrument for measuring health literacy takes the dual aspect more explicitly into account by measuring difficulties of people for different tasks. For more clarifying details, see Pelikan et al (2013; see also Pelikan and Ganahl, 2017a, b). For analysing data, a generic model (see Figure 8.1) has been used (HLS-EU Consortium, 2012; Pelikan and Ganahl, 2017a, b), which distinguishes between health literacy and its personal and situational determinants and its personal consequences for health behaviours, health status and illness behaviours. The model assumes one dominant direction of causality of consequences, but also allows for cyclical causal links in the other direction.

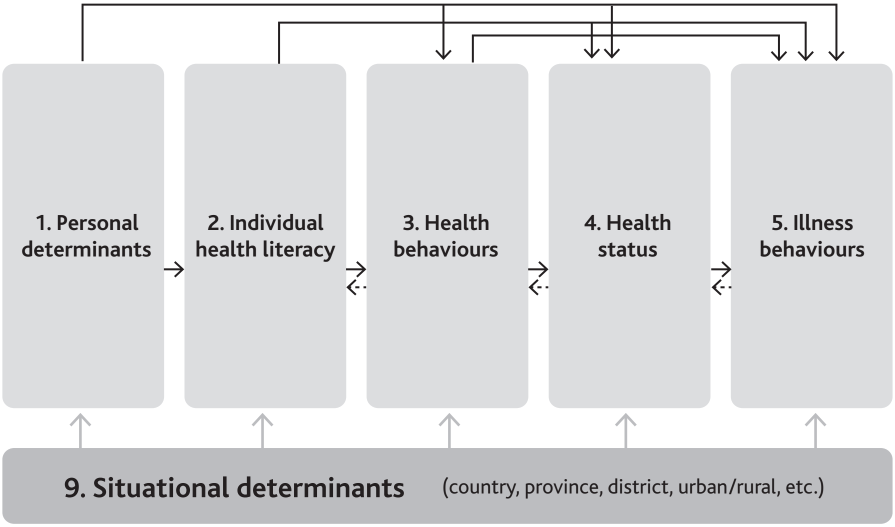
The HLS-EU survey questionnaire

Operationalising health literacy

The questionnaire development (item generation, focus groups, field test/pre-testing, expert consultation, finalisation of the questionnaire, plain language check, translation) is described in detail in Sørensen et al (2013). Here, we highlight the most important strategic decisions taken for operationalising the HLS-EU definition and conceptual model into the final form of the HLS-EU-Q.

The instrument had to be comprehensive, not only in relation to content, but also concerning different kinds of competencies involved. A literature review proved that the existing tools did not cover the HLS-EU definition and conceptual model as they were too specific and were not useful for a population study. Furthermore, for compatibility with the interview-based Eurobarometer approach, it was decided to construct a 'subjective' 'perception-based' in contrast to an 'objective' 'performance-based' (Schulz and Hartung, 2017) instrument.

Figure 8.1: Generic Vienna model of health literacy defining the principal determinants and consequences of health literacy



Source: Pelikan and Ganahl (2017a, b)

The HLS-EU instrument reflects two traditions of measuring health literacy – the example of the HALS (Rudd et al, 2004), where partly complex and concrete tasks of health-relevant decisions or actions of everyday life were tested, and asking about the self-perceived difficulty of a specific task (Chew et al, 2004, 2008).

To operationalise the definition and conceptual model a matrix was constructed focusing on the three overall domains of health and four cognitive information-processing competencies (Table 8.1). For each of the 12 sub-domains relevant concrete tasks were identified. Hence, this 3×4 matrix represents the concept of comprehensive health literacy by 12 different components, each combining one of the three domains of healthcare, disease prevention and health promotion with one of the four stages of information management, that is, finding, understanding, appraising and using information. By this analytical decomposition and a standardised format of items, it is possible to have not just one measure for

Table 8.1: HLS-EU health literacy matrix

(47 items)	**Access/ find/obtain information relevant to health** *(13 items)*	**Understand information relevant to health** *(11 items)*	**Appraise/ judge/evaluate information relevant to health** *(12 items)*	**Apply/use information relevant to health** *(11 items)*
Healthcare *(16 items)*	Ability to access information on medical and clinical issues *(4 items)*	Ability to understand medical information and derive meaning *(4 items)*	Ability to interpret and evaluate medical information *(4 items)*	Ability to make informed decisions on medical issues *(4 items)*
Disease prevention *(15 items)*	Ability to access information on risk factors for health *(4 items)*	Ability to understand information on risk factors and derive meaning *(3 items)*	Ability to interpret and evaluate information on risk factors for health *(5 items)*	Ability to make informed decisions on risk factors for health *(3 items)*
Health promotion *(16 items)*	Ability to update oneself on determinants of health in the social and physical environment *(5 items)*	Ability to understand information on determinants of health in the social and physical environment and derive meaning *(4 items)*	Ability to interpret and evaluate information on health determinants in the social and physical environment *(3 items)*	Ability to make informed decisions on health determinants in the social and physical environment *(4 items)*

Note: Number of items in the HLS-EU-Q47 for each cell was added into the original table of Sørensen et al (2012) for this publication.

Source: Sørensen et al (2012)

comprehensive health literacy, but also additional measures for specific sub- or sub-sub dimensions.

The Consortium opted for questions (instead of rhetorical statements), since questions in an interview can be more easily and directly answered than statements, especially by less educated people.

As an underlying dimension for judging the concrete tasks, experienced difficulty of performing the task was chosen. Thus, one gets information of differences in difficulty of various tasks in one population, and by counting the number of items experienced as difficult by one individual, a measure for his/her relative health literacy. Furthermore, all items are comparable with each other and can be aggregated to different kinds of indices and one general measure, which does not hold true for some other comparable health literacy instruments (Chew et al, 2004; Wang et al, 2012; Osborne et al, 2013).

For answering the questions, a Likert scale of four symmetrical answer categories was chosen. Four categories allow for differentiation and can still be handled easily in an interview, and the symmetrical even number avoids a nebulous middle category. Also, an even number of categories can be meaningfully dichotomised in later statistical analysis of data, if preferred or necessary. (‘Don’t know’ was not offered as an answer category, but spontaneous ‘don’t know’ answers were coded as ‘no answer’ by the interviewer.)

The four categories offered were ordered from ‘very easy’, ‘fairly easy’, ‘fairly difficult’ to ‘very difficult’ to avoid a response set overstating assessed difficulty of items. Thus, the complete formulation of an exemplary item was: ‘On a scale from “very easy” to “very difficult”, how easy would you say it is to understand what your doctor says to you?’ ‘Very easy’ – ‘fairly easy’ – ‘fairly difficult’ – ‘very difficult’ (no answer).

To also guarantee a certain degree of reliability for sub-sub-indices, it was planned to have 3-5 indicators for each cell of the health literacy matrix (see Table 8.1). Concrete items were either chosen from existing examples in the literature or newly drafted by a Delphi procedure among Consortium members or by expert consultation (see Sørensen et al, 2013), yielding a total of 47 items. A list of all items can be found in HLS-EU Consortium (2012) and in Sørensen et al (2013).

In summary, by its specific format the HLS-EU-Q47 fulfils different functions for policy, practice and research very well. By measuring 47 concrete tasks concerning their relative difficulty in handling for specific populations or sub-populations, it offers a solid diagnostic basis for health policy to plan concrete interventions for improving specific aspects of health literacy for these populations. By measuring these tasks in a theory-based and standardised format, answers can also be aggregated to different kinds of (sub-)indices, which can more easily and economically be used in correlation and regression analyses to research the associations of health literacy to other variables, especially to the determinants and consequences of health literacy. Furthermore, the standardised tasks-oriented procedure also allows for developing comparable further sets of items and indices for tasks relevant for specific sub-populations, as has been already done for migrants (Ganahl et al, 2016, 2017), for adolescents (Domanska et al, 2016) or for children (Okan and Bollweg, 2018).

Selecting and operationalising the specific determinants and consequences of health literacy

Besides the 47 items for measuring health literacy, the original HLS-EU-Q (HLS-EU-Q86) contained 39 variables, operationalising factors of the HLS-EU conceptual model into measurable indicators. Where it was possible, validated standard indicators have been selected. The personal determinants of health literacy included the indicators gender, age, education, self-reported social status, indicators for financial situation (including kind of health insurance), main status of employment (including in a healthcare profession), migration status, nationality, family/household situation (for example, legal marital status, children, household living situation) and the Newest Vital Sign (NVS) test for functional health literacy (Weiss et al, 2005). The situational determinants included country, region, postal code and size of locality. Indicators concerning health risks/health behaviours included smoking, alcohol consumption, physical activity and BMI (body mass index). Health status was measured by the three questions of the Minimum European Health Module (MEHM), and illness behaviour by questions on frequency of use of professional healthcare services (emergency services, doctor's visits, hospital and other health professionals). These variables aimed at testing the validity of the HLS-EU-Q47 and for comparing associations of health literacy with possible determinants and consequences between the surveyed countries.

Data collection and data management in the HLS-EU study

Data was collected by computer-assisted personal interviewing (CAPI) or paper-assisted personal interviewing (PAPI). Interviewing for the HLS-EU-Q47 part took on average 10 minutes, and 25 minutes for the total HLS-EU-Q86. The HLS-EU study was based on multistage random samples of about 1,000 EU-citizens aged 15 (for more details, see HLS-EU Consortium, 2012). Meanwhile, the instrument has been used in a self-administered way (Duong et al, 2017), online on the internet (Nakayama et al, 2015), and through telephone interviews (Ganahl et al, 2016, 2017; Finbråten et al, 2018).

The response rates varied by country – from 36 per cent in the Netherlands to more than 70 per cent in Bulgaria. A somewhat differing recruitment process can probably explain the considerable low response rate in the Netherlands. National samples were weighted by gender, age group and size of locality based on national census data to increase representativeness.

Since the eight participating countries are not representative of the EU, no values for the 'average European citizen' could be calculated. Instead, the total sample was used to have an average benchmark for the participating countries, but without a weighting for country size.

Main results (and publications)

Results of the original HLS-EU study have been published and widely presented. Publications compare the eight countries (HLS-EU Consortium, 2012; Sørensen et al, 2015) or are presented for single countries, for example, Ireland (Doyle et al, 2012), the Netherlands (van der Heide et al, 2015), Poland (Słońska et al, 2015) or for an extended sample of Austria (Pelikan et al, 2013).

Data analysis

The format of the HLS-EU-Q47 allows for two kinds of analysis, one for single items and one for aggregated indices. No answer rates for single items were low, with one exception (see HLS-EU Consortium, 2012, table 3). Items have been compared in relation to their difficulty either by using the full four-category distribution or a reduced dichotomous categorisation (combined 'easy' and 'fairly easy' vs 'fairly difficult' and 'difficult'). The difficulty of the 47 items varied considerably by content and also for many items by country (see HLS-EU Consortium, 2012, table 4, figures 4-6), which suggests an acceptable sensitivity of the instrument. Furthermore, all items were positively and partly significantly correlated with each other.

While the results for the concrete single items are relevant for diagnosing problems and deficits concerning specific aspects of health literacy in a country or region for planning tailored interventions and measures to improve health literacy by health policy, aggregate health literacy measures are more convenient and economical for describing levels and associations of health literacy and for benchmarking these.

Indices were constructed for people answering at least 80 per cent of the items underlying a specific index by adding values for answer categories (very easy = 4, rather easy = 3, rather difficult = 2, very difficult = 1). Thus, larger index values suggest higher health literacy. For ease of comparability, the general index and the seven sub-indices were standardised into a scale from 0 to 50 (index = (mean–1)*(50/3)) and the sub-sub-indices into one from 0 to 5.

Cronbach's alpha for the general index and for sub-indices was considerably above 0.7, and for sub-sub-indices, at least near to 0.7 (Pelikan et al, 2014, slide 23). For the general index and the sub-indices a normal distribution with some ceiling effects for higher health literacy was found (Pelikan et al, 2014, slides 24-26), indicating that the indices are more sensitive for lower than for higher health literacy scores.

Mean values and standard deviations of indices differed considerably by country (HLS-EU Consortium, 2012). There was also variation by sub-indices, with lower mean values for health literacy related to health promotion or disease prevention compared to healthcare respectively for appreciation or accessing of information compared to understanding or applying information (Pelikan and Ganahl, 2017a, b, slides 24-26; Pelikan et al, 2014).

Pearson correlations between indices are rather high – for the general index with the seven sub-indices around $r = 0.90$, for the sub-indices among each other between $r = 0.70$ and $r = 0.80$, for the sub-sub-indices with the general index also between $r = 0.70$ and $r = 0.80$, respectively, with the sub-indices between $r = 0.54$ and $r = 0.84$, and among each other between $r = 0.42$ and $r = 0.69$ (Pelikan and Ganahl, 2017a, b). These correlations suggest that the items of the HLS-EU-Q47 are measuring some common health literacy quality, but also that sub- and sub-sub-indices are measuring differing specific aspects of health literacy.

In comparison, the correlations with the NVS were considerably lower, depending on index, between $r = 0.18$ and $r = 0.29$ (Pelikan and Ganahl, 2017a, b), which is in the same order of strength of correlation as with education as a determinant of health literacy.

As for other health literacy measures, health literacy levels have been defined for the HLS-EU-Q47 to allow for comparing percentages of levels that are intuitively more easy to interpret than means or standard deviations of the indices. Four levels of health literacy have been defined: inadequate health literacy (0-25 pts or 50%), problematic health literacy (>25-33 pts or 66%), sufficient health literacy (>33-42 pts or 80%) and excellent health literacy (>42-50 pts or top 20%). For some analyses, the levels of 'inadequate' and 'problematic' were combined to 'limited' health literacy (HLS-EU Consortium, 2012, pp 28-30; Sørensen et al, 2015).

The results show that nearly every second citizen in the total sample had limited health literacy. However, the percentage of limited health literacy varied considerably by country – between 29 per cent for the Netherlands and 62 per cent for Bulgaria. The percentage can be up to 75 per cent for certain vulnerable or disadvantaged groups, for example, people with low education or with financial difficulties, low self-assessed social status, senior citizens, as well as with low self-assessed health (for more details, see HLS-EU Consortium, 2012; Sørensen et al, 2015; Pelikan and Ganahl, 2017a, b).

Analysis of associations of health literacy with determinants and consequences of health literacy

Measured by the HLS-EU-Q47 a relevant social gradient for health literacy has been demonstrated in regression models including gender, age, education, self-assessed social status and financial deprivation in the original HLS-EU study and in follow-up studies. However, the amount of variance explained and the relative importance of the five social determinants differ considerably by country (HLS-EU Consortium, 2012; Sørensen et al, 2015; Pelikan and Ganahl, 2017a, b).

The health literacy results related to health behaviours or health risks show a consistent association with frequency of physical activity and partly with

BMI, but are inconclusive for alcohol consumption and smoking (see HLS-EU Consortium, 2012; Pelikan and Ganahl, 2017a, b). Health literacy is a consistent, significant and remarkable predictor in bi-variate and multi-variate models for indicators of self-assessed health status (see HLS-EU Consortium, 2012; Pelikan and Ganahl, 2017a, b). Finally, there are significant associations of health literacy with usage of health services (see HLS-EU Consortium, 2012; Pelikan and Ganahl, 2017a, b).

Development of short forms of the HLS-EU-Q47

For measuring comprehensive health literacy, the HLS-EU-Q47 is an efficient instrument compared to performance-based comprehensive tests, such as the HALS. However, it is seen as too long for screening purposes. Therefore, short forms have been developed. Two kinds of strategies have been followed with a different approach in Europe and in Asia. A team of the European Consortium using the HLS-EU data developed the HLS-EU-Q16 and HLS-EU-Q6 based on Item Response Theory and Rasch Analysis (for more details, see Pelikan et al, 2014; Pelikan and Ganahl, 2017a, b). Thus, for the short forms, primarily psychometric properties of a one-dimensional scale and representation of the underlying scope and theoretical concept of the long form as far as possible was intended.

For selecting items, a one-parametric dichotomous Rasch model was used, with items dichotomised into two categories, 'easy' ('fairly' or 'very' easy = 1) and 'difficult' ('fairly' and 'very' difficult = 0). Analyses were operationalised for every country and for the total sample, with three split criteria: median, gender and dichotomised level of education within each country. A sub-set of the same 16 items satisfied Rasch characteristics for each of the eight countries, but the item order occasionally varied. In further studies, the Rasch homogeneity of the 16 items was confirmed, for example, for Austrian adolescents (Röthlin et al, 2013) and migrant populations in Austria (Ganahl et al, 2016), as well as in studies of general populations, for example, for the Czech Republic and for Hungary (Koltai and Kun, 2016; Kučera et al, 2016). The HLS-EU matrix is represented by the 16 items except for the cell 'applying information' for 'health promotion', where none of the original items fulfilled the Rasch criteria.

Scale values are calculated as simple sum scores only for respondents who answered at least 14 items, and varied between 0 and 16. Three levels were defined for health literacy: short-scale, inadequate (scale values = 0-8), problematic (9-12) and adequate (13-16). Score values for the sub-scales of the short form can also be calculated, but levels for these have not been defined.

Correlations with the index of the long form were very high – $r = 0.82$ for the total sample – and varied for the countries between $r = 0.73$ and $r = 0.88$. Correlations with functional health literacy (NVS test) were similar to these of the index of the long form ($r = 0.25$ for total), varying between $r = 0.14$ and $r = 0.38$ for the countries. Also, correlation patterns with important determinants and consequences of health literacy were very similar for the short and long form of the instrument. When the short form is calculated using the four categories as for the long form, even better results concerning correlations between the two forms can be achieved.

Applying the HLS-EU-Q16 short form takes about 3 minutes on average. An even shorter version, called the 'short short form', the HLS-EU-Q6, containing 6 of the 16 items, which takes about a minute of interviewing time, was also constructed and validated (for details, see Pelikan et al, 2014). Using data from a survey in Taiwan (Duong et al, 2015) and Principal Component Analysis, a team developed a short form of 12 items, one for each of the 12 cells of the HLS-EU matrix (HL-SF12) (Duong et al, 2017). A team in Norway established another short version of the European Health Literacy Survey Questionnaire – the HLS-Q12 – by using latent trait analyses applying Rasch modelling and confirmatory factor analysis (Finbråten et al, 2018).

Wider application of the HLS-EU-Q in research

Follow-up studies

In the original HLS-EU survey only eight EU member states were included, due to financial limitations of funding from the European Commission. However, the consolidation and advocacy through Health Literacy Europe, the network and national advisory groups that were established with the project, motivated a number of further countries to execute similar surveys using the HLS-EU methodology and instrument. To date, the HLS-EU survey has been conducted in Austria, Belgium, Czech Republic, Denmark, Germany, Hungary, Italy, Malta, Portugal and Switzerland in Europe and in Asian countries such as Indonesia, Israel, Japan, Kazakhstan, Malaysia, Myanmar, Taiwan and Vietnam. Table 8.2 gives an overview of these surveys with a description of their characteristics. Furthermore, the HLS-EU-Q47/Q16 or Q6 has been used in a number of specific studies in different countries (see Pelikan and Ganahl, 2017a, b), which is out of the scope for this chapter.

Wider application in policy

The European Office of the WHO recognises the impact of the HLS-EU study in its publication *Health literacy: The solid facts* (Kickbusch et al, 2013), which is available in English, German (2016), Mandarin (2016) and Russian (2014), and presents the HLS-EU definition, conceptual model, the matrix and the results of the HLS-EU survey. The results of the HLS-EU have initiated public debate on health literacy and stimulated political action to take specific measures for improving health literacy in countries worldwide. The European Health Literacy Consortium received the European Health Award in 2012 for its societal impact on health policy.

Table 8.2: Overview of general population studies using the HLS-EU-questionnaire

Study	Year of survey	Commissioning institution(s)	Executing institution(s)	Design and sampling method
Europe				
HLS-EU	Summer 2011	European Commission and national funds	University of Maastricht (coordination)	Cross-sectional, observational, CAPI, random route sampling method – multi-stage sampling, Eurobarometer standards
HLS-Austria			Ludwig Boltzmann Institute, Health Promotion Research	
HLS-Bulgaria			Medical University Sofia	
HLS-Greece			National School of Public Health, Greece	
HLS-North Rhine-Westphalia			Landesinstitut für Gesundheit und Arbeit, Nordrhein-Westfalen	
HLS-Ireland			University College Dublin	
HLS-Netherlands			National Institute of Public Health and the Environment, the Netherlands	
HLS-Poland			Instytut Kardiologii	
HLS-Spain			University of Murcia	
HLS-AT (Austria)	November 2011	European Commission, Austrian Health Promotion Fund, Scientific Grant Merck, Sharp & Dohme	Ludwig Boltzmann Institute, Health Promotion Research	See design used in HLS-EU
HLS-Kosovo	2011	United Nations Population Fund (UNFPA)	Department of International Health, School for Public Health and Primary Care (CAPHRI), Faculty of Health, Medicine and Life Sciences, Maastricht University, Maastricht, The Netherlands University of Medicine, Tirana, Albania	Stratified, simple random sample, structured interview-administered questionnaire
HLS-Albania	September 2012-February 2014	University of Medicine, Tirana, Albania	Department of International Health, School for Public Health and Primary Care (CAPHRI), Faculty of Health, Medicine and Life Sciences, Maastricht University, Maastricht, The Netherlands University of Medicine, Tirana, Albania	Population-based simple random sample within three health centres and one polyclinic, face-to-face interviews

Regional definition of population	Age definition of population	Sample size	Instrument for measuring health literacy used	Publications
	>15 years	8,102	HLS-EU-Q47	HLS-EU Consortium (2012); Sørensen et al (2015); Pelikan et al (2017a, b)
Austria		1,015		
Bulgaria		1,002		
Greece (Athens region)		1,057		Doyle et al (2012)
Germany (North Rhine-Westphalia)		1,000		
Ireland		1,000		
The Netherlands		1,005		van der Heide et al (2013)
Poland		1,023		Słońska et al (2015)
Spain		1,000		
Extended Austrian HLS-EU sample in order to better reflect the nine Austrian federal states	>15 years	1,813	HLS-EU-Q47	Pelikan et al (2013)
Kosovo	≥65 years	1,753	HLS-EU-Q47	Toçi et al (2013)
Tirana municipality	≥18 years	1,152	HLS-EU-Q47	Toçi et al (2014)

(continued)

Table 8.2: Overview of general population studies using the HLS-EU-questionnaire (continued)

Study	**Year of survey**	**Commissioning institution(s)**	**Executing institution(s)**	**Design and sampling method**
Europe (continued)				
HLS-Denmark[a]	January-April 2013	Supported by the pharmaceutical company MSD Denmark	Department of Public Health, Section for Health Promotion and Health Services, Aarhus University, Aarhus, Denmark	Self-administered paper or web-based questionnaire, random sample derived from the Danish Civil Registration System among citizens in the Central Denmark Regions
HLS-Germany	October 2013-June 2014	German Federal Ministry of Health	Robert Koch Institute	Internet and self-administered paper within the German Health Update Survey (GEDA)
HLS-Belgium	Spring 2014	No information was found	Université Catholique de Louvain + Mutualité Chrétienne/Christelijke Mutualiteit	Internet survey
HLS-Portugal	June-August 2014	No information was found	ISCTE – Instituto Universitário de Lisboa	Random route methodology for selection of dwelling, quota method for selection of interviewee
HLS-Malta	July 2014	Office of the Commissioner for Mental Health within the Ministry for Energy and Health	National Statistics Office, Malta	CATI, stratified random sample
HLS-GER (Germany)	July and August 2014	German Federal Ministry for Justice and Consumer Protection	University of Bielefeld	CAPI, multi-stage random sample
HLS-Czech Republic	January 2015	Czech Ministry of Health and the Country Office of WHO in the Czech Republic	National Institute of Public Health	See HLS-EU methodology
HLS-Hungary	May-June 2015	Association of Innovative Pharmaceutical Manufacturers	Szinapszis Market Research and Consulting Ltd	See HLS-EU methodology

Regional definition of population	Age definition of population	Sample size	Instrument for measuring health literacy used	Publications
Denmark	>25 years	29,473	HLS-EU-Q16	
Germany	≥18 years	2,222 online, 2,730 self-administered paper	HLS-EU-Q16	Jordan et al (2015)
Belgium	≥18 years	9,617	HLS-EU-Q16	Vandenbosch et al (2016)
Portugal	≥15 years	2,104	HLS-EU-Q47	Espanha and Ávila (2016)
Malta	≥18 years	1,514	EU-HLS 16 (same items as in the HLS-EU-Q16 but different index calculations)	Office of the Commissioner for Mental Health (2014)
Germany	>15 years	2,000	HLS-EU-Q47	Berens et al (2016); Schaeffer et al (2016, 2017a, b); Vogt et al (2017)
Czech Republic	>15 years	1,037	HLS-EU-Q47	Kučera et al (2016)
Hungary	>16 years	1,008	HLS-EU-Q47	Koltai and Kun (2016)

(continued)

Table 8.2: Overview of general population studies using the HLS-EU-questionnaire (continued)

Study	Year of survey	Commissioning institution(s)	Executing institution(s)	Design and sampling method
Europe (continued)				
HLS-Italy	2015[b]	Supported by the pharmaceutical company MSD Italy	Department of Management & Innovation Systems, University of Salerno	Random sample, applying Eurobarometer methodology, PAPI
HLS-Switzerland	October-December 2015	Bundesamt für Gesundheit BAG	gfs.bern	Multi-stage random sample, CAPI
HLS-Israel	No information was found	Grant from the Israel National Institute for Health Policy Research	Department of Health Education and Promotion, Clalit Health Services, Tel Aviv, Israel	Random sample of Clalit Health Service members, face-to-face interviews
Health Information Sources study	March-April 2016	No information was found	Université Catholique de Louvain + Mutualité Chrétienne/Christelijke Mutualiteit	Internet survey
HLS-Norway	November 2014	Norwegian Nurses' Organisation, Inland Norway University of Applied Sciences and the Public Health Nutrition research group at Oslo Metropolitan University	Department of Public Health and Department of Nursing, Faculty of Social and Health Sciences, Inland Norway University of Applied Sciences	Telephone survey
Asia				
HLS-Taiwan	February-October 2013	Supported in part by Taiwan's Ministry of Science and Technology and Health Promotion Administration as well as research funding from Taipei Medical University, Shuang-Ho Hospital and Taipei Hospital, MOHW	Taipei Medical University, Taipei, Taiwan	Multi-stage stratification random sampling, similar to Eurobarometer methodology, interviewer-assisted self-report questionnaire
HLS-Japan	Spring 2013	Grant-in-Aid for Scientific Research from the Japan Society for the Promotion of Science (JSPS), KAKENHI Grant No 23390497	College of Nursing, St Luke's International University, Akashi-cho, Chuo-ku, Tokyo	Cross-sectional web-based anonymous health literacy questionnaire

Regional definition of population	Age definition of population	Sample size	Instrument for measuring health literacy used	Publications
Italy	>18 years	1,000	HLS-EU-Q47	Palumbo et al (2016)
Switzerland	≥15 years	1,107	HLS-EU-Q47	Bieri et al (2016)
Israel	≥19 years	600 (Clalit Health Service members)	HLS-EU-Q16[c]	Levin-Zamir et al (2016)
Belgium	≥18 years	5,711	HLS-EU-Q16	Avalosse et al (2017)
Norway	≥16 years	900	HLS-EU-Q47[d]	Finbråten et al (2018)
Taiwan	≥15 years	2,989	HLS-EU-Q47	Duong et al (2015)
Japan	20-69 years	1,054	HLS-EU-Q47	Nakayama et al (2015)

(continued)

Table 8.2: Overview of general population studies using the HLS-EU-questionnaire (continued)

Study	Year of survey	Commissioning institution(s)	Executing institution(s)	Design and sampling method
Asia (continued)				
HLS-Asia	2013-14	Taiwan's Ministry of Science and Technology and the Health Promotion Administration and MJ Health Research Foundation		Multi-stage stratification random sampling, similar to Eurobarometer methodology, interviewer-assisted self-report questionnaire *Taiwan:* community-based nationwide survey *Other five countries:* community-based city or regional surveys
HLS-Indonesia			Dian Nuswantoro University, Semarang, Indonesia	
HLS-Kazakhstan			Kazakhstan School of Public Health, Almaty, Kazakhstan, Kazakh National Medical University, Almaty, Kazakhstan	
HLS-Malaysia			University of Medicine, Yangon, Myanmar	
HLS-Myanmar			University Kebangsaan Malaysia, Selangor, Malaysia, University of Malaya, Kuala Lumpur, Malaysia	
HLS-Taiwan			School of Public Health, Taipei Medical University, Taipei, Taiwan, National Health Research Institutes, Miaoli County, Taiwan, Department of Family Medicine, National Taipei Hospital, MOHW, Taipei, Taiwan, Yuanpei University of Medical Technology, Hsin Chu, Taiwan	
HLS-Vietnam			Hai Phong University of Medicine and Pharmacy, Haiphong, Vietnam, Ha Noi University of Public Health, Hanoi, Vietnam	

Note: [a] The HLS-EU-Q47 was used in parallel to the HLQ, but HLS-EU-Q results have not been published. Results on the HLQ have been published in Bo et al (2014); [b] According to Rocco Palumbo; [c] Data were collected for all 47 HL items of the HLS-EU-Q47, but only the results from the HLS-EU-Q16 were reported; [d] A short version of the HLS-EU-Q47 was developed, the HLS-Q12 (Finbråten et al, 2018).

Regional definition of population	Age definition of population	Sample size	Instrument for measuring health literacy used	Publications
	≥15 years	10,024	HLS-EU-Q47	Duong et al (2017)
Indonesia		1,029		
Kazakhstan		1,845		
Malaysia		1,600		
Myanmar		462		
Taiwan		3,015		
Vietnam		2,073		

Conclusion and future developments

For research, policy and practice of public health, that is, for healthcare, disease prevention and health promotion, a comprehensive understanding of health literacy is valuable and a measurement instrument adequately reflecting this is instrumental. In this regard, the HLS-EU model and definition are highly relevant, and the HLS-EU instruments are a reliable and valid way of measuring the concept. The concept and instrument have been developed by a multinational consortium and have been tested and validated in a multinational study allowing for benchmarking of results. The general trends of health literacy in Europe and Asia have been demonstrated and specific situational/regional/national variations also shown. These kinds of results have stimulated public debate and political action to improve health literacy.

Concerning the future, preparations have begun for the next wave of a multinational European survey. As of spring 2018, an Action Network on Measuring Population and Organisational Health Literacy (M-POHL) within the European Health Indicators Initiative (EHII) of the European Office of WHO has been established and is preparing a population health literacy survey for 2019.

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9

Health literacy and health disparities: A global perspective

Sarah Mantwill and Nicola Diviani

Introduction

Health literacy, defined as '[t]he ability to access, understand, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across the life-course' (Rootman and Gordon-El-Bihbety, 2008, p 11), has been found to strongly correlate with many of the social determinants of health, eventually contributing to disparities in health. In the US, for example, lower educational attainment, income, as well as minority race and ethnicity, have all been associated with lower levels of health literacy (Kutner et al, 2006).

In contrast to many determinants, such as gender, education or income, health literacy is considered an intervenable factor. Although research is not yet conclusive, there is the strong assumption that, by providing and communicating easily understandable information to low health-literate populations or by teaching them relevant skills (see, for example, Kripalani and Weiss, 2006; DeWalt et al, 2010; Negarandeh et al, 2013), health literacy can be operationalised in ways that allow targeted interventions. Support for this argument comes from studies that have identified health literacy to be a potential mediator between the social determinants of health (including education) and health(-related) outcomes. Health literacy may therefore be an important factor to consider when trying to reduce the impact of social disparities on health(-related) outcomes and eventually to reduce disparities in health (Sentell and Halpin, 2006; Osborn et al, 2011). Despite this importance, mechanisms that link health literacy to disparities in health are not well explored (Mantwill et al, 2015), particularly not in ways that would allow generalisations across different contexts and countries to be made.

This chapter aims to discuss three interrelated challenges that likely have influenced current research in the field and that are important to consider when investigating the association between health literacy and health disparities across different contexts and on a global level. The first challenge pertains to lack of general consensus on the conceptualisation and measurement of health literacy, which may have prevented more systematic approaches to the study of health literacy and disparities on a more global level and the development of cross-national surveys. The second challenge concerns structural or contextual factors that are likely to affect both health literacy and health outcomes across different contexts, and should thus be taken into consideration when studying health disparities. The last challenge refers to assumptions on how culture may influence the study of health disparities in diverse populations. Before discussing these challenges, we briefly review some international research efforts to highlight current practices and findings, as well as associated issues relevant to the field.

Setting the stage: international research on health literacy and disparities

Research on health literacy has seen increasing fragmentation (Mackert et al, 2015), which has been mainly driven by two factors. The first factor, which will be discussed later in this chapter in more detail, refers to the consistently growing number of conceptualisations of health literacy and subsequent measurements thereof. The second factor has been the relatively recent growth in interest in the concept of health literacy outside of the US. This has undeniably been a crucial development, as it has led to increased recognition of the concept across the world. Yet it has also led to additional conceptualisations and measurements of health literacy, separated from those that have already been developed, and has raised the question of how far results across different contexts are comparable.

Concerning research on health literacy and disparities, the good news is that until today, studies outside of the US could partly confirm that in other countries health literacy may also follow a social gradient. Results from Europe, for instance, have shown that those reporting lower education and lower income or financial deprivation tend to have lower health literacy levels (von Wagner et al, 2007; Connor et al, 2013; Sørensen et al, 2015). This was also partially confirmed in countries across Asia or the Middle East (see, for example, Fadda et al, 2016; Levin-Zamir et al, 2016; Duong et al, 2017). Further, in line with findings from the US, some studies from Europe point to the fact that health literacy levels are generally lower among immigrant populations compared to the native population (Wångdahl et al, 2014; Quenzel et al, 2016; Mantwill and Schulz, 2017).

These are promising findings, yet results should be carefully evaluated for their cross-cultural validity. Although some studies have used (adapted) measures that were originally developed in the US, so far only few measures are available allowing systematic comparisons of health literacy levels, determinants and outcomes across countries. In this regard, the European Health Literacy Survey (HLS-EU) has been a rather recent effort aiming at assessing health literacy across eight European countries (Sørensen et al, 2015). In direct comparison, findings for the different countries were relatively consistent. In all cases, health literacy followed a social gradient, with those being financially deprived or having lower education presenting lower levels of health literacy (Sørensen et al, 2015). Yet, the magnitude of how these factors influenced health literacy levels largely varied across countries. Regarding financial deprivation, for example, the highest difference was found for Poland and the smallest for Spain (HLS-EU Consortium, 2012). A separate study from Switzerland, which used the same instrument, found that, in contrast to the European study, self-reported social status was negatively associated with health literacy. In addition, most participants showed *problematic* levels of health literacy (gfs.bern, 2016), thus implying that one of highest educated countries in the world is among the least health-literate countries in Europe.

In the meantime, the HLS-EU has also seen application outside of Europe (see, for example, Duong et al, 2017; Mávita-Corral, 2017). A study from Japan, where the survey was conducted in an online sample, found, in contrast to the European findings, that health literacy not only increased with age, but was also not associated with educational level. Further, overall health literacy levels were significantly lower than in the European study (Nakayama et al, 2015).

Other systematic approaches that would allow comparing health literacy and related disparities across countries are, for example, the International Adult Literacy Survey (IALS), the Adult Literacy and Lifestyle Survey (ALL), or the latest OECD (Organisation for Economic Co-operation and Development) programme, the International Assessment of Adult Competences (PIAAC) (OECD, no date). Even though these surveys were initially not set up to measure health literacy skills per se, they have been used to investigate literacy domains relevant to health literacy. Rudd and colleagues (2004, 2007), for example, developed the Health Activities Literacy Scale (HALS), which was based on the National Adult Literacy Survey (NALS) and the IAL, and assesses skills related to health literacy. Even though widely cited, the HALS has seen limited application outside of the US. To the best of our knowledge, only Australia, Canada, the Netherlands and the US so far have adopted the HALS and have also reported on it (Canadian Council on Learning, 2007; ABS, 2008; van der Heide et al, 2013). Further, no systematic cross-national comparisons have been conducted.

Yamashita and Kunkel (2015) used data from ALL to compare the mediation effects of literacy between education and self-rated health across different countries. Based on a conceptual model (Rootman and Ronson, 2005) that describes the influence of different types of general literacy skills on health literacy, and that are likely to explain the effects of education on health outcomes, the authors investigated prose, document and quantitative literacy. They found that literacy skills mediated the effect of education on health, yet there was substantial variation in the strength of mediation and differences between different types of literacy. Among others, it was found that in the US numeracy skills was an important predictor whereas in Italy prose literacy played an important role. On the other hand, in Norway and Canada, after controlling for covariates, none of the tested dimensions of literacy were associated with self-rated health (Yamashita and Kunkel, 2015).

There is still relatively little consistent knowledge on the distribution and comparability of health literacy levels on a global level and consequently on its association with health disparities. Even though it has been found that health literacy often follows a social gradient across different countries, the extent and in which ways this relationship plays out is by no means clear yet.

Challenge 1: Finding consensus on definitions and measurements

Many researchers in the field agree that current conceptualisations of health literacy are not met with appropriate operationalisation and that the situation is likely to remain as long as no general consensus is found (Pleasant, 2014; Malloy-Weir et al, 2016; see Chapters 1, 2 and 5, this volume). Even though the concept of health disparities and its appropriate assessment have not gone without discussion (Mackenbach and Kunst, 1997; Kawachi et al, 2002; Braveman, 2006), compared to the field of health literacy, matters have been much clearer. In general, there has been an implicit consensus that the term 'health disparities', or 'health inequalities', refers to differences in health between groups of which one or more are socially worse off than any other group(s). Groups are often operationalised in terms of socioeconomic status, including educational background, occupational status or income (Whitehead, 1992; Braveman, 2006). In the US the term 'health disparities' is most widely used to describe ethnic or racial disparities. Outside of the US, however, the term 'health inequality' has seen wider application and is mainly used to refer to socioeconomic disparities in health (Braveman, 2006).

Internationally different indicators are used to quantify health disparities, including group comparisons, by calculating general or infant mortality rates. Further, more complex measures are used, such as the Relative Index of Inequality (RII) to identify the extent of socioeconomic disparities in health or the Gini Index as a predictor of health disparities (Wagstaff et al, 1991; Mackenbach and Kunst, 1997; Regidor, 2004; Braveman, 2006).

In contrast to this, the field of health literacy has seen only little consolidation regarding its conceptualisation and measurement. Pleasant, who in 2013 attempted to assess the current state of health literacy efforts on a global level, found that even though in many countries health literacy had become an area of interest to researchers and policy-makers, relatively loose definitions and conceptualisations had also led to increased fragmentation of the field (Pleasant, 2013). For health literacy-related policy activities, see Part 3 in this volume.

Reviewing the international literature, however, reveals that some important and encouraging overlaps between conceptualisations and measurements do exist. Agreement exists on the fact that health literacy is a multidimensional concept, with functional literacy being one of the key dimensions (see, for example, Nutbeam, 2000; Kickbusch, 2009; Sørensen et al, 2012; Schulz and Nakamoto, 2013; see also Chapter 14, this volume). This is also mirrored in the fact that many functional health literacy measures, which were originally developed in the US, have been adapted to be used in other countries (see, for example, Baron-Epel et al, 2007; Jovic-Vranes et al, 2011; Connor et al, 2013; Fadda et al, 2016). However, it is worth mentioning here that many of the disparities in health that we find today may not necessarily (any more) pertain to differences in functional health literacy, but may be due to other dimensions of health literacy, such as critical literacy. Thus, the still large focus on functional health literacy may oftentimes underestimate the true contribution of health literacy on disparities in health.

To move the field forward and to understand the impact of health literacy on disparities in health on a more global level, it will be important to reach some consensus on key definitions. In particular, organisations that have a stake in understanding the impact of health literacy on health disparities, but also in promoting health literacy among policy-makers as an intervenable factor, will need to find common grounds. Whether it is the World Health Organization (WHO), OECD or United Nations (UN) agencies, all of which have recognised the importance of health literacy (see, for example, Murthy, 2009; WHO, 2016; OECD, 2017), larger organisations will have to take, at least partly, the lead in describing the contribution of health literacy to health disparities on a population-based level and support data collection efforts on a cross-national level. This is not only a question of responsibility, but also of practicality, given that these organisations already drive many of the global data collection efforts on health disparities.

Challenge 2: Addressing contextual factors

Research has largely focused on individual factors that are likely to influence health literacy and related disparities. Yet relatively little attention has been paid to assessing, and potentially disentangling, the relationship between structural or environmental conditions and health literacy. Using a social ecological (Golden and Earp, 2012; McCormack et al, 2017) or an integrated social determinants approach (Koh et al, 2010) would support current efforts to address this lack of research. Besides considering disease types and related outcomes, as well as population domains (that is, socioeconomic position, race/ethnicity or gender), an integrated approach would also consider potential risk factors (that is, access to care or environmental risks) and geography (that is, developed vs developing countries) (Koh et al, 2010). Taking such an approach is as much a conceptual, as it is a methodological, issue. From a conceptual perspective, critical appraisal of the influence of social or environmental conditions would not only consider differences in healthcare systems that could explain differences in health literacy levels, but also underlying structural factors that influence individuals' engagement with appropriate healthcare. For example, in many parts of sub-Saharan Africa priority is still largely given to providing first aid medical assistance or basic healthcare rather than providing access to comprehensive, preventive health services. Thus, by taking risk factors as well as geographical factors into consideration, conceptual pathways that describe exposure to or experience with health services as a potential predictor of health literacy should also describe structural factors possibly causing variability in findings.

From a methodological perspective, assessment tools that operationalise health literacy independently of structural factors, such as general knowledge on disease prevention or screening behaviours, may lack relevance in countries that do not provide sufficient access to such services. Further, international comparisons based on these measures would become obsolete. Other structural factors, such as access to education or information, should also be taken into consideration. In its essence, lack of sufficient education and subsequent illiteracy is often considered causative to differences in health literacy, especially when assessed with functional health literacy measures. Further, even in cases where sufficient access to education is provided, access to information may still be limited or not available to all. The concept of 'communication inequalities' (Viswanath et al, 2015), for example, posits that information is not equally distributed throughout a social system. In line with this, it has been found that individuals at the lower end of the socioeconomic spectrum are less likely to access and use health information and communication technologies (Viswanath and Ackerson, 2011; McCloud et al, 2013; Kelley et al, 2016). Knowing where and how to access and use health information is a key dimension of most definitions of health literacy, and assessments thereof include, for example, questions on difficulties for the respondents to find relevant information. However, not considering potential limitations in access to information related to structural conditions and attributing it to individual factors only may conceal the real cause of differences in health literacy levels.

Investigating the link between health literacy and health disparities requires an approach that takes context-specific factors into consideration (Paasche-Orlow and Wolf, 2007), including structural factors that are likely to affect health literacy skills and the conditions in which they are used. We understand that this is a rather complex issue that needs to be addressed from multiple sides. From a methodological point of view, we suggest two distinct ways to address this issue. The first is to develop and adapt measures to the context they are used in, considering the influence of factors that are likely to shape the distribution of health literacy. Assessing health literacy in certain parts of Africa, as compared to the US, for example, will not only vary in terms of assessment mode (such as the REALM or NVS that have been found to be not equally applicable in different contexts; see Fransen et al, 2011; Fadda et al, 2016), but also regarding its scope and what is considered to be a sufficient level of health literacy. Asking individuals about their information-seeking behaviour or whether they know when to get screened for colon cancer is less relevant to individuals living in deprived areas with no access to such services than to understand when to seek medical care for certain symptoms or how to prevent infectious diseases (see, for example, Taffa and Chepngeno, 2005; Abebe et al, 2010). Using context-specific measures would provide new insights into health literacy and add to a better understanding of where interventions may be needed. Yet the drawback of this approach is that it does not allow a direct comparison of health literacy across different contexts. Therefore, as a second way to address structural factors, we suggest that besides finding consensus on what health literacy should entail and how to operationalise it (see above), additional analysis techniques should be promoted. This can include, for example, multilevel analysis (Diez-Roux, 2000), which has seen only limited application in the field of health literacy so far. Including group-level variables (such as country-level factors) with individual-level variables in analyses would allow us to more clearly isolate the relationship between health literacy and health disparities.

Challenge 3: Disentangling and assessing culture

There is relatively little doubt about the fact that the distribution of health literacy varies from one culture to another (Nielsen-Bohlman et al, 2004; Batterham et al, 2016). Cultural differences are likely to occur in terms of the distribution of health literacy levels when comparing different regions, countries or language groups to each other. Especially in the context of health disparities research and the associated study of heterogeneous populations, culture is an important factor to consider.

It would be misleading to argue that the concept of culture has not been a matter of discussion in research on health literacy (Zanchetta and Poureslami, 2006; Shaw et al, 2009; Singleton and Krause, 2009). However, operationalisation of the concept has remained limited, focusing mostly on differences by race or ethnicity, country of origin or native language (see, for example, Sentell et al, 2013; Ng and Omariba, 2014; Mantwill and Schulz, 2017). Using these broad categories may not be sufficient to make any assumptions about cultural practices. Culture is much more than a racial category. On the individual level culture is characterised by its dynamic and continuously changing nature. It is learned through language use, socialisation processes and individual adaptation to environmental conditions. Culture influences the individual's emotional and behavioural responses to the environment and influences how one's social network responds in turn. Reducing culture to a broad categorical or dichotomous variable, especially in multicultural societies where population groups and individuals undergo continuous change, may conceal much of the underlying dynamics and intragroup variations (Kagawa Singer, 2012).

For the field of health literacy, the concept of culture is particularly relevant as measurements tend to largely reflect Western biomedical perspectives, including the description of what constitutes an appropriate level of health literacy, thus leaving little room for cultural-specific practices that may be considered appropriate responses to health issues in other cultures. For example, in some cultures, seeking spiritual help or using traditional remedies when confronted with a health threat may be considered a complementary, if not even a substantial, part of coping and treatment. Yet, from a Western biomedical perspective, these practices may be considered to negatively affect coping behaviour and overall health outcomes (Kagawa Singer, 2012).

An additional methodological concern relates to the often quantitative and increasingly self-reported nature of research in health literacy. One of its drawbacks is a lack of understanding in how far responses to different measures are reflective of actual differences in health literacy, or whether they are rather a reflection of response patterns pertaining to cultural differences. In an earlier mentioned study in this chapter, it was found that participants from Japan, a country with one of the highest life expectancies in the world, scored significantly lower than European participants on the HLS-EU (Nakayama et al, 2015). The authors argued that part of the explanation would lie in the different healthcare systems. Yet we argue that concepts such as self-confidence or self-consciousness may also have influenced response patterns. Research has shown that, in contrast to Western nationalities, Japanese people tend to be more critical of their own behaviour (Heine et al, 2000). Additionally, survey research has found that East Asian people are indeed more likely to indicate lower values on scales than, for example, North American people (Chen et al, 1995; Lee et al, 2002). Explanations for this phenomenon include differences between collectivist and individualist societies that emphasise different values (Chen et al, 1995), or concepts such as explicit self-confidence or self-criticism being more pervasive in some cultures (Heine et al, 2001; Kitayama and Uchida, 2003).

Research on health literacy and disparities is inherently related to the investigation of culturally heterogeneous populations, and must therefore take large variability into account. Culture is a dynamic process that should be considered to shape health literacy throughout the life course in very different ways. Kagawa Singer (2012) recommends a number of steps to enhance research on culture and health disparities, which we believe should be, to a large part, equally considered for research on health literacy. First, researchers considering culture to be an important factor in explaining the relationship between health literacy and disparities need to clearly define and operationalise culture, going beyond simple categorisations. Further, as already partly argued in previous sections, there is a need to further adapt and establish the cross-cultural validity of current measures. This also includes the recognition of the boundaries of those measures, which may not be able to provide a sufficiently nuanced picture of how health literacy varies between cultures and what constitutes a sufficient level of literacy. Last, all this will require more mixed-methods studies to provide more inductive approaches towards the study of culture and its possible association with health literacy and disparities.

Conclusion

This chapter aimed at describing three challenges that may influence current efforts to investigate the relationship between health literacy and health disparities, with a focus on the issue of comparability of findings across contexts and countries. Besides describing potential pitfalls when trying to assess the relationship, the chapter also aimed at highlighting potential solutions. We recognise that the described aspects are often closely interrelated and, at the same time, may often seem to be at two opposite ends of a spectrum. On the one hand, we have discussed how finding a consensus on conceptualisation and definitions would support data collection efforts and comparisons on a more global level. On the other hand, we have also discussed that research on health literacy and disparities should be context-specific, considering structural (contextual) factors and culture. We believe that these should not be seen as two separate approaches to the study of health literacy and disparities, but rather, as complementary. Agreeing on common grounds would allow more systematic data collection efforts across countries and regions, providing the backdrop for researchers, as well as policy and decision-makers alike, to identify *regions at risk* for lower health literacy. Further, it would allow a teasing out of the contribution of systemic factors, including those related to the healthcare system as such, and to think about systemic solutions to the problem that may eventually foster equity in health. To respond to the growing call for research and responses to health disparities within countries, which not only pertain to affluent nations (Braveman, 2002), context-specific research on health literacy will be important. Besides disease-related outcomes and individual factors, research will also have to consider cultural and structural factors to support the design of effective programmes and interventions that may help to alleviate some of the health disparities associated with lower levels of health literacy.

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10

Health literacy in later phases of life: Findings from Germany and other countries

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Background

Societies in the 20th century are ageing, as the proportion of older people in the populations of many countries further increases (UN, 2015; He et al, 2016) – 12 per cent of the world's population was aged 60 or older in 2015 (UN, 2015). Germany has especially been affected by this development. According to figures from 2015, it has the second oldest population in the world (Federal Statistical Office, 2015; UN, 2015), with one-fifth of its population aged 65 or older (Federal Statistical Office, 2015). Based on current population projections, more than a third of Germany's population is expected to be at least 65 by 2060 (Federal Statistical Office, 2015). The share of very old people, aged 80 years or older, will further increase, with a doubling of its proportion expected in the next 25 years (Federal Statistical Office, 2015).

In many countries the younger phase of older age (people aged 65-70) is spent in better health, with a compression of expected for this phase (Fries, 1980, 2000). However, in all phases of old age, the risk of health problems, especially chronic conditions, increases (Garms-Homolová and Schaeffer, 2012; WHO, 2014, 2015; Robert Koch Institut, 2015; Lampert et al, 2016).

According to current data, more than half of people aged over 65 in Germany have at least one chronic condition (Nowossadeck, 2012). In addition, older people often suffer from several disorders at the same time, so multi-morbidity is no exception (Anderson and Horvath, 2004). About 70 per cent of people in Germany aged 65-74, and almost 80 per cent of those aged over 75, have at least two chronic illnesses (Robert Koch Institut, 2015). Furthermore, long-term physical and/or cognitive limitations often, but not always, caused by dementia, emerge with increasing age. This puts older people at risk of decreased autonomy (Kuhlmey and Schaeffer, 2008).

All of this shows that older people face the challenge of having to manage adverse health problems in daily life, usually of a permanent nature, and growing increasingly complex over the course of time. They are required to navigate in a more complex health system, deal with a wide range of health-related information, implement instructions from health professionals, and manage complicated therapy and medication routines (Lorig and Holman, 2003; Müller-Mundt and Schaeffer, 2011; Schaeffer and Haslbeck, 2016). These are only a few of the tasks placed on them, as coping with chronic illnesses is always complex (Williams, 2000; Thorne et al, 2002; Charmaz, 2003; Kralik, 2008; Rijken et al, 2008; Corbin and Strauss, 2010; see also Chapter 12, this volume). Therefore, older people need sufficient health literacy to successfully meet these challenges (Osborn et al, 2010; Berkman et al, 2011; Schaeffer, 2017).

The fact that patients today are assigned a more active part – as emphasised in the debate on the change of the patient's role (Dierks and Schwartz, 2003; Boyer and Lutfey, 2010; Horch et al, 2011) – reinforces increased demands. Unlike earlier times, patients today cannot behave as passive according to paternalistic concepts, but are instead encouraged to actively participate as consumers and co-producers, to make informed health decisions, and to voice their concerns (Bauer et al, 2005; Schaeffer, 2009; see also Chapter 40, this volume). To be able to fulfil these requirements, health literacy – understood as individuals' knowledge, motivation and competences to deal with health-related information – is needed, to be able to access, understand, judge, and apply it in order to make health-related decisions (Sørensen et al, 2012, p 3).

Whether older people possess sufficient health literacy, however, is unclear. The aim of this chapter, therefore, is a closer examination of *health literacy* in the later phases of life. The chapter describes: the prevalence of limited health literacy among older people; the demographic, socioeconomic and health-related determinants associated with limited health literacy among older people; as well as the related health consequences. It is posited that a differentiation of phases in old age is absolutely necessary when considering the health literacy of older people (for more information on elderly people and end of life, see also Chapter 41, this volume).

Limited health literacy in later phases of life

First, current empirical findings on the prevalence of limited health literacy in old age are given. We concentrate on findings and results from Europe, and particularly Germany, as they follow different, newly developed, concepts and methods.

Health literacy studies concerning older populations usually originate from the Anglo-American region (Zamora and Clingerman, 2011; Chesser et al, 2016; Kobayashi et al, 2016), and examine socioeconomic determinants and health indicators associated with health literacy (Zamora and Clingerman, 2011; Chesser et al, 2016; Kobayashi et al, 2016). These studies consistently indicate a high prevalence of low health literacy in older people. However, the proportion varies depending on sample sizes and measuring instruments used, as well as classifications in terms of age group, which differ to a great extent (Gausman Benson and Forman, 2002; Wolf et al, 2010; Ganzer et al, 2012; Kirk et al, 2012; McDougall et al, 2012; Mosher et al, 2012). In most studies among older people, health literacy has been measured with the Wide Range Achievement Test-Revised (WRAT-R), Rapid Estimate of Adult Literacy in Medicine (REALM), Test of Functional Health Literacy in Adults (TOFHLA) and the Newest Vital Sign (NVS) (Zamora and Clingerman, 2011; Chesser et al 2016). Available findings are thus mostly based on a functional understanding of the concept of health literacy (see Chapter 5, this volume).

In addition, population surveys also provide results regarding health literacy in later phases of life (Kutner et al, 2006; ABS, 2008; Rootman and Gordon-El-Bihbety, 2008). They mainly show that older people from the age of 65 and above have significantly lower health literacy than middle-aged adults or younger people. According to the results of the National Assessment of Adult Literacy (NAAL), about one-third of older people lack the sufficient health literacy, for example, to identify an appointment for a medical examination on a leaflet or understand and utilise relevant information on a medical form submitted to them (Kutner et al, 2006). The situation in Canada is similar. The proportion of low health literacy among older people aged 66 or more exceeds 60 per cent (Rootman and Gordon-El-Bihbety, 2008, p 15). In Australia, more than 80 per cent of people aged 65-74 are not sufficiently health-literate (ABS, 2008, p 8).

However, considering these international studies generally reveals that they seldom involve a differentiated examination of older people according to age groups or phases. They mainly only suggest that the proportion of low health literacy increases with age (Baker et al, 2000; Cutilli, 2007; Wolf et al, 2010; Kobayashi et al, 2016), and is higher among the 'old-old' than among the so-called 'young old'. In other words, older people in Anglo-American health literacy studies are usually considered as a homogeneous group.

In Germany and the rest of Europe research on health literacy did not significantly emerge until the European Health Literacy Survey (HLS-EU) was conducted in 2012. The aim was a comparative investigation of the population's health literacy in eight European countries. Based on a systematic literature review a comprehensive definition of health literacy and a corresponding measuring instrument was developed and applied in the participating countries. The results show that the group of older people and, in particular, older people aged 76 or above, have limited health literacy and are among the most vulnerable groups in terms of health literacy; 60.8 per cent of older respondents in that age group have limited health literacy, according to the HLS-EU, and perceive considerable difficulties in dealing with health information (HLS-EU Consortium, 2012).

The European study also provided an insight into health literacy among older people in Germany, although only one of the 16 federal states, the state of North Rhine-Westphalia (NRW), participated. It shows that 53.9 per cent of people older than 76 in Germany (more specifically, in NRW), a slightly smaller proportion compared to the EU average, have a limited health literacy level (HLS-EU Consortium, 2012).

Inspired by the HLS-EU, health literacy studies also began to emerge in Germany. They are all based on its concept and measuring instrument, and mainly address the general population. One study, originating in Germany, focused exclusively on statutory-insured people (Zok, 2014). The German Health Update (GEDA) conducted by the Robert Koch Institute also collected data on the health literacy of older people. These results indicate that people in later phases of life more often have limited health literacy (Jordan and Hoebel, 2015). In both studies the short version of the HLS-EU questionnaire (HLS-EU-Q16) was used, and therefore presumably might not represent all the health literacy components of importance for older people.

Additionally, only a few investigations on the health literacy of specific population groups in Germany have been conducted thus far (Schaeffer and Pelikan, 2017). Consequently, there are hardly any studies about older people. One such study in NRW focused on young people and older people with and those without a migration background (Quenzel and Schaeffer, 2016). It indicated that older people, especially those with a migration background, have limited health literacy (Quenzel and Schaeffer, 2016). However, this study did not include a differentiated examination of the various age groups. The same applies to a cohort study on cardiovascular risk factors and diseases in the older general population, including data on health literacy (Tiller et al, 2015).

The German Health Literacy Survey (HLS-GER) is of special interest in this context (Schaeffer et al, 2017) – a representative population survey based on the HLS-EU concept. The HLS-GER was conducted in a survey of a total of 2,000 German native speakers from the age of 15 with the help of computer-assisted personal interviews (CAPI) (for further details, see Schaeffer et al, 2016, 2017). Underlying the survey is the conceptual understanding and health literacy definition developed by the HLS-EU Consortium (Sørensen et al, 2012). The study results show that two-thirds of older people aged 65 and above have limited health literacy, that is, they face great difficulties in dealing with health information (Berens et al, 2016; Schaeffer et al, 2016). Age-specific analysis of people aged 65 or older indicates great differences in health literacy among different age groups in old age. It shows that only 4.1 per cent of older people aged between 65 and 70 possess excellent health literacy. Another 30.8 per cent have sufficient health literacy, while more than half (52.5%) have problematic health literacy. Another 11.2 per cent possess an inadequate health literacy level. Consequently, the majority of the respondents perceive great difficulties in dealing with health information (Vogt et al, 2017).

People aged 71-75 can be characterised similarly: here, too, the proportion of inadequate health literacy is roughly 10 per cent. Another 48.6 per cent have problematic health literacy. This value is also approximately equal to that shown by the 65- to 70-year-olds. However, the proportion of excellent health literacy among 71- to 75-year-olds is, at only 2 per cent, slightly lower. Accordingly, only very few older people in this age group find it easy, for example, to understand their physician or to assess the pros and cons of various treatment options.

The results among people aged 76 and older show significant differences. Nearly one-third of the respondents in this age group have inadequate health literacy, which is almost three times as much as in the younger age groups. Another 45.7 per cent have problematic health literacy. The total share of limited health literacy among respondents aged 76 or above is therefore 75.5 per cent. Hence, health literacy scores differ significantly compared to the two younger age groups ($p<0.001$) (Vogt et al, 2017). In conclusion, older people generally belong to the vulnerable groups; however, the proportion of limited health literacy is particularly high in the group of the old-old people.

Limited health literacy and associated factors among older people

As a result of these findings, the question arises as to which determinants are related to low health literacy among older people and explain the high proportions of low health literacy in later phases the main explanatory determinants of low functional health literacy in old age (Chesser et al, 2016). Older people with a migration background and low income tend to have lower health literacy. However, the findings on educational attainment are ambiguous. While the level of education is associated with functional health literacy in some studies (Wolf et al, 2005), no relationship can be established in other studies (McDougall et al, 2012). Also discussed as possible causes for worsening health literacy with increasing age are factors such as the deterioration of cognitive and physical resources, which often manifest in later phases of life (Baker et al, 2002; Cornett, 2006; Howard et al, 2006; Levinthal et al, 2008; Federman et al, 2009; Speros, 2009, 2011; Chesser et al, 2016).

In Europe and Germany empirical findings regarding explanatory determinants of limited health literacy in old age are largely lacking. Initial information is provided by the previously mentioned, age-differentiated, analysis of the HLS-GER (Vogt et al, 2017). This shows that functional health literacy among older people is associated with limited health literacy ($p<0.001$); 78.7 per cent of all respondents with limited functional health literacy also have limited health literacy. Financial deprivation and the presence of chronic illness are also associated with limited health literacy. For example, almost 80 per cent of financially deprived people older than 65 have limited health literacy. The proportion in the case of older people with chronic illness is at least 70.6 per cent (Vogt et al, 2017).

The results of multivariate analyses show that financial deprivation is the strongest predictor of limited health literacy in old age (Vogt et al, 2017). Looking at different age groups among older people, the results show that financial deprivation remains the strongest predictor in explaining limited health literacy in all age groups among old people (Vogt et al, 2017). Thus, the findings indicate a social gradient.

Impact of limited health literacy on health

The high proportion of limited health literacy among older people raises the question of health-related consequences associated with this. The existing findings suggest a link between low health literacy and poor health indicators, with most of these studies mostly being cross-sectional studies that examine functional health literacy and its relationship to health-specific indicators. According to these studies, low health literacy is associated with poorer subjective health (Berkman et al, 2011) and unhealthy behaviours. Older people with low health literacy, for example, more often assess their own health as being poor, and have worse self-management skills (Schillinger et al, 2006; Powell et al, 2007; Wolf et al, 2007; Tang et al, 2008). There are also studies that suggest a link between low health literacy and increased mortality risk among older people (Baker et al, 2000, 2007; Sudore et al, 2006; Cavanaugh et al, 2010; Bostock and Steptoe, 2012). These studies focus on assessment of the functional level of health literacy in the context either of country-specific data on mortality or data generated specially for the studies. Regarding increased mortality risk, however, it must be noted that these investigations do not establish any causal link.

Low health literacy is furthermore related to a more intensive use of health services: emergency care facilities such as hospitals and emergency medical services are used more frequently by older people with low health literacy. By contrast, they make less frequent use of preventive measures and screening examinations (for example, mammography, bowel cancer screening) (Baker et al, 1998, 2004; Scott et al, 2002; Berkman et al, 2011).

Similar findings were obtained in Europe and Germany, but in relation to the general population. Here, too, health literacy is associated significantly with the respondents' self-assessed health (HLS-EU Consortium, 2012; Jordan and Hoebel, 2015; Schaeffer et al, 2017). People with limited health literacy less frequently assess their state of health as 'very good' or 'good'. Also, a higher prevalence of chronic illnesses, depressive symptoms, severe pain and further persistent health problems among those with limited health literacy have been shown, indicating an association between limited health literacy and behavioural risk factors (Jordan and Hoebel, 2015). Limited health literacy is additionally associated with greater difficulties in orientation within healthcare systems, lacking knowledge about contact points for health problems, and more frequent hospital stays and more intensive use of medical emergency services (Schaeffer et al, 2016).

So far there is little knowledge in Europe and Germany regarding consequences limited health literacy levels have for older people, and especially very old people aged 80 years and above. One study suggests that among people aged 65 and above, health literacy is associated with health-related quality of life and the probability of falling ill with diabetes, stroke among men and heart attack among women (Tiller et al, 2015).

Conclusion

According to available, yet insufficient, findings, older people have a significantly lower level of health literacy compared to the general population. First, they lack adequate personal skills and competences for accessing, understanding, judging and applying health-related information, for example, to make decisions necessary for maintaining health. Second, the large proportion of limited health literacy indicates the difficulties and complexities of the situational demands placed on the individual, as well as problems communicating with health professions and a healthcare system.

Furthermore, substantial differences between age groups regarding the prevalence of limited health literacy in later phases of life can be shown: people over 76 have especially low health literacy. This is an important result from public health perspective because the likelihood of chronic illness, multi-morbidity and of frailty increases in the phase of old age (Suzman, 2001; Rott and Jopp, 2012; WHO, 2015). At the same time, this involves increased requirements in processing health information. However, personal resources, including health literacy, decrease in old age.

Also noteworthy from a public health perspective is the social gradient related to health literacy among older people. Financial deprivation has been shown to be the strongest predictor of limited health literacy in Germany. This applies particularly to people in later phases of life. This finding is directly linked to discussions on health inequality that have been stressing the great importance of socioeconomic factors for the health of older people for decades (von der Knesebeck, 2008; Lampert et al, 2016). At the same time, the results show that older people with few socioeconomic resources have a higher mortality risk (Huisman et al, 2013), greater functional impairments (Shaw et al, 2014) and a poorer subjective health status (Read et al, 2016). In conclusion, the consequences arising from the findings are discussed. The main points are as follows:

- Although older people and, especially very old people, face great difficulties in dealing with health information, relatively little attention is still paid to them in *health literacy research*. This urgently needs to be changed.
- It is also necessary to pay *more attention to the differences observed among people in different phases of old age* that have long been observed in gerontological research. Studies are needed to enable detailed analyses of health literacy among older people. This includes a differentiation between young old, medium old and old people. Such studies should simultaneously close existent research gaps and clarify, for example, how and which health indicators are associated with low health literacy in later phases of life or examine the significance of psycho-social factors.
- At the same time, it is important to promote the *development of interventions*. Available data – although scarce – already provides an insight into the abilities and skills to deal with health information and provides important approaches for the development of interventions to improve health literacy. One of the main conclusions here is that more attention also needs to be given to age differentiation in the development of interventions.

Likely to be promising for younger old people are interventions aimed at strengthening an individual's health literacy, and containing elements of information and knowledge communication, as well as strengthening competence (Nutbeam, 2000; Chinn, 2011; see also Chapter 14 and Part 2, this volume). By contrast, in order to strengthen the health literacy of old people interventions aimed at a structural and environmental level seem to be more promising, as in this the phase of life people become more vulnerable in terms of health problems and at the same time lose important personal resources. Thus, approaches aimed at improving the health literacy of the health system, its institutions and professions, and thus reducing the demands placed on individuals, are more important. Initial approaches already exist (for example, health-literate organisations; Brach et al, 2012; Dietscher and Pelikan, 2017; see also Chapters 8 and 31, this volume), and their adaptation to the target group of old people is an important task for the future. This is important, as it is necessary to avoid shifting the problem to the individual instead of changing the structural deficits that only manifest in the individual.

Greater attention should also be paid to increasing inequalities in old age. Interventions need to address not only health literacy, but also the healthcare system needs to be accessible to, for example, financially deprived old people. More importance should be paid to the topic of health literacy at the political level as well. This is emphasised by WHO initiatives such as the Shanghai Declaration (WHO, 2016) or the National Action Plans existing in many countries (Puntoni, 2010; Ministry of Health [NZ], 2015), including in Germany (Schaeffer et al, 2018).

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11

Critical health literacy for the marginalised: Empirical findings

Susie Sykes and Jane Wills

Introduction

Definitions of health literacy have differentiated between functional, interactive and critical health literacy (CHL). The latter describes advanced literacy skills that may be used to critically analyse information but also, crucially, to use this information to exert greater control over life events and situations that have an impact on health. CHL includes the development of 'skills and abilities that enable citizens to become aware of public issues to participate in critical dialogue about them, and to become involved in decision-making processes' (Zarcadoolas et al, 2006, p 61). CHL connects closely with the concept of health promotion, and is a key outcome of empowerment strategies that seek to develop personal skills, build healthy public policy and create supportive environments (see Chapters 1 and 14, this volume).

Individual lifestyle factors, social and community networks, living and working conditions and general socioeconomic, cultural and environmental conditions have all been presented as important in determining health (Dahlgren and Whitehead, 1991; see also Chapter 9, this volume). The body of work evidencing the impact of these social determinants of health has grown considerably over the last 10 years and links are now well established and more fully understood (Marmot et al, 2012). Literacy is a social determinant influencing health both directly and indirectly: directly, through the difficulty of gathering and comprehending health information and the organisation and functioning of the healthcare system; and indirectly, through the personal and socioeconomic challenges that often go with limited literacy, for example, self-confidence, employment, income, housing, healthy eating and the stress that comes from constant worry about meeting these basic human needs for ourselves and for our families. Research has shown that people with a better education have lower morbidity rates from the most common chronic diseases (Cutler and Lleras-Mune, 2006), which is, in part, because of the effects of education on adult income, employment and living conditions (Marmot et al, 2012). The opportunities, then, for marginalised, vulnerable and disadvantaged groups to be actively involved in decisions about their health and to take control of their health and the conditions that affect their health may be limited by their health literacy skills. As lifelong learning (both formal and informal) improves health literacy, which influences health outcomes, there is a need to develop health literacy across the life course. There is, for example, substantial evidence that low health literacy is associated with older age and difficulties coping with health system demands, complex information environments including mental health and declining cognitive function (Wister et al, 2010; Murray et al, 2011), yet the opportunities for this age group to develop CHL are correspondingly limited.

CHL has built on the idea of 'critical consciousness' derived from the emancipatory adult education and participatory empowerment philosophy of Paolo Freire (1993). Freire developed a pedagogy in Brazil with illiterate workers based on an education of questioning, in which the development of the vocabulary of the learners' daily life promoted dialogue between the participants that would address the questions of their social conditions. Thus, teaching words becomes a means to teaching about the world rather than an end in itself. Mastering the tools of the dominant language was, for Freire, 'not only to survive but also to fight for the transformation of an unjust and cruel society where the subordinate groups are rejected, insulted and humiliated' (1993, p 135). For Freire, literacy is not just about reading and writing skills, but also about mobilising social resources and social capital in communities to confront and analyse their surrounding social, political and economic structures.

This chapter reports on the available evidence about strategies to improve CHL. Such strategies are important empowerment tools that have the potential to reduce health inequalities because the most vulnerable and disadvantaged people in society are at risk of limited health literacy and are known to have the poorest health outcomes.

Defining 'critical health literacy'

CHL is the domain of health literacy that is least well defined and developed, perhaps because it takes us away from the association of health literacy with health education and forms of communication towards political action. There have been several major attempts to clarify the concept of CHL and each has a different conclusion about its core elements, but they share a view that CHL is not only an individual (as in having abilities to critically assess information) but also a population asset offering a route to greater autonomy and control over health decision-making (Nutbeam, 2008; Martensson and Hensing, 2012).

The first area of CHL identified by Sykes et al (2013) in their concept analysis involves higher-level cognitive and social skills that allow critical thinking and informed decision-making. These cognitive skills enable someone to contextualise health information and apply it to their personal situation and context, in order to make an informed decision that benefits health and wellbeing. This area of CHL can be viewed as an asset, supporting people to engage with health information and the healthcare system, and exert greater control over their own health and decision-making.

The second area of CHL acknowledges the importance of existing structural factors that indirectly influence someone's health and wellbeing, comprising social and community networks, living and working conditions, and socioeconomic, cultural and environmental conditions. CHL encompasses the empowerment of people to challenge and take actions regarding these determinants of health and wellbeing. This might be, for example, challenging drug dealing and associated safety concerns in a neighbourhood or the use of green space. CHL is about people engaging in collective activities regarding such health issues. Porr et al (2006) describe a project with low-income mothers in Australia in which the healthcare professional facilitates the exploration of problems (for example, inadequate financial support, lack of affordable housing and transportation concerns); the underlying commonality is that they have affected the lives of the mothers, thus leaving them powerless. The search for the sources of powerlessness goes beyond the individual, to the surrounding economic, social and political forces. Chinn (2011) identifies the CHL competencies needed for collective actions as recognising that an individual can contribute to community outcomes and having skills in working in groups and knowledge of the local community.

A review of the evidence on the effectiveness of interventions to promote critical health literacy

As the focus on health literacy has expanded over the past decade, so have the number of reported interventions and reviews of effectiveness (Sheridan et al, 2011; D'Eath et al, 2012; Manafo and Wong, 2012; Taggart et al, 2012). As Nutbeam et al (2017) point out, many of the intervention studies that are included in such reviews have very broad definitions of health literacy. Few of the studies included have a focus on developing CHL, although there are other reviews that synthesise the evidence of interventions explicitly designed to build empowerment (Woodall et al, 2010). Four reviews have included intervention studies about building CHL (Taggart et al, 2012; de Wit et al, 2017; Nutbeam et al, 2017; Fernández-Gutiérrez et al, 2018), yet the impact that they have on CHL competencies are not well evidenced and the reviews recognise that this is, in part, due to the limited availability of useful tools to measure CHL.

A review by de Wit et al (2017) focused on CHL in older adults and included interventions that sought to build comparable concepts such as empowerment. De Wit et al's review (2017) found that two practices were important in effective interventions to develop CHL. First, collaborative learning, whereby reciprocal learning about health took place between older adults and family, community members, peers and healthcare professionals, and which de Wit et al (2017) argue is crucial for critical thinking; and second, social support as older adults gave it to and received it from members in their community. The following sections describe the methods, findings and learning from a review of the available evidence on strategies and interventions for improving CHL.

Methods

In identifying the empirical evidence base of interventions designed to build CHL, a search of health, education and psychology electronic databases including Scopus, PubMed, PsycINFO, CINAHL, Academic Search Complete, BioMed Central, PsycARTICLES, Science Direct, SocINDEX and Education Research Complete was carried out using the search term 'critical health literacy'. While it is recognised that interventions may actively work to build the components of CHL without actually using the terminology itself, and may therefore be useful in the learning they identify, this review was specifically interested in those interventions that had a stated intention to build CHL. A decision was therefore made not to include search terms of overlapping concepts such as empowerment or community action (see Crondahl and Karlsson, 2016). Given the limited pool of published literature on this subject, electronic database searches were complemented with a search of Google Scholar, grey literature and reference tracing.

The initial search of databases found 155 papers plus an additional 1,504 references through Google Scholar. Inclusion and exclusion criteria were applied that limited studies to empirical papers that included an intervention designed to build CHL, and theoretical papers or concept analyses were excluded. No limiter was placed on date or geography. Studies were not excluded if they did not include an assessment of levels of CHL as a way of evaluating impact. As there are a limited number of validated tools to measure CHL, this would have restricted the returns too significantly, but impact or outcomes are reported where they have been shown.

Findings

Applying the inclusion and exclusion criteria to the returns resulted in 13 articles included in the review that drew on 12 interventions. Of these studies, three were reflections rather than empirical studies. As they were presented as case studies of interventions and were published in peer review journals, a decision was made to include them.

Table 11.1 shows the approach of the reported intervention, its context or setting, and the participants. The studies were drawn from Australia, USA, UK, Canada, Denmark, the Philippines and Germany. Seven of the studies focused on interventions that targeted young people, the majority of which took place in schools. The rest targeted indigenous communities, socially disadvantaged adults or black and minority ethnic communities.

There was considerable variation in the nature of interventions used to build CHL, as shown in Table 11.1. Two of the studies focused on arts-based and creative strategies such as role-play, iMovies and the creation of graphic novels (Banister et al, 2011; Begoray et al, 2014). Four of the interventions were offered as complementary school curriculum programmes run over a period of several weeks delivered either by external providers or by the teachers (Steckelberg et al,

Table 11.1: Studies of interventions to promote critical health literacy

Study	Country	Setting	Participants	Approach	Evaluation
1. Banister et al (2011)	Canada	Healthcare settings	Adolescent girls	Package of strategies for healthcare providers to develop functional, interactive and critical health literacy. These include use of text messaging, role-playing, targeted internet sources, blog writing and small group work	Case reflections
2. Begoray et al (2014)	Canada	School	Adolescents	Project to involve adolescents in the development of multimedia to build critical media health literacy. Two interventions described using iMovies/puppets and creating graphic novels	Case study
3. Bruselius-Jensen et al (2017)	Denmark	School	Adolescents	A two-week curriculum-integrated programme combining maths and health education to improve physical activity health literacy at functional, interactive and critical level	Deductive data analysis of classroom dialogue using a framework derived from Nutbeam's domains of health literacy
4. Drew (2015)	Australia	Community	Aboriginal community	Develops use of 'natural helpers' situated between those in need and services. They work to develop knowledge and skills on both sides	Reflections
5. Estacio (2013)	Philippines	Community	Indigenous community	Empowerment education model using critical reflection to gain a better understanding of how health is conceptualised within the socioeconomic and political environment and its implications for practice	Case study focusing on the discourses used by participants in the project
6. Gould et al (2010) and Mogford et al (2011)	USA	Schools	Adolescents	Curriculum programme with two components: teaching the social determinants of health and teaching skills to take action on them	Reflections

(continued)

Table 11.1: Studies of interventions to promote critical health literacy (continued)

Study	Country	Setting	Participants	Approach	Evaluation
7. McCuaig et al (2014)	Australia	Schools	Adolescents	The purpose of the HL@RS was to design, implement and evaluate a critically oriented health literacy unit to establish the ability of schools and their teachers to deliver such a unit within a school	Qualitative methods including focus groups with students and teachers to assess experience and responses to the curriculum
8. Muscat et al (2017)	Australia	Adult education	Socially disadvantaged Australians	A 'shared decision-making' training programme designed to build communicative and critical health literacy. Delivered as a core component of a broader health literacy programme	Qualitative interview study with the adult educators delivering the programme
9. Scheib and Lykes (2013)	USA	Community	African-American and Latina women community health workers in post-Katrina New Orleans	Participatory community development project that used photography and a facilitated process of reflection and analysis to document and respond to a range of social inequalities	Participatory action and photo elicitation research project
10. Steckelberg et al (2009)	Germany	School	Adolescents	Curriculum programme to build critical health literacy consisting of six modules and based on concept of evidence-based medicine	Critical health competency test used to evaluate change in critical health literacy
11. Sykes et al (2017)	UK	Community	Socially disadvantaged communities	Participatory community development project using citizen's jury model. Communities identified barriers to healthy eating in their community and identified opportunities and strategies to campaign and implement change	Case study
12. Sykes and Wills (2018)	UK	Community	Parents with low literacy levels	Programme to build all domains of health literacy using informal education strategies. Participants learnt about different health topics, engaged with health providers, researched and appraised health information	All Aspects Health Literacy Scale

2009; Gould et al, 2010; Mogford et al, 2011; McCuaig et al, 2014; Bruselius-Jensen et al, 2017). Curriculum-based programmes were also offered to adults in two of the studies (Muscat et al, 2017; Sykes and Wills, 2018). Four studies were community development interventions using participatory approaches such as lay educators, citizen's juries, critical reflection and community capacity building and community action research (Estacio, 2013; Scheib and Lykes, 2013; Drew, 2015; Sykes et al, 2017).

The detail about interventions is lacking in many studies, but the school-based intervention 'Just Health Action' reported on by Gould et al (2010) and Mogford et al (2011) does describe a 'social determinants of health' curriculum for secondary school children. The curriculum is based on an ecological model and focuses on upstream factors that affect health through a social justice lens. Through interactive activities, students are taught about the social determinants of health and then students are empowered to take action to influence policy and work with communities to reduce societal inequities.

Table 11.1 also reports on the CHL measure if any are used in the intervention. Five of the studies were categorised as case studies of interventions on which observations and data about the process and experience were collected (Banister et al, 2011; Estacio, 2013; Begoray et al, 2014; Drew, 2015; Sykes et al, 2017). Seven of the studies included an evaluative element in order to capture impact or outcome (Steckelberg et al, 2009; Gould et al, 2010; Mogford et al, 2011; Scheib and Lykes, 2013; McCuaig et al, 2014; Bruselius-Jensen et al, 2017; Muscat et al, 2017; Sykes and Wills, 2018). Only one of these studies used a validated tool for measuring CHL (Sykes and Wills, 2018), while the rest used qualitative evaluation.

Key learning from the evidence

Settings for promoting critical health literacy

While schools offer an accessible setting for developing health literacy, it was observed in two studies that the school setting reduces CHL to cognitive skills (McCuaig et al, 2014; Bruselius-Jensen et al, 2017). Gould et al (2010) offer some explanation for this, stating that there is a dominant societal belief that individual choice leads to poor health outcomes and therefore that individual behaviour modification is the dominant pathway to good health. This belief, they observe, translates into an institutional focus on teaching functional and communicative health literacy over CHL.

The hierarchies of the school structure and curriculum expectations may also limit opportunities to develop personal agency in young people. Bruselius-Jensen et al (2017), for example, conducted research into a Danish classroom-based health education programme designed to develop the three tiers of health literacy related to physical activity. Through their analysis of classroom dialogue, they demonstrated that teachers facilitated the functional and, to some extent, interactive, levels of health literacy, but struggled to facilitate critical discussions.

They observed opportunities where teachers could have been more supportive of pupils' attempts to be critical in their discussions and of attempts to identify their own health agency.

Approaches to developing critical health literacy

While all the studies aimed to develop CHL, those that had curriculum or structured programmes were less likely to be effective. Most of the studies point to the value of participatory and action-based learning and reflection (Gould et al, 2010; Banister et al, 2011; Mogford et al, 2011; Estacio, 2013; Scheib and Lykes, 2013; Begoray et al, 2014; McCuaig et al, 2014; Bruselius-Jensen et al, 2017; Sykes et al, 2017; Sykes and Wills, 2018), which several studies liken to an education for 'critical consciousness' advocated by Freire (1993). This approach is more commonly associated with community development work and can be seen to underpin the approaches taken by the four included CHL interventions based in communities (Estacio, 2013; Scheib and Lykes, 2013; Drew, 2015; Sykes et al, 2017). Typical across these interventions are approaches that seek to achieve greater social justice, with communities themselves identifying structural issues that may have an impact on health and working together towards a collective solution. The focus becomes one of developing critically health-literate communities rather than individuals. The community-based studies did not offer measurements of CHL, but the qualitative research associated with three of them (Estacio, 2013; Scheib and Lykes, 2013; Sykes et al, 2017) clearly evidenced action to address the structural determinants of health by participants at a community level, the attribute of CHL less successfully evidenced by curriculum-based approaches.

In Scheib and Lykes' study (2013), participatory action research was used with community health workers in the aftermath of Hurricane Katrina in New Orleans in the US. Participants used photography and a facilitated process of reflection and analysis to document individual recovery responses to a range of social inequalities. The data gathered pointed to an acquisition of skills and capacities that facilitated critical analyses of structural inequalities and selected responses to them among participants. The authors concluded that the creative process that encouraged participants to voice their concerns and understandings through images, storytelling and critical reflections allowed participants to recognise themselves and be recognised by others as both producers of health knowledge and contributors to the responses to the post-disaster challenges.

The case study presented by Sykes et al (2017) demonstrates critical health action for change at a community level as an outcome of a community development project using a citizen's jury model. The aim of this project was for a disadvantaged community to create a vision of a better food system for which community members and the wider organisation could campaign. This was based on a position that community members have a right to be involved in deciding what kind of food system they have. The case study demonstrates that through participatory processes, whereby participants identified barriers faced by the community to eating healthy food and then to question 'expert' stakeholders on why those barriers existed, they became critically informed about the determinants of their diet. The process of identifying areas for change meant they also became agents of change. The processes involved in these projects are complex but address the need identified by Begoray et al (2014) for CHL interventions to involve the broader community to address multiple factors at the intrapersonal, interpersonal and community level.

'Critical health literacy' and the marginalised

Six of the studies were interventions that worked with marginalised communities (Estacio, 2013; Scheib and Lykes, 2013; Drew, 2015; Muscat et al, 2017; Sykes et al, 2017; Sykes and Wills, 2018). Most had a focus on communicative health literacy and the ability to use information. Such interventions, where the goal is for the user of healthcare or information to become autonomous and responsible, are focused on the individual and far away from the view of health literacy and communities that Chinn (2011, p 66) calls the 'collectivist-minded, socially active citizen who prioritizes the common good and public health goals.'

One of the key learning points is the importance of interventions being aware of, and responsive to, the social, cultural and psychological context of participants (Bansister et al, 2011). The tailoring of interventions to the cultural needs of the target groups was emphasised by Begoray et al (2014), who concluded that students' ability to learn was tied to how harmoniously their cultural identifiers aligned with the pedagogical practices used in their learning environment, while McCuaig et al (2014) stress the importance of learning for CHL to be relevant, engaging and contemporary in order to be valued. Sykes and Wills (2018) report that the community/family-based intervention that created learning opportunities in participants' own homes and drew on family experiences in group dialogue helped to create a knowledge-building community of learners.

Measuring critical health literacy

Evaluative findings are rarely reported in the studies and there is no established measure of CHL. Gould et al (2010) describe a pre- and post-intervention survey that measures four dimensions of CHL: knowledge of the social determinants of health, health inequities and health as a human right; attitudes regarding social determinants of health, human rights and activism; feelings of empowerment to use new skills and take action on the social determinants of health; and future intentions to take action. Analysis of the post-test returns is reported as being positive across all four dimensions. Other studies, such as that by Muscat et al (2017), report qualitative data on barriers and facilitators to implementation as well as student reactions. They concluded that a focus on this aspect of health literacy was appropriate and feasible for adult education settings, and could be designed for groups with lower literacy when tailored for population needs.

The study reported by Sykes and Wills (2018) used the All Aspects of Health Literacy Scale (AAHLS) (Chinn and McCarthy, 2012), which includes questions on participants' attitudes about government responsibilities for addressing the wider determinants of health, and found an equal split between those thinking that information and encouragement to lead healthy lifestyles was the most important matter for everyone's health and those thinking that structural issues of good housing, education, jobs and good local facilities were the priority. The post-intervention AAHLS assessment showed a slight increase in participants' understanding of how they themselves could get involved at a political level, but no evidence of participants taking any action.

Although programmes do exist that claim to be developing CHL, and many more will have explicit aims to contribute to the empowerment of individuals and communities (Crondahl and Karlsson, 2016), there is currently little evidence that such programmes are effective in improving health outcomes. Evaluations show improved self-esteem, greater awareness and even broadened networks and social support, but little evidence of community mobilisation or an intention to be more active in taking control over those factors that influence health chances. This is partly due to a dearth of focused measurement instruments for CHL, weak methodologies based on small samples and limited time frames for projects.

Discussion

Despite the huge acceleration in interest and research in health literacy over the past decade, there has been relatively little attention to CHL. This review found only 12 interventions that sought to explicitly develop CHL. The most common target of these interventions is young people, with six of the studies solely working with adolescents. This focus is perhaps understandable given the important stage of their development, their growing involvement with their own healthcare and the large amount of health information that is targeted at them (Manganello, 2007). Schools also offer a relatively accessible setting through which to reach this group. However, the review demonstrates a lack of interventions targeted across the life course, particularly for older people. With an aging population and a growing number of older people living with long-term conditions, there is a need for older adults to fully participate in all aspects of healthcare. Disproportionately high levels of inadequate health literacy levels have been reported among older populations (Bostock et al, 2012). Interventions to address low levels of health literacy among older people tend to focus on functional aspects such as medicine adherence (Chesser et al, 2016), and Manafo and Wong's review (2012) found no studies on CHL that aimed to support greater community action and advocacy. De Wit et al's review of community-based interventions with older people (2017) shows successful strategies and the potential reciprocal benefits of building CHL with this group.

Although some have argued that the interventions that attempt to promote all three aspects of functional, interactive and CHL are more likely to be effective

(Renwick, 2014), this review found that interventions that sought to build all three domains of health literacy as part of a combined programme reported more success in developing the first two domains than the third (McCuaig et al, 2014; Bruselius-Jensen et al, 2017; Sykes and Wills, 2018). CHL then becomes more focused on cognitive skills development than social action. McCuaig et al's (2014) study, which evaluated a critically oriented health literacy unit, sought to build all three domains of health literacy, and found only modest indicators of success in relation to CHL, focusing on critical analysis skills of internet health resources and an increased intention to help others. The study did not show an improvement in either the student or teachers' understanding of the social determinants of health or any evidence of action for change. Outside the school setting, a community-based health literacy programme designed to build the functional, communicative and CHL skills of parents showed similar outcomes (Sykes and Wills, 2018). In this programme, an impact was demonstrated on participants' ability to critically appraise health information and a limited impact on participants' ability to critically question professionals. However, there was no real change in participants' understanding of the determinants of health or involvement in activities to challenge those factors. Without a fully developed mechanism for measuring CHL, understandings of the impact of interventions will remain limited.

Challenges in operationalising CHL and successfully building the empowerment and political action element of the concept can be seen to arise for a number of reasons. Programmes that seek to build all three domains of health literacy may simply be too ambitious with too many skills and knowledge requirements to successfully address within one-time limited programme. In this case, the more tangible and measurable aspects of health literacy are likely to become the focus. The constraints that exist within institutional settings such as schools when developing social and political agency have already been discussed, but the nature of curriculum-based interventions may also create constraints. This review has shown the studies that have most successfully developed an understanding of the social determinants of health and political action for change are those based on a critical pedagogical cycle of identifying the issue, reflection and dialogue on the causes of the issue and the promotion of social action (Freire, 1993). The last stage in this cycle has been shown to be the hardest to achieve (Matthews, 2013, p 608), and has been described as 'difficult and slow … a continuing process, not a single event', requiring advanced facilitations skills with an active commitment to a democratic learning environment (Kaufman and Fobes, 2008; Dawkins-Moultin et al, 2016).

Conclusion

Nutbeam's (2000, p 265) original presentation of the concept of CHL explicitly incorporated within it the 'skills which investigate the political feasibility and organisational possibility of various forms of action to address social, economic and environmental determinants of health.' A lack of understanding and awareness of this aspect of CHL has already been reported (Sykes et al, 2013), and this review of effective interventions highlights the challenges of developing CHL due, in part, to intervention goals that privilege cognitive skills. The report of the Commission on Social Determinants of Health (2008) makes clear how inequities in health both within and between countries could be reduced by focusing on the social determinants of health. *Closing the gap in a generation*, the final report produced by the Commission on Social Determinants of Health (2008), while discussing literacy as a determinant of health, makes little mention of health literacy. This is despite the health literacy movement making claims that health literacy is a critical determinant (WHO, 2013). The report does, however, call for the scope of health literacy to be expanded to include 'the ability to access, understand, evaluate and communicate information on the social determinants of health' (Commission on Social Determinants of Health, 2008, p 189). The Shanghai Declaration on promoting health in the 2030 Agenda for Sustainable Development (WHO, 2017) similarly refers to health literacy as a critical determinant of health, and states that the outcome of health literacy is not only to empower individual citizens, but also to enable their engagement in *collective* health promotion action, which is described as effective action on the determinants of health. Despite the challenges of conceptualising and operationalising the concept of CHL, its contribution within the health literacy movement should not be neglected.

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12

Health literacy and chronic conditions: A life course perspective

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Introduction

Chronic conditions (otherwise known as long-term health conditions) have been defined as 'illnesses that are prolonged in duration, do not often resolve spontaneously, and are rarely cured completely', and which are managed with medication and other treatments (Department of Health and Social Care, 2012). As medical advances and improved healthcare have transformed many life-threatening, acute medical conditions such as cancer, diabetes and acquired immune deficiency syndrome (AIDS) into chronic lifelong conditions, the number of patients suffering from one or more chronic conditions is expanding – chronic diseases account for 86 per cent of the deaths and 77 per cent of the disease burden in Europe (WHO, 2015). And the issue is global: 80 per cent of premature deaths due to chronic diseases occur in developing countries according to data from 2009 (WHO, 2015).

The increasing prevalence of chronic conditions that is currently found in children becomes even more disturbing when considering that its prevalence increases through the life course, peaking among older people. In the UK, 58 per cent of people aged over 60 now have a chronic condition compared to 14 per cent in younger adults. People are increasingly suffering from more than one chronic condition simultaneously (multi-morbidity) (Department of Health and Social Care, 2012). Chronic diseases also have an impact on economies – treatment and care is estimated to take up around £7 in every £10 of total health and social care expenditure in the UK according to data from 2009 (Department of Health and Social Care, 2012).

The aim of this chapter is to explore the associations between chronic conditions and health literacy, both from the perspective of patients and citizens (a cross-sectional view), and through people's life journey from childhood through to adulthood and old age (a longitudinal view). It considers cultural aspects and the role of biomedicine, health promotion and health literacy in advocating healthy lifestyles to promote health and reduce the likelihood and impact of chronic disease. The chapter concludes with implications for research, practice and policy.

Chronic conditions and health literacy

As populations grow and age, the burden of chronic conditions on people and societies will increase. It has been estimated that 50 million people in Europe are living with multiple chronic conditions, which poses major challenges to healthcare systems. Current health services are predominantly disease-orientated, but as patients increasingly have complex needs spanning multiple medical and social specialities, health and social systems are undergoing a shift towards a more patient-centred approach, with greater empowerment and involvement of the patient and their family in medical decisions, expanding the role of patients and families in disease prevention and management activities (Royal College of General Practitioners, 2018). These concerns point to the need to also include certain health promotion and disease prevention competencies (for example, for promoting, facilitating and sustaining healthy lifestyles) when re-thinking and re-shaping health services.

With this shift in focus, the capacities of patients to promote health, prevent illness and manage any illnesses and care processes become key determinants of health. These skills can be referred to as health literacy, and encompass a wide range of capacities, including basic (functional) literacy and numeracy skills needed for health, language numeracy and social skills to participate in health activities and derive meaning from and apply information for health (interactive skills), and the capacity to critically analyse and utilise information (critical skills) (Nutbeam, 2000) (for more information on the conceptual aspects of health literacy, see Chapters 1, 14 and 36, this volume). People with chronic conditions need these capacities to manage their condition(s) and the associated (and often clashing) treatment regimens and self-management activities. It has been established that lower health literacy is associated with poor health outcomes, less healthy behaviours and lifestyle (Berkman et al, 2011; Sørensen et al, 2015), lower self-assessed health (Berkman et al, 2011; Sørensen et al, 2015), more difficulty in acquiring self-management skills (Berkman et al, 2011; Sørensen et al, 2015; Geboers et al, 2016; Mackey et al, 2016), and less efficient use of healthcare services (Vandenbosch et al, 2016). Findings from the European Health Literacy Survey in 2011 indicate that 12 per cent of the people surveyed have inadequate, and 35 per cent problematic, health literacy (Sørensen et al, 2015). Figures from other countries such as England (Rowlands et al, 2015a) and the US (Rudd, 2007) have shown remarkably similar findings. In all cases there is a marked social gradient and association with other social determinants of health (Rudd, 2007; Australian Institute of Health and Welfare, 2012; Rowlands et al, 2015a; Sørensen et al, 2015; Levin-Zamir et al, 2016a). The growing recognition of the importance of health literacy has been emphasised by the World Health Organization (WHO), which has identified health literacy as a critical determinant of health that empowers individuals, enables their engagement in health and in addressing health equity, and must be an integral part of the skills developed over a lifetime (WHO, 2017).

Self-management and health literacy

The mainstay of treatment for chronic disease is effective support for self-management, which can be defined as 'the care taken by individuals towards their own health and wellbeing; … to lead a healthy lifestyle; to meet … social, emotional and psychological needs; to care for their long-term condition; and to prevent further illness or accidents' (Department of Health, 2005, p 1). Self-management can include responding to symptoms, managing acute episodes, lifestyle changes, managing the emotional impact of conditions and working effectively with health professionals and other community resources (Clark et al, 1991).

Promoting patient self-management is, however, challenging. Even though a broad range of interventions to support effective self-management of chronic conditions has been designed and implemented, these have not been wholly successful, resulting in only small improvements in health outcomes (May et al, 2014; Panagioti et al, 2014). A recent Cochrane review of self-management education programmes concluded that these conferred 'little or no benefit' and recommended that future intervention development should consider patient health literacy to increase effectiveness and to explore issues of health equity (Kroon et al, 2014). The situation is complex, however; a study within the European Union (EU)-funded Diabetes Literacy project (Van den Broucke et al, 2014), exploring the impact on diabetes self-management of various types of programmes (group vs individual vs ICT), showed that the programmes had an effect independent of both the method of administration and the health literacy level of the participants (Vandenbosch et al, 2018). It is likely that these different findings reflect varying intervention designs, with some interventions better tailored to patient capacities, including health literacy (further research exploring this is required).

There is evidence of the association of health literacy and management of chronic disease. For example, Schillinger and colleagues (2002) found that patients with inadequate health literacy were less likely to achieve good glycaemic control and more likely to report complications of diabetes. Other research has shown links between health literacy and chronic disease knowledge, poor self-care, including, for example, inhaler use in patients with asthma and medication adherence (Williams et al, 1998; Kalichman et al, 1999).

Current evidence thus shows that health literacy has a vital role in the management of chronic health problems. Viewing the prevention and management of chronic disease through the 'lens' of health literacy can bring new insights into the challenges that people have with understanding their health and how to self-manage to promote health and empowerment. A life course perspective to health and chronic conditions acknowledges the roles that the social and lived environment play throughout life, from pre-conception to old age (Marmot et al, 2008), resulting in the social gradients seen in many chronic conditions.

Health literacy and chronic disease through the life course

Health literacy is dynamic and changes through the life course. These changes are related to changes in cognitive skills, with skills developing in childhood and adolescence (Piaget, 1983) and declining in old age, through normal cognitive decline, mild cognitive impairment and dementia (Ray and Davidson, 2014). That said, chronic diseases are a burden for people throughout life, increasingly beginning in childhood and adolescence (Halfon and Newacheck, 2010; Gore et al, 2011; Vos et al, 2015).

In childhood, chronic illnesses negatively influence children's everyday life and daily activities, and hence healthy development in their life course (Mokkink et al, 2008). Moreover, chronic conditions in children not only affect their own health but also their family's health outcomes and lives (Eccleston et al, 2015). Although the prevalence of chronic conditions in children and adolescents is lower than in adults, in economic wealthy countries there has been a significant shift in disease patterns in the younger age groups from acute to chronic illnesses and conditions worldwide (Schlack et al, 2008; Halfon and Newacheck, 2010; van Cleave et al, 2010). Particularly in Europe, North America and Australia, chronic conditions have limiting effects on physical activities in children and are most commonly associated with allergy, asthma, obesity and painful illness (Eccleston et al, 2015). For example, almost a quarter of US children and young people aged under 17 are affected by a chronic illness (Compas et al, 2012). In African children, the WHO's *World health statistics* (2011a) show that communicable diseases, such as HIV and related diseases, malaria and tuberculosis are among the most prevalent and life-threatening chronic conditions. Further chronic conditions, such us chronic pain, type 1 diabetes or sickle cell disease, are known to be associated with various negative health outcomes in childhood. Regarding chronic pain, the number of schoolchildren suffering from recurrent abdominal pain (RAP) varies between 4 and 25 per cent (Huertas-Ceballos et al, 2008), and various studies conducted between 1998-2012 found that approximately one-third of children in Germany suffer from chronic pain and/or RAP (Ahmad and Grimes, 2011; Albers et al, 2015). These children are at high risk for developing chronic conditions themselves (Hill and Keating, 2015; Hoekman et al, 2015). In addition, children affected by chronic conditions have a higher risk of hospitalisation and higher demands for home health or extensive medical care, which, in turn, decreases quality of life. Among children, risk factors for chronic conditions, such as obesity, which has been shown to be associated with health literacy in children (Shih et al, 2016), are increasing, with a prevalence of nearly a third of children aged 2 to 15 and rising (Department of Health and Social Care, 2017). As a result, chronic conditions such as diabetes, previously only seen in adults, are now being seen in children (Chiarelli et al, 2005). Addressing behaviour and lifestyle factors early in young people can have sustainable effects in their adult life (Gore et al, 2011), making chronic conditions an important target for health promotion and prevention activities as well as for health literacy.

In this context, health literacy skills can be taught from early childhood, and linked with stages of cognitive development (Piaget, 1983); younger children can be taught factual information, while older children can be taught to identify 'hidden', often health-damaging, messages in popular advertising following media health literacy training (Begoray et al, 2013). For more information on health literacy and the cognitive and social development of children, see Chapter 3, this volume.

The potential settings for building such skills are varied and include the classroom and wider school setting (Shih et al, 2016), and family and home settings, the latter of which has the added benefit of engaging parents and siblings (Fairbrother et al, 2016). Parents are also seen as an important intervention target in order to strengthen their adaptive strategies to support children's chronic illness-related behaviours (Logan and Scharff, 2005). An example of an innovative, community-based approach to developing health literacy in adolescents is the 'Bigger Picture Campaign' (The Bigger Picture, nd), a youth-led diabetes prevention social media campaign co-created by the University of California, San Francisco and Youth Speaks. Using social media, young people are encouraged to speak up and combat the lifestyle determinants of the diabetes epidemic. For more information on health literacy-promoting interventions addressing children and adolescents, see Chapters 16, 17 and 20, this volume.

At the other end of the lifespan, people often have to cope with the development of chronic disorders (Department of Health and Social Care, 2012) and with cognitive decline (Ray and Davidson, 2014). Health literacy tends to decline with age – associated with cognitive decline, increased difficulty in seeing and hearing and accentuated among people from minority and deprived backgrounds (Kobayashi et al, 2015). Evidence is emerging, however, that improving health literacy in older people is both feasible and beneficial. The IROHLA (Intervention Research on Health Literacy Among Ageing Populations) project identified 15 programmes focusing on health literacy in older people, with evidence of an impact on chronic diseases and among vulnerable population groups (Brainard et al, 2016). For more information on health literacy and later life, see Chapters 10 and 41, this volume.

In addition to changes through the life course, health literacy changes in relation to stress, such as a diagnosis of a chronic disorder, have an impact on competencies to perform adequate self-management behaviours (Vandenbosch et al, 2018). There is also an association between health literacy and stress in caregivers of people with diabetes (Gibson, 2012), and between health literacy and stress levels in people receiving dialysis for renal failure (Dodson et al, 2016).

On the other hand, stressful life events, both positive (for example, pregnancy) and negative (for example, the development of a chronic condition) can make people more receptive to developing new knowledge and skills. Such 'teachable moments' are 'naturally occurring life transitions or health events thought to motivate individuals to spontaneously adopt risk-reducing health behaviour' (McBride et al, 2003, p 156). The potential of teachable moments is currently under-explored, although Renkert and Nutbeam (2001) undertook an exploratory study highlighting the potential for building maternal health literacy through antenatal classes.

Also important is the individual and/or community's culture, which modulates social and environmental influences throughout the life course, and thus influences both the risk of developing a chronic disease and capacities to self-manage. The next section of this chapter explores what health literacy brings to our understanding, and potentially to better management, of cultural issues in relation to chronic conditions.

Cultural aspects to health literacy and chronic conditions through the life course

The close association between culture and health literacy has been recognised in chronic long-term disease across the life course. This is witnessed on a variety of levels such as prevention, detection and self-management of illness, and in the use of health services. In chronic disease prevention, culture is a critical determinant of lifestyle, in particular, nutrition, physical activity and tobacco use (Levin-Zamir and Wills, 2012). Changing risk behaviour and supporting lifestyle changes requires culturally appropriate interventions to enhance health literacy. Additionally, self-management of disease or illness requires skills to navigate the healthcare system, filling out forms, sharing information and personal history, locating service providers and engaging in chronic disease management (Tsoh et al, 2016). This may be particularly difficult for immigrants, who are experiencing challenges to perform these tasks when moving to another country and encountering new health systems, and often new cultures. Several studies have explored how people with specific conditions from new immigrant groups are informed and educated about their condition. The significant language and health literacy difficulties they face are frequently exacerbated by cultural barriers and economic challenges to accessing health services (see also Chapter 9, this volume). In addition, people's responses to illness and communication of health needs are culturally determined and may be differently expressed in different cultures and languages, including expressing and articulating fear, pain and anxiety, and how 'sick roles' are defined and responded to. The concept of 'health' as well as 'illness' varies widely across cultural groups (Levin-Zamir et al, 2017). Chronic disease is of particular concern for cultures in transition from a traditional to a Westernised culture. As an example, diabetes has been known to develop when such populations change their daily habits from a physically active to a more sedentary one and eat more refined foods. For such populations, whether or not language is an issue, any information and interventions must to be culture-sensitive to be effective (Levin-Zamir et al, 2016a, b).

The scientific literature exploring health literacy, culture and intervention in chronic disease over the lifespan focuses mainly on specific age groups, particularly children or older people, and specific diseases such as asthma and diabetes (Vamos et al, 2015). For example, a review of culture-specific interventions for people with asthma showed that culture-specific education programmes for adults and children from minority groups are likely to be effective in improving asthma-related outcomes (McCallum et al, 2016). Future areas of action and research necessary for improving the care of patients with chronic disorders include recognising that communication through language and cultural competency are different, equally important, factors, and that improving both communication proficiency and the cultural competence of healthcare providers and systems is required to improve health and healthcare (Poureslami et al, 2017). More research is needed to explore the impact of culture on health decision-making and health behaviours. With regard to practice, the American Diabetes Association advocates actions to be taken to address health disparities and develop structured interventions that are tailored to ethnic populations' culture, language, religion and literacy skills. Addressing the impact of the social and living environment and culture on the risk of developing chronic conditions and on the skills to self-manage them through the life course requires a health promotion approach (WHO, 2002).

Health literacy and essential skills for promoting health

The impact of culture on health decisions and health behaviours is linked to the adoption of specific lifestyles that influence health or disease, and to self-management. Belloc and Breslow (1972) highlighted the relationship between chronic disease, physical health status and lifestyles such as alcohol intake, smoking and nutrition, with health increasing as the number of good health habits increased. Building on this, the WHO focused on the role of lifestyle in preventing and reducing the impact of chronic (that is, long-term non-communicable) conditions and diseases, and the importance of leadership at all levels in developing the conditions needed for lifestyle promotion to be effective (WHO, 2011b). This includes both policy-level interventions, such as tobacco and alcohol taxation and control, and public health education to promote healthy diets and physical activity in all aspects of daily living. The medical establishment has responded to this by including the promotion of healthy lifestyles into clinical practice; indeed, a new medical specialty entirely focused on this has emerged: 'Lifestyle Medicine' (Mechanick and Kushner, 2016). Of some concern, however, is the focus on negative 'prohibition' rather than positive 'promotion' messages, which may reduce effectiveness.

Health literacy develops over the life course (Sørensen et al, 2012) and influences healthy lifestyles (Nutbeam, 2000). The promotion of healthy lifestyles is recognised as crucial for preventing and managing chronic disease, as well as for promoting health. Increasingly, those developing health policies are focusing on how people might be supported to adopt healthier lifestyles, and health literacy is one area of growing interest (WHO, 2013, 2017). Most recently the WHO Shanghai Declaration on health promotion put specific emphasis on health literacy promotion in order to address the improvement of individual health and empowerment, the United Nations (UN) 2030 Sustainable Development Goals (UN, 2015) and an increase in health equity (WHO, 2017). It is becoming apparent that the relationship between health literacy and lifestyle choices is complex, indicating the need to address health literacy throughout the life course, and to include both the individual and the environment within action frameworks. Indeed, the adoption of healthy lifestyle choices by individuals is strongly associated with education level, as is the response to public health campaigns (Buck and Frosini, 2012), which tend to benefit those who already have the most resources (educational, financial etc), with the unwelcome consequence of widening health inequalities (Buck and Frosini, 2012). On the other hand, when health messages are tailored to people's skills levels, knowledge and action on lifestyle can improve (Tavistock Institute and Shared Intelligence, 2009). Furthermore, as cited above, studies exploring the outcomes of self-management education programmes for patients with diabetes have shown that they can be effective for all patients, regardless of their health literacy level (Kim et al, 2004; Vandenbosch et al, 2016). Epidemiological research indicates that the associations between health literacy and lifestyle are stronger for some lifestyle choices (that is, diet and exercise), and weaker or non-existent for others (that is, smoking and alcohol consumption) (Sørensen et al, 2015; Friis et al, 2016). More research is therefore needed in this area, especially qualitative research on people's lived experience of learning about lifestyles and health, and of making decisions on action. This would enable the development of health literacy, that is, building people's capacities to not only understand but also act on information on lifestyle and wider self-management skills, to reduce their risk of chronic conditions and to better manage them if they occur.

Implications for research, practice and policy

Health literacy has much to offer in the prevention and management of chronic conditions throughout the life course. We have described some research in the area, but more needs to be done, particularly in low-income communities, among migrant communities and in developing countries, where 80 per cent of premature deaths from non-communicable diseases occur (WHO, 2015).

Healthcare practice needs to develop so that it is more person-centred, and adapts to people's clinical, social and health literacy needs (Brach et al, 2012). Successful developments in healthcare practice need to be more widely adopted, and also extend to other areas of people's lives, such as social care (Rowlands et al, 2017). Education is central to developing and maintaining health literacy across the life course, from pre-school and early years teaching that incorporates health and health skills, through to teaching adolescents key skills as they develop into adults and make lifestyle choices that will affect their future, through to adult learning, where skills are maintained (Rowlands et al, 2017). In order to give every child a good start in life, the review of social determinants and the health divide in the WHO European Region specifically highlights that actions should address early childhood on both the individual, and more importantly, the environmental, levels (Marmot et al, 2012). In this context, parents and parental health literacy are important targets in order to improve not only their own health, but also that of their children and families. Policies that aim to address the issues brought through the increasing burden of chronic disease need to be developed and applied across multiple sectors. 'Health in All Policies' (HiAP) have been seen as essential to develop effective and health-promoting systems; there is now a need for 'Health *Literacy* in All Policies'.

Conclusion

In this chapter we have described the importance of health and education policy, and to a lesser extent, social policy, in building health literacy. Better health literacy might lead to both a lower prevalence of chronic disease, and a reduced impact of chronic diseases when they do occur. However, wider action needs to be taken than merely in health and education, realising the potential impact of policies affecting the workplace and commercial organisations, among many others. Health policies to empower people to live healthily and self-manage chronic diseases will not work unless people can easily incorporate them into their everyday life.

Health literacy is needed for people to have capacities to prevent and support self-management in chronic diseases; it should be operationalised within the context of people's culture and background (Rowlands et al, 2015b), and increasingly in the digital world (see Chapters 18, 39 and 43, this volume). Using diabetes as an example, adopting a healthy diet and regular exercise can prevent or reduce the risk of diabetes, and can help glycaemic control in people already suffering from the disease (Diabetes UK, nd). To maintain a healthy diet and exercise, people need to understand information from a variety of sources, such as health and commercial sources, to appraise the value of this information for themselves, their families, communities and culture, discuss and negotiate the adoption of new ways of living with health professionals, friends, families and employers, and be able to take action, even in the face of barriers. Health literacy is thus needed throughout life, developing from early childhood and through adolescence, through adulthood, and coping with both positive and negative life events such as birth, bereavement and developing chronic conditions, and increasingly employing health literacy in later life, as people cope with increasing frailty, chronic conditions, and sometimes, cognitive decline. People with low skills who have undertaken health literacy training describe developing such capacities (Tavistock Institute and Shared Intelligence, 2009), and can demonstrate a sophisticated understanding of how information for health is evaluated, barriers to implementation identified and sometimes overcome (Rowlands et al, 2015b). As people are embedded into complex social, ecologic and systemic environments, context-related health literacy interventions should be developed and rigorously evaluated, with a focus on those currently facing the highest burden of chronic disease. Such an approach will have complementary effects on health action and outcomes, and has much to offer in reducing the burden of chronic disease through the life course.

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13

Health literacy research in the Nordic countries

Kristine Sørensen and Josefin Wångdahl

Introduction

Across the world, health literacy is gaining attention as a determinant of health. However, so far the research on health literacy has predominantly been produced by the US (Pleasant, 2012). Although research in Europe is increasing at an exponential pace (Quaglio et al, 2016), it is apparent that the Nordic countries Denmark, Finland, Iceland, Norway and Sweden have been relatively slow movers in contrast to, for instance, the UK, the Netherlands and the German-speaking countries Austria, Germany and Switzerland (Sørensen, 2013). Nevertheless, health literacy is now receiving more attention regarding health and welfare in Northern Europe.

Health literacy entails people's knowledge, motivation and competences to access, understand, appraise and apply health information in order to make judgements and decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course (Sørensen et al, 2012; see also Chapter 1, this volume). Furthermore, health literacy can be functional, interactive or critical, dealing with different aspects of managing health (Nutbeam, 2006, 2008; see also Chapter 14, this volume).

Low health literacy is associated with poor health and a low level of education (Berkman et al, 2011; HLS-EU Consortium, 2012), and low functional health literacy is also associated with increased use of emergency care (Morrison et al, 2013), poorer ability to interpret health messages and lower participation in prevention (Berkman et al, 2011). Notably, the prevalence of limited health literacy is linked to a wide range of disparities (Paasche-Orlow et al, 2005; see also Chapter 9, this volume) and injustices (Volandes and Paasche-Orlow, 2007).

This chapter provides a broad overview of health literacy research conducted in the Nordic countries and discusses the scope and scale of how health literacy is adressed. Future avenues on how to manifest health literacy on the Nordic health agenda are discussed in the Conclusion.

Nordic Health Literacy Network

Health literacy research in Europe is steadily evolving (Quaglio et al, 2016), and the European Health Literacy Survey (HLS-EU) accelerated the process and acted as a catalyst for many more countries to follow up with more research (see Chapter 8, this volume). For the first time the HLS-EU provided comparative population data on health literacy in a number of European countries. It revealed that limited health literacy varied from 29 per cent to more than 60 per cent among the eight countries that participated, which included Austria, Bulgaria, Germany, Greece, Ireland, the Netherlands, Poland and Spain (Sørensen et al, 2015). In addition, more European countries have added to the evidence base such as, for instance, Belgium, the UK, Serbia, Kosovo and Switzerland (Jovic-Vranes et al, 2011; Bostock and Steptoe, 2012; Wang et al, 2012; Toçi et al, 2013; Vandenbosch et al, 2016). So far, however, the Nordic countries have scarcely been represented in the evolving European health literacy field (Wångdahl and Mårtensson, 2013).

Brought together by the fact that no Nordic countries had participated in the survey, researchers from Denmark, Norway and Sweden joined forces to discuss how awareness of health literacy in the region could be improved. In response, the Nordic Health Literacy Network was established in Copenhagen in April 2012 to bridge the gap in the lack of research from the Nordic region. Later, members from Finland and Iceland also joined. Since the launch of the Network meetings have taken place in Copenhagen, Oslo, Gothenburg, Aarhus and Brussels. The Network aimed at identifying common grounds concerning research, funding opportunities and to raise awareness among other stakeholders to mobilise progress in research, policy and practice from a Nordic point of view.

Examples of concrete activities undertaken by the Network include a collaborative funding application to the Nordic Council of Ministers and a pre-conference in association with the 2nd European Health Literacy Conference in Aarhus, Denmark and the 3rd European Health Literacy Conference in Brussels, Belgium. Furthermore, the translation of the term 'health literacy' into Nordic languages has been part of an ongoing debate within the Network. Table 13.1 illustrates the most prominent translations used in Danish, Finnish, Icelandic, Norwegian and Swedish. Notably, the way that health literacy is translated reveals insights into how the term has been interpreted and perceived in the various

Table 13.1: Health literacy glossary for the Nordic languages

Language	Translation
Danish	*Sundhedskompetence*, health literacy
Finnish	*Terveyden lukutaito, terveysosaaminen*
Icelandic	*Heilsa færni*, health literacy
Norwegian	*Helsekunnskap*, health literacy
Swedish	*Hälsolitteracitet*, health literacy

national contexts (Sørensen and Brand, 2013). However, it should be noted that often the term 'health literacy' is applied directly in its original form in English in the various Nordic languages, similarly to the practice used regarding the word 'empowerment'.

Nordic health literacy research

The first two Nordic health literacy publications were published in 2008, and the number has slowly increased since. Studies on health literacy are published in a variety of scientific journals reflecting the great span of topics that it is associated with. The studies also vary according to their methodological designs. Unfortunately, no research has yet been published from Iceland.

Denmark

The first study from Denmark was published by Bo and colleagues (2014), who performed a population-based assessment of the dimensions of health literacy related to understanding health information and to engaging with healthcare providers using the Health Literacy Questionnaire (HLQ). They then examined associations between socioeconomic characteristics with these dimensions of health literacy. Between 9 and 20 per cent perceived health literacy tasks as difficult or very difficult. Low levels of the two dimensions were associated with low income, low education level, living alone and to non-Danish ethnicity, and associations with sex and age differed by the specific health literacy dimension (Bo et al, 2014).

The study was followed up by Friis and colleagues (2016) to quantify levels of subjective health literacy in people with long-term health conditions (diabetes, cardiovascular disease, chronic obstructive pulmonary disease [COPD], musculoskeletal disorders, cancer and mental disorders), and to compare these to levels in the general population and examine the association between health literacy, socioeconomic characteristics and comorbidity in each long-term condition group. The study revealed that people with long-term conditions reported more difficulties than the general population in understanding health information and actively engaging with healthcare providers. Wide variation was found between disease groups, with people with cancer having fewer difficulties and people with mental health disorders having more difficulties in actively engaging with healthcare providers than other long-term condition groups. Having more than one long-term condition was associated with more difficulty in engaging with healthcare providers and understanding health information. People with low levels of education had lower health literacy than people with high levels of education. Friis et al (2016) recommend that more effort should be made to respond to the health literacy needs among individuals with long-term conditions, multiple comorbidities and low education levels, to improve health outcomes and to reduce social inequality in health.

To develop health-literate organisations (Brach et al, 2012) it is important to address people's health literacy when providing healthcare (see Chapters 8 and 31, this volume). Health professionals should be aware of and have an insight into people's health literacy when they provide health services. Therefore, health professionals need to be health literate themselves. The study by Elsborg and colleagues (2017) examined the level of health literacy in students in Denmark attending one of four full university programmes related to health, and investigated how their health literacy was associated with their sociodemographic background. The health literacy levels of the students were measured using the HLQ, and it was administered through the students' Facebook groups. The study showed no gender difference, although female students scored higher than male students regarding social support for health. Students attending the public health programme tended to score higher, and those attending molecular biomedicine tended to score lower regarding health literacy. There was a positive correlation between health literacy and the educational level of the students' parents. If one of the parents was employed in the healthcare sector, the health literacy score tended to be higher in some aspects. The same held true for students who had been hospitalised. The study concluded that students' health literacy relates to their personal background and educational path. Hence, this may be important when planning curricula for developing the health literacy of future generations of health professionals (Elsborg et al, 2017). Kayser and colleagues tested the HLQ for use regarding eHealth and developed the eHealth Literacy Questionnaire (eHLQ), a multidimensional tool based on a well-defined *a priori* eHLF framework with robust properties. The questionnaire is designed to be used to understand and evaluate people's interaction with digital health services (Kayser et al, 2018).

Emtekaer Haesum and her team (2015) validated the Test of Functional Health Literacy in Adults (TOFHLA) for adaptation to the Danish setting and culture. It was satisfactorily tested among patients with COPD and a case group through face-to-face interviews (Emtekaer Haesum et al, 2015).

Lastly, research has shown that developing health literacy in early life is critical to reducing lifestyle-related diseases, with schools being identified as central settings for this purpose. Bruselius-Jensen and her colleagues (2017) designed an educational programme, IMOVE, to develop health literacy related to physical activity. IMOVE contributed to the development of functional health literacy by building a relational understanding between everyday practice and step numbers. The presence of interactive health literacy was observed in discussions. However, only a limited number of discussions supported the development of critical health literacy. The research implies that educators can successfully integrate health literacy development into a classroom-based curriculum teaching with pupils' own step counts and associated reflections positively influencing learning (Bruselius-Jensen et al, 2017).

Finland

In Finland, Paakkari and colleagues (2012) also concentrated on health literacy in schools. They explored how health literacy could be defined as a learning outcome in schools with a focus on five core components: theoretical knowledge, practical knowledge, critical thinking, self-awareness and citizenship. They argued that one of the main aims of health teaching in schools should be to foster students' ability to define their own beliefs, identity and social relations along with ethical reflections (Paakkari and Paakkari, 2012; see also Chapter 34, this volume). Based on these findings they recommended three approaches for health education in schools: *facts and skills*, *individual thinking* and *personal growth and citizenship* (Paakkari, 2015). The approaches differ in complexity and can be used in planning for learning experiences aimed at supporting the development of higher levels of health literacy. Furthermore, they can be used in teacher training when the aim is to help teacher trainees become aware of their current ways of seeing school health education, and the differences that may exist between their understanding and more complex forms of understanding (Paakkari, 2015). Paakkari and colleagues (2017) also studied health literacy in relation to participation in sports club activities among adolescents. The aim was to compare levels of perceived health literacy among adolescents who do or do not participate in sports club activities. The settings approach was chosen as organised sport club activities reach a high proportion of adolescents and have the potential to contribute to the development of their health literacy. The study was conducted as a part of the Health Behaviour in School-Aged Children (HBSC) study, using the Health Literacy for School-aged Children (HLSAC) instrument. Sports club participation and its association with health literacy were examined in relation to age, gender, family affluence, school achievement and physical activity. The study indicated that perceived health literacy was higher among adolescents who participated in sports club activities. This conclusion was valid for boys and girls, for both age groups, among those who were physically active 6-7 days a week, had at least moderate school achievement, and those who belonged to middle or high-income families. From the health literacy perspective, participation in sports club activities was especially beneficial for those having low or moderate school achievement levels. Notably, the sports club setting may work towards equalising health literacy differences related to school achievement. However, the clubs should ensure that access is available to as many adolescents as possible, thereby spreading beneficial influences and supporting the development of health literacy among broader population groups (Paakkari et al, 2017).

In turn, Parisod and colleagues (2016) explored the determinants of health literacy in the context of tobacco-related information from the perspective of young adolescents. Today's adolescents are used to a constant information flow, but many face difficulties in processing health-related information due to low health literacy. There is still a need for deeper understanding of the determinants of health literacy in relation to adolescents to guide the development of health literacy instruments and interventions. A qualitative study including 10 focus groups was conducted in two schools in Finland, one representing a typical Finnish public school with students following a general curriculum and the other a Finnish public school with students with special educational needs. The results showed that the young adolescents pointed out new mediating determinants that influence health literacy which are not included in current adolescent-specific models of health literacy. These newly found determinants require attention and further exploration. The acquired knowledge can be used to strengthen existing adolescent-specific health literacy models and as a basis for health literacy instrument and intervention development (Parisod et al, 2016).

Eriksson-Backa and her colleagues (2012) examined the health information literacy of elderly Finns and found significant relationships between education level, interest in health information, seeking activity, self-rated current health and dimensions of health information literacy. Some elderly people are more vulnerable regarding obtaining and use of health information, for instance, those with lower levels of education, those with poor health and those who are not interested in and active in seeking information. The study highlights that health information providers should ensure that available health-related information is understandable and can be accessed without too much effort (Eriksson-Backa et al, 2012). Health information literacy was also studied among young healthy men and adults with an increased risk for metabolic syndrome. The study revealed that adults with increased risk for metabolic syndrome seemed to value health information but had more difficulty in knowing who to believe in health issues and understanding the terminology used. The difficulties applied especially to respondents aged 35 or older. Men, and especially young men, had lower motivation than women in seeking health information (Enwald et al, 2016).

Norway

Gele and her team (2016) from Norway highlight health literacy as the missing link in improving the health literacy of Somali immigrant women in Oslo. They conducted a cross-sectional study using the European Health Literacy Questionnaire (HLS-EU-Q) in its short form. The findings revealed that 71 per cent of Somali women in Oslo could not obtain, understand and act on health information and services and make appropriate health decisions. Being unemployed and socially less integrated were independent predictors of an inadequate health literacy among the Somali women who participated. Gele et al (2016) conclude that enhanced health literacy will most likely increase the chance of better health outcomes for immigrants, thereby moving towards health equity in Norwegian society. Hence, policies and programmes are required to focus on and improve the health literacy of immigrant communities in the future (Gele et al, 2016).

The study by Fredriksen and colleagues (2016) focused on maternal health literacy. The internet is one of the fastest growing information sources for pregnant women, and seems to be used across social and economic strata. However, knowledge on how interaction in web-based discussion forums influence maternal health literacy, regarding how pregnant women access, appraise and apply information to promote and maintain good health, is still lacking. The aim of this study was therefore to explore the role of interactions in web-based discussion forums among women who experienced health problems during pregnancy. More specifically, to explore why media-literate women experiencing the medically unexplained condition, pelvic girdle pain (PGP), during pregnancy participated in web-based discussion forums and how they appraised and applied the information and advice that they gained from the web-based interaction with other women. In the study, women were invited to participate via postings on three different open websites for pregnant women and mothers, the data were collected using synchronous qualitative email interviews and were analysed using thematic analysis. Notably, the study indicated that interaction in web-based discussion forums influenced maternal health literacy in terms of increased health-related knowledge and competencies, increased awareness of health promotion and health protection, and increased system navigation. The women appraised and selectively applied information and advice that resonated with their own experiences. For many, the information provided online by other women in the same situation was valued more highly than advice from health professionals. Women reported that they used their knowledge and competency in encounters with health professionals but hesitated to disclose the origin of their knowledge. Those with a high level of education in medicine-related fields raised a concern about the internet as a source of horror stories and erroneous information, and were actively engaged in trying to minimise potential negative effects by providing biomedical information. The lessons learned highlight that professionals need to recognise that pregnant women access web-based discussion forums for support and information to increase their ability to take better health decisions for themselves. Web-based fora are therefore a potential resource that health professionals may find useful in consultations with pregnant women (Fredriksen et al, 2016).

On another note, one Norwegian study (Bjørnsen et al, 2017) explored mental health education because mental health literacy is an asset for health that educational initiatives can strengthen, and it is a significant determinant of mental health. The study showed that positive mental health literacy was significantly related to adolescents' mental wellbeing. The authors recommend positive mental health literacy concerning how to obtain and maintain good mental health as an integral component of school health services' mental health education among adolescents (Bjørnsen et al, 2017).

Sweden

Swedish researchers were among the first to adopt and explore the concept of health literacy in the Nordic countries. The research has primarily focused on measurement, refugee health literacy and cancer screening.

Health literacy is an important determinant for health and a valuable health indicator within public health. As such, it is a significant outcome variable of health promotion efforts. Valid and reliable instruments are needed to evaluate health promotion interventions and to assess levels of health literacy in a population. One of the few measurements of communicative and critical health literacy is the Japanese Communicative and Critical Health Literacy scale (C & C HL scale), which was validated by Wångdahl and Mårtensson (2014). To make it possible to use this instrument in Sweden, the C & C HL scale was translated into Swedish and different aspects of validity were tested among health experts and bilingual people. The study indicated that the Swedish C & C HL scale was understandable and showed evidence of content validity as the items cover the major aspects of communicative and critical health literacy as identified in the original tool, and are understandable and stable over time, that is, reliable (Wångdahl and Mårtensson, 2014). Wångdahl and colleagues (2015) also validated the Swedish version of the Functional Health Literacy test (S-FHL) from Japan to be used in health promotion and disease prevention. They concluded that the Swedish version of the scale was equivalent to the original Japanese scale concerning language and contents. The scale is reliable and shows consistency over time (Wångdahl and Mårtensson, 2015).

Mental health literacy

The evidence in Sweden suggests that mental health literacy among the public is low and stigmatising attitudes are widespread. So far, the effects of anti-stigma campaigns have been small, and studies demonstrate that negative attitudes have been quite stable through recent decades (see Chapters 4, 17, 19 and 24, this volume). Hence, Svensson and Hansson's study (2016) aimed to explore the relationships between mental health literacy, experience of mental illness and stigmatising attitudes/social distance towards people with depression or psychosis. It included a cross-sectional study in which staff members from public services in Sweden completed questionnaires covering demographic data, self-reported experience of mental illness, identification of a vignette for depression or psychosis, beliefs about helpful interventions for the illness presented in the vignette, and attitudes and social distance towards people with the illness. The results showed that half of the participants could identify depression and less than 40 per cent psychosis. A higher degree of mental health literacy was related to less stigma and social distance but mainly towards people with depression. A similar relationship was shown for having personal or family experience of mental illness and attitudes/social distance. Negative attitudes and social distance were significantly higher in all aspects measured towards a person with psychosis than a person with depression. Notably, a higher degree of mental health literacy relates to more positive attitudes and less desire for social distance towards people with depression (Svensson and Hansson, 2016).

Melas and colleagues (2013) studied mental health literacy among adolescents using two pre-established vignettes that presented an adolescent with symptoms of either depression or schizophrenia. The data were analysed both qualitatively and quantitatively. Interestingly, the data showed that 42 and 35 per cent of the respondents were able to identify depression and schizophrenia, respectively. Depression was recognised more often by females than males. Professional help was suggested by a minority of the respondents for managing symptoms of depression only. Altruistic behaviours, examined through willingness to help an acquaintance with mental illness symptoms, were apparent among almost 60 per cent of the respondents and to a greater extent in females than males. In turn, stigmatising attitudes were identified with relations to schizophrenia in 12 per cent of the participants. Mental health literacy was relatively low among teenagers in Sweden. Raising awareness through introducing psychoeducation in the school curriculum is therefore recommended (Melas et al, 2013).

Health literacy of refugees

Refugees have poorer health compared to indigenous populations, which may be explained by lower health literacy, that is, not being able to access, understand, appraise or apply health information. Wångdahl and colleagues' study (2014) aimed to determine levels of functional and comprehensive health literacy, and factors associated with inadequate health literacy, in refugees coming to Sweden. A cross-sectional study was performed among adult refugees speaking Arabic, Dari, Somali or English at language schools for immigrants using the European Health Literacy Survey Questionnaire (HLS-EU-Q16) and S-FHL. The results showed that the majority of the participating refugees had inadequate or limited functional health literacy (60%) and comprehensive health literacy (27%). Low education and being born in Somalia were factors associated with an increased risk of having inadequate functional health literacy. Also, having inadequate functional health literacy was associated with an increased risk of having inadequate comprehensive health literacy. It can be concluded that the majority of refugees in the language schools had limited or poor health literacy. Health literacy should therefore be taken into consideration in contexts and activities addressing migrants (Wångdahl et al, 2014). A follow-up study explored the refugees' experiences of communication during their health examination and its usefulness in association with their health literacy. The study applied the S-FHL test and the HLS-EU-Q16. The results showed that in the health examination for asylum-seekers, a poor quality of communication was experienced by 36 per cent, receiving little information about healthcare by 55 per cent, and receiving little new knowledge by 41 per cent and help by 26 per cent. Having inadequate as compared to sufficient comprehensive health literacy was associated with the experience of a poorer quality of communication and the experience of receiving little valuable healthcare information. Furthermore, having inadequate as compared to sufficient comprehensive health literacy was associated with the experience of not receiving new knowledge or receiving help with health problems. It could be concluded that the refugees' experiences indicated that a low level of comprehensive health literacy could act as a barrier to fulfilling the purposes of the health examination for asylum-seekers. Furthermore, it seems that comprehensive health literacy seems to be of greater importance in this context than functional health literacy (Wångdahl et al, 2015). In continuation, Wångdahl and her colleagues (2018) wanted to study comprehensive health literacy in more depth using HLS-EU-Q16 in association with general health, psychological wellbeing and having refrained from seeking healthcare among refugees in Sweden. The study was conducted with approximately 500 refugees speaking Arabic, Dari and Somali. Notably, the majority of the participants had limited comprehensive health literacy, and four out of ten reported poor health and had refrained from seeking healthcare (Wångdahl et al, 2018). More research is needed to better understand health literacy among refugees and to develop strategies and methods to increase health literacy, promote optimal health-seeking behaviour and make life easier for those with low health literacy (see also Chapter 17, this volume, on the mental health literacy of refugees in Canada).

In Sweden, according to Svensson and colleagues (2017), migrants have poorer sexual and reproductive health compared to the general population. Health literacy, in the form of the cognitive and social skills enabling access to health-promoting activities, is often poorer among migrants, partly due to language and cultural barriers. Therefore, culturally sensitive health education provides a strategy for enhancing health literacy. Since 2012, specially trained civic and health communicators have provided sexual and reproductive health and rights information to newly arrived refugees in Skåne, Sweden. The aim of this study by Svensson and her colleagues was to explore how information on sexual and reproductive health and rights was perceived by female recipients, and whether being exposed to such information contributed to enhanced sexual and reproductive health and rights literacy. Semi-structured in-depth interviews were conducted with nine women and analysed using qualitative content analysis. Two themes emerged: opening the door to new understandings of sexual and reproductive health and rights and planting the seed for engagement in sexual and reproductive health and rights issues, illustrating how cultural norms influenced perceptions, but also how information opened up opportunities for challenging these norms. Notably, it should be recognised how gender-separate groups may facilitate information uptake while discussion concerning sexual health norms may benefit from taking place in mixed groups (Svensson et al, 2017).

Lastly, Wangmar and colleagues (2018) explored health literacy and views about being invited to screening among participants and non-participants in a national colorectal cancer screening programme. Sweden has not yet implemented a national screening programme for colorectal cancer, but a nationwide study is ongoing. Previous research has shown that the use of healthcare services, together with several health-related outcomes, is associated with an individual's level of health literacy. However, the relation between health literacy and participation in colorectal cancer screening has produced varying results reported within the few studies addressing this issue, and so further research is warranted. The study revealed that the majority, whether they were participants or non-participants in the screening programme, had an acceptable level of health literacy and no significant differences in health literacy levels between the groups were found. Participants expressed that it was important and appreciated to be able to choose information sources on an individual basis. Among non-participants, the importance of receiving invitations with a clear message that quickly draws one's attention was highlighted. However, both groups expressed a positive outlook towards the invitation. A majority of individuals displayed acceptable levels of health literacy, regardless of whether they chose to participate or not. Similarities between the groups were seen in the qualitative findings regarding views of the invitation. The findings indicate that in the future a more dynamic approach could be valuable to increase clarity in the message about the importance of screening (Wangmar et al, 2018).

Scope and scale of health literacy in Nordic countries

The research presented here reveals a wide scope in how health literacy has been studied in a Nordic context. The topics have ranged from population health literacy to the health literacy of refugees, health literacy in schools, mental health literacy among adults and adolescents, validation of measurements and health information literacy regarding screening and different diseases. Although the Nordic countries are welfare countries, the studies reveal the clear health literacy divide that challenge the people's response to what is offered through health and social services. Studying the health literacy scale in more depth, the studies so far indicate that 10–20 per cent of the population and often those more in vulnerable groups are subject to suffer from limited health literacy, which hinders equal access to healthcare and preventive means.

Whereas this chapter has focused primarily on recent health literacy research conducted in the Nordic countries, it should be noted that health literacy projects and interventions are currently being carried out in all five countries, although they have not yet been published. While political buy-in is generally weak, a variety of stakeholders from practice have embraced health literacy as an important cornerstone for their health-related activities. One example is the MILSA project from Sweden that educates communicators to help migrants in understanding and navigating the health system (Länsstyrelsen, 2018).

While health literacy has been embraced and integrated more quickly by other European healthcare systems, it has been less prominent in the Nordic countries until a few years ago. One barrier could be the inconsistent translation of the term so that research efforts have not been mainstreamed. A second barrier could be the fact that the Nordic countries presume themselves to be well developed and focus to a high degree on empowerment and self-management. However, recent research from all five countries shows that health literacy remains a challenge that cannot be neglected. Notably, health literacy research seems to have gained momentum, which is promising for the years to come. Furthermore, the Nordic

Health Literacy Network has become involved in preparations for the second wave of the HLS-EU, and time will show how health literacy will evolve further in policy, research and practice in Denmark, Finland, Iceland, Norway and Sweden.

Conclusion

It is of the utmost importance that health literacy is addressed more strongly in the Nordic health agendas in the future and the new research developments as described in this chapter are promising. Proposals for action include national action plans on health literacy, health literacy included in the curriculum at all levels, the development of health-literate organisations that facilitate people-centred health and a monitoring programme that follows health literacy developments. More research is warranted to provide the evidence to decision-makers to engage more strongly in improving health literacy for all. The Nordic countries have the means and ability to address the health literacy divide, and the Nordic welfare model building on universal health coverage makes a solid foundation for creating health-literate organisations and, in turn, health-literate communities and people.

Acknowledgements

We wish to thank members of the Nordic Health Literacy Network for support; in particular: Lena Maartenson, Lars Kayser, Helle Terkildsen Maindal, Gill Rowlands, Kjeld Sverre Pettersen, Hanne Søberg Finbråten, Héðinn Svarfdal Björnsson, Leena Paakkari and Suvi Karuranga.

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Part 2

PROGRAMMES AND INTERVENTIONS TO PROMOTE HEALTH LITERACY

Health literacy as a set of skills empowering people to positively influence their health and wellbeing is, to a certain degree, receptive to change throughout the life course. In order for this to take place, it is important that the needs of specific groups and populations be recognised. This understanding provides the basis for the implementation of well-planned effective interventions. Health literacy is content- and context-specific, so the design of interventions and programmes must reflect these aspects if they are to bring effective and lasting results.

Following Part 1 of this handbook, the chapters in Part 2 present a variety of interventions and programmes to promote health literacy. They explore action in which specific aspects of health literacy may be promoted for special populations as well as for various age groups within the lifespan. The contexts vary, whether in the family, the community, the workplace or in the electronic and mass and social media. In doing so, Part 2 is structured into three sections to guide the reader through the practice- and population-related actions on health literacy, and provides an overview of interventions and programmes, as well as introducing interventions and programmes for children and adolescents and adults and older adults.

An overview of interventions and programmes

Chapter 14, by Don Nutbeam with Bronwyn McGill, sets the scene by focusing on improving health literacy in clinical and community populations. The authors show that strengthening health literacy involves more than the transmission of health information, and that developing confidence and abilities to act on knowledge, promoting greater independence in health decision-making and successful self-management can be achieved through a more sophisticated understanding of the potential of health literacy-centred educational approaches.

Interventions and programmes for children and adolescents

The next series of chapters present interventions for influencing health literacy among children, adolescents and their parents. A description of an intervention project focusing on the use of media, targeting parents, children and teachers and implemented in a multi-setting approach is found in Chapter 15 by Paula Bleckmann and colleagues. In comparison to the classical model of eHealth literacy, their intervention is underpinned with a theoretical framework based on a model of digital balance literacy that specifically addresses the reduction of risky screen media use. In Chapter 16 Paola Ardiles and colleagues then propose a model for promoting youth health literacy using Photovoice embedded into an upstream approach, and introducing the model of the Circle of Health. Their contribution outlines fundamental principles on how to incorporate the comprehensive understandings of health, health literacy and social participation across the lifespan into the design of interventions. E. Anne Marshall and Deborah L. Begoray, in Chapter 17, present the results of mental health literacy research among a youth refugee population, using a cultural approach as an essential element in planning and implementing interventions. For the purpose of education and training considerations, they specifically present youth mental health figures and discuss mental health literacy in general, in youth populations and in refugee youth. Diane Levin-Zamir and Isabella Bertschi describe in Chapter 18 how media health literacy (MHL), digital health literacy and eHealth literacy are all relevant throughout the entire lifespan – from childhood through the elder years – and are related to health behaviour change. As settings are important for health promotion interventions, likewise they present an important platform for promoting health literacy. Thus school-based intervention related to mental health literacy is the main topic of focus of Chapter 19 in this section by Kathryn Cairns and Alyssia Rossetto, who offer an overview of the topic and examples of various school-based initiatives from different countries, and provide a synthesis of the supporting evidence for these varied approaches. This first section ends with Chapter 20 by Andrew Pleasant and colleagues on health literacy interventions for children and adolescents, highlighting the challenges of overweight and obesity and continuing on to present conceptual models and evidence-based interventions.

Interventions and programmes for adults and older adults

Continuing throughout the lifespan, the next set of chapters focus on health literacy interventions among adults. Laura Sahm and colleagues in Chapter 21 describe health literacy interventions in pharmaceutical care, exploring the unique role of the pharmacist. As such they outline the core competencies of pharmaceutical professionals and how their use can be facilitated in the context of medication adherence and in relation to specific, often vulnerable, populations. Kenneth Yongabi Anchang and Theckla Kwangsa Mbunwe follow with Chapter 22 describing a unique health literacy intervention on non-communicable diseases in sub-Saharan Africa, using a qualitative perspective on sustainable development. They emphasise the need to develop culturally appropriate health literacy interventions considering the existing social, financial, cultural, gender, educational and cognitive barriers in African countries, highlighting the importance of the involvement of the sociocultural characteristics of individuals. Occupational health literacy is then presented by Marie Birk Jørgensen and Anne

Konring Larsen in Chapter 23, who introduce operationalising a health literacy intervention into a workplace setting. They provide an overview of the features of the workplace setting, draw on health-literate workplaces, and outline the key pillars of what they understand to constitute their relational model: individual abilities to navigate occupational safety and health information; the management's abilities to address their employees' occupational health situations and the whole workplace's abilities to implement preventive or health-promoting actions. Anthony F. Jorm in Chapter 24 offers a comprehensive description and analysis of mental health literacy among adults, describing public initiatives and campaigns from Australia and around the world. His focus is on how the improvement of mental health literacy could also facilitate healthy behaviours and intervention outcomes related to mental health literacy. The reader learns more about mental health literacy from Kathrin Schulze and colleagues' contribution, Chapter 25, who use an empirical approach. Addressing the mental health promotion of children in general, but of children from families with mental health issues in particular, they address professional staff in health and social care settings as well as school teachers in the context of school health promotion. Finally, Maricel G. Santos and Julie McKinney, in Chapter 26, stress the importance of interventions focusing on adult literacy, and their experience in promoting people's ability to practically and effectively help people navigate the health system. They make the case for developing interventions that use pedagogical methods and content in relation to literacy learning, that are based on an understanding of health literacy as an autonomous set of skills rather than constrained by ideologies and normative principles about low literacy and patient competencies.

We hope that this part of the book succeeds in stimulating the readers' interest in learning from international health literacy initiatives, and in exploring the availability, relevance, improvements and shortcomings of health literacy interventions and programmes in a wide variety of populations.

14

Improving health literacy in clinical and community populations

Don Nutbeam and Bronwyn McGill

Evolution of the concept of health literacy

The past 25 years has seen extraordinary growth in interest in health literacy among researchers, policy-makers and practitioners. This interest has been underpinned by academic debate about the concept, definition and measurement of health literacy, and further strengthened by a growing volume of research that has investigated the relationship between health literacy and a wide range of health and social outcomes. A smaller but growing number of studies report on interventions to address the practical challenges of low health literacy in clinical settings, and describe approaches to improving health literacy in different clinical and community populations.

The reasons for this rapid expansion in interest are not hard to understand. It has long been established that low literacy in a population is associated both directly and indirectly with a range of poor health outcomes. Indirectly, low literacy is often linked to poor socioeconomic circumstances, and this, in turn, is associated with adverse effects on health that are independent of other risk factors. The World Health Organization (WHO) Commission on the Social Determinants of Health identified literacy as having a 'central role' in determining inequities in health in both lower- and higher-income countries (CSDH, 2008). Research conducted mainly over the past 20 years has also clarified the relationship between low literacy levels and declining use of available health information and services. This is observable in relation to responsiveness to health education, the use of disease prevention services and in poor self-management of chronic disease (Berkman et al, 2011).

This chapter draws mainly on literature relevant to adults across the life course, but has findings that are also relevant to younger people. It shows that improving health literacy involves more than the transmission of health information, although this remains a fundamental task. It demonstrates that helping people to develop confidence to act on knowledge and the ability to work with and support others will best be achieved through more personal forms of communication in clinical settings, and in populations, through community-based educational outreach. The goal of promoting greater independence in health decision-making can be achieved through a more sophisticated understanding of the potential of education to strengthen both personal and community action to improve health. The chapter concludes that developing health literacy in this way will support more comprehensive options for health improvement, disease prevention and for successful self-management among individuals with established illness.

Literacy and health literacy

Literacy is generally understood as having two distinct components – those that are task-based and those that are skills-based. It can be measured in absolute terms by distinguishing between those who can perform the tasks of reading and writing basic text and those who cannot, and in relative terms by assessing the skill differences between those who are able to perform relatively challenging literacy tasks and those who are not able to do so (NAAL, 2003). These distinctions can also apply to numeracy skills. Individuals with higher levels of general literacy (high-level skills in reading, writing and understanding text) are more able to apply their skills in situations requiring specific content knowledge or in new and unfamiliar contexts.

Literacy is not a fixed asset. It can be improved through education, and is both content- and context-specific. Although the possession of generic literacy skills in reading, writing and understanding text improves the ability of an individual to access, understand and act on new information, it is no guarantee that a person can consistently apply their skills in situations requiring specific content knowledge or in unfamiliar settings. In this context, more specialist knowledge and more specific skills may be required. This understanding of the dynamic nature of literacy has led to the recognition of different specialist *literacies*, such as financial, science or media literacy. This distinction reflects the fact that individuals have varying capacity to apply their general literacy skills in different contexts.

Health literacy may be considered one of many domains of literacy. Health literacy can be described as the possession of literacy skills (reading and writing) and the ability to perform knowledge-based literacy and numeracy tasks (acquiring, understanding and using health information) that are required to make health-related decisions in a variety of different environments (home, community, health clinic). It has been defined and conceptualised in multiple ways (Peerson and Saunders, 2009; Sørensen et al, 2012), but is ultimately based on an observable set of skills that can be developed and improved through effective communication and education.

Functional, interactive and critical health literacy

These differences in skills have been categorised as *functional*, *interactive* and *critical health literacy* (Nutbeam, 2000). Such a classification is derived from mainstream literacy studies and has the advantage of signalling the impact that differences in skill levels may have on health-related decisions and actions. *Functional health literacy* describes basic-level skills that are sufficient for individuals to obtain relevant health information (for example, on health risks and on how to use the health system), and to be able to apply that knowledge to a range of prescribed activities. Individuals with these basic health literacy skills are generally able to respond well to education and communication based on factual information on health risks, and on how to use the health system.

Interactive health literacy describes more advanced literacy skills that enable individuals to extract health information and derive meaning from different forms of communication; to apply new information to changing circumstances; and to engage in interactions with others to extend the information available and make decisions. Individuals with these more advanced health literacy skills are well positioned to respond to education and communication that is focused on the development of personal skills and improved personal capacity to act independently on knowledge, and strategies designed to improve motivation and self-confidence to act on information obtained. This type of health education is generally more interactive and often delivered through more structured educational settings (for example, school health education, well-designed interactive websites).

Critical health literacy describes the most advanced literacy skills that can be applied to critically analyse information from a wide range of sources, and information relating to a greater range of health determinants, and to use this information to exert greater control over life events and situations that have an impact on health. This may include not only information on personal health risks, but also on the social, economic and environmental determinants of health. This type of health literacy can be more obviously linked to population benefit alongside benefits to the individual.

Such a categorisation also helps to distinguish between communication and education that is task-based – designed to develop specific skills to manage prescribed activities (medication adherence, behaviour change), and interventions that are skills based – designed to develop generic, transferable skills that equip people to make a range of more autonomous decisions relating to their health and to adapt to changing circumstances.

The concepts of interactive and critical health literacy connect closely to modern concepts of health promotion. In this case, health literacy has been viewed as a personal and population *asset* offering a route to greater autonomy and control over health decision-making (Nutbeam, 2008; Pleasant and Kuruvilla, 2008; Mårtensson and Hensing, 2012). It is through this focus on skills development and empowerment that the concept of health literacy has the potential to have a distinctive influence on the purpose and methodologies of health education and communication. For more information on critical health literacy, see Chapter 11, this volume.

Health literacy in context

More recently, greater emphasis has also been given to better understanding the impact of the context in which people are required to use their health literacy skills and capabilities. Health literacy is mediated by the situational demands and complexities that are placed on people. Obtaining nutritional information from a food label is a quite different experience from receiving complex, jargon-laden instructions on how to manage diabetes, and quite different again from receiving information on childbirth at an antenatal clinic. Even a person with a high level of health literacy may experience real challenges in applying those skills in an environment (like a hospital) or in interacting with a person (like a doctor) that they find unfamiliar and intimidating. This has led to much greater attention being given to ways of reducing the situational demands and complexity in which an individual is making a health decision. Research in the emerging area of organisational health literacy explores the features of health-literate organisations as well as the barriers preventing these features from being addressed (Brach et al, 2012; Palumbo, 2016; see also Chapters 8 and 31, this volume). A range of models and practical strategies has been proposed to help create health-literate organisations that are implementing practical strategies to reduce the environmental demands on people engaging with those organisations and health professionals. While these strategies range from modification of the language used in various forms of communication through to changes in the organisation and management of health services, there is limited evidence to support recommendations being made particularly in terms of organisational improvements leading to better health outcomes. Brach and colleagues (2014) highlighted the important role of the health professional within the complexity of a health-literate organisation, but also outlined their dependence on organisational policies and infrastructure to achieve health literature communications with.

Figure 14.1 (adapted from a model proposed by Parker, 2009) provides a summary of this dynamic relationship as a product of personal skills and situational demands. This model also helps to illustrate how observable differences in health literacy emerge as a consequence of differential exposure to health information content and communication media that are designed to improve personal skills and ability, subsequently moderated by the environment in which a person applies their literacy skills.

Figure 14.1: Health literacy as a product of personal skills moderated by environmental complexity

Improving health literacy in clinical populations

In response to surveys that have indicated high rates of poor health literacy in populations, governments and national agencies in countries as diverse as the US, China, Australia and some European nations have developed national strategies and targets to improve health literacy in their populations (Chinese Ministry of Health, 2008; USDHHS, 2010; ACSQHC, 2014; Heijmans et al, 2015). As these policies and other government responses have emerged, increasing attention has been given to interventions to address the challenges posed by low health literacy in populations and to improve health literacy in populations.

Health literacy can be improved through the provision of information, effective communication and structured education. It can be regarded as a measurable outcome to health education or patient education. Improvements in health literacy can be assessed through the measurement of changes to the knowledge and skills that enable well-informed and more autonomous health decision-making. Differences in communication methods, media and content will result in different learning outcomes and associated behavioural and health outcomes. In turn, individual responses to information and education will be moderated by the environment in which they occur.

To date, the majority of research into health literacy has focused on the development of effective interventions for use in clinical practice. There are compelling reasons for this in healthcare systems where there is a need for more effective prevention, a commitment to patient-centred care, and greater than ever dependence on patient self-management of chronic conditions. Research from the European Health Literacy Survey (HLS-EU) has demonstrated that there is a strong social gradient in the population, with lower levels of health literacy much more common among the socially and economically disadvantaged – indicating that those with greatest need are generally least able to respond to the demands of the healthcare system (Sørensen et al, 2015).

There are very practical challenges to overcome in the implementation of strategies to minimise the impact of low health literacy in hospitals and clinics. The restricted time available in clinical consultations will often limit communication to factual information on health risks and on how to use medications and healthcare services. For these reasons, patient communication will often be directed towards well-defined outcomes – such as compliance with the use of prescribed medicines. Where more structured patient education can be offered in the clinic, it can also contribute to the development of a wider range of knowledge and skills necessary for successful self-management of non-communicable diseases (NCDs) such as diabetes and heart disease, and related clinical risks such as hypertension, elevated cholesterol or obesity (Wallace et al, 2009).

As indicated earlier, the effects of poor health literacy can be mitigated by improving both the quality of health communications and by improving the sensitivity and practical skills of health professionals to the impact of low literacy on individuals. In addition, increasing attention is being given to simplifying the organisational and administrative complexities faced by patients in using the healthcare system. This is leading to modifications to patient registration procedures, greater flexibility in making appointments and improved way-finding in hospitals and health clinics.

Practical responses to the challenges of poor health literacy can be observed in a range of adaptations to traditional patient and population health education methods in print, broadcast and increasingly in digital and mobile communication, as well as closer attention to improved interpersonal communication between clinicians and their patients.

Improving health literacy through modified patient education

There are a growing number of examples of different approaches to patient education that are intended to improve functional health literacy and related clinical outcomes. The great majority of these studies are using the health literacy concept to better understand the likely response of patients to clinical advice and instruction, the impact on compliance and longer-term success in disease management. In this context, low health literacy is understood as a risk to successful clinical care.

As the number of reported intervention studies has increased, there have been some helpful reviews (Sheridan et al, 2011; Manafo and Wong, 2012; Taggart et al, 2012). In an excellent review including mainly clinical interventions, Sheridan et al (2011) report on the outcomes of 38 intervention studies. This review highlights common features of successful interventions including mixed strategy and high-intensity communications, the use of theory, pilot testing, an emphasis on skill building and delivery by a health professional. They also emphasise the use of teach-back methodologies that have been shown to be effective in other literacy interventions. Teach-back typically involves asking a client to explain in their own words the information or advice they have been given to demonstrate their understanding of the important information. Importantly, it places the onus on service providers to confirm they have communicated information effectively. Teach-back has been reported to be effective in a range of contexts, especially in obtaining informed patient consent (Wadey and Frank, 1997; Fink et al, 2010). It has been used to educate, assess learning and improve recollection of health information. It may also help health services improve client satisfaction and meet their expectations.

Taken as a whole, these reviews provide broadly consistent evidence that comprehension of health information and advice among individuals with low health literacy can be improved through modifications to communication, and that intensive mixed-strategy interventions (for example, combining adapted communications with behavioural skills coaching) produces improved health outcomes. These improved outcomes include reduced reported disease severity, unplanned emergency department visits and hospitalisations. Despite evident progress, the constraints on patient education in a clinical setting often mean that the most commonly used educational methods still tend to be more functional, and less likely to enable interactive communication or support a high level of autonomy in decision-making. Good progress has been made, but much remains to be achieved.

Improving health literacy in community populations

Just as formally organised education is the main route to improved literacy in populations, it follows that organised and structured *health* education has the potential to improve general, transferable *health* literacy skills in individuals and community populations. Health education has been an essential component of action to promote health and prevent disease for more than a century. Many campaigns have been and continue to be characterised by their emphasis on the transmission of information, often based on a relatively simplistic understanding of the relationship between communication and behaviour change.

These interventions are mostly based on the well-established knowledge/attitudes/behaviour (KAB) conceptual framework, and do not always reflect the skills-directed methods and learning theories that are required to develop interactive and critical health literacy. Over time, it has become clear that campaigns that focused only on goal-directed transmission of information – developing functional health literacy – were not achieving the results that had been expected in terms of their impact on health behaviour. In addition, where health education programmes have been found to be effective, these successes have been most observable among the most literate and economically advantaged in the community. We can observe that higher levels of general education and literacy, personal skills and economic opportunity significantly improve the capacity of people to receive and respond to health messages communicated through traditional media. As a consequence, interventions that rely heavily on KAB communication have struggled to achieve substantial and sustainable results in terms of behaviour change, and have made little impact in terms of closing the gap in health status between different social and economic groups in society.

As a tool for health promotion and disease prevention, health education has been considerably strengthened by the development of more sophisticated, theory-informed interventions over recent decades (Nutbeam et al, 2010; Suggs et al, 2015). These theories are not only focused on the transmission of information (although this remains important) but also the development of personal and social skills that fit with contemporary concepts of interactive and critical health literacy.

These contemporary programmes also integrate the social context of behavioural decisions, and enable people to develop the transferable personal and social skills that are required to make health-related decisions at different times and in different contexts across the life course. Several theories of behaviour change have helped to identify and explain the complex relationships between knowledge, beliefs and social context. These provide practical guidance on the content, sequencing and delivery of health education programmes to improve interactive and critical health literacy, and support positive health-related decision-making in a variety of circumstances, emphasising the following:

- The importance of *knowledge and beliefs* about health. All models imply a central role for health education, and refer to individual knowledge about health. They emphasise the importance of *personalising health information*, and stressing *the short-term consequences* of decisions that communication is more immediately relevant to an individual.
- The importance of *self-efficacy*: the belief in one's competency to take action. Health education that enables the development of interactive and critical health literacy skills, for example, through personal observation, supervised practice and repetition, is often vital to sustainable skills development.
- The importance of *perceived social norms and social influences* related to the value an individual places on social approval or acceptance by different social groups. The influence of social *role models*, family and peer groups is emphasised here, and the potential for individuals with higher-level health literacy skills to positively influence others is also recognised.
- The importance of recognising that individuals in a population may be at *different stages of change* at any one time. This understanding highlights the sequencing and targeting of health education messages to the right person at the right time across the life course.
- The importance of shaping or changing the *environment* or people's *perception of the environment* as an important element of health education, reflecting the importance of interventions to reduce situational demands and complexity.

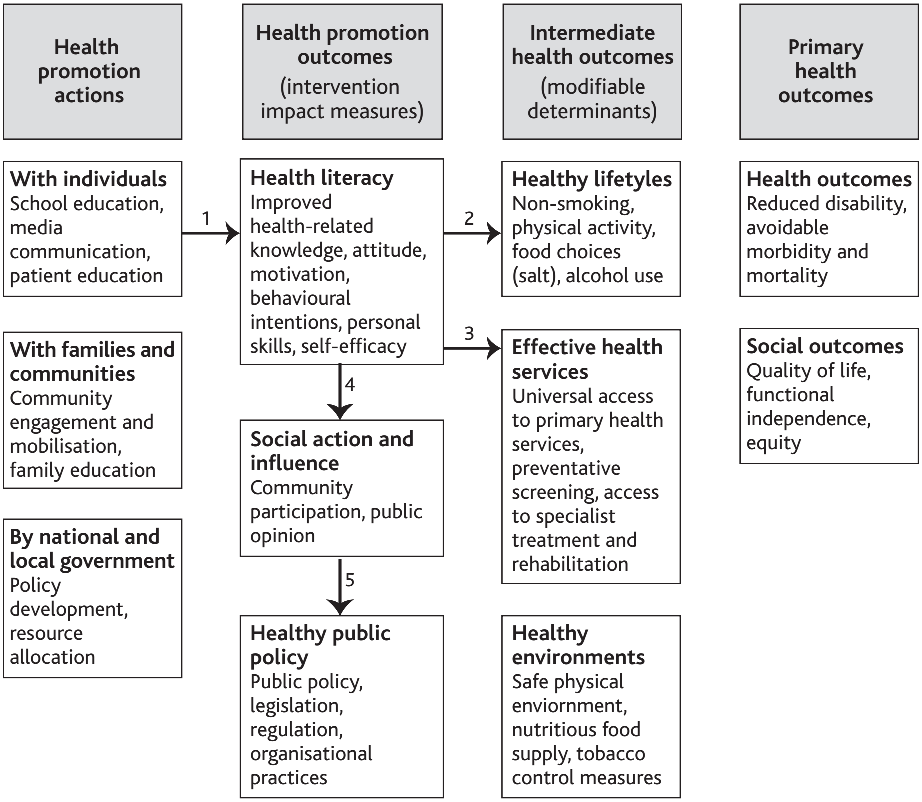
Access to a wider range of communication tools and methodologies that have evolved with the development of the internet and mobile communications have both broadened the repertoire of health communication and education and made it more complicated (Viswanath et al, 2015). Many people have a far wider range of communication channels open to them. This enables access to a wide variety of sources of information and opens opportunities for more personalised and tailored health communication. It also means that those wishing to communicate health messages are entering a more crowded marketplace for attention, and challenges health consumers to discriminate between different sources of information. There are increasingly sophisticated online health education programmes that are targeted to specific populations and capable of a high level of personalisation. These generally make good use of the theoretical models described earlier to guide content and sequencing of messages. There are a growing number of eHealth and mHealth programmes that are addressing specific risks and/or disease management strategies for NCDs (Watkins and Xie, 2014; Urrea et al, 2015; Jacobs et al, 2016).

Health education and health literacy in context

Figure 14.2 provides a logic model for health promotion that illustrates the relationship between health education and health literacy, and the place of health education and health literacy in the wider context of a range of potential interventions for health promotion and disease prevention (Nutbeam, 1996, 1998).

In the model the end-stage of interventions is described as *health and social outcomes*, usually expressed in terms of reduced mortality, morbidity and disability, and may also incorporate social goals related to greater equity in outcomes. *Intermediate outcomes* in the model represent the most immediate determinants of these health and social outcomes. Personal behaviours such as smoking or physical activity may increase or decrease the risk of disease, and are summarised as *healthy lifestyles* in the model. *Healthy environments* consist of the environmental, economic and social conditions that can both impact directly on health as well as support healthy lifestyles – for example, by making it more or less easy for an individual to smoke, adopt a healthy diet or engage in physical activity. Access to, and appropriate use of, health services are acknowledged as important determinants of health status, and are represented as *effective health services* in this model.

Figure 14.2: Logic model for prevention planning



Health promotion outcomes represent those personal, social and structural factors that can be modified in order to change the determinants of health (that is, intermediate health outcomes). These outcomes also represent the most immediate target of planned health promotion activities. Within this level of the model, health literacy refers (as above) to the literacy, cognitive and social skills that enable individuals to access, understand and use information to promote and maintain good health – typically the outcome of health education activities. Social action and influence describes the results of efforts to enhance the actions and control of social groups over the determinants of health. These may also be influenced by health education and communication as well as other forms of community development. Healthy public policy and organisational practices are the result of efforts to overcome structural barriers to health – typically the outcome of government action that may lead to environmental, organisational, policy, regulation and/or legislative change. Success in the introduction of comprehensive tobacco control legislation in many countries represents a contemporary example of this outcome.

The most effective health promotion and disease prevention programmes consist of interventions targeted at all three of the factors identified as health promotion outcomes above. For example, a programme to promote healthy eating might consist of health education directed at individuals about basic food groups, to develop practical skills in food preparation and selection, alongside community and policy actions to improve access to healthier food choices through supply-side intervention. These could include, for example, efforts to improve the food choices available in school and worksite canteens, and interventions with food retailers to improve the supply and promotion of healthier food choices.

This logic model also provides the bridge between an intervention (described as health promotion actions) and the goal of an intervention (modification of the determinants of health). These *health promotion outcomes* are the bridge between what we do and what we are trying to achieve in health promotion interventions. These health promotion actions in the model include health education and communication, organised efforts to mobilise people's collective energy, resources and skills towards the improvement of health, and government actions that promote health.

Use of this model places health education into the wider context of health promotion, and importantly, positions health literacy as a key outcome from health education. The arrows in the model illustrate potential relationships. There is the obvious linear relationship that links health education, health literacy (1) and health behaviour (2), and to more effective use of health services (3). But other relationships can also be planned and observed. Health education can also be directed towards the development of relevant interpersonal and social skills. People who have better developed health literacy will thus have skills and capabilities that enable them to engage in a range of health enhancing actions not only in making positive decisions about their own health, but also enhanced capability to influence others (family, community) towards healthy decisions (4). This influence may range across encouraging behaviour change, moderating public opinion or even collective action to influence political processes and decisions in favour of health (5).

Health education to improve health literacy

Health education remains a crucially important tool in public health, but the evidence from numerous studies highlights how emphasis has to shift away from promoting simple compliance with pre-determined behavioural goals to the development of a set of empowering personal skills that enable engagement in a range of actions that can protect and improve health. The growing interest in the concept of health literacy has emerged from this more sophisticated understanding of health education.

To date, there are relatively few reported interventions that incorporate the concepts of health literacy described above. In contrast to the rapid growth in experimental research in clinical settings, a recent review of studies with community populations found relatively few that were actively using the concept of health literacy in their design and evaluation (Nutbeam et al, 2017). Those identified in the review covered a range of settings, including online programmes, adult education, school and a supermarket-based multimedia programme. All included education or communication strategies designed to develop functional health literacy skills directed towards specific improvements in knowledge and understanding, and most were also directed towards pre-defined behavioural responses. Most also had elements that were compatible with the development of interactive and/or critical health literacy skills. Educational methods varied considerably from formal classes, home visiting and study circles, through multimedia and eHealth/online interventions (Nutbeam et al, 2017).

Encouragingly, the interventions demonstrated the potential to meet the needs of specific adult population groups throughout the adult life course (parents, adult learners, older people), and addressed a range of topical health issues including food choices, physical activity and parenting. Most were also targeted at populations and in settings that have a higher proportion of individuals with lower health literacy. Although this review found few reported studies, it did highlight a pipeline of studies underway that indicate a growing base of evidence that will enable us to better understand how to organise and deliver more effective population interventions in the future.

Overall, the authors report that the concept and rhetoric relating to health literacy has excited the interest of public health researchers, practitioners and policy-makers, but that this interest has not yet been converted into substantive advances in public health interventions.

Conclusion

In this chapter we have identified the rapid increase in interest in health literacy over the past 15 years, and how this interest is transitioning from conceptual and observational studies to practical interventions to improve health literacy and reduce the impact of poor health literacy, especially in clinical settings. It is not difficult to understand why health literacy has become a subject of wide interest in the past decade. For researchers interested in health and disease causality, health literacy offers a convenient and logical summary definition of a pre-existing condition/risk that can be used to understand and explain variation in health and disease outcomes. There is a substantial and growing literature that confirms the importance of the concept in clinical practice and public health. For those interested in the evaluation of information, education and communication interventions, health literacy has long been proposed as a useful outcome measure (Nutbeam, 1998).

For clinicians, work over many years, mainly in the US, has established health literacy as an identifiable and manageable risk in clinical care, of particular importance in the management of long-term and complex conditions that depend on successful patient engagement and management. For public health practitioners, health literacy is conceptually attractive in its fit with contemporary health promotion, understood as a personal 'asset' that can be developed through educational and other interventions to support greater personal and community control over a range of determinants of health. For policy-makers, health literacy has the attraction of being a sufficiently flexible concept to be used to support a full spectrum of policy positions.

All of this attention is undoubtedly supporting advances in our knowledge and understanding of the concept, its relative importance as a health determinant, its measurement and its potential for use to guide clinical practice, public health and public policy. However, the academic interest and attractive rhetoric surrounding health literacy needs to be tested more often and more systematically through intervention experimentation in a wide range of populations using valid and reliable measurement tools.

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15

MEDIA PROTECT: A setting- and parent-targeted intervention for a healthy childhood in the digital age

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Introduction

Screen media usage encompasses a variety of activities including television, DVDs, video games, computers, the internet, smartphones and tablets (Vanderloo, 2014). These activities are playing a progressively integral part in children and young people's daily lives. In a representative sample of children in the US aged 8 to 10, mean daily screen time was nearly eight hours with different types of media, and more than 11 hours per day for 11- to 18-year-olds (Rideout et al, 2010). Health departments, practitioners and experts recommend that children under the age of three should not be using screen media at all (Strasburger, 2010; Vaala and Hornik, 2014). A maximum of half an hour per day is recommended for children in nursery and of one hour per day for 7- to 12-year-olds (Bitzer et al, 2014). However, national and international studies report an increase in the amount of time children are spending with screen media (Vaala and Hornik, 2014). Excessive use of screen media during childhood is connected with various negative outcomes, for instance, poor school performance (Nunez-Smith et al, 2008; Mößle et al, 2010; Ferguson, 2011), obesity/adiposity (Nunez-Smith et al, 2008; Bener et al, 2011; Staiano et al, 2013), low sleep quality (Cain and Gradisar, 2010; Marino et al, 2016), anti-social behaviour (Robertson et al, 2013), neurological changes (Sigman, 2017), attention problems (Christakis and Zimmerman, 2007; Nunez-Smith et al, 2008; Gentile et al, 2012) and addictive use (Mößle and Rehbein, 2013). For all these outcomes, screen media use has been identified as an independent risk factor in models controlling for other determinants (Mößle, 2012).

All in all, problematic screen media use in childhood is considered a major public health issue (Christakis et al, 2013), and an urgent need for primary prevention has been identified (Sigman, 2017). It has been argued that for effective prevention of problematic screen media use, the three dimensions of time, content and function should be taken into account, so that each dimension could be separately assessed as beneficial, neutral or problematic (Schmidt et al, 2012; Bleckmann and Mößle, 2014).

Meta-analyses and reviews reporting on the frequency and effectiveness of media literacy training-centred interventions to reduce problematic screen media use are not available in the international literature. In contrast, the effectiveness of programmes aiming to reduce the time spent using screen media is well documented in reviews and meta-analyses (Maniccia et al, 2011; Schmidt et al, 2012; Friedrich et al, 2014). These studies contain hardly any information on children's media literacy, and much less on children's eHealth literacy in the narrow sense in which the term is widely used, which comes as no surprise since this evidence is based mainly on trials that report on obesity reduction as the primary outcome, with 'screen media reduction' being only a mediator (Schmidt et al, 2012).

Regarding preventive actions in the field of digital media, this chapter provides a more detailed overview of the current practice and literature on German interventions. In Germany there is currently a focus on media literacy training and on the content dimension of problematic screen media use, with the screen time and function/dysfunction dimensions being largely neglected, and a focus on online rather than face-to-face preventive offers (Bitzer et al, 2014). There are many German initiatives that design websites targeting children, parents and teachers to give advice on screen media. Some of these provide scientific articles, information regarding the digital world and a place for discussion and exchange (for example, FLIMMO and juuuport). Individual federal states in Germany have various projects and initiatives that are financially supported by the respective states. Most offer workshops, training or information to support children, parents or teachers in how to promote media literacy, for instance, integrating digital media in school (such as multimediamobile or MedienkomP@ss) or empowering parents in supervising their children when playing computer games (such as Eltern-LAN), but also reflecting problem behaviour (for example, medienscouts and Eltern@home).

Additionally, certain associations exist that address the support of media competence while targeting children, parents and teachers (for example, smiley and internet-ABC). Most offer interventions that are not evaluated. In general, only a few interventions in Germany regarding screen media are scientifically monitored. These are either school-based, like Medienhelden (Möller et al, 2012; Schultze-Krumbholz et al, 2014), or combine different settings, for example, KidSMART (Müller et al, 2012) or ESCapade (Fachstelle für Suchtprävention der Drogenhilfe Köln, 2014). The goals of these programmes are to first address media literacy and second prevention: two focus on promoting media health literacy, either in order to reduce cybermobbing (Schultze-Krumbholz et al, 2014) or to level out the differences in digital skills between children with or without a migration background (Müller et al, 2012). In their intervention, Möller et al (2012) addressed media content, in particular reducing violent media consumption and promoting critical viewing skills. However, ESCapade focused on adolescents with problematic computer (online) use, and in this case on reducing computer time and problems due to their usage behaviour (Fachstelle für Suchtprävention der Drogenhilfe Köln, 2014).

We conclude from this that there is a need for interventions with a universal approach toward preventing problematic screen media use considering in particular young children and the three problem dimensions that seem all the more pressing when considering the continuous increase in the amount of time children are spending with screen media and the associated negative outcomes documented by media effects research.

In this chapter we describe the MEDIA PROTECT intervention, designed to close the gap identified in the German prevention landscape. The intervention aims to reduce problematic use of screen media in younger children (aged 4–7) by addressing their parents, educators and the children themselves. We describe the components of the intervention for all three target groups as well as the training of trainers delivering the intervention. In an attempt to integrate the only seemingly disparate goals of promoting more skilled use of digital media to support healthy behaviours in a more classical understanding of eHealth literacy (see Chapters 18 and 43, this volume), and enabling caretakers to reduce children's use of digital media to support a healthy childhood, we briefly sketch a model of digital balance literacy (DBL) that focuses on developmental stages in childhood. The introduced DBL model forms a provisional theoretical basis for the MEDIA PROTECT intervention. To conclude the chapter, we suggest improvements to the intervention based on the results of the formative evaluation, and comment on the need to further develop and expand current eHealth literacy models in order to account for the age-dependent balance of digital risks and benefits for health in the future.

Applying models of eHealth literacy to children and adolescents

eHealth literacy is a facet of general health literacy that evolves over the life course, starting in early childhood (Zarcadoolas et al, 2005). However, a recent systematic review on definitions and models of health literacy in childhood and youth reveals a lack of suitable health literacy models for children younger than 10 (Bröder et al, 2017).

Most models that explicitly consider the health literacy of children strongly focus on parental or caregivers' competencies in order to enable them to promote a child's health. Given the fact that the younger children are, the more dependent they are on their caregivers, it is certainly justified to take an adult perspective on health literacy. But children already 'take on an active role in their health. Viewing children … as active social agents draws attention to considering children's perspective of health' (Bröder et al, 2017, p 22).

However, most health literacy models for children and young adolescents are fairly similar to adult ones. They take a strong skills-based perspective, where skills such as knowledge, comprehension, responsibility, communication, critical thinking and evaluation are central parts of the models (Brown et al, 2007; Sanders et al, 2009; Schmidt et al, 2010; Subramaniam et al, 2015). This insufficient incorporation of life phase specificities leads to the conclusion that it is necessary to shift the focus from an individualistic and skills-based perspective to models that also address contextual factors. Children have been shown to learn and master health literacy-related skills through their social environment (Borzekowski, 2009), supporting the assumption that system-related factors may be even more important for the health literacy of children than individual health literacy skills.

Another important aspect mentioned in the review by Bröder and colleagues (2017) is that digital media, which play an increasing role for children and adolescents, remain underrated in current health literacy models. eHealth literacy models take the important role of new media for health into account. Common models of eHealth literacy focus on the skills and knowledge of individuals. Norman and Skinner (2006, p 4) define eHealth literacy as 'the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem'. Norgaard et al (2015) have introduced a broader framework for eHealth literacy with skills on three different dimensions, namely, individual, system and interaction dimensions. The individual dimension includes the ability to process information and engage in one's own health. The system dimension addresses access to digital technologies that work and suit individual needs. The interaction dimension comprises individual ability and motivation to engage with digital services and the feeling of being safe and in control of digital technology. This model focuses both on the individual skills and technology characteristics level to master digital technology (Kayser et al, 2015).

For the family setting, in addition to the well-documented fact that children growing up in a family setting with problematic use of digital media are likely to develop unhealthy digital behaviours themselves, recent studies support the hypothesis that changes in the setting (reducing availability of screen media, especially in children's bedrooms) will be more effective in preventing problematic use than individual skills-centred strategies (supporting children in self-regulating their screen media use) (Bleckmann and Mößle, 2015). Consequently, for eHealth literacy there are specific reasons to criticise the unreflected application of individual skills-centred adult models to children and adolescents.

Another such reason is that there is a complex field of both positive and negative effects of screen media use on children's health, leading to possible counterproductive long-term effects of well-meant interventions to increase eHealth literacy in young age groups. So far, current concepts of eHealth literacy include the potential and proven benefits of the use of digital media for health, but largely neglect the potential and proven negative health effects of problematic screen media use. This is surprising because problematic screen media use is – as stated at the beginning of this chapter – a noticeable public health issue. To contribute to a balanced use of digital technology, which will contribute to a healthy childhood in the digital world, the current models turn out not to be suitable for the age group addressed in the MEDIA PROTECT intervention (pre-school and elementary school age), above all given the evidence of the harmful effects of screen media use for young children. The MEDIA

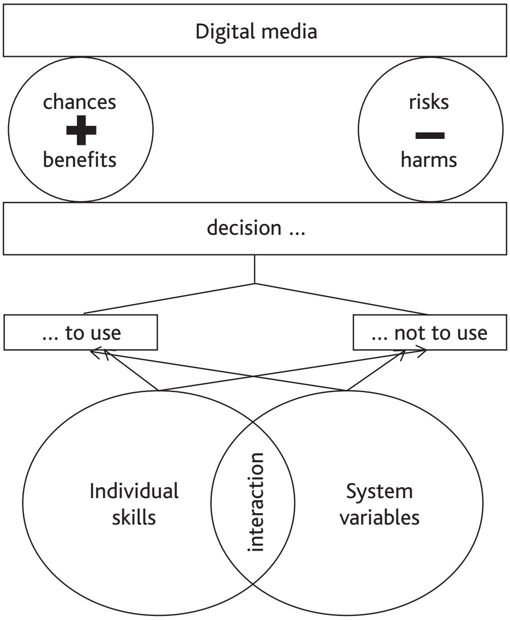
PROTECT intervention therefore needs to rely on a model that encompasses these considerations. To our knowledge, such models have not been published to date.

Therefore, in an attempt to compensate for the difficulties described in applying current adult eHealth literacy models to children (individual vs system contributions, positive and negative effects of screen media on health), we are developing the more comprehensive 'model of digital balance literacy (DBL) for children in settings' (see Figure 15.1).

The model encompasses a meta level of informed decisions of when and why to use electronic media for promoting health, and when and why not to use them based on comprehensive knowledge about screen-related health risks and benefits for different age groups, following the tradition of sound technology assessment. This meta level is especially important for decision-makers on interventions and frameworks on the health systems level. The two subordinate areas of our eHealth literacy framework are media use-oriented skills on the one side, and media reduction-oriented skills on the other. The first has a high conceptual overlap with the previously mentioned eHealth literacy models, and is especially important for adult individuals. The latter encompasses skills needed to reduce problematic screen media use at the individual and system levels, and is especially important for caretakers of young children.

In order to allow children to develop these skills step by step, the educational setting has the core responsibility for creating the conditions that support them

Figure 15.1: Outline of the digital balance literacy (DBL) model on which the MEDIA PROTECT intervention is based



in a way that minimises the risk of harmful consequences from digital media use. The systems level could apply both to the family environment (for example, when parents make decisions on the availability and use of screen media for their children) to educational systems (for example, when teachers decide on the availability and use of screen media in school and for homework), and to directly health-related systems (for example, when doctors and parents decide on the use of digital technology for health purposes, such as diabetes apps). In very young ages the system needs to empower children and support them to develop real-life skills first; digital skills should successively evolve in later stages of the child's development.

The intervention and its components

MEDIA PROTECT is a programme to sustainably prevent children's problematic and, in the long run, addictive use of screen media in a multisetting approach through the targeting of parents, children and teachers.

Our theoretical model suggests putting a focus on changing the system or setting rather than children's individual skills. Parents and nursery or elementary school teachers were therefore chosen as core target groups for the intervention. Parents are central mediators of children's media use with an influence on bedroom media equipment, use times and use of age-inadequate media content, with children from disadvantaged family backgrounds being exposed to more developmentally inappropriate screen media use (Vandewater et al, 2005; Mößle, 2012; Bleckmann and Mößle, 2014). Besides parents, childcare settings, such as nurseries and grade schools, also play an important role for limiting screen time, because nearly every child at the age of three and older is enrolled there. They spend many hours in care, and the institutions provide opportunities for pre-schoolers to learn and adopt healthy behaviours (Vanderloo, 2014; Yilmaz et al, 2015). Research indicates that a negative association exists between screen viewing in children and levels of staff education – that is, children in day care with high-educated teachers watch less TV than children in day care with lower-educated staff (Vanderloo, 2014). Thus, increasing parents and teachers' digital balance literacy in an intervention seems a promising way to enable them to guide children in the digital world.

Considering the arguments for an effective prevention by Schmidt et al (2012) and Mößsle (2012), the three problem dimensions of media use, namely, time, content and function (Bleckmann and Mößle, 2014), were taken into account. The time dimension focuses the issue of time displacement by screen media in children ('How long are they exposed?'). The content dimension deals with (non-)compliance with age recommendations, such as FSK and USK, which are awarded on the basis of violent and pornographic content ('What type of information is transmitted to the child, or also from the child to the medium?'). The function dimension refers to the questions 'Why are children exposed to screen media? What are the motivations to use?' Examples on the negative side of this dimension are the instrumentalisation of children's screen media use by the parents for their care and educational purposes. The repression of real-world stress or failure experiences through screen media use (escapism) can also be counted as a functional dimension, as can the substitution of real-world social contacts with virtual ones (Bleckmann and Mößle, 2014). So children should be protected from problematic media use in all three dimensions in early life. This will not automatically increase their real-life resources, however, so the intervention should additionally aim at fostering children's 'life skills' (Griffin and Botvin, 2004; Mößle, 2012) as well as their caretakers' skills for providing a healthy real-life environment.

The intervention follows a multidisciplinary approach involving teachers, parents and children, targeting parents with children aged between four and seven as well as teachers working with this age group. Figure 15.2 gives an overview of the components of the MEDIA PROTECT intervention.

Teachers

A central part of the intervention is a training session for teaching staff, which is delivered as a group intervention. Educators in schools and nurseries can choose between participating in the two units of 2.5 hours each on one day or two separate days. The training sessions take place directly in the schools or nurseries or at a neutral location. These are conducted by certified multipliers, more than 50 of whom have been trained in many regions of Germany so far.

The overall objective is to empower teachers to promote healthy and prevent unhealthy use of screen media in the family in their daily work with parents and children. In particular, teachers receive information on media education, media addiction prevention and parental-directed communication strategies. A large variety of methods (presentation by multipliers with discussion, quiz, partner and team work, and case discussions) are used. Furthermore, the staff assemble a

Figure 15.2: Components of the MEDIA PROTECT intervention

Teachers	**Parents**	**Children**
• Training: a total of 5 hours	• Parents' evening: advice and information	• 'Tivi Tivi' interactive children's theatre RADELRUTSCH
• Content: media education, prevention, guide to parent talks on media education	• Technical evening: installation and configuration of security software	• Follow-up to the play (eg, summary, movement games)
• Creating a local 'leisure map' with alternatives to the screen media	• Individual advice: telephone calls and consultation	
WRITTEN MATERIAL: Training manual	**WRITTEN MATERIAL:** Flyer, 'Media counsellor for parents'	**WRITTEN MATERIAL:** Flyer for children and teachers for follow-up

'screen-free leisure map' for parents that shows no-cost or low-cost alternatives to screen media use. On the one hand, they use photographs and text to describe alternatives for playing indoors, such as helping with household chores, feely bag play (see http://makethefirstfivecount.ca/activities/feely-bag-game/), and so on, and on the other hand, possibilities and locations for playing outside, such as picking flowers, playing catch, and so on, are shown. Suitable nearby locations for the outdoor activities such as playgrounds, parks, animal parks and so on are shown on a map. The training also contains ideas and materials for taking up the topics of theatre play for children (described in the Children section) in nursery or school hours after the play. This includes 'finger play' (see https://momlovesbest.com/blog/fingerplay-ideas-for-preschoolers), songs, short poems accompanied by movement, drawing pictures of scenes from the play, re-staging short scenes from the play and other follow-up ideas.

During the training session, all participants receive a MEDIA PROTECT manual containing all the information conveyed in the session and additional written material (for example, theoretical basics, exercises, material and methods for individual counselling) as well as materials from other projects (for example, 'Facing the screen dilemma' by the Campaign for a Commercial-Free Childhood [CCFC]).

Parents

The intervention includes a parents' evening in nursery or school, with a 45-minute MEDIA PROTECT input included in the agenda of a regular parents' evening. This is carried out by the multiplier, who visits the nursery or school. The multiplier gives information and advice on media education and media addiction prevention. The methods used are presentation by the multiplier partly with a PowerPoint presentation, a think pair-share (see www.readingrockets.org/strategies/think-pair-share) discussion based on a handout with a case example from everyday family life, a small mock TV advertising show performed by the multiplier as the TV host and staff or parents as the multiplier's assistants, demonstrations using images (for example, a sailing boat) and finally live objects (such as chocolate vs bread) as metaphors for media education topics.

One week after the parents' evening, all parents receive a letter containing written materials irrespective of whether they attended the event or not. They receive the screen-free leisure map (described earlier). They also get a media guide for parents, which contains information divided into four different age groups, between 0 and 13. For each group, the child's developmental stage with specific needs and vulnerabilities is described and illustrated graphically, a brief case report from a family, as well as four to five bullet points of practical advice for 'stressless media education in the family' are provided. Moreover, the media guide provides information on and explanations for screen media effects in different areas: sensorimotor and speech development, parent–child interaction and bonding, school achievement and learning, obesity, sleep and aggression/

empathy. In addition, the parents receive a telephone voucher for individual counselling by the multiplier on media education.

Interested parents also have the opportunity to visit a technical support evening, which is carried out by the multiplier and lasts for approximately two hours. Parents bring along their children's digital devices to the event and receive hands-on support as well as written step-by-step guidelines for installing and configuring child protection software (filter and time limitation software for devices with different operating systems).

Children

For children, an interactive theatre play is part of the intervention. This involves the children in the audience advocating screen-free leisure activities to a screen-fixated main character. After the play, the children receive a colouring book while teachers conduct a follow-up according to the methods they acquired in their training session (described earlier).

Training of multipliers

To realise the intervention, professionals from either pedagogical or therapeutic fields (for example, teachers, psychotherapists and social education workers) were trained as multipliers. The training consists of three units, each lasting two days (overall 50 hours supervised attendance course), plus self-study assignments from a 400-page manual and three practice phases (around 150 hours in total). Around 200 hours of training are thus performed in the course of a year.

The first training unit covers the following topics: theoretical foundations, history of media education, media effects studies, defining and discussion of separate problem dimensions, basics of public health and prevention science, and risk and protective factors of computer game addiction. Central topics in the second unit are (media) education programmes, marketing and advertising, public perception management by multinational corporations and strategies to counter them, presentation and moderation techniques and opportunities to practise them, as well as the follow-up for the interactive theatre play for the children. The final unit covers parental mediation, family dynamics, systemic counselling techniques, legislation and practice of age-rating systems like the Pan-European Game Information (PEGI), technical skills for using child protection software and considerations as to their limitations. Between the three units extensive assignments for self-study and three practice phases take place. Practice phase 1 is the delivery of the 45-minute parental input by the multiplier to be recorded as an audio file and assessed and reflected together with a personal mentor. Practice phase 2 is the delivery of a mock training course for professionals in the private frame also recorded on audio file with mentor feedback, and in practice phase 3 two novices act as a team to deliver two training sessions at nursery or school under real life conditions. Again, the mentor gives personal feedback to both multipliers.

Practice phases can be repeated if unsuccessful. Individual feedback is also used to reflect on the balance of prevention of digital risks and empowerment to use digital chances in the personal theory of the multipliers, to shift this balance in the desired direction according to the DBL model. Multipliers are required to attend regular refresher courses of two days' duration every two years to keep the certificate they are awarded after successful completion of all training components.

Future changes and adaptations

We conducted a formative evaluation of the MEDIA PROTECT intervention in the same institutions that participated in the controlled trial. Results of the trial have not been published, but the results of the evaluation (*n*=59 nurseries and schools in the intervention group) based on semi-standardised questionnaires and qualitative interviews were predominantly positive. Feedback by the multipliers and parents was slightly more positive than that of the nursery and elementary school teachers (professionals). The multipliers and professionals made a number of suggestions for improving the intervention. Other suggestions can be derived from the parents' feedback and also the reactions of the children to the theatre play. For more details on the results of the formative evaluation, see Stiller et al (2018).

Based on the results of the evaluation, some changes are planned and others have already been performed: for nursery children, for example, a second and simpler play with identical core messages has been developed. More focus will be put on the professionals and their skills both to advise parents on matters of media education and to create a digitally well-balanced environment for the children in their educational setting. The basic qualification requirements of the multipliers have already been raised in accordance with the national health insurance guidelines to ensure the quality of preventive interventions in settings: MEDIA PROTECT multipliers are required to have an academic educational, medical, psychological or digital media-related training background. In the meantime the intervention has been re-named and is now called *ECHT DABEI – gesund groß werden im digitalen Zeitalter* ('REALLY PRESENT – growing up healthy in the digital age').

The DBL model adds a systems and digital risks perspective to current eHealth literacy models. It might prove worthwhile to integrate these additions into the debate on adolescents (cf Bröder et al, 2017) and adults' eHealth literacy. The model could also be applied to the broader context of eHealth at the national or international health systems level as well as on medical professionals' use of digital media. Although the model was developed for children and the settings in which they live, it seems advisable to consider the balance of harm and benefit in a wider understanding of 'harm' than just a failed digitally assisted operation. Data security, the political power of 'dopamine labs', ethical questions related to the use of technology inside the human body and so on not yet explicitly included in the DBL model would have to be additionally considered on the risks and harm side.

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16

Using Photovoice as a participatory approach to promote youth health literacy

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Introduction

Health literacy is critical to empowerment (Kickbusch, 2005) as it entails the knowledge, motivation and competence to access, understand, appraise and apply information to form judgements and make decisions in everyday life (Sørensen et al, 2012; see Chapter 1, this volume). It encapsulates healthcare, disease prevention and health promotion to maintain and promote the quality of life. Health literacy goes beyond the narrow concept of health education and individual behaviour-oriented communication by addressing the environmental, political and social factors that determine health (WHO, 2016; see also Chapters 11 and 14, this volume). Understanding health literacy, in turn, contributes to an in-depth comprehension of health education, aiming to influence individual lifestyle decisions and enhance the awareness of the determinants of health through methods that go beyond campaigns and information sharing (WHO, 2016). Health literacy emphasises social participation (see Chapters 40 and 44, this volume) and critical thinking, leading to enhanced health literacy with personal and social benefits as well as community action that supports the development of social capital (WHO, 2016).

We need a shift in how we perceive, measure and design interventions to incorporate the comprehensive understandings of health, health literacy and social participation across the lifespan. This chapter presents a case study related to the use of Photovoice to promote youth health literacy. The potential challenges and benefits of using Photovoice, along with future recommendations that arose from conducting the case study, are discussed in the following sections.

Background

Health literacy

The concept of health literacy, embedded in modern-day health promotion practices (Stewart et al, 2008), is grounded in the principles of empowerment, human rights, ethics, values and equity, in accordance with the Ottawa Charter for health promotion (Lindström and Eriksson, 2011). In line with the health promotion perspective of enabling people to increase control over and improve their health, health literacy is recognised as being critical to empowered, active and informed participation in health and healthcare (Coulter and Ellins, 2006; Kickbusch and Maag, 2008). The importance of health literacy is well established by numerous researchers as an important public health goal and aspect in modern health promotion practice (Nutbeam, 2008; Mitic and Rootman, 2012).

To date, health literacy has largely been constructed through an individual healthcare lens that emphasises preventive services, skills and competencies needed to effectively navigate through primary healthcare systems (Massey et al, 2012). Current health literacy understandings do not encompass broader concepts of health (Osborne et al, 2013), and fundamental factors of health are insufficiently identified or taken into account (Baker, 2006; Nutbeam, 2008). As such, Nutbeam (2008, p 2077) states that:

> improving health literacy in a population involves more than the transmission of health information, although that remains a fundamental task.… If the goal of promoting greater independence in health decision-making and empowerment among the individuals and communities is to be achieved, there is a need for more sophisticated … efforts to ensure that the content of health communications not only focuses on personal health but also on the social determinants of health.

With this statement, Nutbeam (2008) emphasises the importance of active citizenship and focuses on the broader social determinants of health in current health literacy conceptualisations.

Youth and participation

Youth health literacy policies and initiatives have primarily been viewed using a lens that focuses on adults (Bennett et al, 2003). It is undetermined how health literacy can successfully be applied in interventions targeting youth (Brey et al, 2007; Manganello and Shone, 2013). Moreover, the perspectives of youth on the constituents of health and its influencing factors are relatively unknown (Woodgate and Leach, 2010). Including participatory approaches among youth and recognising their contributions is often the exception rather than the rule, so their strengths and assets in addressing health issues have been insufficiently recognised (Wong et al, 2010). Thus, it is necessary to conduct more research about health literacy regarding youth in order to improve their outcomes.

Citizen participation is an important element in the promotion of health (Rodrigues Coser, 2010), since it acknowledges that individuals, including youth, need to be engaged in the process of designing solutions to their own health problems through meaningful participation, capacity building and development (WHO, 1986; Rootman et al, 2001). Youth participation is defined as 'the democratic practice of young people actively engaging with their social environment' (Wong et al, 2010, p 106), and seen as 'the process of involving young people in knowledge development at the community level' (Checkoway and Richards-Schuster, 2004, p 85). In this participatory view, youth are not merely seen as subjects in health promotion initiatives, but as directors and decision-makers (Rodrigues Coser, 2010) who have a central and meaningful participation in the process (Checkoway and Richards-Schuster, 2004). Applying a participatory approach with youth means that their 'opinions and experiences are valued and recognised in the knowledge creation, by giving them decision-making power through the processes of collaboration, co-learning and capacity-building' (Rodrigues Coser, 2010, p 6).

Collaborative efforts with youth employing strength-based approaches are acknowledged for their potential to engage youth to critically analyse complex health and social issues (Checkoway et al, 2003). As these participatory approaches actively involve youth and build on their intrinsic strengths, issues that they self-identify can be addressed (Wong et al, 2010). Moreover, youth are enabled to recognise and further develop their own assets, become critical thinkers and engage as problem solvers (Cargo et al, 2004). Participatory approaches have been associated with enhanced problem-solving capacities, in which participants learn to critically analyse social problems and become agents for social change themselves (Cargo and Mercer, 2008).

Participatory asset-based approaches in studies, such as youth empowerment, have been emerging in empirical literature over the last few decades (Cargo et al, 2004). Prior to this recognition, children and adolescents were rarely asked to voice their opinions and were often not included in the development of research and programmes designed for them (Wong et al, 2010). Nygreen et al (2006) state that there is a strong need to investigate the particularities of involving youth as collaborators. In order to arrive at a deeper understanding of youth's health issues and their perceptions of health, research employing participatory procedures with youth is advocated (Woodgate and Leach, 2010).

Photovoice as a participatory and empowerment tool

For the last few decades, the Photovoice method has been widely recognised as a participatory action and empowerment tool used to engage underserved youth to increase their critical consciousness (Freire, 1970). Photovoice is referred to as a process in which people can identify, represent and enhance their community through a specific photographic technique that is used as a means for the production of knowledge. Photographic cameras are provided to people, enabling them to be potential catalysts for change as this promotes an effective, participatory means of sharing expertise and needs (Wang and Burris, 1997). People are given the possibility to record and catalyse change in their communities, rather than being the passive subjects of other people's intentions and images. The images produced, and issues addressed and framed, by the participants may stimulate social action, as they 'become advocates for their own and their community's wellbeing' (Wang and Burris, 1997, p 373).

The requirement to engage the youth throughout the participatory action research process is acknowledged in academic literature. As such, Photovoice is not commonly used in isolation and often accompanied with methods supporting and providing reflection on the photos produced (Strack et al, 2004; Necheles et al, 2007; Shea et al, 2013). In doing so, accompanying methods potentially mobilise the process of action and change on issues identified and captured in the participants' photos (Necheles et al, 2007). The importance of the incorporation of an action component in the Photovoice process is highlighted, as action research directly contributes to and facilitates the development of capacities, learning and empowerment (Rice and Franceschini, 2007; Wagemakers, 2010). Participatory action research is about seeing people as assets and partners in research, and holds the promise of empowering people and engaging them in community-level action and change (Koch and Kralik, 2006). The following section presents some of the benefits and challenges of a Photovoice method for youth.

Benefits in using Photovoice with youth

Fostering advocacy and empowerment

Photovoice is recognised as a tool to foster advocacy and empowerment with regard to health issues, through which youth are encouraged to identify and take action on personal and community-level issues (Necheles et al, 2007; Williams et al, 2007; Wilson et al, 2008; Gray et al, 2010; Markus, 2012; Shea et al, 2013). As such, Photovoice is a strengths-based approach, emphasising individual and community assets, and recognises youth as critical thinkers and problem solvers (Wilson et al, 2008; Markus, 2012). Additionally, Photovoice as an empowerment method enables group dialogue and reflection, and elicits deeper thinking that can lead to action (Wilson et al, 2008).

A means for sharing and knowledge exchange

Youth can present their identified issues and understandings to promote knowledge exchange and facilitate community awareness (Strack et al, 2004; Bader et al, 2007; Necheles et al, 2007; Gray et al, 2010; Markus, 2012; Shea et al, 2013). By sharing work that contains a health-related message with peers, family members, friends and other community members, the youth can contribute to a health promotion process that may have an impact on their communities (Gray et al, 2010; Markus, 2012). As such, the photographs can stimulate dialogue between participants and function as catalysts for discussion (Necheles et al, 2007).

Fostering youth's skills

Photovoice builds on youth's capacities and strengths as a means for health promotion activities and increases their confidence in initiating social action (Strack et al, 2004; Necheles et al, 2007; Wilson et al, 2008; Markus, 2012). As such, youth's problem solving, teamwork and leadership skills are promoted, leading to social action, perceived influence over the world and civic participation (Bader et al, 2007; Wilson et al, 2008). Furthermore, youth develop a sense of social morality to become active members in their communities (Strack et al, 2004). Importantly, for this case study, Photovoice can be used to complement skill building and leadership programmes (Necheles et al, 2007).

Youth as an ideal target group

Youth have limited social capital to initiate change and action, and often feel marginalised in a world controlled by adults in which their voices are often unheard and undervalued (Wilson et al, 2008; Shea et al, 2013). Photovoice serves as a mechanism for people with a lack of financial ability, power or social status to engage and advocate for change (Strack et al, 2004; Bader et al, 2007) that allows their voices to be heard, their wisdom and strengths to be integrated in health promotion initiatives and their leadership potential to be acknowledged (Wilson et al, 2008; Markus, 2012). Furthermore, Photovoice is a culturally appropriate method as it engages participants through creative expression, traditionally used in indigenous communities (Gray et al, 2010; Shea et al, 2013).

Highly adaptive method

Photovoice is a flexible participatory method, and can be adapted to the specific needs of the project and target group (Strack et al, 2004; Necheles et al, 2007; Shea et al, 2013). As such, it can be used in a number of contexts, and can accommodate different groups, communities and health-centred topics (Strack et al, 2004; Necheles et al, 2007; Shea et al, 2013).

Appreciation by youth

Youth are highly receptive and enthusiastic with regards to the engagement method of Photovoice (Bader et al, 2007; Necheles et al, 2007). They enjoy the opportunity to express their opinions and share their stories, and thereby feel empowered (Bader et al, 2007).

Challenges with using Photovoice

Time restrictions

A sufficient amount of time needs to be allocated for the photo-taking process, and developing the final product for the Photovoice project (Strack et al, 2004). Time is also required to enable critical dialogue and reflection for resultant learning to occur (Wilson et al, 2008). The number of participants and facilitators influences the time needed (Bader et al, 2007; Necheles et al, 2007), and a fewer number of participants due to time restrictions leads to broad generalisations (Bader et al, 2007; Necheles et al, 2007).

Consistent engagement of youth participants

Getting youth interested in taking pictures, as well as addressing real-life issues and facilitating a group discussion, can be challenging (Strack et al, 2004). As such, some youth will need heavy guidance and structure (Strack et al, 2004). In order to keep youth actively engaged, hands-on activities should be incorporated into each Photovoice session (Strack et al, 2004).

Need for flexibility

The importance of being adaptable in the Photovoice research design is highlighted, in which room for flexibility with respect to the photographs made and also the method of Photovoice is important (Strack et al, 2004; Shea et al, 2013).

Further research needed

In order to substantiate the effectiveness of the Photovoice method when used with youth, further research is needed to determine the efficacy of Photovoice (Wilson et al, 2008; Gray et al, 2010; Markus, 2012). Also, future research is needed to determine the potential of youth initiatives using Photovoice as a method to raise awareness about the social determinants of health (Wilson et al, 2008).

Case study: Moving health literacy upstream

For this case study we proposed a conceptualisation of health literacy that includes a comprehensive understanding of health literacy focusing on: (1) having the skills and capacity to understand that health is not merely physical health, but entails emotional, mental and spiritual health (for example, holistic health); (2) is largely influenced by the everyday circumstances in which people live (for example, determinants of health); as well as (3) understanding the importance of active engagement and participation in the promotion of one's health and wellbeing.

An explorative study using participatory research was conducted based on group interviews, the Circle of Health and Photovoice to induce youth's critical thinking to holistic health principles and to provide them with a means to reflect on their fostered knowledge. The participatory research was carried out by members of Bridge for Health (Bridge for Health, 2014), a local and global co-operative association promoting social innovation in health based in Vancouver, Canada. The youth participants were recruited from the Youth Warrior Program involving participants from two partner organisations: Red Fox Healthy Living Society and Big Brothers of Greater Vancouver. The participants were aged between 16 and 19; primarily newcomer immigrant or refugee youth and Indigenous urban youth.

The Youth Warrior Program supports and empowers youth coming from lower socioeconomic families who face challenges in everyday life. Its main goal is to engage the youth in a participatory approach by supporting them in gaining leadership and life skills. This focus on leadership and life skills stems from the notion that interventions and outcomes focusing solely on prevention have been insufficient for youth to fully prepare for healthy adulthood. Youth need to develop life, academic and vocational skills (Pittman et al, 2003) to cultivate their assets and strengths (Rodrigues Coser, 2010). It is assumed that in order to learn life skills, 'youth need … ongoing support and challenging opportunities to encourage growth, healthy relationships, empathy, critical thinking and leadership skills' (Rodrigues Coser, 2010, p 5). These components are considered essential for promoting healthy behaviour and improving youth's health and wellbeing (Kreipe, 2006).

Participatory research sees community members as active players joining the research team to identify the problem, needed information, preferable methods, procedures to obtain data, analysis of data and desired action (Koch and Kralik, 2006). The use of participatory research fitted the Youth Warrior Program vision of supporting youth to become active community agents for social change. The aim was to induce critical thinking and foster youth's health literacy through the use of Photovoice along with accompanying methods provided in the workshops.

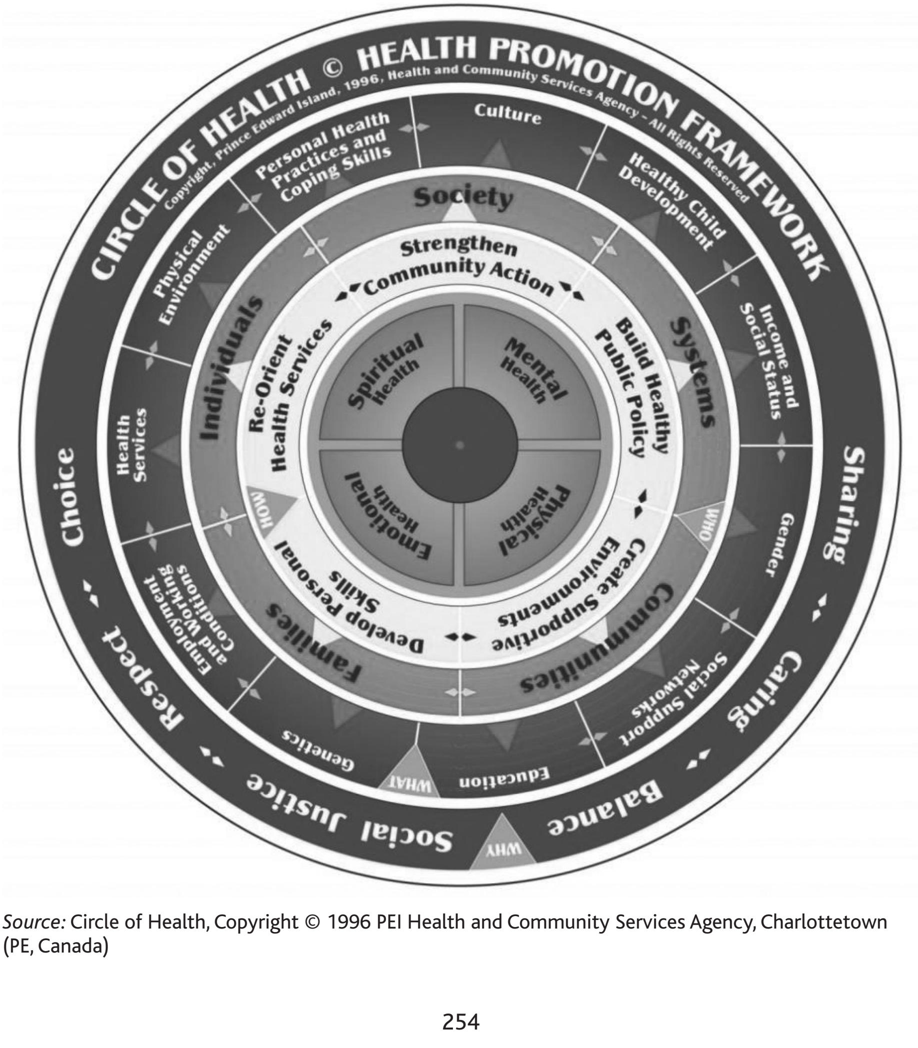
Workshops and group discussion

Nine Youth Warrior workshops with 12 participants were held between October and December 2014. The workshops were two hours in length on weekday evenings. Three of the nine workshops were organised by Bridge for Health and consisted of group discussions using the Circle of Health framework (see below). The remaining six workshops were organised by youth coordinators from two partnering organisations, and focused on the themes of personal health, community engagement and physical activity.

The Circle of Health (see Figure 16.1) was used for the first Youth Warrior workshop and is based on the Ottawa Charter for health promotion (WHO, 1986). It is a dynamic and interactive educational tool that provides a complete picture of health promotion at a glance, including its values and strategies. The circle is used to induce critical thinking towards health and understand how health is influenced by culture, environment, economic status, lifestyle 'choices' and health behaviours (The Quaich Inc, 2009). The centre circle of the tool depicts four domains related to health – physical, mental, emotional and spiritual components – that the researchers referred to as 'holistic health' for the purpose of this case study.

Group discussion using the Circle of Health included questions such as 'What does health mean to you?' and 'What did you do to improve (or affect) your health today?' Also, questions such as 'What does "holistic" health mean to you?' and 'Have you ever considered how your education (income/social support/living and housing situation/community/neighbourhood) influences your health and

Figure 16.1: The Circle of Health



Source: Circle of Health, Copyright © 1996 PEI Health and Community Services Agency, Charlottetown (PE, Canada) wellbeing?' were asked. Additional group discussions formed a central component throughout the Youth Warrior workshops, in which a certain theme or topic was discussed with the youth to elicit critical thinking and dialogue.

Introduction of Photovoice

Following the group discussion in which the terms 'holistic health' and 'social determinants of health' were introduced, Photovoice was explained to the youth. As such, Wang and Burris (1997) state that it is crucial for participants to know what is expected from them, as well as how to use a camera correctly and for the right purpose. Since all youth had access to a camera through their mobile phones, there was no need to provide disposable cameras. Next, the Youth Warrior Photovoice project was explained to them. The youth were invited to 'walk around in your community/neighbourhood and make pictures of things that remind you of health.' In this way, they were provoked to put their fostered knowledge about holistic health and the social determinants of health into practice. The participants had five weeks to make photos, until the end of the Youth Warrior Program. They were allowed to take pictures of anything and take as many as they liked, as long as it depicted their perspective on health and wellbeing. Furthermore, they had to write a short paragraph explaining (1) why they made this/these picture(s) and (2) what the photo says about their perception of health and wellbeing.

Analysis

Content analysis, a flexible method for analysing qualitative data, was used to analyse the data (Cavanagh, 1997; Bowling and Ebrahim, 2005). The method is derived from phenomenology and requires the identification of codes to begin the categorisation of data (Bowling and Ebrahim, 2005). The photos produced by the youth were organised in overarching themes: culture; family/friend; food; physical activity and physical space/nature. Codes were informed by the data produced by the youth and categorised by the researcher. The field notes and written captions supported the categorisation of photos as they clarified the theme of the photos and the link to physical, emotional, mental and/or spiritual health: (1) culture and health; (2) loved ones and health: family/friends/pets; (3) food and health; (4) physical activity and health; and (5) physical space/nature and health.

Results

Eight of the twelve participants shared their photos, and the number of photographs submitted per youth differed, ranging from one photo to ten. The four participants who did not submit photos explained that either they forgot to, had no time or just did not feel the need to do so.

The photos produced by the youth demonstrate how they perceived health after their active involvement in the Youth Warrior Photovoice project. Many of the photos represented the youth's families, loved ones and their cultural heritage; referring to emotional and spiritual health, as well as the social and economic determinants of health. The vital influence of physical settings (for example, playgrounds, recreational parks, streets and alleys) on their physical, mental and emotional health and wellbeing was also evident in many of the photos. Furthermore, the data revealed that youth reported physical activity as related to staying fit, but also to stay mentally and emotionally healthy. Having the ability to clear one's mind, going into nature to 'unwind', was pointed out as very important for one's sense of wellbeing. Furthermore, the presence of healthy food options and grocery shops was perceived as being important for one's physical fitness, emotional health and healthy lifestyle, alluding to the importance of food security as an important social determinant of health. As such, the photos produced by the youth and supported by their written statements represented various aspects of holistic health principles and social determinants of health.

Discussion

Many health literacy interventions that focus exclusively on individuals or specific diseases often fail to acknowledge the core health promotion principles of empowerment, the holistic nature of health, the influence of the determinants of health and the importance of youth participation. This case study developed by Bridge for Health aims to contribute to the broadening of current youth health literacy understandings, taking into account health promotion principles, social determinants of health and a youth engagement approach. The collaboration with community partners provided an opportunity to demonstrate how youth's health literacy can be fostered through a participatory approach, inducing critical consciousness among youth about holistic health and determinants of health. The Circle of Health and group discussions served as a means to start and support the critical thinking process. In turn, the photos produced by the youth functioned as a reflection of their gained knowledge and skills throughout the Youth Warrior Program.

The case study has provided a first step towards identifying Photovoice as an approach to incorporate a 'determinants of health' lens in youth health literacy. In doing so, it applies a holistic and participatory approach towards an 'upstream' conceptualisation of health and health literacy. Active engagement and follow-up of the youth in the research process is required to fully establish the potential of Photovoice as a mechanism to move health literacy upstream.

Limitations

Throughout the implementation of this project it became evident that its impact was limited without ongoing and active youth engagement. Due to time and resource limitations, no action component could be added to the Youth Warrior Photovoice project. The youth's photos did not serve as a needs assessment and no follow-up was taken place on identified issues. A future research project informing about the use of Photovoice with youth should acknowledge the importance of the incorporation of an action component in the method.

Furthermore, a comprehensive youth Photovoice curriculum is lacking, and future research is needed to validate the effectiveness of Photovoice to engage and empower youth, and advocate for change. The importance of action, reflection and in-depth follow-up methods is highlighted in order to substantiate the potential of Photovoice and accompanying methods to foster youth's health literacy and health promotion.

Several recommendations for future research follow from the discussion. First, it seems urgent to develop a youth Photovoice curriculum, depicting the importance of incorporating an action component and follow-up methods to fully empower youth and foster their health literacy. Second, more research is needed to study the effectiveness of participatory approaches such as Photovoice to foster youth health literacy.

Conclusion

The case study shows the potential that the Photovoice method has to serve as an empowerment and advocacy tool (Necheles et al, 2007; Gray et al, 2010; Markus, 2012; Shea et al, 2013). The photos reflected the youth's perception of health after their active engagement in the programme, and served as a means for knowledge exchange with family members, peers and other members of the community. Furthermore, it provided the youth with an opportunity to reflect on strengths and concerns prevalent in their community, and promoted critical thinking towards holistic health principles.

The Youth Warrior Program provided the Bridge for Health literacy project with a valuable case study and helped identify research gaps in current academic literature. Therefore, it exemplified how a participatory approach can be used to promote youth's perceptions towards a holistic and 'upstream' understanding of health. Moreover, future research is needed to (1) employ a youth Photovoice curriculum that validates the importance of the incorporation of an action component, and (2) test the effectiveness of the use of Photovoice to engage and empower youth, specifically, under-served youth populations.

Acknowledgements

We would like to acknowledge that Bridge for Health Cooperative is on the ancestral, unceded and traditional lands of the Coast Salish Peoples. We are very grateful to the staff and youth participants of the Youth Warrior Program, Red Fox Healthy Living Society and Big Brothers of Greater Vancouver who kindly participated and gave their time to make this case study possible. We would also like to thank and recognise the review of manuscript from alumni of Simon Fraser University and Bridge for Health members – Shehlina Arshad, Suman Ayaz and Henrietta Ezegbe.

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17

Mental health literacy for refugee youth: A cultural approach

E. Anne Marshall and Deborah L. Begoray

Introduction

Mental health problems affect one in five youth today, according to several research estimates (Bourget and Chenier, 2007; Jorm et al, 2008; Wile Schwartz, 2009). Effective treatments are available; however, research indicates that less than half of those with a mental health problem access mental health services (Pinto-Foltz et al, 2011; Marcus and Westra, 2012). Of those who seek treatment, scholars link factors such as lack of information, accessibility and mental illness stigma to premature termination (Pinto-Foltz et al, 2011). Thus, as a group, young people have a high rate of unmet mental healthcare needs.

Mental healthcare needs, however, are even more urgent for refugee youth and those who have experienced forced migration. The world is currently facing a global refugee crisis. The United Nations High Commissioner for Refugees (UNHCR) estimates that there are over 16 million refugees worldwide (UNHCR, 2016), and more than half that population is under the age of 18. Researchers have found that traumatic experiences in their home countries, the stress of forced migration and the challenges of relocation are associated with higher rates of mental health problems among refugee youth as compared to non-refugee youth (Colucci et al, 2015). Healthcare and education professionals have been advocating for an increased focus on culturally relevant mental health education and interventions that are specifically tailored for refugee and immigrant youth (Whitley et al, 2013). Moreover, mental health practitioners and researchers have recommended that teachers, counsellors and other adults who work with youth acquire the knowledge and skills to support them to seek help for mental and emotional difficulties (Pinfold et al, 2005).

A frequently cited reason for youth not seeking help for mental health problems is that they lack *mental health literacy* (MHL) – they may not have sufficient knowledge to identify mental health symptoms and/or they may not know how to access mental health support and treatment (Jorm et al, 2008; Marcus and Westra, 2012). For refugee and immigrant youth who may have recent war or other trauma experiences, family losses, language difficulties, resettlement challenges and other stressors, there are often additional barriers to help-seeking, such as discrimination and stigma, problems with treatment access and lack of cultural safety. To improve mental health outcomes for refugee youth, culturally and contextually appropriate strategies and resources to increase MHL are needed. Although the potential negative impacts of forced migration are clear, it is important to note that refugee youth also have significant strengths, resilience, courage and community support – these positive factors can mitigate harmful effects and provide a base for positive growth and adaptation (Tedeschi and Calhoun, 2004).

In this chapter, a cultural approach is suggested as an essential element in programmes and strategies addressing refugee youth MHL. First, we present a snapshot of youth mental health figures. Next, we discuss MHL, youth MHL and MHL for refugee youth. We then present education and training considerations, including the Mental Health First Aid (MHFA) approach, and briefly discuss several successful resources and programmes. The chapter concludes with suggestions and implications for practice and research.

Youth mental health

Approximately 20 per cent of adolescents and young adults aged 15 to 24 in North America and other OECD (Organisation for Economic Co-operation and Development) countries have reported a mental health and/or substance abuse problem (Marcus and Westra, 2012). Depression and anxiety are the most common problems, with girls often reporting higher rates than boys. Conduct disorders, attention deficit hyperactivity disorders, psychoses and substance use disorders are less frequent but on the increase (Chalmers et al, 2014).

Although the incidence of mental health problems among the general youth population is of concern, the incidence among refugee youth is particularly urgent. This situation underscores the need for treatment and prevention programmes and strategies to address mental health and mental illness among refugee youth. A focus on improving MHL for both youth and adults who work with youth represents an important step to achieving this goal.

Schools are the only institutions that touch the lives of all adolescents: 'schools have evolved into community "hubs" offering services and programmes to families within the school community' (Freeman, 2013, p 1). Schools are significant contributors to the acculturation of refugee youth, particularly in mental health areas such as psychosocial and emotional development (Quinlan et al, 2015). School personnel can all contribute to MHL.

Definitions of mental health literacy

MHL is a relatively recent concept, a more specific aspect of the broader notion of health literacy. The first widely accepted definition of MHL – 'mental health literacy comprises the knowledge, beliefs and abilities that enable the recognition, management or prevention of mental health problems' – was proposed by the Australian psychiatrist Anthony Jorm and several colleagues (Jorm et al, 1997, p 183; see also Chapter 4, this volume). A lack of MHL negatively affects understanding, recognition and treatment seeking for mental illnesses. Moreover, the stigma associated with mental illness has been identified as a major barrier to help-seeking (Marcus and Westra, 2012). Jorm et al (2008) argued that improving MHL among professionals and the public should be a key strategy for improving mental health overall.

In a report to the Canadian Alliance on Mental Illness and Mental Health (CAMIMH), Bourget and Chenier (2007, p 4) proposed a broader definition of MHL: 'mental health literacy is the knowledge and skills that enable people to access, understand and apply information for mental health.' This definition puts more emphasis on empowerment, an important concept in health promotion and health literacy. MHL involves more than providing information; it includes support for skill development and empowerment so people can make informed decisions and take effective action to promote positive mental health for themselves and others. Those with high levels of MHL are better able to identify mental health 'strengths and needs in themselves and others, are better equipped and more empowered to seek appropriate supports, and report lower levels of mental health stigma' (Potvin-Boucher and Malone, 2014, p 346). Bourget and Chenier's (2007) approach to MHL guides this chapter and includes an emphasis on the key role of professionals and practitioners.

Youth MHL

Over the past two decades, many countries have sought to improve MHL (see Chapter 24, this volume); few, however, have explored MHL among youth, and even fewer have included refugee youth. In Australia, Reavley and Jorm (2011a, 2011b) conducted a computer-assisted national telephone survey focusing on MHL and stigma with 3,021 young people aged 15–25. Respondents were read one of six case vignettes portraying a young person (named John or Jenny) with depression or another mental disorder. They were then asked questions about MHL (for example, 'What do you think is wrong with John/Jenny?'), stigma, exposure to mental disorders and beliefs about interventions. About 75 per cent recognised depression while about one-third recognised psychosis (for example, schizophrenia) and post-traumatic stress disorder (PTSD). Family members were named as the most likely source of help. Reavley and Jorm concluded that most young people's MHL for recognising signs of depression was good, although it was much lower for other disorders. There was also a tendency to overgeneralise the term *depression* and considerable reluctance to endorse professional help-seeking for mental health problems, indicating that stigma continues to be a limiting factor. The authors recommended more MHL education and media information to promote increased mental health knowledge among youth and to reduce the stigma associated with mental health problems.

In a Canadian study, Marcus and Westra (2012) analysed the responses of 123 young adults aged 18 to 24 who were part of a computer-assisted MHL telephone survey (n=1,004). The survey began with a short vignette of a person (named Robert or Mary) suffering from depression, anxiety or schizophrenia (psychosis). Participants were then asked questions about problem recognition, knowledge about mental illness, possible causes and management or treatment options. Marcus and Westra found no significant difference between younger and older adults in terms of rates of recognition and mental health knowledge, with higher rates of depression recognition (~80%) in contrast to anxiety or schizophrenia (~50%). However, young adults were significantly less in favour of accessing professional care (for example, a family doctor), less likely to view medications as helpful and marginally less likely to believe that psychotherapy could be helpful. These young adults, especially young men, reported more interest in managing mental health problems either on their own or with the support of friends or family. The authors recommended development of MHL interventions aimed at help-seeking behaviours, attitudes about treatment options and 'alternative youth-friendly options for managing mental health problems' (Marcus and Westra, 2012, p 10).

In the US, McCarthy and colleagues (2011) investigated adolescent MHL with a group of high school students (n=36) using vignettes depicting depression and suicidality. Teens were able to differentiate depressed from non-depressed vignettes and could identify (1) common symptoms of depression and (2) sources of help. The authors recommended including adolescents more actively when planning and providing mental health education or treatment services. They suggested additional research with culturally diverse groups since understanding of mental health risks, behaviours and help-seeking is affected by cultural values, beliefs and practices. As discussed in the next section, cultural factors are particularly salient for refugee youth.

Refugee youth MHL

A number of scholars and researchers assert that understanding and addressing mental health needs and MHL among refugee populations requires a cultural approach that recognises the ethnic, familial and national elements that influence how mental health problems and help-seeking are viewed. Colucci et al (2015) investigated facilitators and barriers to mental health service delivery in Australia for youth with refugee backgrounds. Analysis of focus groups and key informant interviews with 115 service providers identified eight key themes: cultural concepts of mental health, illness and treatment; service accessibility; trust; working with interpreters; engaging family and community; style and approach of mental health providers; advocacy; and continuity of care. The authors consulted with refugee young people; all emphasised the importance of obtaining the views and experiences of youth themselves, particularly when designing services and mental health programmes.

Rather than constituting a health crisis within an individual, Thira (2014) maintains that mental health problems should be seen as a *community crisis* with social, political and economic causes that call for a cultural approach. This approach recognises the importance of diverse worldviews and values, family and kinship connections, the role of community, a holistic understanding of wellness that includes religion or spirituality and the intergenerational impacts of forced or asylum-seeking migration (Marshall et al, 2016).

Potvin-Boucher and Malone (2014) suggested three elements to be considered when promoting MHL with refugee youth. First, refugees come from a diverse array of cultures and ethnicities; although there may be commonalities, there are important differences of experience that warrant recognition. With regard to gender, for example, Guruge and Butt (2015) noted that more female than male refugee youth are diagnosed with mental health problems. Tastsoglou et al (2014) suggest that giving refugee women opportunities to share their stories could have a positive impact on societal awareness. There is also a need to address structural barriers that may segregate and devalue female refugees in schools, agencies and community settings (Marshall et al, 2016).

The second element is promoting refugee youth engagement in MHL. This includes fostering an understanding of cultural past and present that acknowledges strengths and overcoming obstacles; this can be a precursor to developing a sense of cultural identity (Potvin-Boucher and Malone, 2014). Cultural approaches emphasise experiential activities, community rituals and intergenerational social gatherings. Teachers, counsellors and mental health professionals can work with community members to help youth integrate traditional and host country ways. Mentoring and leadership activities can build teamwork and healthy relationships that foster a sense of belonging and self-esteem – key aspects of positive mental health. Opportunities to engage in art, singing and storytelling activities help develop skills while facilitating youth's learning of culture and language (Lopes et al, 2012). Schools are often seen as the preferred setting for refugees to access mental health support (see, for example, Kutcher et al, 2016, p 156). School-based health clinics offer a timely and multisectoral approach to healthcare that includes physicians, nurses, substance use counsellors and social workers; these clinics can be co-located with other community resources such as language services and day care to provide refugee youth the best possible chance to develop MHL. Research indicates this coordinated approach is effective (Chiumento et al, 2011).

Facilitating youth empowerment to make healthy choices is the third element to consider. Potvin-Boucher and Malone (2014) maintain that respect is a key aspect for empowerment as well as the expectation that everyone takes responsibility for their actions. Encouraging youth to ask for help from peers and adult allies and viewing this as a sign of strength can address the problem of stigma or shame associated with needing and seeking help for mental health difficulties (Moses, 2010).

The above discussion has underscored the importance of culture, engagement and empowerment as the elements needed to promote and improve MHL among refugee youth. The next section focuses on how to foster MHL among the professionals who support these youth.

Enhancing professionals' mental health literacy

Several principles and practices have been demonstrated to be effective for teachers, counsellors, mental health practitioners and other adult allies who wish to enhance their own MHL to work more effectively with refugee youth (Whitley et al, 2013). These include establishing cultural safety, implementing Mental Health First Aid practices and addressing stigma. In addition, concepts such as *post-traumatic growth* (Tedeschi and Calhoun, 2004) and the use of culturally appropriate mental health resources enhance professionals' own MHL capacity as well as their intervention effectiveness.

Cultural safety

Cultural safety is essential to any discussion of refugee MHL; culturally safe practices recognise and respect the cultural identities of others and safely meet needs, expectations and rights (Brascoupe and Waters, 2009; Josewski, 2012). Although people understand mental health in culturally bound ways, this fact is not always acknowledged in mainstream mental health education and service delivery (Pinto-Foltz et al, 2011). Researchers have identified a number of help-seeking barriers among refugees (Colucci et al, 2015); these include access to services, misunderstandings due to cultural and language differences and the perception of stigma associated with mental illnesses (Chalmers et al, 2014). A lack of cultural safety is one explanation for this reluctance to seek help.

Cultural safety includes both process and outcome aspects (Josewski, 2012). As a *process*, cultural safety provides a critical lens to address the unequal power relations in education and health services delivered to refugee and other minority populations. Professionals need to become aware of how power and privilege operate in their relationships with youth. Furthermore, they need to discuss signs and symptoms of mental illness within a cultural context. Achieving the *outcome* of cultural safety involves adopting culturally sensitive and respectful attitudes and practices as well as making cultural adaptations to health education programmes (Brascoupe and Waters, 2009).

Mental Health First Aid (MHFA) practices

MHFA is based on the familiar practice of providing first aid in physical health situations and is defined as 'the help provided to a person who appears to be developing a mental health problem or in a mental health crisis' (Kitchener and Jorm, 2008, p 55). MHFA training includes the following: attitudes, knowledge and beliefs that help in recognising, managing and preventing mental illnesses; information about specific disorders; knowing how to find mental health information; understanding risk factors and causes; how to promote appropriate help-seeking; and learning about self-help strategies and what professional help is available (Ganshorn and Michaud, 2012).

Originally intended for a broad range of public audiences, specialised versions have subsequently been developed for educators, helping professionals, first responders, youth workers and cultural groups, including refugee adults and youth (Kanowski et al, 2009). Evaluation studies have consistently demonstrated that completion of MHFA training results in positive changes in MHL, knowledge and use of skills and decreases in mental health stigma (Kitchener and Jorm, 2008; Health Canada, 2012).

The action-oriented *first aid* aspect of MHFA is captured in the acronym ALGEE: **A**ssess risk of suicide or harm, **L**isten non-judgmentally, **G**ive reassurance and information, **E**ncourage the person to get appropriate professional help, and **E**ncourage self-help strategies. These five actions can be applied to diverse mental health problems, including depression and anxiety. They also have been adapted for use in schools and community settings (Health Canada, 2012).

Youth Mental Health First Aid (YMHFA) is a variation of the standard MHFA course that is specifically designed to improve the MHL of adult service providers who work with adolescents (Kelly et al, 2011). The YMHFA programme emphasises the importance of early intervention to minimise the impact of mental health problems. Evaluation of a YMHFA programme showed improvements in participants' knowledge, attitudes and helping behaviours (Kelly et al, 2011). An adaptation of the programme was designed specifically for assisting refugee and Indigenous Australians (Kanowski et al, 2009). Historical, cultural and political forces affecting refugee mental health were recognised in the adaptation.

In a recent study by Chalmers et al (2014), a panel of youth mental health professionals reached consensus about culturally appropriate communication strategies for providing YMHFA to refugee adolescents. Several guidelines were recommended: incorporating cultural influences, using culturally appropriate communication, discussing options with youth and handling cultural challenges. Barriers to accessing service were identified, such as language, mobility, discrimination and shame. Empowering refugee adolescents to make informed choices about seeking mental health assistance was a strong theme among this diverse group of practitioners.

Addressing stigma

Myths about mental illness comprise a significant part of MHL (Jorm et al, 2008), leading to stigmatising beliefs and attitudes that result in discrimination. In spite of 50 years of research and recommendations to address the stigma of mental illness, it continues to be a major hurdle in the help-seeking process (Moses, 2010). Therefore, challenging the underlying myths of stigma is a significant component of promoting positive MHL. Professionals need to understand the multiple elements of stigma and to develop strategies to combat cultural and other stereotypes that undermine positive mental health attitudes (Health Canada, 2012).

Post-traumatic growth

Coined by Tedeschi and Calhoun (2004, p 228), *post-traumatic growth* refers to 'the positive change that many people experience as the result of their struggle with highly stressful circumstances.' It is important to differentiate this concept from resilience, which is the ability to 'bounce back' or return to normal levels of functioning following adversity (Tedeschi and Calhoun, 2004). In contrast, post-traumatic growth denotes a transcendent change 'that goes *beyond* an ability to resist and not be damaged by highly stressful circumstances; it involves a movement *beyond* pretrauma levels of adaptation' (2004, p 4). Viewed in this light, significant pain or suffering can lead to a positive and transformational change in functioning. Tedeschi and Calhoun (2004) propose three types of positive change associated with posttraumatic growth: (1) *changes in self-perception* – increased sense of personal strength, a change in priorities and life choices or an increased appreciation for life and one's existence; (2) *interpersonal relationship growth* – an increased sense of closeness in significant relationships or with others who have experienced significant suffering or pain; and (3) *spiritual and existential growth* – developmental changes in spiritual beliefs or existential questions. This concept of post-traumatic growth seems particularly relevant for refugee populations.

Resources to support refugee youth MHL

There is a growing number of interventions and programmes that aim to reduce mental illness stigma and improve MHL among children and adolescents (Pinto-Foltz et al, 2011), including school-based curricula, knowledge-contact initiatives, multimedia tools, online resources and theatrical drama. Several examples are described below; all have cultural components, and a few have been developed specifically for refugee youth.

Visual resources have been used to promote health, MHL and wellness for refugee young people: graphic novels (similar to comic books), DVDs, posters and mobile phone apps. Multimedia and arts-based activities also offer refugee youth opportunities to work with and learn from other refugees and with host country youth (Schwarz and Crenshaw, 2011; Ferrari et al, 2015; Gavigan and Albright, 2015). Canadian research indicates that refugee youth are 'likely to take advantage of such opportunities if they were offered' (Edge et al, 2014). These activities are not only therapeutic for refugee youth (Quinlan et al, 2016); they can also raise self-confidence by increasing social connections with non-refugee peers (MacNevin, 2012). Such activities can also increase connections in the community (Correa-Velez et al, 2010), helping to integrate refugees into broader society. Participating in extracurricular and community activities that are not heavily language-based can help increase self-esteem, prevent social isolation, and build social networks (Stewart, 2014).

In Canada, the Healthy Aboriginal Network (2014) publishes graphic novels that address health and social issues. *Just a Story*, for example, is about mental health stigma; another entitled *Lost Innocence* is about the impact of residential schools. These graphic novels can be used with individual youth in counselling and health service contexts as well as with groups in schools, cultural programmes and community organisations.

Beyondblue (2015) is a national initiative established in Australia in 2000 to address issues associated with depression, anxiety and related disorders. The *beyondblue* four-part message is Understand, Do Something, Help Someone, and Get Involved. The main website provides general information; there is a separate site for young people aged 12 to 25 called *youthbeyondblue* (nd). The user-friendly website offers a 24-hour helpline, online chats, information, apps, downloadable resources, videos and links to people's stories.

The Pan-Canadian Joint Consortium for School Health (nd; see also Morrison and Peterson, 2015) has created a 'Positive mental health toolkit' to promote positive mental health perspectives and practices for youth in school contexts. The intent of the toolkit is to facilitate a process for engaging school and community strengths to support youth mental wellbeing. It is paired with a 'Better practices' document that includes information, activities and resources for all school levels.

An intervention entitled *In our own voice* (NAMI, nd) is designed to improve MHL and reduce stigma (Pinto-Foltz et al, 2011). Administered by NAMI in the US, this one-hour programme uses narrative storytelling, discussion and a video presentation. Initial evaluations of the intervention have demonstrated some improvements in MHL and reduction of stigma among adolescents and young adults (NAMI, nd).

Fostering a climate for learning

Developing a positive, engaging climate for learning is important when considering sensitive and emotion-focused topics such as refugee MHL (Westeman, 2010). In addition to culturally appropriate content, educators need to draw on their knowledge and skills regarding youth communication and learning. Adolescents look to teachers as knowledgeable adults they can trust. Using youth-friendly communication styles and avoiding assumptions can facilitate the discussion of mental health topics. Since youth today spend much of their time online, digital formats are a good way to engage their attention. A few suggestions are highlighted below.

Moses (2010) observed that mental health information and treatment-seeking among adolescents is significantly influenced by the opinions of peers and influential adults. Adolescents often prefer to discuss mental health issues with their peers, but may be reluctant because they anticipate negative responses and stigmatisation (Jorm et al, 2008). Because mental health beliefs and mental health stigma are grounded in social relationships and contexts, it is important to establish a climate of openness and acceptance in the classroom and other learning environments. In recent research with mental health practitioners who worked with refugee youth (Marshall et al, 2016), acceptance, relationship building and trust were universally endorsed as essential for success.

Professionals need to adopt youth-friendly communication approaches when attempting to engage refugee youth. Westeman (2010) outlined an 11-step model of engagement for youth in mental health treatment that has been tested with rural and urban youth. It includes elements such as relationship building, choosing appropriate locations for conversation, sitting side by side with youth, acknowledging non-verbal expressions, being aware of belief systems and having access to a cultural consultant. Westeman acknowledged that particular or local contexts have specific values, expectations and practices; however, her model has universal elements that can be adapted or extended. Although developed for mental health practitioners, teachers can easily implement most of the steps.

Although each person's context is, to some extent, unique, Chalmers et al (2014) found that helping professionals endorsed many of the same communication practices with refugee adolescents as with non-refugee adolescents. These practices include asking where they feel comfortable and safe to talk, taking time to build rapport and trust, being reliable and consistent, listening without interrupting, being genuine, talking calmly, having awareness of body language and offering possible courses of action. Many educators and helpers will possess knowledge and skills that are appropriate and adaptable for refugee youth, particularly if the youth are living in urban environments or away from traditional homelands. Moreover, as Chalmers and colleagues observed, those helping refugee youth should not be so focused on cultural awareness that they lose sight of the often universal emotional needs that are present.

Avoiding assumptions is another key point. Teachers and other professionals should consider the particular challenges that some refugee youth may be facing, such as problems due to discrimination, bullying, multiple deaths or losses among family and friends or anger related to past injustices (Chalmers et al, 2014). At the same time, it is equally important that helpers not *assume* that a young person is facing any or all of these problems. As a research participant in Chalmers et al's study noted: 'It is important to recognise historical factors that may lead to shame but essential that the first aider takes the adolescent on face value without pushing previous trauma upon them' (2014, p 8). It is also important to look for strengths and signs of resilience in youth; this emphasises the positive aspects of MHL in contrast to a problem focus.

Digital formats should be considered as effective media when working with adolescents. Today's youth spend significant time online: US figures suggest nine hours a day (Rideout, 2016). Youth are comfortable online and can easily keep pace with new technologies that enable the revitalisation of traditionally text-heavy materials into something they can access readily. Mental health information and resources can be transformed into digital visual formats such as graphic novels, videos and websites (for example, www.youthbeyondblue.org). The popularity of mobile phone apps, online chat services and e-counselling among youth attest to the importance of using these new technologies in efforts to enhance youth

MHL. Online formats can be more accessible and less threatening for hesitant help-seekers, especially if there are language barriers.

Conclusion

Many refugee adolescents and young adults will continue to forgo beneficial and potentially life-saving mental health treatment unless help-seeking barriers such as access, cultural context, stigma and lack of understanding are effectively addressed. A key strategy is to focus on adopting culturally relevant and culturally safe programmes and practices to improve MHL – among the youth themselves as well as among the professionals working with them. Schools, community youth programmes and youth-serving agencies can offer developmentally appropriate learning and skill-building environments in which the promotion of MHL should be a priority. A central consideration is how to actively engage and empower refugee youth in culturally safe ways. To date, there is little information or evidence published about how teachers and educational programmes can successfully foster MHL among refugee youth; more research and evaluation studies are needed.

As Potvin-Boucher and Malone assert: 'Our youth are our future and our responsibility' (2014, p 344). A cultural approach can foster MHL among refugee youth and supporting adults. In this chapter we noted several promising strategies, programmes and resources; most are readily adaptable to diverse environments, including schools. A culturally relevant and culturally safe approach to MHL will benefit refugee as well as non-refugee youth, and support them along the path of mental wellness.

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18

Media health literacy, eHealth literacy and health behaviour across the lifespan: Current progress and future challenges

Diane Levin-Zamir and Isabella Bertschi

Introduction

Health literacy (HL) is crucial to health as it is associated with a variety of health behaviours and a predictor of many health outcomes (Berkman et al, 2010; Paasche-Orlow and Wolf, 2010; Levin-Zamir et al, 2016). HL is not evenly distributed within the population or across the lifespan. Groups at risk for low HL include people with limited financial resources, members of minority ethnic groups – especially those with a mother tongue other than the local language – people with low educational attainment and older people (Nielsen-Bohlman et al, 2004; Vernon et al, 2007; ABS, 2008; Ng et al, 2014; Sørensen et al, 2015).

In a highly media-saturated and digitalised world, health information is increasingly available and accessed via diverse media. The skills to navigate this environment are strongly linked to HL, and as such are not equally distributed within the population. This chapter presents two constructs – media health literacy (MHL) and eHealth literacy (eHL) – and offers an overview of their associations with health behaviour both across different age groups and among special populations. Interventions to improve MHL and eHL are discussed, and conclusions for further research on health literacy and health behaviour in the digital era drawn.

Media health literacy and eHealth literacy

MHL (Levin-Zamir et al, 2011) is based on the foundations of health literacy and media literacy. The concept builds on the premise that unlike health content and information intentionally generated by the health system, mass media content is often implicit and can be either health promoting or health compromising. Based on the components of the Nutbeam model of HL (Nutbeam, 2000; see also Chapter 14, this volume), MHL is conceptualised as a continuum, ranging from the ability to identify health-related content (explicit and/or implicit) in the media; recognise its influence on health behaviour (comparable to functional HL); critically analyse the content (comparable to critical HL; see Chapter 11, this volume); and express intention to respond through action (personal health behaviour or advocacy) (comparable to interactive HL). Thus, the validated measure of MHL is comprised of these four categories and was shown to be highly correlated with health empowerment. As such, MHL can be considered the precursor to eHL.

The rapidly growing number of digital health offers has led researchers to reflect on the skills necessary for users to effectively navigate the services and health information provided. Consequently, Norman and Skinner (2006b, p 1) coined the term eHL, meaning 'the ability to seek, find, understand, or appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem.' Tasks related to eHL are highly complex, and several barriers to completion exist (Chan and Kaufman, 2011). To date, there is one eHL measurement tool that has been used in different settings throughout the globe: the eHealth Literacy Scale (eHEALS) by Norman and Skinner (2006a). It consists of eight items for which respondents self-rate their ease and skills when navigating the internet for valid health information. The original English scale has been translated into many languages, including Japanese, Korean, German, Italian, Spanish, Greek and Hebrew. Although widely used, its validity has been questioned, mainly due to the lack of correlation between eHEALS scores and actual task performance in online health information seeking (van der Vaart et al, 2011; Quinn et al, 2017), and because it does not sufficiently address critical and interactive health literacy skills (Norman, 2011; van der Vaart and Drossaert, 2017).

eHealth literacy, health information seeking and sociodemographics

The internet is an increasingly important source for health information. People from different age groups, socioeconomic backgrounds and from diverse ethnic groups refer to online sources when seeking information on health topics (Borzekowski, 2009). As early as 2006, 80 per cent of adult American internet users confirmed having browsed the web for health information (Fox, 2006). More recently, similar numbers of online health information seeking have been shown in Eurobarometer data from the 28 member states of the European Union (EU) (European Commission, 2014). Among US college students, the internet even appears to be the single most important source of health information (Rennis et al, 2015). Still, socioeconomic differences in online health information seeking have been reported. Studies showed low rates of online health information seeking among older adults, among people with low educational attainment, in men compared to women, and among adults belonging to minority ethnic groups (Kontos et al, 2014; Nölke et al, 2015; Baumann et al, 2017; Nguyen et al, 2017).

Frequent online health information seeking, the use of sophisticated search strategies and thorough checking of identified health information sources are indicators of high levels of eHL. According to Neter and Brainin (2012), people with high eHL are younger and better educated than people with low eHL scores. These associations are confirmed by data from various samples, for example, financially disadvantaged US families (Knapp et al, 2011) and immigrant communities in Canada (Zibrik et al, 2015). High eHL levels were associated with the use of social media for seeking health information, and with frequent use of electronic devices in general (Tennant et al, 2015). Similarly, eHL scores were high for students actively involved in searching for health information online (Ghaddar et al, 2012). Data also suggest that parental online health information seeking was positively associated with adolescents' eHL and engagement in online searches for health information (Chang et al, 2015).

eHL scores are positively associated with frequency of use of the internet (Choi and Dinitto, 2013; Richtering et al, 2017) or with the number of web searches for health information (Guendelman et al, 2017). This finding is consistent with theoretical considerations underpinning the development of the Integrative Model of eHealth Use (IMeHU). In the IMeHU, individuals with low eHL have lower self-efficacy regarding their Internet searches for health information. Similarly, low eHealth-literate individuals are theorised to have a low health information orientation, reducing their general motivation to seek health information. Both factors lead to reduced online health information-seeking efforts. This in turn means low engagement with online health information sources, and eHL levels remain low (Bodie and Dutta, 2008).

Digital health interventions and health behaviour

When examining the association between eHealth use, MHL and eHL and health behaviour, the importance of mobile apps should be considered. The global trend of mobile applications for promoting health behaviour in illness management, lifestyle modification and navigation of the healthcare system (Santo et al, 2016) deserves attention, as does the increase of health apps that focus on access to medical care and disease-specific apps (Hsu et al, 2016).

An increasing number of intervention studies suggest that digital tools are useful. A meta-analysis (Cushing and Steele, 2010) showed that eHealth interventions have promising results using a behavioural approach. The authors suggest that eHealth interventions make health-related goals more attainable by (1) breaking treatment goals into smaller, more manageable components, (2) automatically assessing success, and (3) modifying previously attained goals in response to programme success. A Cochrane review (Gurol-Urganci et al, 2013) showed moderate evidence regarding the benefits of mobile phone messaging interventions in increasing diabetic patients' self-management capacity, in improving hypertensive patients' rate of medication compliance and in affecting the peak expiratory flow variability for asthma patients. The review showed less evidence for the impact of eHealth on health service utilisation, and no evidence for long-term effects on health outcomes. Yet, a later review concluded that the mobile phone can be a tool to address gaps in access, coverage and equity in low-resource settings. Mobile health (mHealth) interventions showed a positive impact on chronic diseases in low- and middle-income countries (Beratarrechea et al, 2014).

Although digital tools for promoting health behaviour are highly accessible, their use is not consistent among all populations (Kontos et al, 2014). A systematic review of 74 studies suggests that most online health content is not adjusted to user readability levels and is therefore inaccessible (Kim and Xie, 2017). The authors added that even adults with high levels of health literacy sometimes evidenced low levels of self-efficacy, which deters finding reliable online information to inform health behaviours. However, an increasing body of knowledge suggests online sources of health information can be adapted to cultures, language and to groups with a particular status in society (Kreps and Neuhauser, 2010). For example, text-to-speech apps may help people with low health literacy to access important online health information (Kim and Xie, 2017).

The limited number of studies and participants support the need for continued research and a review of evidence on health outcomes and service utilisation. Most of the studies available have also tested technologies among populations with an illness or chronic condition. More studies are needed in order to draw more significant conclusions regarding populations at large.

Media/eHealth literacy and health behaviour across the lifespan

A large proportion of eHL research has focused on associations of eHL with individual variables and health information seeking. Recently, attention has shifted towards the relationship of eHL with health outcomes and health behaviours. The IMeHU (Bodie and Dutta, 2008) states that people with high eHL are inclined to seek health information online, have a good ability in understanding and evaluating the information they find, and use quality information retrieved from online sources to make informed health decisions. Applying IMeHU, studies have shown that the use of health information from the internet can affect dietary habits, physical activity levels and exercising (Dutta-Bergman, 2004; Lee et al, 2015). Although this branch of research is relatively recent, some of the few studies that have been published to date are presented in the following sections.

Childhood

The use of digital tools commences at an increasingly earlier age (Livingstone et al, 2017). Born into a media-rich environment, younger children are continually exposed to the media and digital world through mobile phones, tablets and other digital means, in addition to traditional media sources. Research on eHL in early childhood focuses mainly on young parents of babies and toddlers. Skranes et al (2015) found that Norwegian mothers' self-efficacy could be improved and parental anxiety reduced using a specifically designed website. A meta-analysis of mHealth interventions for maternal, newborn and child health in low- and middle-income countries suggests simple interventions involving SMS messaging can improve rates of breastfeeding (Lee et al, 2016). More recently, eHealth interventions have been applied to tackling the rising rates of obesity in early childhood, particularly as screen time is considered a risk factor for obesity. A meta-analysis (Hammersley et al, 2016) showed very few studies conducted between the ages of birth to five years, and as mentioned, those existing focused on the parents. As early childhood is important for establishing healthy lifestyles later in life, more research needs to be conducted on the association of digital media use and health outcomes. The evidence is even more scarce for associations between eHL/MHL and health behaviour in school-aged children. To our knowledge, no study explicitly investigating these relationships has been published to date, perhaps due to challenges in research implementation. Regarding eHL and MHL research, adolescence is the first developmental period where skill sets can be researched.

Adolescence

Early, middle and late adolescence are the first periods where the individual is considered independent, regarding his/her media use and health behaviour. A wealth of studies has proven the strong association between exposure to media and health behaviours in adolescence on into the transition into adulthood. Specifically, eating habits, substance use and abuse (cigarette smoking and alcohol use), sexual behaviour and violent behaviour have all been clearly correlated with exposure to related content in mass media, including the internet. The concept of MHL (Levin-Zamir et al, 2011) was developed and validated with respect to health behaviour among adolescents. Levels of MHL among 1,516 adolescents aged 13, 15 and 17 were predicted by socioeconomic determinants, including mother's education and family income. MHL was also found to be significantly and positively associated with health behaviours among adolescents: nutrition, physical activity, sexual activity, safety behaviour and substance use. Also, competency in acquiring health information both online – that is, eHL – and offline are related to health behaviour: Chinese adolescents reported a higher intention to perform positive health behaviour when they felt more competent in obtaining health information (Lam and Lam, 2015).

Acknowledging that new channels of intervention need to be developed and applied for health promotion among adolescents, Wharf Higgins and Begoray (2012) developed the concept of critical media health literacy, whose attributes include skill sets, empowerment and competency of engaged citizenship. Regarding eHealth and eHL, Tercyak et al (2009) showed that eHealth interventions were acceptable to adolescents with multiple risk behaviours. Bitzer and colleagues (2016) reviewed tools for measuring eHL among children and adolescents, and are currently developing new measures as part of the Health Literacy in Childhood and Adolescence consortium (HLCA; see Chapter 15, this volume). Future studies that focus both on eHL and health behaviour among adolescents will contribute to the body of knowledge on the association between them.

Early adulthood

Two studies from Taiwan investigated the associations of eHL with health behaviours in nationally representative samples of college students. Hsu et al (2014) examined the interplay of individual factors, eHL and health behaviour. Their data showed that high eHL is associated with good self-reported health status and a high degree of health concern. Additionally, students with high eHL levels showed an increased likelihood of favourable dietary habits, physical activity levels and sleep patterns. Specifically, the domain of critical eHL, referring to skills needed to analyse and apply online health information, predicted positive health behaviour. The authors conclude that in order for online health information to influence one's health behaviour, he/she not only needs to identify it, but also be able to critically appraise it. Yang et al (2017) investigated the association of eHL and positive health-promoting lifestyle behaviours, namely, the psychological health behaviours of self-actualisation, health responsibility, stress management and interpersonal support, as well as exercising and eating a healthy, balanced diet. They found that even when controlling for individual factors such as the degree of health concern, eHL levels remained positively associated with the six areas of positive health behaviour examined. However, the association was evidenced only for levels of critical eHL, stressing the importance of advanced skill sets to deal with online health information.

Adulthood

Data from South Korea suggest that eHL is the strongest predictor of health behaviour when controlling for general characteristics, such as gender, age, education and income. Participants generally agreed with statements indicating that online health information influenced health-related behaviours such as interacting with a healthcare professional or adopting a healthier lifestyle. The authors conclude that eHL can be an important factor in the promotion of individual positive health behaviour (Kim and Son, 2017). Mitsutake and colleagues (2016) examined eHL levels and their associations with health behaviour in a Japanese sample of adult internet users. eHL was significantly related to exercising and eating a healthy diet. However, the associations of eHL with the negative health behaviours of cigarette smoking, alcohol consumption and eating between meals were insignificant.

eHL is also linked to preventive health behaviours. An Israeli study on vaccination decisions of young children's parents (Aharony and Goldman, 2017) analysed characteristics of subgroups of their sample: hesitant parents, especially vaccination refusers, reported a variety of search strategies and sources when looking for health information online. They also demonstrated abilities in evaluating the quality of the information retrieved. The authors conclude that parents who deliberately decided not to vaccinate their children had high levels of self-reported eHL. However, eHL of hesitant and non-hesitant parents did not differ significantly. Thus, it remains to be further investigated how exactly online health information seeking, one's perceived efficacy in evaluating and appraising said information (that is, eHL), attitudes and health behaviour are linked. Two additional studies on the association of eHL levels and preventive health behaviours produced contradictory evidence. While Mitsutake et al (2012) found a slight positive association of eHL levels with colorectal cancer screening practices, Park et al (2014) did not find a significant relationship between eHL and cancer screening tests.

Older people

eHealth, mHealth and other digital tools are often assumed to be relevant mainly for younger populations. However, older adults, especially those with chronic disease, report increasingly widespread use of these tools to positively influence health behaviour and self-management. A test for eHealth literacy has been validated for older adult populations (Chung and Nahm, 2015), although the population used for the validation was not completely representative (higher education and predominantly white, male). The use of the web by older adults for seeking information was studied by Leung et al (2007), noting that older adults who had high eHealth skills still preferred acquiring health information through face-to-face opportunities (Levin-Zamir et al, 2017).

Special populations

In a sample of 63 HIV-infected women from the Bronx, New York, researchers investigated the association of eHL and HIV transmission risk behaviours (Blackstock et al, 2016). In multivariate regression analysis, age and eHL were both positively associated with HIV transmission risk behaviours, even when adjusted for socioeconomic variables and health status. This finding is contrary to other findings reported above, where higher levels of eHL are associated with more positive health behaviours. The authors conclude that caution is warranted when drawing conclusions regarding the associations between eHL and health behaviour due to considerable variability based on the participants' social status and the study design.

eHL and MHL interventions throughout the lifespan

A systematic review on eHL among college students concluded that even a young, well-educated population has major shortcomings in some areas of eHL, and that interventions to improve eHL would not only benefit traditional at-risk groups (Stellefson et al, 2011).

Several findings suggest that eHL levels can be improved through guidance in online health information-seeking activities as well as in structured learning environments. For example, Chang et al (2015) showed that active parental mediation of their adolescent children's internet use was related to adolescents' eHL. Respondents in focus groups of Spanish primary school students reported use of the internet as a tool for learning about health topics and habits, but preferred their searches to be guided and supervised by their parents to promote their efficacy and confidence in dealing with online health content (Hernan-Garcia et al, 2015). Similarly, in a sample of elder Hispanics with type 2 diabetes, participants reported the internet as a useful information source about their condition, but often relied on the help of relatives and friends when assessing the information (Aponte and Nokes, 2017). Similar strategies have been observed for Mexican American breast cancer survivors in the US; managing online health information in their case was always a responsibility they shared with their offline social networks (Sørensen et al, 2009). Results from a nationally representative Israeli survey study indicate that participants with low eHL for whom finding someone (offline) to help them perform and analyse their online health information searches was easy, partly compensated for their lack of eHL through social support (Hayat et al, 2017). Caregivers or significant others' guidance and support are thus vital in the development of abilities relevant to eHL. This is consistent with Nutbeam's (2000) model of health literacy stating that the ability to extract and derive meaning from different forms of communication, referred to as communicative/interactive health literacy, is a key component of health literacy. Thus, not only is general health literacy critical for eHL (Norman and Skinner, 2006b), but also for interactive health literacy.

eHL can further be developed in structured learning environments. A systematic review on eHL intervention studies for older adults (Watkins and Xie, 2014) showed that eHL interventions were scarce, that only few of the available studies applied high-quality research design, and that many interventions were not theory-based. Still, some studies present promising results for eHL interventions. For example, Hernandez-Rabanal et al (2017) showed that even after a single training session on how to identify reliable health-related information and resources online, upper secondary school students showed a significant increase in self-reported eHL. An intervention to improve eHL of adolescents composed of three online training lessons administered during computer classes yielded significant, though marginal, improvements of eHL levels of the participating students. High involvement in intervention was one of the strongest predictors of changes in eHL, stressing the need to make eHL personally relevant to participants (Paek and Hove, 2012). A programme consisting of four two-hour sessions aimed at helping older adults perform online health information searches yielded significant improvements of eHL. Participants also reported changes in health-related attitudes and behaviours following participation (Xie, 2011a, b, c).

Designing eHL/MHL interventions for different target groups

Regarding eHL/MHL intervention, one size usually does *not* fit all. Expert consensus on methods to promote eHL in older adults emphasise the importance of identifying the target population's needs (Manafò and Wong, 2013). Focus groups with socioeconomically disadvantaged people from different ethnic groups living in the southwestern US showed that many participants avoided health information from '.edu' or '.gov' web pages due to perceived complexity and lack of trust in the government for health information (Mackert et al, 2009). Yet, an Australian sample with a high proportion of college graduates stressed their trust in government endorsement as a means to assess the quality of online health information (Kasparian et al, 2017). Trust in traditional authorities such as the government or academia should be taken into consideration when designing eHL interventions for specific populations.

Considering the target group is also highly critical when designing eHealth or mHealth tools intended to promote health-related behaviours. Coughlin et al (2016) emphasise the importance of the cultural tailoring of mHealth applications for weight control by considering the cultural dieting habits of the target population. Not only the content, but also presentation to the users matters greatly when designing eHealth tools (Meppelink et al, 2015). Finally, digital health interventions should be considered in context. In the case of diabetes literacy, a project that included eight European countries, Israel, Taiwan and the US, examined the effectiveness of a variety of self-management interventions for people with diabetes, the relative effectiveness of individual counselling, group intervention, self-help groups and eHealth tools. All interventions were proven effective in the countries' contexts, including eHealth interventions, the main recommendation being that interventions must be accessible and available to all (Saha et al, 2017).

Ethical challenges

Ethical considerations must be exercised when researching and implementing interventions related to eHealth, MHL and eHL. Data safety and privacy issues are currently among the most important topics related to ethics. Consumers or patients need to be sure their data are safe and protected by the developers of the tools they engage with (Fernandez-Luque and Staccini, 2016). Kluge (2016) emphasised the need for a code of ethics, particularly for health information professionals.

As highlighted above, accessibility and comprehensibility of health information are major concerns. In the interests of equity, it is critical to ensure access to understandable and applicable health information to all populations, guaranteeing that no one is excluded and/or offering parallel and complementary avenues of access. Underserved populations, although they may have access to the internet, often show limited eHL (Connolly and Crosby, 2014). These groups may be under-represented in online eHealth and health behaviour research. For example, Cho et al (2014), authors of an important study examining the relationship between eHL, health app use efficacy, health consciousness and health information orientation, acknowledge that the sample included a high proportion of people with college degrees, and a more representative sample would be needed to draw more generalised conclusions.

Frequent criticism directed at digital health offers is that the aim is to save manpower and to lower costs, and that they mainly benefit the healthcare industry but not the patients. Schneider et al (2013, p 1) assert that the purpose of internet-based health tools 'is not to take over the roles of healthcare providers; on the contrary, [they] should reinforce the alliance between healthcare providers and patients' as they allow patients and consumers to take on a more active role. Whether the tools in question will eventually succeed in empowering their users needs to be carefully assessed.

Conclusion

Evidence from theoretical and empirical work has highlighted the importance of traditional and digital media, especially internet-based tools, in relation to health literacy and health behaviour. The concepts of MHL and eHL as skill sets to obtain and apply health information from the media and online sources have been discussed in detail, and their associations with health behaviour across the lifespan presented. Electronic health offers have promising potential to support health information seeking and health behaviour change in many populations. Yet accessibility and comprehensibility might not be guaranteed for all social groups. Careful consideration of the inclusivity and target group specificity of such offers is therefore needed. In general, the field will benefit from further research as the evidence to date is limited.

Future directions

Due to rapid developments in the digital world, eHealth research is delicate and time-sensitive. For example, the above-mentioned and frequently cited conceptual model of eHL was questioned by its first author Cameron Norman (2011) five years after it was published. During this period, social media and Web 2.0 tools and environments were developed, making the original conceptualisation of eHL partly outdated. As is recognised in research on emerging technologies, it is highly probable that the technology or service in question becomes outdated by the time a theoretically and methodologically sound study to assess it is conceptualised, conducted and analysed, let alone its findings published (Baker et al, 2014). Research concerning MHL and eHL therefore needs to carefully consider whether the instruments and methodology used are able to reflect the current state of technology. Finally, future research is necessary regarding the extent to which digital and media tools can be considered a panacea for solving HL and health promotion challenges. The importance of continued research and reviews cannot be overstated due to the significant investment in innovative tools and their sweeping uptake by health systems globally.

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19

School-based mental health literacy interventions

Kathryn Cairns and Alyssia Rossetto

Introduction

Mental disorders such as anxiety and depression often emerge for the first time during adolescence and early adulthood, with about three-quarters of mental disorders having their first onset before the age of 25 (Kessler et al, 2005). Evidence suggests that incidence rates for depressive disorders increase in early adolescence, with prevalence continuing to rise throughout adolescence (Lewinsohn et al, 1998; Lewinsohn and Essau, 2002; Costello et al, 2003). Age of onset for anxiety varies by disorder, with specific phobia, separation anxiety disorder, social phobia and obsessive compulsive disorder (OCD) most likely to onset during the adolescent years (Kessler et al, 2007, 2009). The experience of mild levels of depressive and anxiety symptoms that do not meet the threshold for diagnosis, but can nevertheless cause significant psychological distress, is also common during adolescence (Hankin, 2006).

This is concerning because of the potential for mental health difficulties that onset at this time to set up developmental cascades of vulnerability, which may extend well into adulthood (Masten and Cicchetti, 2010). Adolescence is a time of prominent transitions, and this developmental stage heralds significant physical, cognitive, psychological, interpersonal and socio-contextual changes (Weir et al, 2012). Depressive or anxiety disorders may interfere with the young person's capacity to effectively navigate these transitions and complete key developmental milestones (Kessler and Wang, 2009). A failure to detect and treat these conditions in a timely manner can lead to numerous adverse life course consequences (Kessler et al, 2001; Merikangas et al, 2010), which presents a strong moral and economic argument for intervention early in life. One approach that holds promise for this developmental period involves interventions that target students' *mental health literacy* (MHL). In this chapter, we introduce and discuss the key interventions approaches to promoting MHL that have been adopted within the school setting, and provide a synthesis of the supporting evidence for these varied approaches.

Adolescents' mental health literacy

The term MHL refers to '… knowledge and beliefs about mental disorders which aid their recognition, management or prevention' (Jorm et al, 1997, p 182). The construct encompasses:

> (a) knowledge of how to prevent mental disorders, (b) recognition of when a disorder is developing, (c) knowledge of help-seeking options and treatments available, (d) knowledge of effective self-help strategies for milder problems, and (e) first aid skills to support others who are developing a mental disorder or are in a mental health crisis. (Jorm, 2012, p 231; see also Chapter 4, this volume)

Young people are consistently found to have poorer MHL relative to adults (Jorm et al, 2007; Reavley and Jorm, 2011; Yap et al, 2013). Areas of deficiency in adolescents' MHL include: correct recognition of mental disorders, particularly anxiety disorders (Reavley and Jorm, 2011); knowledge of effective prevention strategies (Yap et al, 2012); and knowledge of, and willingness to seek, professional help for mental health problems for themselves (Yap et al, 2013) or others (Yap et al, 2012). Adolescents perceive many barriers to accessing professional help (Yap et al, 2013), which can increase the time between first onset of the problem and receipt of treatment, resulting in poorer prognoses and longer recovery times (Scott et al, 1992; Perkins et al, 2005). Around a quarter of adolescents indicate that they would seek help for mental health problems from their peers (Reavley and Jorm, 2011); however, adolescents may not have the capacity or capability to appropriately manage these types of disclosures. For example, they are more reluctant than adults to recommend seeking professional help or to inquire about suicidal thoughts (Jorm et al, 2007). A substantial minority of adolescents endorse the use of mental health first aid actions that are perceived as unhelpful or actively harmful by professionals, such as using alcohol to cope with problems (Yap et al, 2012). This is especially concerning given that adolescents' beliefs about the helpfulness of particular mental health first aid actions predict their subsequent helping behaviour (Yap and Jorm, 2012). Improving the MHL of young people may increase their uptake of self-help behaviours that protect against mental ill health, and facilitate early and appropriate responses to emerging mental health problems in both the individual and those in their social network (Jorm, 2012).

Role of schools in promoting mental health literacy

Growing evidence supports the influential role of schools in promoting adolescent health and wellbeing. Schools provide access to the majority of young people from diverse socioeconomic backgrounds, most of whom spend the better part of their day at school. Further, schools have an educational mission and a pre-established infrastructure to support the development of emotional and social learning (Spence and Shortt, 2007; Jorm, 2012). In this chapter, we describe key approaches that have been adopted to promote the MHL of adolescents in the school setting, providing examples from across the spectrum of intervention, and a synthesis of the supporting evidence for these programmes. Table 19.1 maps the components of MHL (following Jorm, 2012) that have been targeted in school-based interventions to the corresponding parts of the spectrum.

Mental health promotion programmes

Mental health promotion includes whole-of-population interventions that aim to '… enhance individuals' ability to achieve developmentally appropriate tasks (competence) and a positive sense of self-esteem, mastery, well-being, and social inclusion, and strengthen their ability to cope with adversity' (O'Connell et al, 2009, p 66). These interventions focus on creating supportive environments within schools, and promoting acquisition of the social and emotional competencies that are prerequisites for positive mental health. In so doing, they also contribute to the reduction of risk for mental health problems. School-based mental health promotion can direct MHL interventions towards students, teachers, parents and the wider school community.

An example of this type of intervention is MindMatters, which has been rolled out within a large number of Australian secondary schools since the late 1990s (Wyn et al, 2000). MindMatters is described as an organising framework for various mental health activities and interventions, and adopts a whole-school approach that is aligned to the *health-promoting schools model* (Nutbeam, 1992). Key intervention components include: professional development for classroom teachers; whole-school planning workshops for leaders and school health teams; and provision of educational resources. This includes curriculum support materials to enable teachers to improve, among other things, the MHL of their students; the

Table 19.1: Promoting mental health literacy across the spectrum of mental health interventions

Facet of mental health literacy (Jorm, 2012)	Relevant segment/s of the spectrum of mental health intervention (O'Connell et al, 2009)
Knowledge of how to prevent mental disorders	Mental health promotion Prevention
Recognition of when a disorder is developing	Early intervention
Knowledge of help-seeking options and treatments available	Early intervention
Knowledge of effective self-help strategies for milder problems	Prevention Early intervention
First aid skills to support others who are developing a mental disorder or are in a mental health crisis	Early intervention

'Understanding Mental Illness' module covers the definition, aetiology, prevalence, symptomatology and treatment of five mental illnesses, and also discusses stigma in an effort to engender attitudinal change (Hazell et al, 2002).

Prevention programmes

Prevention interventions occur before the onset of a clinically diagnosable disorder, and aim to reduce the number of new cases of the disorder (Mrazek and Haggerty, 1994). Mrazek and Haggerty (1994) describe three types of prevention: *universal*, designed to prevent the occurrence of mental illness in the whole classroom or school regardless of individual risk; *selective*, targeting students whose risk for developing mental disorders is above average due to the presence of known risk factors; and *indicated*, targeting those displaying early or subclinical levels of symptoms. Preventive interventions aim to improve MHL by equipping young people with the knowledge and skills to reduce the likelihood that mental disorders develop in the first instance, or to employ effective self-help strategies when milder levels of symptoms first manifest. MHL surveys suggest young people are receptive to the idea of preventive action for mental health problems, and endorse a range of potentially helpful strategies, however their understanding of both helpful and harmful strategies can be enhanced (Jorm et al, 2010; Yap et al, 2012).

The HeadStrong programme is a universal prevention programme designed to improve participating students' MHL, personal stigma and help-seeking (Perry et al, 2014). This programme delivers lesson plans and associated resources aligned to the Australian curriculum to high school students in their Personal Development, Health and Physical Education (PDHPE) classes. The HeadStrong programme comprises five modules (equivalent to 10 hours of class time) that provide basic education about mental health and ill health, how young people can help themselves and others who are experiencing mental health difficulties, and how they can take action to promote mental health within their local community. The programme was designed with the implementation setting in mind; in providing ready-to-use, curriculum-mapped classroom activities and resources, HeadStrong modules reduce teachers' preparation time and fulfil schools' curriculum requirements (Werner-Seidler et al, 2016).

Early intervention programmes

MHL approaches with a focus on early intervention aim to increase the likelihood that adolescents access evidence-based treatments when needed, by improving knowledge, attitudes and behaviours in relation to help-seeking and mental health first aid. Adolescents are reluctant to seek professional help for their mental health problems: they often report that they did not know their symptoms were serious enough to warrant formal help-seeking, and indicate a preference or belief that they should be able to address the problem on their own (Gulliver et al, 2010).

This reticence is problematic, as appropriate help-seeking can reduce the duration and extent of impairment associated with depressive symptoms, and help to prevent associated problems such as the development of comorbid conditions (Wilson et al, 2007).

An example of a school-based early intervention programme that targets MHL is the teen Mental Health First Aid (tMHFA) programme (Hart et al, 2016). tMHFA seeks to develop participants' knowledge and skills in: recognising when a peer is developing a mental health problem; knowing how to speak with a peer about their mental health; when to involve a responsible adult; where and how to find appropriate resources on mental health, mental illness and professional help; and how to address crisis situations, such as when a peer is thinking about suicide. tMHFA is taught in three classroom-based sessions, each of 75 minutes' duration, led by an instructor with experience and training in youth mental health. tMHFA uses a multimedia presentation, videos, group discussions and small group activities to engage students, and includes a manual for students to work from during the class which they can keep as a resource. The programme uses a five-point action plan (Look for warning signs, Ask how they are, Listen up, Help them connect with an adult, Your friendship is important) to assist participants to recall its key messages.

Evidence synthesis

In the last two decades, research focusing on school-based mental health interventions has proliferated. A recent review of reviews identified 12 systematic reviews focused on mental health promotion, prevention or early intervention for mental health problems within the school setting, many of which included intervention components designed to improve participants' MHL (Das et al, 2016). However, only a small subset of the interventions included in this review explicitly measured MHL, which is expected to mediate the relationship between the intervention and changes in behaviour and, subsequently, mental health outcomes. Here, we review the extant evidence to address three key questions:

1. Are school-based interventions effective in increasing MHL (knowledge and attitudes about mental disorders)?
2. Do changes in knowledge and attitudes subsequently lead to changes in behaviour (for example, help-seeking, mental health first aid)?
3. Do changes observed in MHL or behaviour lead to subsequent improvements in mental health?

Impact of school-based interventions on knowledge and attitudes

MHL programmes with an early intervention focus commonly include measures of knowledge and attitudes as primary outcomes. In their review of MHL interventions implemented in schools, Wei et al (2013) identified 15 studies that included an assessment of knowledge acquisition. Of these, 12 reported a significant improvement in knowledge attributed to the intervention, although the effect sizes were highly variable. They also identified 16 studies set in secondary schools, of which 11 demonstrated reduced stigmatising attitudes following exposure to the intervention. A recent randomised controlled trial (RCT) of a curriculum-based MHL intervention (The Curriculum Guide) found that knowledge improvements predicted a corresponding improvement in attitudes toward mental illness, suggesting that these two outcomes are interrelated (Milin et al, 2016).

There is a paucity of evidence to allow for an assessment of the longevity of observed changes in knowledge and attitudes. In the review by Wei et al (2013), only 20 per cent of interventions assessing knowledge acquisition, and 38 per cent of those assessing stigmatising attitudes, included follow-up assessments beyond post-test. Some studies have demonstrated enduring improvements in MHL at two- and three-month follow-up (Pinto-Foltz et al, 2011; Mcluckie et al, 2014; Ojio et al, 2015), although another found that gains in MHL scores did not persist at six-month follow-up (Pinfold et al, 2003). Longer follow-up times may also be needed to better assess the longevity of a programme's effects on knowledge and attitudes. To this end, a RCT of the tMHFA programme, incorporating a one-year follow-up of student participants, concluded in 2017 (Hart et al, 2018). Additionally, given the relative brevity of most interventions (typically only a few sessions, of up to one hour's duration; see Wei et al, 2013), and the finding that knowledge gains may weaken over time (Perry et al, 2014), booster sessions may be required to support the internalisation of key programme messages, and provide regular opportunities for students to enact the skills they are taught.

While many promotion and prevention interventions promote MHL by building students' understanding of factors that can prevent the onset of mental health difficulties, their evaluations often neglect to explicitly assess the acquisition of this knowledge, focusing instead on the symptoms that are expected to improve as a consequence. This is problematic given the implicit meditational model that underpins these interventions; that is, by increasing students' knowledge of how to prevent mental disorders they will be more likely to change their behaviour in accordance with this knowledge, thereby leading to a reduction in symptoms indicative of an emerging mental health problem. Future evaluations should include measures of knowledge acquisition to enable mediation analyses that can point to the 'active ingredients' of effective MHL interventions with a preventive focus.

Impact of school-based interventions on behaviours

Considerable evidence suggests that knowledge and attitudes do not reliably translate into behaviour change (Armitage and Conner, 2000). It is therefore pertinent to explore to what extent the knowledge and attitude gains observed in school-based MHL trials translate into corresponding desired behaviours, particularly help-seeking, provision of mental health first aid, and preventive or self-help behaviours. However, the evidence in this area is sparse.

Wei et al's review (2013) identified three studies that measured self-reported help-seeking at the conclusion of the intervention. The evidence across these studies was mixed, and varied by source of help (for example, psychiatrist, teacher, friend). No study assessed help-seeking behaviours beyond post-test, and none used validated measures of help-seeking. Although another study found that a brief, teacher-delivered MHL intervention significantly improved reported intentions to seek help for themselves and to support peers with mental health problems at both post-test and three-month follow-up (Ojio et al, 2015); again, validated measures were not used. In the HeadStrong evaluation, no significant differences emerged in students' attitudes towards seeking help from mental health services by intervention condition (Perry et al, 2014). A pilot evaluation of tMHFA attempted to evaluate the quality of students' mental health first aid responses towards a peer (Hart et al, 2016). Although too few responses were recorded at three-month follow-up to detect statistically significant differences, trend information suggested that most students who had provided first aid believed that their actions had been helpful, and that information from the tMHFA programme positively influenced the action taken.

School-based prevention and promotion interventions typically target behaviours that flow from improved MHL, such as preventive or self-help behaviours. However, these trials often omit an examination of these behaviours, which complicates an understanding of the causal mechanisms by which interventions exert their influence. For example, interventions seeking to decrease internalising symptoms by changing students' problem-solving orientation should explicitly measure both symptoms and the application of the problem-solving skills taught. For example, the Penn Resilience Program aims to promote a more optimistic explanatory style, which is protective against the development of internalising disorders. However, a review by Bastounis et al (2016) found no evidence for the impact of the programme on this variable, nor on depression and anxiety outcomes, thus helping to elucidate the null effect pathway to internalising outcomes.

Impact of school-based interventions on mental health outcomes

Many promotion and prevention trials have included internalising symptoms or disorders as primary outcome measures. However, in the absence of measures of MHL, it is not possible to attribute changes in these outcomes to the health literacy components of these interventions over other potential change mechanisms. Only the HeadStrong RCT has included measures of both MHL and internalising symptoms. The authors used the Depression Anxiety and Stress Scales as a measure of psychological distress, and selected items from the Moods and Feelings Questionnaire to measure suicidal ideation, but found no significant associations between the intervention condition and these outcomes at either post-test or six-month follow-up (Perry et al, 2014). Further research that explicitly measures adolescent participants' knowledge of how to prevent mental disorders and effective self-help strategies for mild levels of symptoms, as well as corresponding behaviours and mental health outcomes, is warranted.

Promising approaches

This synthesis indicates several intervention approaches and components that may hold promise. We summarise these intervention features here, to guide researchers and schools in prioritising MHL interventions.

School-based MHL programmes have been delivered by both endogenous (for example, teachers; see Perry et al, 2014; Milin et al, 2016) and non-endogenous (for example, mental health professionals or consumers; see Pinto-Foltz et al, 2011; Hart et al, 2016) providers. Significant, positive effects have been demonstrated in studies using both kinds of providers. Endogenous providers allow MHL programmes to be easily and inexpensively delivered at scale within existing educational systems, and may also improve teachers' MHL (Kutcher et al, 2016). However, within the context of prevention interventions focused on the acquisition of complex skills and behaviours in lieu of knowledge and/or attitude change, non-endogenous providers are mostly found to be superior (Hetrick et al, 2015; Brunwasser and Gillham, 2016). A conservative approach would be to establish the effectiveness of MHL programmes delivered by teachers in engendering desired changes in behaviour and mental health outcomes before ruling out the use of non-endogenous providers.

The provision of explicit, practical guidelines to guide schools in implementing programmes, for example, in the form of manuals and professional development programmes, are associated with superior outcomes and support programme fidelity (Weare and Nind, 2011; Milin et al, 2016). Evidence also suggests MHL programmes that take a holistic school approach, focusing simultaneously on different layers of the school ecology and individual students' skills and behaviours, are more effective than more narrowly focused interventions (Weare and Nind, 2011); however, these are more challenging to implement, and schools require specific and actionable guidance to successfully implement whole-school approaches (Rowling and Hazell, 2014).

Many interventions adopt a lecture-style presentation, where the teacher or another presenter delivers health education to students to improve their MHL. Some interventions have also incorporated group discussion, posters, role playing, drama, games and internet searching (Wei et al, 2013). In the tMHFA pilot trial, students' feedback indicated they were less receptive to programmes adopting didactic teaching methods. They expressed a strong preference for approaches that required them to interact more with the instructor and other students, and provided more opportunities to practise the skills taught in the programme. Greene and Hecht (2013) suggest that adolescents be encouraged to actively engage with health messages by weighing or choosing alternatives, envisaging the future consequences of different decisions, and hypothesising about the relationship between different behaviours and their outcomes. They argue that this approach respects adolescents' growing desire for autonomy, and increases the probability that adolescents will process the information at a deep level. It may thus be advantageous to minimise didactic methods and emphasise experiential learning methods to support the acquisition, retention and application of MHL.

MHL programmes that adopt a curriculum-based approach are readily incorporated into school life, and can directly support schools with their core business of achievement, which may improve uptake and sustainability. Several promotion and universal prevention trials have adopted this approach, to positive effect. Although there is evidence regarding the acceptability of these approaches, more rigorous research is needed to provide evidence of their long-term effectiveness in improving MHL and associated mental health outcomes (Wei et al, 2013).

Interventions that involve social contact and first-person narratives have been widely perceived as effective in improving MHL and reducing stigma (Yamaguchi et al, 2011). In particular, video-based interventions that employ these features may be attractive to schools, because they involve minimal staff training and preparation time, and to researchers because of the assurance of programme fidelity. A recent systematic review (Janoušková et al, 2017) found that video-based interventions incorporating first-person narratives can improve knowledge about the aetiology of mental illness and attitudes towards people with mental illness, possible treatments and help-seeking at post-test and, occasionally, short-term follow-up. However, another systematic review did not support the proposition that contact reduces stigma in the medium to long term (Mehta et al, 2015). Further research is needed to establish the value-add of these interventions over other approaches.

Finally, programmes that leverage technology also hold promise, although they have not been a significant focus of school-based MHL programmes to date. Merry et al (2015) note that interventions delivered through computers, tablets and mobile phones potentially afford advantages over traditional implementation methods as they require less staff time and expertise, ensure programme fidelity, offer greater flexibility in delivery, and, if well designed, can support student interest and engagement in the subject matter.

Summary and future directions

MHL supports young people to attain positive mental health and wellbeing, and to facilitate timely access to appropriate help when mental health problems occur. The extant evidence suggests that there is much to be optimistic about regarding the potential impact of school-based MHL programmes. As the evidence connecting mental health status and academic outcomes accumulates, schools are increasingly accepting of the role that they play in developing the MHL of their communities. A variety of novel approaches from across the spectrum of mental health intervention have been trialled, of which many have effected demonstrable change in the knowledge and attitudinal domains of MHL.

However, this overview of the evidence for school-based MHL programmes reveals that this is a field in its infancy. Heterogeneity in study methodology and intervention design, a lack of long-term follow-up data and insufficient attention to behaviour change and mental health outcomes associated with intervention exposure limit the conclusions that can be drawn regarding the effectiveness of these programmes. Replication of positive outcomes is the exception rather than the norm (Brunwasser and Garber, 2015), and insufficient attention has been paid to the variance in the implementation of these programmes that occurs once they are transported into the real-world setting of schools.

There is much work to be done before widespread dissemination of these programmes can be justified. Further research must elucidate what the active and essential ingredients of interventions are that lead to change in adolescents' MHL, associated behaviours, and mental health outcomes, and what adaptations can be made by schools to suit their local environments without compromising effectiveness. Researchers must increasingly become pragmatists, and consider how they can leverage the opportunities afforded by the school as a setting for promotion, prevention and early intervention, while providing sufficient flexibility in their programmes to accommodate the challenges that schools face in promoting a mental health and wellbeing agenda. As noted by Patton et al (2000, p 592), '… understanding the context in which [school-based mental health] innovations will take place is crucial in ensuring that the processes that are used to initiate, sustain and institutionalise practices are relevant, feasible and effective.'

Involving school personnel as providers of programmes arguably represents the most sustainable and scalable approach to rolling out MHL programmes. While this approach is effective in producing short-term gains in knowledge and attitudes, its long-term impact on behaviour and mental health outcomes has not been established. Working in partnership with schools to design interventions is likely to support the acceptability, uptake and sustainability of these programmes, which may, in turn, help to bridge the observed efficacy-effectiveness gap (Fazel et al, 2014).

Methodological limitations and logistical challenges notwithstanding, school-based MHL programmes appear to represent a promising approach to reducing the burden of affective disorders, and promoting positive mental health at a population level. We hope this overview may inspire future research and practice within this important field, and prompt consideration of MHL within the broader health literacy agenda.

Acknowledgements

We gratefully acknowledge Tony Jorm for his editorial assistance in preparing this chapter.

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20

Health literacy interventions for children or adolescents: An overview and insights into practical applications

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Introduction

Three of the most recently published academic literature reviews focusing on health literacy among children and adolescents agree that we don't know enough about health literacy among children and adolescents (Perry, 2014; Okan et al, 2015, 2018; Bröder et al, 2017). While the appeal of 'more research is needed' is overly common among academic publications, in this case, it seems entirely justified.

Given the dearth of formal research on health literacy in youth and adolescents, in this chapter we first identify effective strategies for youth and adolescents in the context of a single health issue, overweight and obesity. Then, we focus on findings that are compatible with the evidence-based best practices and conceptual models of health literacy. Our overarching goal is to expand the knowledge base about testable approaches that align with health literacy and have evidence of effectiveness and feasibility among youth and adolescents.

In 2012 we completed a literature review on childhood obesity interventions. Many of the best practices that review identified are aligned with the best practices of health literacy, whether that was explicit or not in the original article. Articles in that review included 14 randomised or cohort interventions, 5 cross-sectional and 1 longitudinal assessment, along with 12 literature reviews. Reviewer reliability was evaluated on 10 per cent of the total articles, with a 99 per cent reliability rate.

Based largely on that review, we offer a brief discussion of programme design and evaluation considerations relevant to overweight and obese youth and adolescents. Thus, this chapter does not focus on summarising and reporting universal truths about the role and structure of health literacy in children and adolescents. Instead, we summarise potential best practices and lessons learned from our own practical application of health literacy programmes that were designed for children and their families.

Approaches to health literacy programmes for youth: the role for parents and adults

One primary issue in designing and conducting interventions with a focus on children and adolescents is what role their extended family (especially parents/caregivers) should play in any effort to improve health and wellbeing. Many interventions focus on the youth alone; many more are designed only for adults. We found only a minority of interventions engaged both children and their caregivers at the same time in an intervention.

Our review found programmes targeting childhood obesity were predominantly school-based and interacted primarily with children (Blom-Hoffman et al, 2008; Bellows et al, 2010). We did find one review comparing parent-only versus parent-child and child-only programmes that found programmes involving only parents were the most effective for children's weight management (Branscum and Sharma, 2011).

Further, whether the adult(s) are primarily interested in addressing their own health concerns or solely concerned about the children's health is a consideration that emerged from the literature review and our experience. In general, our review concluded that if adult family members are included in the effort, messages about parental health should be integrated into the intervention without deviating too far from the central messages about children's health. One review article observed that while the focus on parents/caregivers in interventions is usually on their influence over children, children's behaviour changes can affect parental behaviour as well (Dalton and Kitzmann, 2008). While results for parent biometric outcomes in child-targeted programmes are mixed, parents may benefit from involvement even though the primary focus is on children's health and behaviour changes (Davis et al, 2003; Rodearmel et al, 2007; Cronk et al, 2011).

We are confident that bringing a focus of health literacy to programmes tailored for youth and adolescents (whether or not they include adult parents and caregivers) will be effective. Studies of parents' perceptions of their children's health and their own abilities to help their children make changes found that parents are concerned about their children's health issues but can be misinformed about risk factors or burdened by their own low self-efficacy and social barriers (Garrett-Wright, 2011; Glassman et al, 2011). While only one of these studies explicitly addressed health literacy, any analysis of parental perceptions of health in effect describes their health literacy regarding their own children's realities, futures and needs (Garrett-Wright, 2011).

Specific design elements when addressing health literacy among youth

Overall, we suggest that younger children constitute a promising population for promoting sustainable lifestyle change, because younger age provides more time and opportunity for prevention, early intervention and establishing healthy patterns and norms. Because children of different ages process and respond to lifestyle change efforts differently, it may be advisable to restrict the age range of participants' children to within five years of one another, or even less, so that materials and parenting strategies can be most effectively tailored to youth in a similar stage of the life course with similar cognitive levels.

Further, following a best practice of health literacy, we suggest programme designers build in a process to help participants tailor small, personalised goals per child or family. This approach has proven effective and well received in other studies, and does not demand extensive resources (Dreimane et al, 2007; Rodearmel et al, 2007). We also recommend that programme design focuses on messages that are encouraging rather than critiquing.

When determining what will indicate success of an effort targeting the health and wellbeing of children and adolescents, we suggest working with participants to define and tailor realistic and health-promoting goals. Especially with children and adolescents, when physical, mental, behavioural and spiritual health indicators are experiencing nearly constant change due simply to normal growth, placing too much emphasis on – for example – weight loss or decrease in BMI (body mass index) could create unhealthy and unwarranted outcomes including stigma. Focusing equally on qualitative improvements in healthy behaviours, perceptions and levels of self-efficacy could help programmes and participants to successfully define and reach meaningful and sustainable goals (American Dietetic Association, 2006; Wickins-Drazilova and Williams, 2011).

We have discussed extensively elsewhere the important potential of combining the best practices of health literacy with an integrative approach to health (mind, body, spirit, emotion) in order to help participants of health programmes improve their health and prevent chronic disease. Another best practice of health literacy, as we have already recommended, is to engage participants early and often in the programme design and implementation. When that early and deep engagement is combined with a truly integrative approach to health, it is unavoidable that the programme begins addressing a person's whole life and the determinants of health that person or family is facing. As a result, the intervention and goal setting inherently shifts toward prevention rather than treatment of poor health.

When we turned our attention to the design and use of materials (for example, handouts) we often found that materials taken home by children to families were mixed or moderate in effectiveness. Thus, we do not strongly recommend sending materials home as a common practice, as take-home material can present barriers regarding relevance and time commitment outside of the classroom environment (O'Connor et al, 2009). When this practice is part of a programme design, we strongly recommend the materials be practical, easy-to-use, fun and relevant.

We also see merit in engaging the entire family in practical, collaborative and cooperative goal-setting activities that may serve to encourage opportunities for children to assist parents in cooking or shopping and to promote outreach, social engagement and self-reflection among the entire family. Activities like those in studies that involve family and community traditions and stories are excellent examples of invoking a sense of purpose in ways that are meaningful and fun for children (Davis et al, 2003; Cronk et al, 2011; Savoye et al, 2011). There is evidence that searching for and achieving a sense of purpose during adolescence is a developmental asset; however, that search may create stress and have a negative impact on self-esteem (Blattner et al, 2013).

Our review of the literature on childhood and adolescent overweight and obesity interventions identified effective elements that should be, and often are, grounded in the best practices of health literacy. These practices include promotion of small changes and the setting of personalised, manageable goals; acknowledging and addressing perceived barriers; the reduction of sedentary behaviours in addition to (that is, as distinct from) increased physical activity; the integration of social engagement; healthy adaptation of traditional recipes as a way of invoking sense of purpose; and at least some, if not all, adult-only sessions to help the children/adolescents lead healthier lives (Davis et al, 2003; Rodearmel et al, 2007; Tyler and Horner, 2008; Epstein and Wrotniak, 2010; Glassman et al, 2011; Savoye et al, 2011).

Another critically important area for consideration when designing health literacy programmes for children and adolescents is mental health literacy. A recent systematic review of research on attitudes toward mental health found that mental health literacy was the most common focus of research, followed by stigma (Angermeyer, 2017). For example, a study in Australia of people aged between 15 and 25 found that:

> patterns of stigmatising attitudes differed according to disorder, with notable differences between psychosis/schizophrenia and social phobia. Anti-stigma interventions should focus on individual disorders rather than on "mental illness" in general and may need to address beliefs about unpredictability, social phobia as due to weakness of character and dangerousness in those with more severe disorders. Interventions should also focus on bringing beliefs about public perceptions in line with personal beliefs, as the latter are much less stigmatising. (Reavley and Jorm, 2011, p 1033)

Such findings are not only found in Australia, but also in the US, Canada, and other nations. Canadian researchers found that young male adults expressed a preference to manage problems on their own, and indicated they were more likely to seek out informal sources of help (Marcus and Westra, 2012). Among youth, the relationships between mental health literacy, stigma, care-seeking and perceptions of others who may have mental health challenges is clearly an area worthy of further exploration (Burns and Rapee, 2016).

Approaches to programme evaluation

While many programmes reviewed did not include substantial evaluation, we suggest complete and thorough evaluation of programmes as a best practice. Some programmes, for example, limited participant burden by omitting requirements for keeping personal wellness journals or participating in evaluations; this can come at the cost of tracking progress, identifying effects of the intervention and learning to improve programme design and effectiveness (Epstein and Wrotniak, 2010; Hollar, 2011; Savoye et al, 2011).

While participant burden is a valid concern, there is evidence that the very act of self-monitoring and/or being enrolled in a study contributes to healthy gains (Ruiz et al, 2011). No health literacy intervention should overburden participants, but designers should also not underestimate the motivation of participants, which will already be evidenced to an extent by their willingness to enrol in the programme. An evaluation plan described from the outset may be very beneficial to the sustainability and adaptability of efforts to help children and adolescents – not to mention the parents and caregivers – live healthier and happier lives through increased health literacy.

To our awareness, financial cost and benefit analyses are absent from nearly all health literacy studies. A strong awareness of costs and benefits is critical both for programme efficiency and future planning. Costs – and paybacks through improved health status – are a central concern for funders, and could provide an entry point for public interest and support. The topic of cost analyses should include the long-term economic savings potentially gained by improving health literacy which, in turn, should improve objective health status. For children, the potential for cost savings through improved health literacy and health is a long-term possibility. We highly recommend the evaluation of all health literacy interventions incorporate the necessary indicators of both objective health markers as well as financial costs and benefits.

An additional contextualising factor for health literacy interventions is research that associates children and adolescent health with school performance. At least one review concluded that student engagement and school performance are higher in students with better overall health status (Basch, 2011). Again, the long-term potential benefits from such gains resulting from improved health literacy begs for further analysis in health literacy programme evaluation for children and adolescents.

Examples of youth and adolescent health literacy interventions

We now turn our focus to providing a brief description of three programmes grounded in the best practices of health literacy that address youth and adolescents. All three are explicitly based on the theoretical construct of health literacy described in the Calgary Charter on health literacy (Coleman et al, 2009):

> Health literacy allows the public and personnel working in all health-related contexts to find, understand, evaluate, communicate, and use information. Health literacy is the use of a wide range of skills that improve the ability of people to act on information in order to

> live healthier lives. These skills include reading, writing, listening, speaking, numeracy, and critical analysis, as well as communication and interaction skills. (Coleman et al, 2009, p 1; see also Pleasant, 2011, 2013a, b)

Healthy Community Program

We designed the Healthy Community Program to target youth and their parents together. Fundamentally, the philosophical basis is that children who grow up in safe and supportive families and neighbourhoods, free from abuse, neglect and other negative influences, are more likely to live healthier and more productive lives.

The Healthy Community Program is an integrative health community-based intervention based on the best practices of health literacy that aims to improve health outcomes for youth and their families. We piloted this programme in partnership with a middle school serving a predominantly Hispanic/Latino population living in an under-served, low-income neighbourhood on the south side of Tucson, AZ in the US.

The initial pilot included a pre/post evaluation of participants. The Program initially consisted of four sessions held on consecutive Saturday mornings for four hours. Participants rotated through interactive sessions focused on:

- exercise/body movement
- stress management
- healthy cooking
- gardening.

Participants were recruited through a partnership with a local medical practice, a nearby federally qualified community health centre and the school. A total of 82 adults and youth experienced the initial pilot. On average, people attended three of the four sessions. Adults were a mix of parents, grandparents and other caregivers; youth were aged between 6 and 14. Eighty per cent of participants reported being Hispanic/Latino, reflecting the surrounding community. Program sessions were held in English. See Table 20.1 for selected outcomes.

For youth participants – who also said their favourite aspects of the Program were the cooking, gardening and exercise sessions – other reported outcomes from participating included eating fruit and vegetables more often, helping prepare dinner at home more often and eating snacks in front of the television less often.

What we learned from this experience of developing and piloting the Healthy Community Program was significant. We have redesigned the Program based on this initial experience so that it is now six sessions versus the original four, we added goal setting/sense of purpose discussion sessions, and modified and expanded our training of core team members who facilitate the Program. We are continuing our efforts to identify dose and response relationships from varying the intensity and scope (and thus the cost) of health literacy interventions.

Table 20.1: Selected outcomes for adults and youth in the Healthy Community Program

Selected outcomes reported by adults	Selected outcomes reported by youth
• One adult lost 35 pounds	• Blood pressure 8.8/4.3 points lower
• Lower blood pressure	• 1.5 less unhealthy days per month
• Blood glucose 40.3 points lower on average	• See their family and themselves as happier
• PHQ-9 depression scores 21.2% lower	• See their family and themselves as healthier
• Stress 25.9% lower	• 63.8% increase in frequency of exercise
• 12.5% increase in health knowledge	• Increased ability to identify the food groups
• 22% increase in health literacy	• 75% decrease in watching TV/playing video games (ie, screen time)
• Increase of two self-reported mentally/physically healthy days per month	• Decrease in the number of times their family eats at drive-thru restaurants
• Increase in the amount of exercise for 28.6% of adult participants	• Increase in eating meals with their entire family
• Eating as a family 2.8 more times per week	• Decrease in soda consumption
• Decrease in running out of food in the household	• Increase in water consumption

Life Enhancement Program for families and for teens

Another intervention we designed for youth and adolescents is an adaption of our Life Enhancement Program (LEP) that has been successfully offered to adults for the past decade. We adapted the LEP in two different ways: (1) the LEP for families was designed to include children aged between 5 to 10; and (2) the LEP for teens was designed to address youth aged 13 to 18. In practice, we recommend that partners offering the LEP, based on our formative research findings, recruit participants for each group in tighter age ranges, for example, 5-7 or 8-10. However, the reality of family dynamics necessarily must balance with that recommendation.

During the initial pilots, we deliberately included parents and caregivers along with the youth, but in both versions some sessions were explicitly designed so that the youth and parents would be separated. For example, a session on human sexuality in the teen version of the LEP is conducted with teens alone, in parallel with another for the parents/caregivers alone. Then, the two groups come together for a moderated discussion.

The LEP for teens focuses on improving health literacy across a range of topics, including integrative health, sense of purpose, nutrition, oral health, physical activity, stress management, healthy relationships and dating, and healthy home and community. Social support is emphasised, and some sessions are 'hands-on' – such as cooking, grocery shopping and exercise.

The LEP for families aims to help adult and youth participants make a lasting and personal connection to a life of disease prevention and optimal wellness. It is designed to help individuals and families to:

- embrace a starting point and outline a change process to improve their own health and wellbeing;

- share their histories and discuss lifestyle habits;
- make a personal connection to their health and wellness.

As with the core LEP methodology, the LEP for teens and for families are tailored to each community and individual so that the messages resonate in a culturally competent and health-literate manner. That tailoring is based on formative research conducted in each community before a programme is launched.

Development of the LEP for families began with the earlier discussed review of existing research. Key findings were incorporated into the LEP for families curriculum. For a programme to be successful in improving the health and wellness of families' lives, it should strongly consider:

- including parents, guardians and other caregivers as change agents;
- including lessons and practice on parenting skills and creating a supportive family environment;
- a focus on health, wellness and fun – not weight loss;
- including a robust mix of group practice and support, plus individual counselling;
- avoiding over-reliance on traditional take-home education through inclusion of significant in-person activities for participants;
- promoting health literacy through integrative methods.

Focus groups and key informant interviews were conducted with community members, health centre professional staff, youth education experts and youth aged 5-9 in Tucson, AZ. We also obtained input from a Curriculum Advisory Group of experts in health literacy, integrative health, public health, family theory, parenting, youth and family nutrition, youth and family fitness, youth and family wellness, youth and adult education and youth mindfulness. Key recommendations included:

- ensure the cultural appropriateness of the programme's curricular materials, implementation professionals and location;
- ensure the credibility and motivational abilities of speakers/session facilitators;
- capitalise on the influence that children have on their parents/guardians, not just the other way around;
- develop both youth and adult capacity for personal and community advocacy;
- focus on behaviour changes via 'small steps';
- celebrate small successes with participants;
- employ the best practices of health literacy in materials design and programme implementation;
- ensure that families are provided meals or snacks, as appropriate;
- help individuals and families set achievable short-term and long-term goals;
- consider barriers to participation, such as parents/guardian work schedules, youth school and extracurricular schedules, family transportation and childcare needs.

We conducted a very similar process to create the LEP for teens. Key outcomes of that effort included an expansion of the core elements of the LEP with new sessions on healthy relationships and dating and workforce development. The LEP for teens includes:

- integrative health
- behaviour change
- sense of purpose
- social support
- nutrition
- stress management
- physical activity
- oral health
- healthy home and society
- healthy relationships and dating
- workforce development.

Overall, the LEP for families consists of 14 group sessions and 6 one-hour-long one-on-one consultations with participants. The team that provides the LEP consists of specialists in integrative health (a paediatrician), behaviour change, nutrition, fitness, spirituality, sense of purpose, pharmacology and child development.

Overall, the LEP for teens consists of 16 group sessions and 6 one-hour long one-on-one consultations with participants. The team includes experts in teen development, integrative health (a paediatrician), behaviour change, nutrition, fitness, spirituality, sense of purpose, pharmacology and oral health.

Highlights of what we learned from the initial pilots of the LEP for families include the following:

- Children teach parents. Parents teach children. Engaging both magnifies the effects of a complex social intervention like the LEP for families.
- Parents and children find support from one another to enhance their healthy lifestyle changes. This social connection encourages sustainable, positive behaviour changes.
- Children can learn about and use complex ideas of health, nutrition, exercise and sense of purpose.
- Families at risk may need referral to additional treatments or therapies before, during or after joining a group programme focusing on prevention of poor health.
- A best practice is to recruit and group families by the age and development of their children, as families with similar-aged children saw increased social bonding.

What we learned from a small initial pilot of the LEP for teens was that at this stage of development we now disagree with our initial decision to include both parents/

caregivers and teens in the programme simultaneously. We do see advantages in parents/caregivers experiencing the original LEP designed for adults – but not to go through the experience along with their teens. The relationships between teens and parent/caregiver are often tenuous, and for the teens to improve their own health and wellbeing they need to be able to be entirely candid in their participation. We do believe parents should remain aware of and actively support their teens' participation in the programme; future efforts will devise a smaller series of parallel sessions for parents to ensure that support and engagement.

Further, while we traditionally only offered the LEP for adults in partnership with a healthcare provider organisation of some sort – for example, a hospital system or a federally qualified healthcare centre – patient protection and privacy restrictions in the US make it challenging to recruit both teens and their adult parents/caregivers from patient populations. For example, healthcare organisations may provide specialised care for teens (for example, a 'teen clinic') from which teens can receive care without their parent's knowledge or permission. Recruiting from that population would potentially reveal that relationship to parents and, in the initial pilot, avoiding that possibility certainly hampered our recruitment of participants. Thus, in the future we look to offer the programme in a way that incorporates healthcare professionals on the core team providing the programme, but without the direct participation of a healthcare organisation. Instead, we can look to schools or other community-based organisations to offer the programme.

The sample size from this initial pilot is too small to conduct analysis of statistical significance. Overall, however, the participants in the initial pilot did experience health gains. See Table 20.2 for selected outcomes.

Theater for Health

Our Theater for Health programme was not specifically designed only for youth or adolescents. This is a community-wide intervention using theatre as the means to improve health literacy and to create informed decision-making and healthy behaviour change.

The Theater for Health methodology integrates practices from the *Theatre of the oppressed* family of methods with the best practices of health literacy. The *Theatre of the oppressed* was largely developed by practitioner Augusto Boal (Boal, 1985) who based his work on Paulo Freire's (1970) *Pedagogy of the oppressed*. The *Theatre of the oppressed* family of methods aims to empower communities to develop their own truths based on their lived experiences and interactions (Boal, 1985; Freire, 1970).

Distinct from the *Theatre of the oppressed*, in Theater for Health there is a defined role for evidence-based information to be introduced into the dialogue between the performance and the community. However, the power to reshape the narrative remains within the community as is appropriate, and effective, from health literacy, *Theatre of the oppressed*, and Freirean perspectives. Participating community members are engaged in devising and modifying the narrative as

Table 20.2: Selected outcomes reported by adult and youth participating in the LEP for teens

Selected outcome for adult participants	Selected outcomes for teen participants
85.7% gain in healthy days per month (mentally and physically)	33.3% increase in self-reported health status
92.9% decrease in days health limits usual activities per month	100% (to zero) days when health limits them from conducting their usual activities
75% gain in self-reported health status	100% improvement in sleep
87.5% increase in exercise self-efficacy	100% decrease in feeling scared or nervous
100% increase in family eating meals together	60% improvement in self-reported mental health
66.7% decrease in fried food consumption	100% increase in playing/exercise per day
60% decrease in soda consumption	50% increase in frequency brushing teeth
100% increase in using nutrition facts label	75% decrease in eating fried foods
200% increase in using ingredient lists	100% increase in eating fruit
66.7% increase in eating breakfast	100% increase in helping prepare meals with family
300% increase in drinking water	300% decrease in eating snacks in front of TV
6% increase in health literacy	200% increase in fruit being available at home
43.8% increase in self-reported health knowledge	75% decrease in eating at restaurants with a drive-thru window
116.7% increase in civic engagement	50% decrease in frequency feeling sad or depressed
27.6% increase in time on treadmill with increasing resistance	400% increase in number of books read in the past month

'spect-actors,' but in Theater for Health they do so from a more fully informed position than in *Theatre of the oppressed* methodologies (Pleasant et al, 2014).

The first pilot of Theater for Health was held in a small community in the surrounding hills of Lima, Peru, and consisted of 12 episodes structured and performed as a telenovela (drama or soap opera) over 11 weeks. Overall, the strategies used to encourage participation were street parades, printed materials, mototaxi/megaphone announcements, community-based radio announcements, community meetings, bring-a-neighbour and get a reward incentive, direct incentives to attendees, empowerment workshops, arts workshops, knowledge contests, games and a talent show. The overall attendance at the performances went well beyond initial expectations, as average attendance across episodes was 172 adults and 59 children. The youth played a key role, as it turned out, in our recruiting methods.

For example, the street parade consisted of actors, musicians, jugglers and clowns marching through the community (a shantytown) in order to draw attention and attract an audience. Invariably, it was the youth of the community who would hear the commotion and begin to follow and participate in the parade. Parents and caregivers would follow.

The methodology of Theater for Health explicitly embraces audience participation. Community members expressed interest in having a talent show. Therefore, we wrote a talent show into the ongoing narrative of the theatrical performances – which was entirely community members performing and demonstrating their artistic talents. Youth played a great role in the performances – attracting their friends and extended family members to come and watch our theatrical performances as well.

What we urge readers to take from this very brief discussion of the Theater for Health programme is that it would be inappropriate to consider youth as agents with little or no power. A youth's participation has the ability to induce participation of parents and caregivers. In fact, we have found in all our health literacy programming for youth that they can be very powerful actors in a family dynamic.

Conclusion

We began this chapter by asserting that not enough is known about health literacy interventions for youth and adolescents. We maintain that position. We need more evidence-based and rigorous research to advance our understanding of how to improve health literacy among youth and the short- and long-term implications of those interventions (see Table 20.3). Ideally, we urge researchers to design and conduct long-term longitudinal cohort studies with intervention and comparison groups.

We also urge inclusion of health literacy in educational curricula in schools and development of a standardised approach to testing so we can track the development of health literacy across the development phases of youth. Interventions like the ones described above are also needed, but to expose youth to health literacy early

Table 20.3: Key points for consideration when building health literacy interventions for youth and adolescents

- More rigorous research is needed
- Give careful consideration to who is included in the intervention – youth alone, adults alone focusing on the youth, or adults and youth together
- Help participants actively engage in personalising their own health and health literacy goals
- Encourage, don't criticise. Don't focus on the negative outcomes of low health literacy. Do focus on what people can do with the health literacy skills they have. Avoid creating stigma
- Focus on the whole person, not just the conditions of any health conditions they may have
- When sending informational materials – in any form – home with youth, focus on making them practical, easy-to-use, fun and relevant
- Rigorously evaluate your efforts. Try to establish a long-term methodology (at least one year, ideally longer) to determine the sustainability of any changes

and often through formal education would be a powerful approach to education and development in our opinion.

To reach those goals, funders need to prioritise complexity, not only short-term studies and brief interventions. A truly longitudinal study of youth would take decades, not the normal three- to four-year funding period that seems to dominate research. Further, we encourage researchers and practitioners to prioritise collaboration. Collaborate with other researchers and practitioners. Collaborate with funders. Collaborate with community-based organisations, and most of all, collaborate with your participants. Empower youth through their direct engagement with your health literacy work – the rewards will last a lifetime.

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21

Health literacy interventions in the delivery of pharmaceutical care

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Introduction

Medication is the most common intervention to prevent, treat and manage disease and illness. However, its usage has inherent risks and unintentional misuse can lead to increased morbidity, mortality and associated healthcare costs. Patients frequently experience difficulty correctly interpreting medical information and prescription drug label instructions; older patients, patients taking multiple medications and patients with limited health literacy are at a relatively greater risk for experiencing these difficulties and subsequently making medication errors. Multiple factors, such as unnecessarily complex and variable instructions, may contribute to patients' misunderstanding of labels. The US Institute of Medicine (IOM) has highlighted the variability in the way clinicians write prescriptions and pharmacists transcribe clinicians' instructions, an issue that has been reported by many studies (IOM, 2004), which can lead to confusion for the patient. Pharmacists are the healthcare professionals who will dispense prescriptions for medication, and as such, have a unique opportunity to advise the patient on any queries relating to their medication and to counsel on appropriate use.

This chapter has several objectives, as follows:

1. To examine the core competencies of the pharmacist as they have evolved over the last number of decades.
2. To define and contextualise the term 'pharmaceutical care', in relation to patients and their medicines.
3. To discuss the importance of medication adherence as a modifiable barrier to improve health outcomes.
4. To examine the older adult as a specific demographic in Ireland due to their multimorbidity and polypharmacy.
5. To discuss the impact of health literacy on health outcomes and medication adherence.
6. To discuss the role of the pharmacist in improving medication adherence.
7. To look at the wider implications for other vulnerable groups with a specific example of those with schizophrenia.

Core competencies of the pharmacist

The role of the pharmacist is continuously evolving. The traditional role was that of compounder of medicines, with pharmacists spending much of their time hidden in the dispensary, devoid of meaningful interaction with their patients. However, the current pharmacist is primarily concerned with the safe, effective and appropriate use of medication and the provision of enhanced pharmacy services, including smoking cessation, influenza and herpes zoster vaccinations, blood pressure, cholesterol and diabetes monitoring and emergency contraception, all of which necessitate patient–pharmacist interactions. In Ireland, the pharmacy regulator, the Pharmaceutical Society of Ireland (PSI), is charged with regulating the profession. The PSI is responsible for defining and ensuring the standards of education and training for pharmacists qualifying in Ireland. This includes developing standards, policies and carrying out accreditation of pharmacy degree programmes. The PSI also ensures that registered pharmacists undertake appropriate continuing professional development (CPD). One of the most important documents relating to the profession is the Core Competency Framework (CCF) (PSI, 2013).

What is the Core Competency Framework?

Competencies refer to the knowledge, skills, attitudes and behaviours that an individual develops through education, training and work experience. When combined, these competencies form a competency framework. In Ireland, this framework for pharmacists is based on a global competency framework, drafted by the Pharmacy Education Taskforce (PET). This provides a blueprint for describing the competencies and behaviours of pharmacists in their daily practice, and is divided into six domains of practice: professional practice, public health, supply of medicines, safe and rational use of medicines, organisation and management skills, and personal skills. It also identifies a number of competencies expected of a pharmacist within each domain and provides a number of behavioural statements for each competency, to demonstrate how individuals who possess that competency will behave in practice. For example, in the domain of professional practice, an associated competency reads that the pharmacist 'practises "patient-centred" care', with an associated behavioural statement, 'acts as a patient advocate to ensure that patient safety is not jeopardised' (PSI, 2013). The CCF permits pharmacists to reflect on their practice and identify learning needs for CPD, provides a platform for the development of specialisation and advanced practice within pharmacy and provides a public statement of the professional role of the pharmacist.

Pharmaceutical care

Pharmaceutical care is the responsible provision of drug therapy for the purpose of achieving definite outcomes that improve a patient's quality of life (Hepler and

Strand, 1989). These outcomes are: curing a disease, elimination or reduction of a patient's symptoms, arresting or slowing disease progression or preventing a disease or symptoms. Pharmaceutical care involves the process through which a pharmacist interacts with a patient and other healthcare professionals in designing, implementing and monitoring a therapeutic plan that will produce specific therapeutic outcomes. This process involves identifying, resolving and preventing potential and actual drug-related problems.

In the US the American Pharmacists Association (APhA, nd) has provided a definition of pharmaceutical care: a patient-centred, outcomes-oriented pharmacy practice that requires the pharmacist to work in concert with the patient and the patient's other healthcare providers to promote health, to prevent disease, and to assess, monitor, initiate and modify medication use to assure that drug therapy regimens are safe and effective. The goal of pharmaceutical care is to optimise the patient's health-related quality of life, and achieve positive clinical outcomes, within realistic economic expenditures. To achieve this goal, the following five requirements should be accomplished:

1. A professional relationship must be established and maintained.
2. Patient-specific medical information must be collected, organised, recorded and maintained.
3. Patient-specific medical information must be evaluated and a drug therapy plan developed mutually with the patient.
4. The pharmacist assures that the patient has all supplies, information and knowledge necessary to carry out the drug therapy plan.
5. The pharmacist reviews, monitors and modifies the therapeutic plan as necessary and appropriate, in concert with the patient and healthcare team.

Medication adherence: a modifiable barrier

Medication adherence may be defined as the 'extent to which the patient's action matches the agreed recommendations' (NICE, 2009), or 'the extent to which patients take medications as prescribed by their health-care providers' (Osterberg and Blaschke, 2005, p 487). High medication adherence is associated with positive health outcomes (Simpson et al, 2006; Cramer et al, 2008), with the risk of mortality for patients who adhere to therapy approximately half that of those who do not (Simpson et al, 2006). Low adherence is a lost opportunity for health gain and has an impact on a number of stakeholders including the patient, the employer, the Exchequer, the health service and the taxpayer. The sequelae include waste, increased pressure on the health service, loss of productivity, sick days and negative effects on gross domestic product (GDP). Low medication adherence is a substantial obstacle to successful treatment and presents a challenge to healthcare professionals (Miller et al, 1997). The reported prevalence of non-adherence to medication varies depending on how and where adherence is measured, and the length of follow-up. However, it has been demonstrated that chronic conditions are more likely to be associated with low medication adherence when compared with acute illnesses (Osterberg and Blaschke, 2005), and it has been reported that 20–50 per cent of patients are non-adherent at some stage in their treatment (DiMatteo, 2004; Osterberg and Blaschke, 2005; Brown and Bussell, 2011).

The multidisciplinary team of healthcare providers consists of a prescriber, who will diagnose and recommend therapy if indicated, a dispenser, who will assess the instructions provided by the prescriber to prepare and dispense the medication and the administrator, who will give the mediation to the patient, which may also be the patient him or herself. While this process may appear simple, there are human factors that should not be underestimated. It would be incorrect to assume that as soon as a patient receives the medication he/she will follow the instructions blindly and there are many factors that can have an impact on the willingness and ability to follow the advice given. These can include the system or process, the duration of the condition, as already described, the complexity of the regimen and human factors (Sabaté, 2003). To increase the likelihood of positive patient outcomes via medication adherence, healthcare practitioners need to understand and acknowledge the individual patient beliefs and attitudes regarding medication (Kripalani et al, 2007). These beliefs and attitudes are established in early life, independent of gender (Unson et al, 2003; Wrubel et al, 2005), and can have a positive or negative affect on medication adherence, in a similar manner as described by Ponieman et al (2009). The negative impact of side effects (DiBonaventura et al, 2012; McKillop and Joy, 2013), regimen complexity and polypharmacy (five or more medications) (Vermeire et al, 2001; Stone et al, 2001; Golin et al, 2002; Murphy et al, 2003; Vik et al, 2004; Vlasnik et al, 2005; Munger et al, 2007; McKillop and Joy, 2013) on medication adherence is repeatedly and universally reported across a range of diseases, ages, countries and races. However, improving clinical and patient outcomes can be achieved through interventions that improve medication adherence (UN DESA, 2008; Chummun and Boland, 2013). Simplification of medication regimens offers a practical solution (Claxton et al, 2001; Golin et al, 2002; Murphy et al, 2003). Cues, reminders and visual aids can be used to ameliorate the effects of regimen complexity (Ogedegbe et al, 2004). Recognising low or non-adherence presents an opportunity to provide assistance to patients (Munger et al, 2007). As outlined above, it is the duty of the pharmacist to assess these variables, ensuring that the patient has all supplies, information and knowledge necessary to adhere to the treatment plan and to review, monitor and modify this plan as necessary and appropriate, in accordance with the specific needs of the patient. For example, a community pharmacist may offer a monitored dosage system to ameliorate a complicated regime (Zedler et al, 2011).

The older adult

The demographic of the Irish population is changing, with the number of older people, that is, those aged 65 or older, increasing. In Ireland, 11.0 per cent of the population was aged 65 years or more in 2005, and this figure is expected to increase to 24.2 per cent by 2050 (Matthes and Albus, 2014). While those aged 60 or more comprise only 12–18 per cent of the population in developed countries, they are responsible for 60 per cent of medication-related costs (Sabaté, 2003). Therefore, the increasing age of the population places further strain on already stretched healthcare systems. The longitudinal study TILDA reported in 2012 that 34 per cent of Irish community-dwelling adults aged over 65 were taking five or more medications (TILDA, 2012). Similarly, Qato et al (2016) reported a rate of polypharmacy among community-dwelling older people in the US in 2010–11 of 35.8 per cent, a figure that has increased from 30.6 per cent in 2005–06 (Qato et al, 2016). It is evident that providing care for the older adult is complex: a 2016 publication entitled *Multimorbidity: Clinical assessment and management* (NICE, 2016) provides healthcare professionals with recommendations and guidance on how to care for patients with multimorbidity, more prevalent among older adults as mortality rates have declined (see also Salive, 2013). Pharmacists must be cognisant of potentially impaired cognitive, hearing and sight abilities when consulting with the older adult. However, they are perfectly positioned to review prescriptions, to monitor compliance and adherence on dispensing and to advise the older adult and/or their carers on how to minimise drug-drug interactions, potential side effects and adverse drug events.

Health literacy: impact on health and medication adherence

The Organisation for Economic Co-operation and Development's (OECD) International Adult Literacy Survey found that 25 per cent of adults surveyed in Ireland in 1994 did not display the literacy skills and confidence needed to take part effectively in society (OECD, 2000). Furthermore, it has been reported in the US that people with limited literacy find health-related documents such as appointment cards, consent forms and prescriptions difficult to read and understand. Research suggests that there is a direct link between individual health literacy and health outcomes (Nielsen-Bohlman et al, 2004), with limited literacy having a direct, negative effect on health (Dewalt and Pignone, 2005). Patients with limited health literacy may have less health knowledge (Gazmararian et al, 2003), poorer self-management skills (Schillinger et al, 2002), lower use of preventive services (Miller et al, 2007), increased hospitalisation rates, worse self-rated health (Baker et al, 1998) and increased mortality (Sudore et al, 2006). Overall, individual literacy skills have repeatedly demonstrated to be a stronger predictor of health status than age, income, employment status, education level and racial or ethnic group (Wolf et al, 2007). Research conducted by this group, involving over 1,750 Irish adults found that, at a minimum, one in seven participants had limited health literacy, which may affect their ability to promote, protect and manage their health (Sahm et al, 2012b). As in the US and the UK, improving health literacy should be a public health objective for Ireland.

Patients with lower health literacy may have difficulty understanding their medication regimen. Marvanova et al (2011) evaluated patients' understanding of their medicines on admission to hospital and found that patients with marginal or limited health literacy were less likely to understand their medicines when compared to those with adequate health literacy (Marvanova et al, 2011). Similarly Persell et al (2007) reported that patients with limited health literacy were not as able to recall the names of their anti-hypertensive medications when compared to those with adequate health literacy (40.5% vs 68.3%, p=0.005). Having conducted a study in which patients were asked to interpret the instructions provided on the prescription label of a medicine container, Wolf et al (2007) reported that patients with lower literacy were more likely (63%) to misunderstand the instructions compared to those with marginal (51%) or adequate literacy (38%), (p<0.001), a finding confirmed by Davis et al (2006). In addition, studies that have focused on drug warning or auxiliary labels have shown that those with poor literacy skills have great difficulty in their interpretation, which could have significant safety implications (Davis et al, 2006; Wolf et al, 2006).

The role of the pharmacist in improving medication use

Pharmacists also actively contribute to increasing the health literacy of patients, which will empower them to exert greater control over their healthcare (Marshall et al, 2012) and adhere to medication (Ngoh, 2009). Many strategies have been applied to improve medication use in patients with limited health literacy. Clear written and verbal communication is an essential aspect of any consultation between a pharmacist and a patient. Whether it is the provision of a vaccine, the explanation of a new therapy or the recommendation of a product to treat a minor illness or ailment, appropriate questioning and listening are imperative. Pharmacists must consider the factors affecting the patient's involvement in a consultation, such as physical or learning disabilities, sight or hearing issues and difficulties with reading or speaking English, and to consider ways of making information accessible and understandable to the patient by using pictures, symbols and large (NICE, 2009). Research in the US and Ireland has centred on the medication label instructions that patients receive with their prescription medicine, which can be unnecessarily complex and highly variable (Shrank et al, 2007). Therefore, an effort has been made to standardise the instructions provided, leading to the development of the patient-centred label (PCL) (Wolf et al, 2011). The PCL seeks to organise information on the label from a patient's perspective, and encourages the prescribing of medication around four standard time periods (morning, noon, evening, bedtime), a format that accounts for how nearly 90 per cent of solid dosage-form medications, that is, tablets and capsules, are prescribed (Hernandez, 2008). It was reported in a study of 500 adults that the PCL format was more likely to be interpreted correctly compared to standard instructions (Adjusted Relative Risk [RR] 1.33, 95% Confidence Interval [CI] 1.25-1.41, p<0.001) (Wolf et al, 2011). In addition, individuals with low literacy levels were more likely to correctly interpret PCL instructions compared to standard label instructions (low literacy: RR 1.39, 95% CI 1.14-1.68; *p*=0.001). Interestingly, once a graphic was added to the PCL format, levels of correct interpretation decreased (Wolf et al, 2011). A similar study conducted in an Irish cohort of 94 participants reported similar results. While there were no differences in comprehension between the label types among participants with adequate health literacy, those with limited health literacy had better understanding of instructions on the PCL compared to standard labelling formats (91% correct interpretation of PCL labels compared with 66% correct interpretation of standard labels) (Sahm et al, 2012a). Although further studies are needed to refine the use of the PCL to account for situations such as the use of as-required medications or for patients working shift work, the consistent findings in these studies across two jurisdictions suggests that the PCL may be a positive approach to labelling medication, in particular among low-literate patients.

Pharmacists must also consider their verbal communication skills when interacting with these patients. Interactions should begin with an open-style question, such as, 'What do you already know about…?' (Kripalani and Weiss, 2006). Based on the response to this question, the pharmacist can tailor the nature of the information they provide, using plain language and avoiding medical jargon, where necessary. The patient should not feel overloaded, limiting information to no more than three key points. Another potential strategy, which should not be underestimated, is the 'teach-back' method, used to confirm understanding of the provided information. This strategy involves asking the patient to demonstrate the knowledge that the pharmacist has imparted, giving the opportunity to clarify any misinformation. Due to the large amount of complex information that patients are often provided, reinforcement is an effective strategy to ensure that information is not lost; supplementing oral communication with simple written information, providing visual medication schedules and simplified drug levels can aid the patient in assimilating and retaining information. Finally, providing patients with multidisciplinary disease management education can be extremely effective, especially when dealing with complex medical conditions such as chronic obstructive pulmonary disease and heart failure. A coordinated approach from pharmacists, physicians, nurses, physiotherapists, speech and language therapists and occupational therapists can provide a holistic care package to the patient to ensure optimum health outcomes.

Special populations

While we acknowledge that those who have limited health literacy are at a disadvantage relative to those with higher levels of high literacy, this is especially true of special populations, that is, those with mental illness. A study conducted by our group showed that in patients with schizophrenia, the information provided on medicines is not tailored to the target audience (Brosnan et al, 2012). The patients in this study were receiving clozapine for the management of treatment-resistant schizophrenia, a medication that is required to be administered in the in-patient setting due to its potentially fatal side-effects. The manufacturer-provided information consists of a DVD and a patient information leaflet (PIL). We developed a PIL using guidelines from the National Adult Literacy Association (NALA) and called this the 'Pharmacist-designed PIL'. We assessed the health literacy of the patients using the Rapid Estimate of Adult Literacy in Medicine (REALM) screening tool. In total 40 patients (of whom 65% were male, 95% unemployed and 70% smokers) of average age 38.0 (±11.2) completed the REALM and gained an average score of 60.6 (±8.7) out of 66. Twenty-nine patients (72.5%) were found to have 'adequate' health literacy. The remaining 11 patients were found to have 'marginal' health literacy. This means that they would struggle with most patient education materials, while 5 per cent with 'low' health literacy would not be expected to be able to read prescription labels. Only 23 per cent of those interviewed recalled watching the DVD on clozapine that is given to them at the initiation of clozapine therapy. The reading levels for the study population were compared to the readability of the manufacturer-produced PIL and the pharmacist-designed PIL. The results of the REALM indicate that 95 per cent of the study population would be expected to be able to read the pharmacist-designed PIL, whereas only 72.5 per cent of the study population would be expected to be able to read the company-produced PIL. It is important to be aware of a patient's health literacy when providing information, as health literacy is strongly correlated to health outcomes. Although the pharmacist-designed PIL may be a more easily read document, further research is required to design a PIL that meets the needs of low-literacy patients.

Conclusion

This chapter has shown that limited health literacy is an issue for many people and particularly for older adults. Healthcare professionals should be taught how to recognise these difficulties at undergraduate level while studying for their respective professions. By teaching undergraduate students about the inequities surrounding their patients, including limited health literacy, there can be a greater understanding of the challenges of taking medication. Learning communication skills, using role-play, can help to highlight the needs of those with limited health literacy and encourage the student to modify their practice. As practitioners, doctors and pharmacists should be encouraged to adopt the guidelines available from the NALA when providing information on medicines to their patients, and also to recognise the unique learning needs of each patient and to tailor their guidance appropriately, recognising that a 'one-size-fits-all' approach will not suffice. At policy level, there should be a move towards more patient-friendly information to be made available on medicines, via a variety of different media, rather than relying solely on information provided by manufacturers and regulators. Now that we have this knowledge and awareness, it is crucial that doctors and pharmacists work independently and together to improve the understanding and knowledge around medicines for the older adult. Every interaction between a healthcare professional and a patient presents an opportunity to discuss their medicines and any queries that have arisen regarding their medication-taking behaviour. Through partnership with the patient, pharmacists and doctors can learn to adapt their communication skills to enable clear, simple and concise information to be given to the patient, to enhance health outcomes for all.

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22

A stated preference discrete choice health literacy intervention framework for the control of non-communicable diseases (NCDs) in Africa

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Introduction

In Africa, vis-à-vis the fact that Africans are generally and comparatively not health-literate, this chapter includes (but is not limited to) a key conceptual definition of health literacy and its contextualisation. In doing so, this chapter also discusses the pitfalls of the current health structure in Africa, looking at the underlying reasons exacerbating the increase in non-communicable diseases (NCDs) on the continent and introduces a stated preference discrete choice health literacy intervention framework for the control of NCDs. It also provides age-sex disease prevalence in Cameroon and general aspects of health promotion and disease prevention strategies with respect to NCDs.

Health literacy is an indispensable key component of ensuring a healthy condition in individuals that transcends into the entire community (Adams et al, 2009; Dodson et al, 2015), if individuals are knowledgeable in health information, and are able to synthesise it, use it through their individual convictions for decision-making and consequently, improve their health, then the entire community is bound to be healthy (Remais et al, 2012; Dodson et al, 2015; WHO, 2016). However, such access to health information remains under-utilised thus far (O'Sullivan et al, 2003; Baye and Fambon, 2010).

The function of health literacy in ensuring a healthy condition in individuals and communities is especially relevant in Africa, which is plagued with high endemic diseases, and in settings in which healthcare resources and infrastructure are, for the most part, limited (O'Sullivan et al, 2003; Remais et al, 2012). There is therefore a need to evolve an appropriate health literacy intervention for individuals in Africa (Remais et al, 2012; Wiesner and Pfeifer, 2013). Because there are so many social, financial, cultural, gender, educational and cognitive barriers in Africa (Lopez et al, 2006; Remais et al, 2012; Wiesner and Pfeifer, 2013), a health literacy contextual framework would have to capitalise on the sociocultural peculiarities of an African individual: like the 'Ubuntu' philosophy, 'I am because you are' and hence like Descartes, 'I think, therefore I am'. This implies that, if one individual becomes health literate in a community, it is likely that the knowledge would cascade to other community members, thus rendering the entire community health literate. Africans believe and live in solidarity with supportive mutual tendencies to one another, which ties to the "Ubuntu" concept. These social, cultural and cognitive barriers are determinants that characterise an African individual and would form the basis of a sustainable health literacy intervention at the individual level to mitigate the rising risk of NCDs. Better health-literate people have an impact on the wider community in which they live (Bandura, 2004; Nutbeam, 2000, 2008; Oguoma et al, 2014). Community starts from individuals first, with each individual likely to influence others to lead to a healthy community.

Generally, in most African communities, an individual who is suffering from cancer or any other chronic disease easily draws attention from the entire community (Uchenna et al, 2012; Udenze et al, 2013). It soon attracts neighbours, extended family members, social group members and religious group members (Harris et al, 2011), and most likely affects the entire community psychologically (a psychopathic effect) (Harris et al, 2011; Stellefson et al, 2013; Udenze et al, 2013). These effects and experiences are to be exploited in building health literacy intervention and promotion to prevent NCDs. Global figures of NCDs in Africa clearly suggest that they are on the rise (WHO, 1998; Kiawi et al, 2006; Nwose et al, 2013). A case study showing the incidence of NCDs in Cameroon is now shown, highlighting the gravity of the problem (O'Sullivan et al, 2003).

Age-sex disease prevalence in Africa, with a focus on Cameroon (2011-16)

In this section a brief overview of the rising trend of NCDs such as diabetes, hypertension and cancers in Africa is described, with Cameroon chosen as a case in point. Cameroon is presently experiencing the double burden of infectious and chronic NCDs (Echouffo-Tcheugui and Kengne, 2011). It is undergoing social and economic changes, which are resulting in increased urbanisation with a potentially negative impact on health-related behaviours. Experience and empirical evidence has revealed that certain NCDs have predominated in Cameroon within the last 10 years. Notably for men, the following rates can be reported: diabetes (5.3%), hypertension (26.4%), stroke (15%), rheumatism (4.8%), prostate cancer (19.2 /10,000) and asthma (1.5%); and for women: diabetes (5.3%), hypertension (29.6%), rheumatism (4.8%), asthma (1.5%), breast cancer (27.9/10,000), and cervical cancer (24.0/10,000) (Echouffo-Tcheugui and Kengne, 2011).

Apart from the known risk factors for NCDs that cut across all continents, in Cameroon in particular, local diets and certain traditional meals are high risk factors. In Kom village in the Boyo county in the North West region of Cameroon, the traditional meals that are eaten daily, seven days a week, and in great quantity, are largely corn starch and unbleached palm oil-based mixed with salt and little vegetables. These meals are eaten in all traditional celebrations (personal communication with chiefs, 2017). This is along with heavy alcohol intake of both beer and local liquors that are largely starch-based. Several such traditional meals in the country are risk factors for hypertension and diabetes. Many people are unaware of their health status and consume large amounts of these foods and drinks.

Most Cameroonian people (as with most Africans) are not vegetarians, and generally eat fewer vegetables compared to other continents (Udenze et al, 2013). The nutritional value of vegetables is well known, but there is a cultural perception that eating vegetables in some tribes in Africa is a real stigma (personal communication with local people, 2017). For instance, the nomadic Fulani pastoralist tribe in Cameroon considers eating vegetables or salads as herbivorous or synonymous with cattle. Furthermore, lifestyle changes in diets have been seen in most villages in the last 30 years (WHO, 1998; Kiawi et al, 2006), with some traditionally healthy foods abandoned in lieu of more exotic foods (Udenze et al, 2013). For example, millet, sorghum and red maize are healthy grains that were previously well consumed, but nowadays they are consumed less and are less cultivated by local people in Cameroon and Nigeria (personal communication, 2016).

Another risk factor for chronic obstructive pulmonary disorders (COPDs) is poor indoor air quality. This is due to increased fuel wood consumption as well as tobacco consumptions, which presents a double risk factor for COPD. Most traditional meals in Cameroon are prepared by women in poorly ventilated, smokey kitchens. They do this almost daily – we can only imagine the amount of toxic gases and phenols they may have inhaled.

Pitfalls in the current health promotion and disease prevention approaches

In this section the shortcomings of the present health picture and infrastructure in Africa are presented. These shortfalls are described in relation to why NCDs are on the rise despite other therapeutic and palliative management systems being in place. The necessity of an appropriate health literacy intervention approach as a way of addressing these pitfalls is highlighted.

It is important to build health literacy in African communities via a Behaviour Change Communication (BCC) in order to convey messages geared towards awareness and permanent adoption of good practices in such a way that people are able to abandon their old, unhealthy habits and embrace and use new knowledge (Baye and Fambon, 2010; Stellefson et al, 2013). The use of audiovisual gadgets, health talks/video projections, role-plays in health facilities, schools and social groups alone doesn't seem to have had a profound impact (Harris et al, 2011). Using the BCC programme cycle, beginning with primary data collection followed by formative research, monitoring of programme activities, outcome and impact evaluations, may have a positive health outcome. A stated preference discrete choice intervention is needed and requires these attributes:

- a situational analysis or reality check that identifies individual health literacy skills and assets for communities across Africa;
- village assets, beliefs, customs and convictions held by the individual with the leaders and individuals supported to be co-involved in the concept mapping, assets measurement, evolving the interventions together.

The stated preference here is to delve into specific customs and rituals that promote risk factors for acquiring NCDs to check adherence to these belief systems and reasons for these adherences, and whether or not any perceived punishment enshrined in the customs is applicable if there is a navigational change in lifestyle. Health literacy could be a tool in the context of health promotion or disease prevention in Africa with respect to the control and prevention of diabetes, hypertension, cancers and mental health disorders.

Reflections on the stated preference discrete choice health literacy intervention framework

In this section we explore what a stated preference health literacy intervention is, and why it is a critical tool to use in controlling NCDs across Africa. Appropriate health literacy interventions are those that are fit for purpose and contextualised to solve the specific health needs of individuals and communities at large, recognising the social, gender, cultural and educational characteristics of that individual or community (Nutbeam, 2000, 2008; Kiawi et al, 2006; Uchenna et al, 2012; Udenze et al, 2013). Individual and community health needs differ, from village to village and from continent to continent. For health literacy to be effective and sustainable, it should be administered as 'health literacy packages' that are customised for the respective cultural, gender and educational competencies of a particular community. This is what we mean by 'stated preference discrete choice health literacy intervention. Health literacy at the individual level needs to be intensified across Africa, considering the rising incidence of NCDs (Kiawi et al, 2006; Harris et al, 2011; WHO, 2016) – it is easier for a community to be healthy if individuals are healthy, which then cascades down into the entire community.

Current health promotion interventions in current use in Cameroon and Africa at large are inadequate as they are too exo-centric in style, language and construction – a health literacy intervention culled from a very exo-centric set-up and tailored for the European context, for instance, may not be transferable to Africa. In this case, a stated preference choice health literacy package is advocated. The most important barriers in this context are differences in educational, occupational and population literacy, such as a strong sense of person-to-person interaction and community and social relatedness in African cities and villages that are different from Eurocentric and American-Australian contexts.

Health literacy interventions in Africa still need to be thorough and well targeted, but typically an epistemic understanding of the individual and their related health needs would signal the type of intervention to apply and anticipated outcome. Health promotion exercises in Africa are currently too linear in application. Linearity here means providing a solution to a certain problem without taking into account the contextual barriers of its wider implementation, which may be entirely different from what the researcher or facilitator wants to provide, as well as its perceived urgency and necessity. This probably explains the persistent endemicity of certain diseases on the continent despite concerted efforts in treatment applications and the failure of several development-based interventions provided, both in the past and present. For instance, in Africa, health literacy and health promotion for people with diabetes is widespread, but focuses mostly on how the patient needs to take their pills, regular exercise, diet and, of course, sugar level monitoring, but very little and no such organised efforts target individuals who are non-diabetic in the community for preventive measures.

This health literacy approach remains inadequate so long as the specific health literacy needs of the individual and the targeted communities are not adequately measured (Kiawi et al, 2006; Harris et al, 2011; Uchenna et al, 2012; WHO, 2016). Additionally, the theoretical tenets of health literacy are not well understood in Africa; the element of understanding health knowledge and applying it for informed decision-making for better health outcomes and equity is grossly lacking, both for the individual and health professionals. An entire overhauling of the health literacy and promotion strategies are required if the Sustainable Development Goals are to be realised.

An holistic integrative health literacy approach is critical to curb the rising incidence of NCDs in Africa. An holistic, integrative health literacy approach can contribute to people's education, knowledge and belief systems, leading to long-term sustainable change. Individual health literacy on NCDs and its processes connected to its development are also closely linked to an individual's emotional factors such as trust and sense of belonging. For this purpose, trust and confidence toward the provider of health-related information and the providers track record in his or her respective community in which the person hails can positively or negatively affect uptake of an intervention. To this effect, this can be effectively realised via a health literacy laboratory

There are already effective measurements of health literacy in Western societies (Bandura, 2004; Dodson et al, 2015), but a thorough measurement of health literacy in NCDs across Africa must be done. Although health literacy appears well known in Western communities, its conceptual tenets and practice are not well enshrined in the various African cultures and ways of life. Since it is therefore not well measured, the outcomes of any haphazard interventions so far reported are pretty much assumed and presumptive. The underlying explanation for the fast epidemiological transition of NCDs in Africa still needs to be studied. It cannot simply be explained with the known reported risk factors for NCDs; there are other cultural specific factors yet to be espoused. As no one cause can explain this, the force of the argument here is that it is far from being just lifestyle changes, an exotic food diet, alcoholism and cigarettes, but local culture and customs are also likely cause factors. This is because there are increasing numbers of people living in village settings across Africa who are not attuned to exotic lifestyles and certain foods except for local foods and customs, who are increasingly diabetic, hypertensive and with cancers or at high risk of developing cancers or COPDs.

A bottom-up approach in quantitatively analysing these latent root causes as well as appropriate intervention strategies is part of the discrete choice preference in this scenario. Individuals in Africa for the most part grow up either with no health knowledge, little health notion or wrong health information that has been passed on from their parents. Some health information is misconstrued and parcelled into local beliefs systems and superstitions, thus making it difficult to dispel over time and space. Health literacy interventions in this case would start with appropriate measurements of how the individual or community is so attuned to the belief systems, then any intervention can only be built by carefully talking them out of these cultural perceptions, thus facilitating people to be self-convinced. This can then enable them to access, process and apply health-related information themselves, allowing for sustainable change.

Therefore, the provision of knowledge (that is, health information) ought to be connected with education about options of how to apply that knowledge autonomously. For example, in a community whose priority is potable water, a health literacy intervention on curbing diabetes and cancer may not be quickly be accepted and sustain. This urgent need may mask the need for a literacy programme that addresses hypertension or cancer. To this effect, a joint intervention approach of providing potable water and then educating people on hypertension and cancer is the way to go. In a case scenario with the people of Balikumato village in Boyo County, a village in the North West Cameroon, we undertook a health literacy and promotion package in 2013 where it was noticed that the people (a population of 350) had as a priority potable drinking water.

To effectively gain entry and get their individual attention, a health literacy package built on cancer, hypertension, diabetes prevention and empowerment, with skills on household water purification carefully packaged. This integrated, cloned health literacy package gave the opportunity for the community to group themselves and begin training other members on the skills acquired. The community became highly mobilised so that two years afterwards, a revisit to the community indicated the level of awareness as not only high, but having cascaded down to others.

At this point it must be emphasised that this community was mostly illiterate and uneducated. The same approach was applied with the Sayawa community living in Gwallameji, in Bauchi State Nigeria, and the same proactive response was registered a year afterwards, with an impromptu monitoring visit to the community indicating an increase in level of uptake and practice of health knowledge. With the introduction of the right health knowledge, the community members started to build a perception change that the risk factors for cancer, stroke and epilepsy were medical and empirical rather than following their traditional beliefs. In general, it was observed that mutual interaction between the health literacy provider and the community empirical evidence is vital before a health literacy intervention was applied, for the people to see and believe and in order to gain their confidence.

Diagnostic evidence proving the diagnosis of cancer, hypertension and diabetes and the attending route causes was demonstrative and illustrations aided in individual decision-making for health-related issues. A health education intervention would begin with the scientific-cum-ritual relationship explanation that the evil spirit in the person with the infirmity is a tumour or elevated blood pressure or excess sugar in the blood. In our experience from feedback, health literacy becomes effective and sustainable if the right explanation on the causes of disease is made to the community members to dissuade them from a wrong notion that the causes of disease were linked to rituals and bad spirits. These are vital practical approaches to be built on in order to attain sustainable development across communities in Africa.

As encountered in preliminary interactions with these communities, this intervention approach has the potential for success, as acceptance for the intervention was created by an interactive needs assessment and by taking seriously and responding to the local population's perception and narrative of their problem concomitantly with demonstrating the empirical evidence. It was also noted both among the Sayawas in Bauchi State, Nigeria and the Bikoms in the North West regions of Cameroon the importance of being aware of the communities' adoption of their local language used for describing NCDs, for example, cancer, diabetes, cardiovascular diseases etc. Accordingly, it was noted that interventions for health literacy and promotion must always be built first on the 'available local health knowledge' that might, for the most part, differ from what researchers and health literacy providers would consider as evidence or knowledge.

Our experiences as described above also suggest that health literacy, knowledge and capacity are evolutionary systems, evolving with time and space. This was why a more individual interaction was deemed important. For this purpose, we used a One Resource Learning laboratory (ORLlab), a one health resource community-based education and empowerment programme in which a health literacy baseline for NCDs is mapped in context with local perceptions, customs and traditions, and a joint community needs assessment done by each individual in the community.

Intervention approach of the One Resource Learning laboratory

In this section we state that the ORLlab was a sustainable intervention approach to curb rising incidences of NCDs in Africa. We also provide an example using this model.

The ORLlab team had meetings twice a month between members of a local community (Boyo County) and experts in the respective fields of nutrition and

NCD prevention. During a workshop setting, members were encouraged to educate themselves (using their own dialect) about NCDs, and to discuss critically and come up with their own creative solutions to the local health problems they faced, as a community and as individuals.

Over the course of about six months one 'wave' of members from the target population became experts in the respective fields and skills acquired. For instance, in one case scenario it was generally noticed that mental and psychiatric health disorders among widows were high and escalated due to loss of properties and estates to the heir of the deceased. Many widows noted that their husbands had died mostly due to NCDs, which, at the time of death, had been attributed to poor understanding of NCDs, with the cause of death presumed to be witchcraft or sorcery.

These participants went on to educate the next 'wave', enabling interactive, intergenerational learning. The creation of people's sense of belonging and responsibility for the health of the whole community was considered crucial in this learning format, which lasted for three years (2014–17), and was considered successful as children's awareness was visibly raised. It was noted through interactive visits, for example, that there was more awareness about diabetes, sickle cell disease, breast cancer and mental health.

Health literacy interventions for NCDs across Africa can only succeed and be cascaded on to the next generation if they are built on evidence rather than on assumptions or generalisations. This evidence should not only encompass scientific 'knowledge' that can, in some cases, be biased or undergo changes, but also the experience and perceptions of the respective target population, and the dynamics of the population as well as its structure and diversity. This invariably means that theoretical models and findings are not deemed valid if they have not been validated in practice – in Africa, more than 50 per cent of theories and models in health literacy and interventions are yet to be practised by individuals and communities.

Furthermore, published material in the Cochrane Library, Google Scholar and PubMed and other databases mostly describe models that do not come from the context of Africa and may not yield sustainable results. Sympathetic and statistically convincing as this material is, it may not be suitable in meeting the health literacy needs of people in low- and middle-income earning countries, as these studies and models are mostly linear.

The ORLlab provides a unique platform for assessing discrete choice preferences in health literacy needs and interventions. It provides room for interventions to be effective and comprehensive, enabling target populations to secure the ability to change. This is the kind of strategy to apply if SDGs are to be met in Africa.

In the ORLlab, interactive experience shows that local people defined sustainability as the *sine qua none* of their culture. From the communities we interacted with, they noted that their local diet, local foods and their traditional governance were sustainable. According to them, these things had been in existence from time immemorial, and would continue to be so. This implies that if the conceptual meaning of health literacy (not the literal definition and translation) is to be incorporated into the traditional way of life and local languages, it should be cautiously weaved into the traditional way of life, both now and for the next generation. This is the perspective to be considered in the control of NCDs in Africa and to meet the SDGs.

With levels of literacy comparatively low in Africa, and on a continent with more than 250 ethnic groups and languages, achieving health literacy for NCDs is a daunting task, especially among older people who are not literate, but who are, however, traditionally literate in their own customs, local calendar and dialect. The ORLlab will potentially address these limitations. While literacy itself might not be a prerequisite of health literacy and health-literate behaviour, it might still facilitate a learning process related to health. Health-related content can be transferred verbally (that is, without adequate literacy). Accordingly, it is possible to educate people about NCDs without them being literate. The long-term sustainable impact of the ORLlab is that it can enable the transmission of (health) information without requiring interaction with an expert. Accordingly, learning processes can also be initiated by non-verbal (for example, written) pieces of information that reduces the time an expert needs to 'invest' before achieving a desired level of knowledge or awareness in a target population.

Conclusion

The ORLlab can help to improve health outcomes in context of NCDs, reduce barriers to healthcare services and improve uptake of and access to interventions and programmes. Further research on how local customs pose a risk to the rising incidence of NCDs and the building of discrete choice interventions strategies could reduce not just the incidence of NCDs in the foreseeable future, but may also reduce inequalities and optimise the level of individual responses to seeking healthcare. This chapter has highlighted that the ORLlab could serve as vehicle to meet SDG No 3 in Africa.

Health and wellbeing are essential to achieving sustainable development, and this is enshrined in the Shanghai Declaration on promoting health (WHO, 2017) and SDGs. To get the right policies implemented for the right health literacy intervention strategies, local realities and the right scientific knowledge of the medical problem must be taken into consideration. If this is not done quickly, subsequent policies will be predicated on wrong or inappropriate interventions that will be in unsustainable in the foreseeable future.

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23

Occupational health literacy: Healthy decisions at work

Marie Birk Jørgensen and Anne Konring Larsen

Introduction

The ability to access, understand, appraise and apply health information is useful in all phases and settings in life, but highly dependent on the environment or social context. The work environment is a social context that determines health in a large proportion of the adult population, and can be a determinant for how health is maintained or promoted and how disease is managed. Therefore, the workplace constitutes an essential setting, and introducing a workplace-specific health literacy concept is highly relevant for the preservation of health and management of disease in everyday life. This chapter gives a short overview of the features of the workplace setting, introduces the occupational health literacy model, and gives an example of an operationalisation of the model and its prospects. The chapter primarily concerns adults in working age, due to the nature of the workplace setting.

Workplace setting

The workplace setting has specific characteristics that influence the social constellations and individual positions, and ultimately how each employee manages their health. First of all, most workers are employed due to their professional competencies and paid to perform certain tasks. Also, employees traditionally have an employer and one or more supervisors to frame their job tasks. Colleagues and potential customers, clients or users also have an impact on how job tasks are framed and performed, and in many cases employees also have some discretion themselves to take decisions regarding their job tasks and how to perform them. The framing of the job tasks and determinants and decisions regarding how they are performed are highly associated with health outcomes (Linton and van Tulder, 2001; Costa et al, 2006; Tveito et al, 2010) and health behaviour (Jørgensen et al, 2016). In the workplace, health and safety is typically managed by an occupational safety and health (OSH) management system. This ensures the dissemination of information regarding health hazards and risks associated with the job tasks and ongoing evaluation of employee wellbeing and health with concomitant initiatives to preserve a safe and healthy work environment. The OSH management system usually ensures that the workplaces comply with OSH-related local regulations, it formulates OSH contracts and procedures, and is constituted by OSH professionals such as occupational physicians or occupational therapists, managers and union representatives or OSH representatives, depending on the local OSH management system. The employer has the overall responsibility for keeping the work environment healthy and free of risks of hazards and for maintaining a qualified OSH management system.

The OSH management regulations are highly variable between countries, but the International Labour Office (ILO) has published guidelines on what a qualified OSH management system should entail (ILO, 2004). It states that 'maintaining a preventative safety and health culture require making use of all available means to increase general awareness, knowledge and understanding of the concepts of [occupational] hazards and risks and how they may be prevented or controlled' (2004, p 3). This ambition mirrors central features of what we consider that a qualified health-literate organisation at the workplace has, which we call 'occupational health literacy'. We therefore suggest a model for occupational health literacy that can guide OSH management systems, empowering both the individual employees and the management with knowledge and competences about prevention and health promotion effectively, and furthermore build organisational structures that enable communication and facilitate action.

The OSH management system constitutes the direct, legislative link between occupational demands and health at the workplace, and often has one or more employee representatives, which qualifies initiatives and eases implementation of initiatives. However, workplace health promotion activities can also be implemented through the human resources (HR) departments to strengthen the link to the business case (see, for example, Sørensen and Brand, 2011). Regardless of whether implemented through the HR department or OSH, awareness and competences regarding the occupational demands of the employees are essential to obtain good implementation of health promotion at the workplace (Jørgensen et al, 2016). Therefore, this model specifically addresses the OSH management system to build a strong occupational health literacy system that is also likely to build the grounds for effective health promotion (Jørgensen et al, 2016; see also Sørensen and Brand, 2011).

The occupational health literacy model

For the individual to make good health decisions at work, health literacy needs to be high among both the employee, the supervisor and colleagues and in the entire organisational system. Thus, in the workplace, the OSH management system (including general management) and colleagues constitute the systems and social context that determine the individual's occupational health literacy. For example, for the employee to make good decisions as to whether to turn in sick or not in case of, for example, mental over-exertion at work, a proper social security system regarding sickness absence or presence is needed (that is, financial support for the workplace, keeping a worker in the workplace despite functional limitations), communication from the organisation and the supervisor regarding potential adjustments of the work tasks, breaks and so on, and sufficient support from colleagues to perform those possible adjustments. To ensure a constructive stream of communication from the societal system through to the organisation, supervisor and employee and return, health literacy competencies need to be present at all levels. The employee needs to have the ability and opportunity to communicate their health problem and how it interacts with their work to colleagues and management. Colleagues and management need to have the ability to understand and appraise the situation (the consequences for the individual as well as for the workplace) and the manager in particular needs to have the skills to communicate organisational practices and opportunities relevant for the specific employee in the specific situation. To best support the health of the employee, a number of actions and adjustments may be needed from the manager, colleagues or the employee. And while such actions may be rather well-established routines when it comes to certain situations (for example, a few days with the flu), other situations are much more complex and require a higher level of health literacy among everybody involved (see the example in Box 23.1 below). Therefore, based on our knowledge of the OSH management system's challenges, an occupational health literacy model was built integrating the OSH management system with ideas from health literacy models to generate an understanding of the competences and features of occupational health-literate workplaces.

Box 23.1: Example of (some of) the occupational health literacy competences required to ensure good return-to-work for a previously sick listed employee

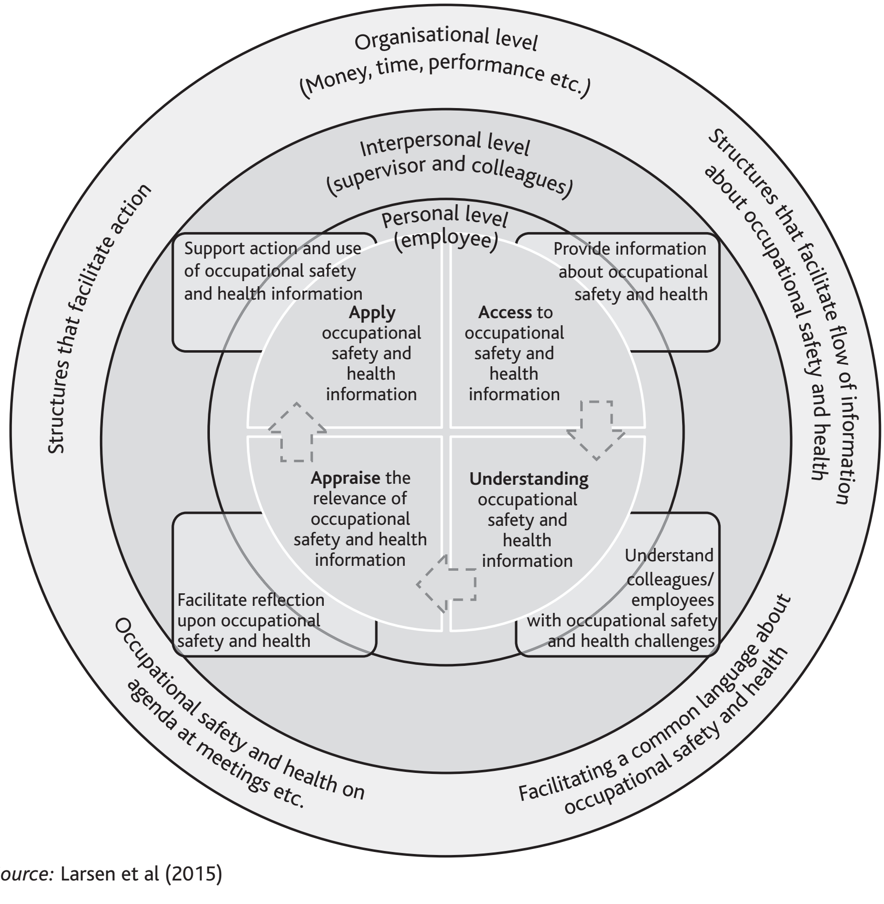
The supervisors' knowledge of the characteristics and consequences of the disease is likely to be limited, so employees need to communicate information about the disease to the supervisor based on their knowledge gained in the healthcare system – for example, in primary healthcare. The employee may return with some functional limitations that may require adjustment of the job task. Job task adjustments require proper knowledge regarding the ergonomics of the job task and how it interacts with the functional limitations. Furthermore, such job adjustments may affect both the effectiveness of the employee, but also colleagues may be affected either socially or by increased job burden due to taking over for the sick colleague. Finally, legislative incitements (for example, the presence or absence of paid sick leave) may have an impact on decision-making – both of the supervisor and of the employee – so making good health decisions at the workplace can be highly complex.

Occupational health literacy is a relational concept that comprises:

- the *individual's* ability to navigate in the OSH management system (access, understand, appraise and apply information and possibilities at work);
- the ability of the *management* to access, understand, appraise and apply information regarding the individual employee's occupational health situation; and
- the ability of the *workplace* to create accessibility to, and support the use of, relevant preventive or health-promoting actions.

The occupational health literacy model is illustrated in Figure 23.1. The model takes its stance at individual abilities and how interpersonal and organisational surroundings can support these and provide opportunities for the abilities to develop. Individual abilities consist of the employee's abilities to access, understand, appraise and apply information regarding health and the work environment. The features of these abilities equal the abilities addressed in the health literacy model of Sørensen (Sørensen et al, 2012). Surrounding the individual level is the

Figure 23.1: The occupational health literacy model



Source: Larsen et al (2015)

interpersonal level of supervisors and colleagues and their actions and roles in social relations to support the continuous opportunity for the employee's abilities to unfold and develop. Finally, the outer ring represents the organisational level that constitutes the physical and organisational features that support the opportunity for the supervisors and colleagues to provide the opportunity for social interaction and support the employee and supervisors' abilities to unfold and develop.

The occupational health-literate workplace entails an organisation where (1) employees and supervisors have common levels of knowledge about prevention and handling of occupational safety and health challenges, risks and hazards as well as health promotion within their workplace; (2) structures for communication about occupational safety and health across all levels in the organisation are provided; and (3) structures and management facilitate and enable relevant action.

Fitting occupational health literacy to the context

An occupational health literacy intervention in practice must to be tailored specifically to the organisation it needs to work within. OSH management systems differ between workplaces and occupational health literacy challenges vary highly, which impose various areas for improvement. For example, an information technology (IT) business with 300 highly qualified specialists employed with primarily sedentary job tasks need to consider other tools than a public sector cleaning department with 20 ethnically diverse cleaning assistants employed with highly variable physical job tasks. In these cases both the health competencies of the employees may differ, the organisational competencies and resources most likely differ, the occupational health hazards differ and the most relevant health promotion efforts differ. Therefore, fitting occupational health literacy into each of the different settings requires thorough evaluation of the context.

An example of an operationalisation of occupational health literacy

Structures, education and frequent communication regarding health practices and communication pathways and empowerment of employees and supervisors are some of the tools identified as useful in a workplace intervention to improve individual and organisational health literacy (Brach et al, 2012; Wong, 2012; Linton et al, 2016). Recently, based on the occupational health literacy model, an intervention was developed to fit occupational health literacy into a workplace setting. Six nursing homes (385 employees and 34 managers) were targeted. The aim was to investigate whether the occupational health literacy model was a suitable tool to frame interventions to reduce the highly prevalent challenge of musculoskeletal disorders for low-income workers, by empowering both the individual employees and the management with knowledge and competences regarding the topic. The idea of introducing an occupational health literacy intervention is supported by previous effective interventions in this setting, which have included structures for communication, building knowledge, improved self-management and participatory ergonomics (George et al, 2003; Rasmussen et al, 2015). Furthermore, involving all levels in the organisation has been shown to be more effective than targeting a single layer in the organisation (Linnan et al, 2001; Baron et al, 2014). To address both individual and organisational factors concomitantly and also their interconnectedness, it was necessary to pursue an integrated intervention approach with multiple facets (building knowledge, competencies and structures for communication and action) at both the organisational and individual level. Table 23.1 illustrates the components of the intervention (courses and dialogues) and their purpose and focus, while Figure 23.2 illustrates the expected path from strengthening knowledge and communication and facilitating action to a more active handling of OSH issues (employees and organisation) to a strengthened handling of OSH issues and a better work environment.

To fit the intervention to the specific needs at each workplace, a formative evaluation was conducted to evaluate the workplace readiness for the intervention and to optimise the tailoring of the intervention. Through interviews with all levels of the organisation, the existing framework for supporting employees with health and work environment challenges was uncovered (for example, workplace

Table 23.1: Components of the intervention and the purpose and focus of the components for employee and supervisor

Intervention components in an occupational health literacy intervention among nursing aides		
Component and purpose	**Employee**	**Supervisor**
Courses, 2 × 3 hours every six months for employees and managers separately, external consultant		
The purpose was to organise a joint fundament of knowledge and understanding of pain, how physical activity or physically demanding work may negatively or positively relate to pain	Focused on strategies for prevention and coping, tools for improving communication and the ability to function and have a good quality of life despite pain	Focused on handling and supporting employees with pain and building a platform for communication and action in relation to preventing and handling pain in the organisation
Dialogues, monthly between employee and supervisor		
The purpose was to enable the workplace to generate knowledge about employee resources and health challenges and to act and convey this knowledge into initiatives at the workplace	Constituted a structured communication about work environment and pain at the workplace with a particular focus on developing specific plans to prevent and reduce pain and its consequences. Employees were supposed to come well prepared with respect to a specific health or work environment issue and suggestions for solutions. The manager was supposed to contribute with insights into organisational solutions and suggestions that could help	

Figure 23.2: Path model

procedures for employees with chronic diseases or pain, possibilities to adjust work routines, health promotion initiatives and possibilities for employees to access healthcare specialists such as physiotherapists or psychologists) as well as possible barriers for implementation and expectations at each workplace. This information was used to produce a resource assessment, identifying the existing support system in the workplace, and a business case identifying barriers and possibilities for successful implementation and the local workplace objectives for engaging in the intervention. This formed the basis for the final organisation of the intervention in each workplace.

The overall outcome of the intervention was measured pain perception among the employees; however, the occupational health literacy intervention was also evaluated with intermediate outcomes, for example, employee knowledge, understanding and action as well as communication with and support and action from a supervisor. Figure 23.2 illustrates the expected path from strengthening knowledge, information and communication and facilitating action among employees and in the organisation to a more active handling of OSH issues to a strengthened handling of OSH issues and ultimately a better work environment.

Learning from the operationalisation

During the intervention, the participation rate on the courses and the dialogues were tracked and a monthly questionnaire by text messages collected data on occupational health literacy outcomes. The questions on occupational health literacy were inspired by, among others, the Health Literacy Questionnaire (HLQ) (Osborne et al, 2013). The questions posed and presented in Table 23.2 are divided into four overall groups: Access, Understanding, Appraisal and Applying. All questions started with: 'How much do you agree with the following statement…?' and respondents were asked to answer with a number between 0 (totally disagree) and 10 (fully agree).

Table 23.2: Occupational health literacy

	Access to information	Understanding information	Appraisal of information	Applying information to act
Employee	'I am sure I have all the information I need to manage pain and discomfort in my body'		'It is easy to find solutions at the workplace if you experience pain or discomfort' AND 'It is easy to get to talk to your supervisor, if you need to'	'There are things I do regularly to prevent pain and discomfort'
Interpersonal		'When I experience pain and discomfort my colleagues really understand what I am going through'		
Organisation	'My supervisor helps me to identify possibilities for preventing or handling pain and discomfort in the organisation'	'When I experience pain and discomfort my supervisor really understands what I am going through'	'I can have good dialogues about pain and discomfort with my supervisor'	'Your supervisor takes action when you draw attention to your pain and discomfort'

Participation on the courses and the percentage of dialogues held varied considerably between nursing homes. As illustrated in Table 23.3, between 63 and 84 per cent of employees participated in the initial courses, and for supervisors it was between 50 and 100 per cent. Between 23 and 107 per cent of the planned dialogues were held, indicating highly variable implementation at the different workplaces.

Generally, 'access to information' (for both supervisors and employees) increased, indicating that probably the courses and/or the dialogue may have improved flow of information between employees and the supervisors about work environment issues and pain. This was supported by employees and supervisors, who explained that the courses had built up a common level of knowledge about OSH and handling of pain, and expressed that it also strengthened openness in the organisation, making it easier to discuss pain; for example, one supervisor said: "We are more open [in regard to pain and OSH]. I think especially my first dialogues with employees was a wake-up call … there were things I didn't know about at all." Increases in 'appraisal' and 'applying' (for both supervisors and employees) were found in some, but not all, of the nursing homes. This could be due to the considerable differences in the percentages of dialogues held. At a nursing home where they held nearly all planned dialogues the supervisor said:

> 'We experience that this all [courses and dialogues] has changed a lot and we get much knowledge about each individual employee and his or her needs and where there are some work-related or environmental issues. But that also leads to a lot of more work for us [supervisors]. A lot.'

This could indicate that even though the dialogues were successful in themselves, the actions planned at the dialogues may have been time-consuming to fulfil, and thus the issues weren't handled sufficiently. Finally, 'understanding' from supervisors did not change and understanding from colleagues decreased in some nursing homes. This was particularly the case in nursing homes with a low percentage of dialogues held. Some employees explained that they felt frustration and a lack of understanding from management when their supervisor did not offer them the planned dialogues and took the time to listen to them and understand their situation. Further follow-up on employees after the dialogue was crucial to building an understanding and trustful relationship between employee and supervisor: "It is good to have this one on one with my supervisor, where we can focus on pain or other issues … however, it is so important that there is a thorough follow-up otherwise you can lose trust."

Results regarding support from colleagues were inconsistent. Some employees explained that they experienced good support from colleagues whereas others expressed lack of support. It was a declared aim of the intervention to improve collegial understanding regarding pain and work environment issues. Therefore, employees who didn't feel that these expectations were met may have been disappointed. One employee explained: "I do not have the possibility to go anywhere and say, unfortunately, I cannot do this task because my shoulder hurts. That is not possible, because my colleagues do not understand that. They just say, but there is this task, and it is yours…."

Generally, the results pointed at a significant difference between workplaces supporting the expectations that health literacy competences vary considerably between workplaces and further, that the same intervention has different effects on different workplaces. Therefore, it seems to be relevant to develop a tool to evaluate all aspects of the occupational health literacy competences at a workplace to be able to focus interventions on the most relevant challenges at a specific workplace. Table 23.3 illustrates participation on courses, percentage of dialogues held and the overall effect of the intervention within each of the four groups. The arrows illustrate an increase (↑) or decrease (↓) within the specific group, while the highlighted arrow (**🡅**) indicates a stronger, more consistent effect.

Overall, this example of an occupational health literacy intervention indicates the highly important role of communication between supervisors and employees in the administration of OSH issues. It also indicates that introducing higher

Table 23.3: Participation in the courses

Nursing homes		*N* = 6
Participation (*n*)	Employee	46-99
	Manager	3-7
Course participation (%)	Employee	63-84
	Manager	50-100
Dialogues (%)		23-107
Access	Employee	↑
	Manager	**↑**
Understanding	Employee	↓
	Manager	–
Appraisal	Employee	↑
	Manager	↑
Applying	Employee	↑
	Manager	–

levels of health literacy among supervisors and employees places a responsibility for action that the organisation needs to be willing to take and to invest in. That is, the organisation needs to invest time and resources in handling the OSH issues that are addressed in the frequent communication between employees and supervisors. Finally, it indicates that an occupational health literacy intervention may introduce a number of strengths in the collaboration between employees and supervisors, in terms of higher levels of communication, trust and mutual understanding. The overall evaluation of the trial will be published in the coming years with both effectiveness studies and process evaluation elaborating on the prospects of that specific intervention. In the future, interventions on occupational health literacy may be based on the occupational health literacy model presented in this chapter, but may likely be operationalised differently than the example given here, as the final intervention protocol should always rely on the context in which its supposed to be used.

Perspectives of occupational health literacy

Occupational health literacy interventions in workplace settings have several prospects for the individual employees, workplaces and society. The individual employee becomes more aware of the complex interaction between their own health and their work tasks, and gains access to information about how to act on this, to maintain both health and work ability. Employees are empowered to take a timely dialogue with their supervisors or other relevant OSH personnel, and know how and when to act. In addition, workplaces may gain more efficient OSH management systems. First, recognition of the employees' literacy levels may help organisations build better communication structures and strategies for the important health and safety issues in the workplace. For example, accidents can be prevented if information about safety is communicated in a meaningful way that targets employees' comprehension. Furthermore, increasing employees' occupational health literacy may increase employee involvement and thus qualify the OSH work. But building an OSH management system that increases occupational health literacy may also build competences among the employees that the individuals can use outside the workplace, that is, empowering employees with health literacy competencies through their workplace. Using the workplace as a setting for the health promotion of labour market active citizens is not a new idea. The World Health Organization's Ottawa Charter was already suggesting using the workplace for health promotion back in 1986 (WHO, 1986). However, to build competencies according to a health literacy-inspired framework puts the idea of workplace health promotion into a new frame, and sheds new light on some of the important interpersonal factors of a good OSH management system. Thus, the concept of occupational health literacy presented in this chapter aims both to inform the field of OSH management systems with more nuanced features and to expand the arenas for health promotion and for building a health-literate population.

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24

Mental health literacy interventions in adults

Anthony F. Jorm

Introduction

This chapter gives an overview of interventions to improve mental health literacy aimed at adults. To be within the scope of this chapter, an intervention must aim to improve mental health literacy, as defined in Chapter 4. However, improving mental health literacy is not an end in itself. It is assumed that changing mental health literacy will lead to a change in behaviours that benefit mental health, which will, in turn, produce an improvement in mental health, as illustrated in Figure 24.1. For this reason, the chapter also looks at whether mental health literacy interventions change behaviour and mental health. Some of the interventions reviewed are aimed at outcomes additional to mental health literacy (for example, stigma), but where this is the case, only the outcomes related to mental health literacy are covered.

Although there are is a wide range of interventions aimed at improving mental health literacy in adults, many have not been evaluated. Rather than try to cover all of these, this chapter focuses on those interventions for which there is some quantitative evidence of effectiveness. The interventions have been classified as multi-component community campaigns, internet-based interventions or training courses for the public.

Figure 24.1: Hypothesised links from mental health literacy to behaviours that benefit mental health and improved mental health

Multi-component community campaigns

beyondblue

In the 1990s, the Global Burden of Disease study found that depression was a major source of disease burden globally and its impact was projected to increase. In response to this impact, the Australian national and state governments established 'beyondblue: the national depression initiative' in 2000 (www.beyondblue.org.au). beyondblue operates as an independent not-for-profit organisation, with funding support from government as well as from philanthropic sources. Its vision is 'a society that understands and responds to the personal and social impact of depression, and works actively to prevent it and improve the quality of life of everyone affected by it' (Pirkis et al, 2005, p 36). While depression is its primary focus, beyondblue also aims to cover related anxiety and substance use disorders and, more recently, suicide. Over its first decade of operation, beyondblue engaged in a broad range of activities, many of which are relevant to the aims of this chapter, and a number of these are summarised below:

- *Consumer and caregiver participation and advocacy:* beyondblue founded a national consumer and caregiver organisation, blueVoices, which aims to encourage consumers and caregivers to voice their experiences and to become advocates (Pirkis et al, 2005).
- *Community forums:* beyondblue partnered with Rotary clubs and other organisations to run a large number of community forums (Pirkis et al, 2005). These exposed attendees to consumer and caregiver stories, gave information about depression from professionals and allowed community discussion of depression and other mental health problems.
- *Website:* beyondblue created a website in 2000 with extensive information about depression and related disorders. An independent evaluation of content quality found that this was one of the best Australian websites giving information on depression (Griffiths and Christensen, 2002).
- *Media advertising:* in 2004 beyondblue began media advertising. Key messages were about the effects of depression on the person, that help is available, and referring to the website for further information. Campaign feedback has been positive, but specific impacts are not known (Pirkis et al, 2005).
- *National workplace programme:* in 2004, beyondblue launched a programme of workshops for employees and managers to help them recognise depression in the workplace, to encourage early intervention and to support workers affected by depression (Szeto and Dobson, 2010). Questionnaires given before and after the workshops showed increases in knowledge of the signs, symptoms and prevalence of depression, and increased confidence in assisting someone with depression in seeking help.

Because beyondblue has involved a wide range of activities across the whole of Australia, it has not been possible to conduct a controlled evaluation. However, in its early years, beyondblue was more active in some states of Australia than others, allowing comparison of changes in high-exposure versus low-exposure states (Jorm et al, 2005). Awareness of beyondblue in the states that provided funding was found to be around twice the level of those that did not. Using the low-exposure states as a control, the high-exposure states had greater change in beliefs about some treatments, particularly counselling and medication, and about the benefits of help-seeking in general. Recognition of depression improved greatly at a national level, but slightly more so in the high-exposure states.

While beyondblue has successfully engaged many Australians in its programmes, a comprehensive review of the campaign has concluded:

> Despite these major successes, it is fair to say that beyondblue's vision has not yet been realised. Society does not yet understand and respond to the person and social impact of depression, nor does it work actively to prevent it and improve the quality of life of everyone affected by it. beyondblue has begun to make an impression, but it is unrealistic to expect systematic and cultural change of this magnitude to occur rapidly. (Pirkis et al, 2005, p 49)

European Alliance Against Depression

The European Alliance Against Depression began as the Nuremberg Alliance Against Depression, a whole-of-community intervention in Nuremberg, Germany, with the city of Würzburg as a control community. The intervention involved four levels: interventions with primary care physicians, a public campaign aimed at the general public, interventions with community facilitators (for example, clergy, teachers, police), and interventions with people with depression, people who had attempted suicide and their relatives (Dietrich et al, 2010). It is the public campaign that is most relevant to mental health literacy.

The key messages of the public campaign were that 'depression can affect everybody', 'depression takes many forms' and 'depression is treatable'. These messages were spread in a variety of ways, including posters, a website, leaflets and brochures, cinema, and radio, TV and print media. To evaluate the effect of the campaign on knowledge and attitudes, baseline surveys were carried out in Nuremberg and Würzburg, followed by surveys at 10 months and 22 months after the start of the campaign. Few changes were found for the public as a whole, but more pronounced changes were seen in those who were aware of the campaign and those who had a family member or friend affected by depression. For people who were aware of the campaign, there was a decline in stigmatising causal explanations of depression (for example, due to lack of self-discipline) and a trend towards more positive attitudes towards medication. For those who knew someone affected by depression, there was greater awareness of the campaign and the resulting discussion about depression. Many of the changes observed declined in the second year of the campaign, which was less intensive, which argues for the need for ongoing depression awareness action (Dietrich et al, 2010).

While the effects observed in the surveys were small, there were impressive changes in rates of attempted and completed suicide during the period of the intervention. For Nuremberg, suicidal acts decreased by 24 per cent, while for the control city of Würzburg they increased by 7 per cent (Dietrich et al, 2010).

The success of the intervention in Nuremberg led to the spread of the approach to more than 100 other regions in Germany and other European countries, collectively known as the European Alliance Against Depression (Hegerl et al, 2013). The success in reducing suicidal acts in Nuremberg has been replicated in Hungary, with a more pronounced reduction in suicide in an intervention region compared to a control region (Hegerl et al, 2013).

Swedish national anti-stigma campaign

Sweden has had a national anti-stigma campaign called Hjärnkoll (meaning 'Braintrack') since 2009 (Hansson et al, 2016). While the major focus has been the reduction of stigma, the impact of the campaign on mental health literacy has also been examined. The campaign involved four main approaches: involvement of people with lived experience ('ambassadors') in activities; media campaigns through newspapers, television and the internet; promotion of sustainable activities at a local level; and promoting the role of managers to take responsibility for mental illness in the workplace.

The campaign was rolled out in a gradual fashion, starting in 2009 with three regions comprising around a quarter of the population and later, in 2012, extending to another five regions comprising another quarter. This stepped roll-out facilitated evaluation of the campaign, which was carried out using annual web-based population surveys, involving both the three initial campaign regions and the whole country. Mental health literacy was evaluated with the Mental Health Knowledge Scale, which consisted of items assessing stigma-related mental health literacy and knowledge of mental illness. Mental health literacy was found to improve to a greater extent in the campaign regions between 2009 and 2014 than for the whole country. Although there was no control region, Hansson et al believed that the campaign had a positive impact based on the timing of changes, with improvements occurring in the initial regions from 2010, but not in the national surveys until 2013.

Treatment and Intervention in Psychosis (TIPS)

The Treatment and Intervention in Psychosis (TIPS) programme ran in a region of Norway from 1997 to 2000 (Joa et al, 2008). It aimed to get people with first-episode psychosis into treatment more rapidly. This aim was based on the known association between longer duration of untreated psychosis (DUP) and worse patient outcome. The programme had two components. The first was a community information campaign targeting the general public, GPs and schools with information on how to recognise psychosis, the importance of early intervention and the availability of an easy access clinical team. The second was the availability of an early detection team who could be contacted by anyone.

The information campaign involved numerous elements, including: newspaper advertisements in newspapers, cinemas, TV and radio; brochures and posters; free postcards in restaurants, car stickers and t-shirts; courses and lectures for teachers; and an educational programme for GPs.

To evaluate the campaign, a comparison was carried out between the region in Norway where TIPS operated and two control regions, one in Norway and the other in Denmark. Although there was no direct assessment of changes in public knowledge and beliefs about early intervention for psychosis, there was evidence that the information campaign changed community behaviour in the TIPS region (Joa et al, 2008). Duration of untreated psychosis was reduced compared to the control regions. Furthermore, after the campaign ceased, the duration of untreated psychosis increased again, even though the early detection team was still operating, showing that the information campaign was an essential element. A 10-year follow-up of patients who entered treatment during the period of the TIPS campaign has been carried out, and the authors claimed that it resulted in better recovery rates (Hegelstad et al, 2012), although this has been disputed (Amos, 2012).

VIdarbha Stress and Health ProgRAM (VISHRAM)

The VIdarbha Stress and Health ProgRAM (VISHRAM) is a community-based programme in an area of rural India designed to reduce risk of suicide by encouraging more people into treatment for depression (Shidhaye et al, 2017). The rationale for the programme is that many people with depression do not receive treatment, thereby increasing their risk of suicide.

The programme involved increasing demand for care by improving community mental health literacy and also increasing the availability of evidence-based treatment. To increase mental health literacy, the programme used community health workers who were residents of a village, most of whom had no formal training. These workers conducted small group meetings and household visits to increase understanding of mental disorders and to inform people about the availability of treatment. More than 1,000 small group meetings were held over an 18-month period. In addition, a documentary on the programme was screened in many villages, while wall paintings to increase mental health literacy were produced in some villages. The workers also provided Mental Health First Aid to villagers in distress and referred some of these people for professional help.

Community surveys carried out at baseline and 18 months found improvements in a number of aspects of mental health literacy, including belief in recovery, perceived effectiveness of intervention and willingness to seek care. Furthermore, the treatment rate for current depression increased from 4.3 to 27.2 per cent, while the prevalence of current depression fell significantly from 14.6 to 11.3 per cent, and the prevalence of suicidal thoughts fell from 5.2 to 2.5 per cent.

MindWise

MindWise was a campaign aimed at the students and staff of an Australian university (Reavley et al, 2014). It aimed to improve mental health literacy, facilitate help-seeking and reduce psychological distress and alcohol misuse. The campaign delivered messages over two academic years using a variety of means, including social media, emails, factsheets and booklets, stalls at campus events, posters, student-designed projects and Mental Health First Aid (MHFA) training provided by the student counselling service.

Because the university had multiple campuses within the same city, the campaign was evaluated using a cluster randomised trial. Campuses were paired for similarity and one of each pair received the campaign, while the other served as a control. Although the students on the intervention campuses were more likely to recall campaign elements, there were few differences in mental health literacy, and there were no effects on alcohol use or psychological distress. One limitation of the study is that some students moved between campuses during the two-year period, so the difference was in degree of implementation rather than absolute. Reavley et al concluded that for an intervention of this type to be effective, it would need to be more personalised and intensive.

Internet-based interventions

The internet is arguably now the major source of mental health information available to the public. Initially this area was dominated by websites, but more recently mobile applications (apps) have become increasingly important.

Information websites

Websites are now a major source of public information about mental disorders. A number of studies have been carried out to assess the quality of this information, with many of these studies concluding that the quality is poor (Reavley and Jorm, 2011). However, a study of Wikipedia is notable, because this website is now in widespread use (Reavley et al, 2012). This study had experts rate the quality of content on depression and schizophrenia from 14 frequently accessed websites providing information on these disorders (including Wikipedia), Encyclopaedia Britannica and a psychiatry textbook. It was found that the quality of information on Wikipedia was generally as good as, or better than, the other sources, although it required a high level of reading ability to comprehend.

More recent research has focused on whether websites can produce changes in users. A systematic review of web-based interventions to improve mental health literacy found 14 controlled studies, with 10 being randomised controlled trials (RCTs) (Brijnath et al, 2016). There was a wide variety of interventions with variable effects on mental health literacy. Brijnath et al concluded that a web-based intervention is more likely to be effective in improving mental health literacy if it 'comprises a structured programme where participants are guided through a series of sequential steps, targets specific population or consumer groups, delivers evidence-based content … and is underpinned by a pedagogical approach that promotes interactivity and experiential learning' (2016, p 7). Conversely, unsuccessful interventions were those that 'do not fully utilise the interactive potential of the Internet, and deliver generalist information to consumers using an unstructured, didactic approach, and/or where participants can navigate and access the website in any way they chose' (2016, p 7).

Three of the studies in the Brijnath et al (2016) review measured changes in help-seeking behaviours, but only one found a positive outcome. Despite this, three studies with people who had mental health problems found that mental health literacy websites improved mental health. On the other hand, four other studies found no effect on mental health, but these did not specifically target people with mental health problems.

The two most extensively tested programmes, according to Brijnath et al (2016), were BluePages (http://bluepages.anu.edu.au/), a website promoting evidence-based information on depression, and MoodGYM (https://moodgym.com.au), which teaches cognitive behavioural skills. Both these interventions are aimed primarily at people with depressive symptoms, and have been found to increase depression literacy and reduce depressive symptoms. However, a downside is that both have high attrition rates because of the time commitment involved.

While RCTs provide the gold standard in demonstrating efficacy, they do not reflect the use of information websites in everyday life, where use is initiated by the consumer, possibly via a search engine, and may involve no more than a cursory look at the content. Such everyday use is not amenable to RCT methodology. However, there have been studies of naturalistic use, where users who access the website answer a pop-up questionnaire and are then followed up later to ask whether the information on the website changed their behaviour. Such studies have been carried out for spontaneous use of MHFA guidelines and bipolar caregiver guidelines on the internet (Hart et al, 2012; Berk et al, 2013). It has been found that small minorities of users report that they did make practical use of the information provided to assist others.

Mobile apps

Many mobile apps have been developed to assist mental health, some of which provide information on mental disorders. A review of mobile apps for bipolar disorder, for example, included 82 apps, with 32 aiming to provide information, while the other 50 were management tools (Nicholas et al, 2015). This review found that most of the information apps failed to cover core bipolar information topics and very few followed best practice guidelines. Furthermore, comprehensiveness of information and adherence to best practice guidelines did not correlate with average user ratings, making it difficult for consumers to identify quality educational apps.

There has also been limited research on mobile apps using RCTs. Where trials have been carried out, they have been with therapeutic apps rather than ones aiming to improve mental health literacy (Menon et al, 2017).

Nicholas and colleagues (2016) have argued that RCT methodology is not well suited to the timeframe of app development. By the time an RCT is carried out, an app can become out of date with such a rapidly developing technology. Instead, they propose greater use of participatory research methods and single case designs. Nicholas et al (2016) have also discussed the challenge of informing consumers about evidence-based apps. The possible solutions include app quality portals, tools to assist consumers to assess the quality of apps and technology for automatic quality accreditation. However, at this point in time, none of these are in operation.

In conclusion, mobile apps have great potential as a medium for improving mental health literacy, allowing individual tailoring and acquisition of user data, but there is limited evidence of their effectiveness, and there are considerable challenges involved in researching this area.

Training courses

A wide variety of face-to-face, online and blended training courses are available to improve the mental health literacy of the public, but most have not been rigorously evaluated. Here I cover two approaches that have a substantial evidence base.

Mental Health First Aid (MHFA)

Mental Health First Aid (MHFA) is a face-to-face training course for members of the public in how to assist a person developing a mental health problem, experiencing the worsening of an existing mental health problem or in a mental health crisis situation (for example, the person is suicidal, self-harming, having a panic attack or has experienced a traumatic event) (Kitchener and Jorm, 2002). Various adaptations of the course have been made, including youth MHFA for training adults to help adolescents (Kelly et al, 2011), versions for specific occupational groups (for example, financial counsellors, medical and nursing students) (Bond et al, 2015, 2016), and adaptations for various cultural minority groups (for example, immigrants, Indigenous people) (Kanowski et al, 2009; Minas et al, 2009). The course has also been delivered in eLearning as well as face-to-face modes (Jorm et al, 2010). MHFA training began in Australia in 2000, but has spread to over 20 other countries, with over 2 million people trained by 2017.

There has been a large number of evaluation studies on MHFA training. A meta-analysis of 15 uncontrolled and controlled trials, including 4 randomised trials, was carried in 2014 (Hadlaczky et al, 2014). This included knowledge outcomes (measured by treatment beliefs and recognition of the problem in vignettes), which were found to have a mean effect size of 0.56 standard deviation units, and behaviour outcomes (measured by the number of times that help was provided during the time between course completion and follow-up), which were found to have a mean effect size of 0.25. The latter effect size was thought to be an under-estimate because some participants had no opportunity to provide help during the follow-up period. No difference was found in effect size estimates between uncontrolled and controlled trials. Hadlaczky et al noted that an important unanswered question is whether MHFA actually improves the mental health of the people helped by first aiders.

Suicide gatekeeper training

A 'gatekeeper' is a community member who is trained in how to recognise someone at risk for suicide, and to refer them to professional help where needed. There are a range of gatekeeper training courses available, which vary in their content. However, common elements are education about suicide or mental health, suicide risk factors, risk assessment, communication skills, resources available and referral skills. Two of the best known are Question, Persuade and Refer (QPR) and Applied Suicide Intervention Skills Training (ASIST).

A review of this area found 53 evaluation studies, but only 8 were RCTs (Burnette et al, 2015). The authors concluded that there is substantial evidence that gatekeeper training produces knowledge gains, including ability to recognise warning signs of suicide and to choose effective intervention strategies. There was also evidence that training reduced reluctance to intervene with suicidal individuals, and that it increased self-efficacy to intervene. However, there was a lack of evidence on whether these changes affected actual behaviour following training, and the effects on preventing suicide attempts are unknown.

Future directions

This chapter has covered a wide range of interventions designed to improve aspects of mental health literacy in adults. These include multi-component community campaigns, internet-based interventions and training courses. This final section proposes ways in which this work could be improved in the future.

Many of the interventions have been found to improve aspects of mental health literacy. However, associated changes in behaviour and mental health have been less investigated. The causal model in Figure 24.1 implies that changes in mental health literacy will produce changes in behaviour and in mental health. Changes in associated behaviour and mental health should be measured wherever possible. A related direction for the future is to more directly test the mediating role of changes in mental health literacy in producing behaviour and mental health changes. An example of this approach comes from a study by Morgan and colleagues (Morgan et al, 2013) on automated email messages promoting evidence-based self-help strategies for depressive symptoms. In an RCT comparing the self-help emails with control emails containing non-directive depression information, the self-help emails were found to increase the use of the promoted self-help strategies and to improve depressive symptoms. A mediation analysis showed that use of the self-help strategies mediated the effect of the intervention on symptoms, providing a strong test of the model implied by Figure 24.1.

A challenge for mental health literacy interventions aimed at adults is their sustainability. Such interventions need to be ongoing, which requires a sustainable funding and propagation mechanism. Some appear to have lapsed, despite successful outcomes (for example, TIPS and some information websites), whereas others have been able to spread to other communities (for example, European Alliance Against Depression, MHFA). The conditions necessary for sustained implementation of successful approaches merit greater attention.

Finally, from a global perspective, mental health literacy interventions have been evaluated in a limited range of high-income countries, with most of the world's population neglected. VISHRAM is a notable exception. Because interventions to improve mental health literacy are embedded in a cultural and health system context, approaches may not be portable to very different communities. There is clearly a need for greater effort to implement interventions appropriate to the cultural context and health systems of low- and middle-income countries.

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An empirical perspective on the concept of mental health literacy in the field of families with parental mental illness

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Introduction

Worldwide, about 14 per cent of the burden of disease is dedicated to mental illnesses (Prince et al, 2007). The relevance of this topic is going to increase in the coming years if one considers the forecast by the World Health Organization (WHO) (2011) predicting that depression will be the most common illness in the Western world by the year 2030. Hence preventing mental diseases is increasing in importance, and, regarding the WHO definition of health, promoting mental health is also necessary to reach a 'state of complete physical, mental and social well-being' (WHO, 1948). Therefore, including mental health explicitly is a critical component when discussing health promotion and health education.

In this context, mental health literacy (MHL) is gaining attention and should be considered a relevant factor for promoting mental health and preventing mental disorders. The concept of MHL was first defined by Jorm et al (1997) as the:

> knowledge and beliefs about mental disorders which aid their recognition, management or prevention. Mental health literacy includes the ability to recognise specific disorders; knowing how to seek mental health information; knowledge of risk factors and causes, of self-treatments, and of professional help available; and attitudes that promote recognition and appropriate help-seeking. (Jorm et al, 1997, p 182; see also Chapters 4, 17, 19 and 24, this volume)

Research about MHL shows that people know less about mental illnesses than about physical illnesses, regarding, for instance, prevention or treatment opportunities (Jorm, 2012). The lack of knowledge and of treatment options is the main reason for delayed help-seeking (Thompson et al, 2004). Poor MHL is also associated with inadequate help-seeking and misunderstandings during treatment (Rickwood et al, 2004). Having a history of mental health problems seems to improve a person's ability to recognise mental illnesses only a little

(Dahlberg et al, 2008). Therefore, extensive promotion of MHL for caregivers and professionals seems promising for improving the situation of people with mental illness or mental health problems, so that those with mental disorders receive early, effective (self-)help and adequate support from others in the community (Jorm, 2000).

MHL promotion might be especially promising for high-risk groups for mental health problems. Children with parents affected by a mental illness constitute a high-risk group with a predisposition to develop mental health problems in childhood, youth or adulthood (see, for example, Rasic et al, 2014; Weissman et al, 2016). Furthermore, parental mental illness has a strong influence on children's needs and everyday interactions. These children do not understand what is going on, worry about their parents, strive for normality (Wahl et al, 2017) and are impacted by processes like tabooing (e.g. implicit rule not to talk to others about the family situation or parent's illness) or parentification (e.g. reversal of social roles – children take more responsibility for originally parental tasks like caring for younger siblings) (Boszormenyi-Nagy and Spark, 2014). Children, as well as parents, have a strong desire for knowledge about the illness to deal with uncertainties and difficulties resulting from mental illness (Wahl et al, 2017). Therefore, these children are a target group for preventive interventions and will most likely benefit from MHL promotion.

The concept of MHL might meet the challenges of the field's special characteristics, such as the fact that the affected and burdened parents are at the same time both a risk factor and the main source of support for their children. Therefore, all family members are in need of effective coping strategies and comprehensive knowledge about their own/parental illness, the risk for the children and formal and informal sources of assistance/support.

Children affected by parental mental illness are part of a complex social system and therefore should not be observed without looking at the context in which they live. Despite their high risk of developing a mental illness, studies show that these children are mostly 'invisible' to the help system (Gullbrå et al, 2014). They often do not receive adequate opportunities for help and for prevention. One explanation for their invisibility and inadequate support might be that those interacting with the children have a low level of MHL. Increasing the MHL of caregivers and professionals, especially improving knowledge about risk, treatment options and prevention, might help diminish this shortcoming. For example, in schools children can be reached for mental health promotion with a low risk of stigma, and the school setting can offer good access to students' families (Bibou-Nakou, 2004). But there is barely any research on teachers' MHL and their ability to identify families' mental health situations or to support children affected by parental mental illness in everyday school life (Bruland et al, 2017). Also, providers of care, such as social workers in child and youth welfare, are not adequately qualified to deal with families affected by parental mental illness (Rehder, 2016). This relevance of MHL outside the mental healthcare system is increasing because stays in hospital are shortened, shifting the recovery from hospital to the family setting (Wagenblass, 2012) hence professional support by social workers in everyday life becomes more and more important for such affected families. MHL promotion may be an opportunity to prepare teachers and providers to better support the children. In this context the following main questions are discussed in this chapter:

1. MHL is seen as a helpful concept to underpin measures of mental illness prevention and mental health promotion. How can it be used for the field of children affected by parental mental illness? What benefits does it hold to be used in the field of children affected by parental mental illness?
2. Which adaptations of the concept are necessary to satisfy the requirements of work with this target group?

To answer these questions, insights into the empirical research of three different projects are reported, projects belonging to the mental health literacy working group of the research consortium 'Health Literacy in Childhood and Adolescence' (2015-18), which analyses the situation of children of parents with mental illness. The findings are then brought together to evaluate, discuss and expand the concept of MHL (Jorm et al, 1997; Jorm, 2000).

Insights into empirical research and results

In this chapter our findings are summarised along three dimensions that occurred in the projects and that are most relevant for assessing and informing the concept of MHL – knowledge (familial and professional), challenges and structures. The first dimension, 'knowledge', is a key component of MHL. According to Jorm et al (1997, p 182) 'knowledge of risk factors and causes, of self-treatments, and of professional help available' leads to mental health-literate action concerning the recognition, management or prevention of mental health issues. The findings presented below arose from qualitative interviews with families, providers and teachers. These experts refer to the kinds of knowledge that affected families, providers and teachers emphasise as relevant in their everyday and professional life. The second dimension, 'challenges', focuses on context-specific challenges. The third dimension, 'structures', which embeds the presented context-specific challenges of social workers and teachers into structural conditions, emerged out of the data as important determinants for MHL. Whereas the most common method to assess MHL is quantitative research (Wei et al, 2015), due to the complexity of the field and the inadequacy of quantitative methods to capture all relevant aspects sufficiently, a qualitative approach is regarded as the research method of choice in all three projects. An advantage of this approach is that it is expected to explore specific conditions of the field and generate deep insights to provide evidence of if and how the MHL concept could be adapted for mental health promotion in families, teachers, and providers (Coe, 2009).

Knowledge

From the point of view of family members of the affected family, firstly, MHL is associated with everyday family life. Family members ask for knowledge about the illness, which might help them develop an understanding of the illness and be able to make sense of the things that are happening. A 55-year-old father, for example, described that his wife was struggling with understanding the illness: "It was a long time that my wife was not able to imagine how this could happen." Family members also need practical knowledge on how to deal with a situation, how to interact with the affected person, and even how to support them. In particular, children need information about the parent's illness and how they could respond to confusing situations. For example, children want to "differentiate, is it the illness or maybe just normal life?" (daughter, aged 14).

Social workers constitute another group of actors working closely together with and for the families on a regular basis, for example, in the context of child and youth welfare. As professionals, they are not as personally affected as family members, but still have good insights into the family situation and may be able to have an impact on it. Social workers argue that they need a synthesis of an interdisciplinary form of knowledge, focusing on different dimensions of mental health. In that sense, social workers first point out that a knowledge base of therapeutic skills is highly relevant to be able to recognise mental illnesses and their developments.

Besides the wish to reduce insecurity when dealing with affected families, social workers highlight that this knowledge might be a framework to reflect professional attitudes and organisational structures:

> 'Let's say – before that training – the team was very normative regarding the role of the mother. If she wants to have a child then she must be able to guarantee the child's supply.… After some training on clinical knowledge we realised that we have to adapt our claims to the specific situation of mentally ill parents. It changed our professional attitude and action: now we are starting way early to provide support; not just when someone is totally out of order. Now we are able to recognise that it is a great effort when the mother is able to say, "Now I need help" – and then we help.'

This quote demonstrates that the possession of psychotherapeutic knowledge may lead to a reflection of professional attitudes and organisational structures.

Additionally, social workers stress a systemic, family-orientated perspective that seems to enable them to see parental mental illness as a family disease that affects all family members in different ways. Systemic theories might help to take into account the different roles of the family members in keeping up and/or irritating this family mental illness. Furthermore, social workers maintain referral knowledge, knowledge on development psychology, knowledge on education and a sensitivity of the interplay between social inequalities and mental health problems.

Concerning the children, educational professionals, and in particular teachers, are most likely to be able to recognise the behavioural and mental health needs of children, and can play an important role in preventing the onset or deterioration of the mental health issue of children of parents with mental health problems (Bibou-Nakou, 2004; Reupert and Maybery, 2007). This can be done by identifying children who show symptoms of mental health issues by supporting them within the school setting or referring them to other support services. Overall teachers stress that the family situation has a huge impact on the child's school behaviour and performance. However, teachers are limited in their sphere of influence because, for example, they lack knowledge on mental health disorders and are widely untrained on identifying mental health issues or in working with affected families and family issues in general. Because there was no evidence-based, structured training for teachers on how to support children affected by a critical family life situation, most of the teachers' knowledge derived from personal or prior work experiences; for example: "We'll get the knowledge if we have such a case" (primary school teacher) or "I primarily use my knowledge as a private person. In my family, there are people who are experiencing a diagnosed depression" (teacher from a secondary school).

Challenges

During our analysis, various challenges became apparent that are related to emotions, interactions and role definitions. This dimension is not a component of MHL, but for all groups it may be a highly important aspect to influence and interact with MHL. Besides interactive and emotional issues, one of the main challenges for the families is participation in 'normal life'. 'Normal life' within a family with mental health issues can differ (immensely) from a family without mental health issues. There are specific family dynamics that might occur, and generally mental illness is a family illness, challenging the children and other related people in their everyday life. One example of a stressful and impairing life situation is to live with a person whose illness is not getting better and supporting this person emotionally, often accompanied with feelings of guilt/resignation, as a 10-year-old girl stated: "I can't deal with it [step-father's illness]. And then she [mother] always says, that it will get better, but it didn't get better." A demand-orientated supply situation could help the child to understand, cope with and normalise the familiar situation. On the other side, social work providers state that – despite existing services – a certain number of affected families are not reached. Besides structural barriers (presented next), social workers named parental feelings of shame and guilt as well as diffuse fears of losing the child and becoming stigmatised as main reasons for avoiding help. Within direct work with affected families, social workers are challenged in keeping the needs of the children in mind. Within professional interactions the children's needs often get lost either because of an excessive focus on parental suffering from their mental illness or because of an assessment of the children's behaviour as pathological itself (for example, deviant behaviour in school), and therefore because of a relocation of the problem to the child. Social workers state that regular supervision and sufficient opportunities to distance themselves from these situations are necessary for a professional working with affected families.

Teachers are well able to recognise changes in students in school performance, social behaviour and outward appearance but express challenges mainly in recognising the causes of such behaviour. They report that this may be attributed to a diverse critical family situation such as parental mental health issues. Yet the interviewed teachers state that it is extremely difficult to find out about family circumstances (and even more about family mental health problems), and therefore they mostly operate with assumptions: "Colleagues teaching the same students have often the same assumptions about a child's family situations, we are talking about that and what to do, but mostly it remains speculative!" (primary school teacher). Furthermore, they report that there is no school strategy on how to respond to children, and feel highly insecure in supporting them.

One further challenge of MHL is related to the role each person involved plays and its limitations to influence the situation. Our results demonstrate that especially teachers have to redefine their role towards children from affected families. In general, teachers' primary role is to educate the child in two forms (academic learning and social learning, including helping children to fulfil typical development tasks). Whereas the subject-specific school curriculum is described in detail, there are diverse and unclear interpretations of working with family and/or mental health issues, even differing between teachers in the same school. Hence, supporting children in the school setting depends highly on 'personal commitment': for example, "This is a personal commitment what you do, and mostly it is the interest acting for the good of the child. Every teacher takes a different route and different understanding of own limits" (primary school teacher).

Structures

Our results point out the relevance of structural dimensions when dealing with MHL in the field of affected families. Teachers express that school structure matters a lot in order to support the children, for example, whether there are school social workers, counsellors and after-class support services available. Teachers perceive it as important to have a common school approach to working with children affected by critical family life events, and also to have good and strong networks to other support services. For some parents, school is a probable source of help for their children. One father also mentioned school structure as relevant, claiming that 'contact people' were missing, and that "it would have been nice if they would have maintained social worker[s] in the schools" (father, aged 55). Social workers also refer to structural dimensions of provision, such as a misfit between available services and the needs of affected families, for example, a high level of bureaucracy even before using services and the prevalent 'come-structure' of services, which means that there is no outreach counselling available but users must go to the services themselves. Consequently, users are expected to be able to initiate the support and to know where to go if they need help. In that sense a so-called come-structure does not include outreach work and is based on assumptions of a high user-sovereignty. Our results reveal that the services available are not conceptualised flexibly enough to give adequate consideration to the different episodes of mental illness, and are often terminated too early. Additionally, the supply situation is not easy to deal with, even for professionals working with broad and longstanding job experience.

The circumstances are generally described as 'confusing', action seems to be 'uncoordinated' and the whole support and service situation is described as an 'impassable jungle', and so hard to understand. One of the reasons for this non-transparency is seen in the lack of economic capacity because most services are based on project funds, which are not continuously available and are low. Therefore, there is a permanent change in the supply situation, and this change has a negative impact on the work of professionals and the situation for affected families. It is also perceived by the families that "some financial stops are put to it" (mother, aged 49). The providers also mentioned a permanent lack of temporal and personal resources for being able to deal with the families in a professional way. Therefore, some services seem to get flooded by the most urgent demands and are unable to meet needs. Regarding social workers' wellbeing, the lack of personal and temporal resources manifests itself in regular overtime (hours) and in the feeling of pressure and personal strain.

A summary and MHL complementation/adaptation

Looking at the MHL concept from various perspectives, it becomes obvious that the current concept suggested by Jorm et al (1997) is useful, but should be complemented and adapted. Besides the original dimensions of MHL, organisational structures or family systems as well as everyday life/routines and professional roles are important. Moreover, dimensions like 'knowledge' have to be adapted. For example, as the interviews with family members revealed, the concept of MHL should be expanded and should also integrate the social aspects of mental health and illness to a larger extent. Different family members emphasise the necessity of dealing with stress and taking care of oneself and also integrating pleasant activities and positive social relationships or sports into their lives.

In the following eight boxes the initial concept introduced by Jorm et al (1997) is compared against our own findings. Thereby, the headings of Boxes 25.1 to 25.4 highlight the original dimensions of Jorm et al's concept, while Boxes 25.5 to 25.8 include four new dimensions that became apparent during our own research. In each box, the results from our empirical research are added below the dimensions, and it is clearly mentioned how the specific dimensions have been manifested in each interviewed group. Despite the need for knowledge about recognition, management and prevention, our research showed that it is utterly important to take into account the structures, attitudes and professional roles of the actors, the family as a system, everyday life in the families/social support system/educational setting as well as the professional roles. Even though all aspects are relevant for each group investigated, the results demonstrate clearly that the manifestation of each dimension varies from group to group in broadness, content and depth. Therefore, our findings support having adapted role-specific MHL concepts.

Box 25.1: Knowledge and beliefs

Families

- Asking for knowledge that is relevant for their everyday life
- Wanting to understand and be able to make sense of the illness
- Complaining about stigmatising attitudes in public

Social workers

- Requiring an interdisciplinary knowledge base

Teachers

- Having knowledge of the impact of a family situation on school children and an explicit professional role of support, for example, as gatekeepers
- Being highly aware of the needs of children in general and the necessity for handling case-related and complex situations sensitively,
- But not being sufficiently and adequately sensitised in responding to the needs of children of parents with a mental health issue (Jorm et al, 1997)

Box 25.2: Recognition of disorders to facilitate help-seeking

Social workers

- Expertise is differently distributed: while some in the field only finished their studies; others have done long-lasting training

Teachers

- Facing challenges in ascertaining or assessing a family situation. In many cases, teachers work with assumptions derived from observations of indices, often children's school performance and social behaviour, and conversations with students and parents (Jorm et al, 1997)

Box 25.3: Knowledge of professional help and treatments available, of effective self-help strategies and skills to give first aid and support to others

Families

- Having a need to deal with the disease, its symptoms and consequences in everyday life
- Often not being aware about help available (especially for the children)

Social workers

- Emphasising referral knowledge as a necessary base for adequate work with affected families, but describe the situation as challenging (see Box 25.5 below)

Teachers

- Utilising knowledge derived from their experiences with other family situations, therefore teachers often follow the same procedure as for other (critical) familial situations
- Seeking help initially inside schools from colleagues and/or school management. In addition, contact the youth welfare service and local school psychological service which are the most frequently addressed help services
- Being in need of more than their gain suspicions to be able to state anything official or on a legal basis (Jorm et al, 1997)

Box 25.4: Knowledge of how to prevent mental disorders

Families

- Often a biopsychosocial understanding of mental disease prevention and mental health promotion

Teachers

- Having general knowledge related to school processes but not related to prevention of mental disorders (Jorm et al, 1997)

Box 25.5: Structures (additional dimension)

Families

- Claiming for an improvement in the care of children and parents, and for more education about opportunities for help

Social workers

- Facing a non-transparent supply situation

- Facing challenging working conditions
- Facing organisational barriers in accessibility and a mismatch between the needs of the affected families and the conceptual organisation of services

Teachers

- Defining the possibilities for teachers and their support in working with children, for example, the number of children in the class, learning targets, the availability of school social workers, and the support school management

Box 25.6: System (additional dimension)

Families

- As a system (to be of use in dealing with everyday life-related challenges)

Box 25.7: Everyday life (additional dimension)

Families

- Everyday life in the family and its genuine challenges

Social workers

- Everyday life of social workers with limited resources and bureaucracy

Teachers

- Everyday life of teachers striving for teaching and supporting a whole class of individuals and further aspects of the educational setting

Box 25.8: Professional role (additional dimension)

Families

- Professional role of family members as protective factors but also co-affected

Social workers

- Professional role of social workers with the scope of tasks they are allowed to perform

Teachers

- Finding a balance between fulfilling the professional role as a teacher and its requirements (teaching a large class) and paying attention to individuals and responding to their needs. Also finding a balance between being impacted by and investing in the child's life and his/her family and drawing and sticking to healthy boundaries and acknowledging the limitations of one's own influence.

Discussion and conclusion

We first had to consider the research gap for MHL in this field (see, for example, Bruland et al, 2017). Building on our own results, in the following we discuss the MHL concept in the field of children affected by parental mental illnesses, and which adaptations of the concept are necessary to satisfy the requirements of this field. MHL is mainly seen as a functional ability including the key component knowledge about various psychiatric diseases and their treatment, as well as the handling of symptoms of affected people, for example, seeking professional help (Mårtensson and Hensing, 2012).

Knowledge

Regarding the dimension of knowledge, all three actors (affected families, social workers and teachers) stress in different ways that knowledge about mental health problems, symptoms and their causes is highly relevant to be able to deal with parental mental health problems. The study assessing the MHL of teachers, in particular, shows that teachers are widely untrained in identifying mental health issues. Also, social work providers highlight a required knowledge base to help them in recognising mental health problems. But they also argue that they need different kinds of knowledge resulting from various academic disciplines such as psychology, sociology and pedagogy. Family members desire knowledge with reference to everyday life, knowledge that will help them to understand and make sense of the situation, and empower them in dealing with confusing situations. Regarding the dimension of knowledge, these findings show that in the field of affected families, mental illness itself needs to be considered in its multidimensionality (for example, mental illness and its symptoms and causes; mental illness as a family disease; mental illness and its interplay with social inequalities). Behind that background, the studies suggest extending the underlying understanding of mental illness within MHL to a more holistic understanding of health and illness. In the field of affected families, the understanding of mental illness should not be reduced to pathological, behaviourist and individual-centred dimensions.

Mental health-literate organisations

The studies also reveal different challenges concerning the life and working with families with parents with mental ill health. The articulated challenges depend on the different social contexts where they were gathered. It follows that MHL needs to be seen as a context-specific and flexible concept (Kutcher et al, 2016) that is able to adapt its components to the specific characteristics of different contexts. These always depend on structural dimensions that enable or limit mental health-literate actions. Especially teachers and social workers' actions are embedded into organisational frameworks. These findings show that first, MHL for social workers and teachers depends on enough financial, personal and temporal resources as well as the implementation of setting specific structures (for example, school social workers, all-day support, coordinated and permanent cooperation between different support services) that allow a professional, mental health-literate support for children of parents with mental disorders. Second, the studies suggest reflecting on organisational barriers that limit accessibility to services for affected families (for example, 'come-structure', a high level of bureaucracy, a misfit of services and needs). Both findings refer to the necessity for extending the concept of MHL in the sense of an integration of organisational dimensions. According to Kutcher et al (2016), MHL has to be adapted to specific social and organisational structures.

Within health literacy debates, concepts of health-literate organisations are discussed that explicitly 'refers to the capacity of organisations to provide programs, services and information in ways that are accessible to all individuals and communities' (Trezona et al, 2017). Also, Brach et al (2012) define 10 attributes as guidelines for conceptualising health-literate organisations. They stress health literacy as a cross-sectional task that needs to be considered at all levels of the organisational hierarchy (see Chapters 31 and 35, this volume). These perspectives on organisational barriers and conditions need to be transmitted to MHL discussions, especially in the field of families with parental mental health problems. In that sense, Parker and Ratzan (2010) highlight that individual abilities and system demands and complexities are two sides of the same coin. This means that the MHL of professionals and organisations is likewise important to individual MHL as they steadily interact with each other in the context of mental health promotion activities – at least in healthcare or social care settings.

In general, our findings suggest that the concept of MHL is a valuable framework for mental illness prevention and mental health promotion. MHL interventions can be classified into four categories: whole community campaigns, community campaigns with a special focus on young people, school-based interventions and individual training (Kelly et al, 2007). For all these interventions it is necessary that the application of the concept is context-sensitive and flexible to adapt to the specific requirements of the applied field. This requires adjustments. According to our research, different actors require concepts that are underpinned by a holistic understanding of mental health/illness; perspectives that enable us to understand mental health/illness in its multidimensionality (for example, as a pathological phenomenon; as a 'family disease'; as part of the interplay with social inequalities) seem highly relevant for a mental health-literate work, and not only in the field of affected families. Additionally, our studies suggest expanding the concept of MHL to structural and organisational dimensions that are highly influencing professional actions in the field (for example, adequate working conditions; implementation of setting specific infrastructures). But the focus on organisational dimensions is also relevant to reveal organisational barriers that limit the accessibility of services. In this sense, our studies suggest more research on the special structures of organisations (for example, structures of access, conceptualisations of services), in our case regarding their fit to families suffering from mental health issues.

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26

Putting the literacy back into health literacy: Interventions in US adult literacy and English language programmes

Maricel G. Santos and Julie McKinney

Introduction

This chapter poses a fundamental – and increasingly urgent – question in the field of health literacy: how do we prepare adults with low basic skills in English, reading/writing and maths to navigate today's healthcare system? In the US it is impossible to answer this question without a working understanding of our federally funded adult basic education (ABE) system. It is also impossible to answer this question without an informed appreciation of how enrolment in ABE courses can lead to meaningful change in areas such as improved health, employability and civic participation. This chapter seeks to fill this knowledge gap for health literacy practitioners, researchers and policy-makers who may not be familiar with the US ABE skills system.

We make the case for developing health literacy interventions that (1) harness the pedagogical expertise about literacy learning already well established in the ABE field and (2) are not constrained by ideologies about low literacy and patient competence that treat health literacy as an autonomous set of skills that a patient/learner does or does not master (for more information on autonomous literacy models, see Chapter 36, this volume). Our argument is not wholly original, as researchers working at the nexus of adult education and public health (Rudd, 2002; Papen, 2009; Black et al, 2013) have long argued for such an ideological shift, and yet the level of investment in partnership building and interdisciplinary collaboration with the ABE system remains disproportionately thin compared to investment in the development of new health literacy measures, the creation of easy-to-read health materials or clinical communication strategies.

After making the case for re-thinking our assumptions about health literacy, we shift our attention to the promise of health literacy interventions based in the ABE context. In what ways are ABE classrooms uniquely qualified to support health literacy growth? We argue that a broader understanding of health literacy as a cognitive skill and social practice will lead to a fuller, more accurate appraisal of how adult educators support health literacy growth. A narrow view on health literacy as a bound set of reading and speaking skills does not account for the work adult educators do to leverage their learners' knowledge and skills to navigate a variety of contexts, such as healthcare, employment and their children's schools. Many adults with low basic skills view their classrooms as safe, non-threatening environments where asking questions and active problem-solving are encouraged; these classrooms warrant more attention as vital gateways to equitable access in healthcare. We draw attention to the unharnessed promise of health literacy interventions in ABE classrooms as valid spaces for meaningful health literacy growth.

Framing health literacy in the adult basic skills educational context

For many adult basic skills educators, it is pointless to teach the cognitive dimensions of literacy (that is, the mental processing of information when reading, writing or speaking) without taking into account the functional purposes of literacy (that is, the real-world tasks that require these skills) or the social value of those literacy tasks, such as getting a better job or enrolling in health insurance. With this emphasis on the active application of literacy skills, the pedagogical goals of many adult education classrooms are most in line with health literacy definitions and intervention approaches that emphasise the acquisition of new social practices in the healthcare environment, not merely the acquisition of reading/writing skills or the 'depositing of health content into learners' minds' (Freire and Macedo, 2013). While early health literacy frameworks tended to link improved health literacy to increased patient comprehension and compliance with healthcare instructions, adult learning frameworks tend to focus on literacy as a vehicle for learner empowerment and social agency (cf Knowles, 1980; Wallerstein, 1983; Nash et al, 1992).

To bridge cross-disciplinary boundaries between health literacy and adult education, we need health literacy frameworks that can unify a focus on literacy as a social practice and learning process. The definition from the Calgary Charter on health literacy is particularly valuable because it recognises the cognitive, linguistic and social skills that contribute to one's health literacy competence:

> The use of a wide range of skills that improve the ability of people to act on information in order to live healthier lives. These skills include reading, writing, listening, speaking, numeracy, and critical analysis, as well as communication and interaction skills. (Coleman et al, 2011)

The Calgary Charter also emphasises that health literacy is an attribute of 'the public and personnel working in all health-related contexts', not an individual characteristic. This definition enables us to appreciate that our health literacy is linked to the health literacy competence of those around us (for example, peers, teachers, family members and health professionals). The Calgary Charter is unique in that it specifies principles for curriculum design, providing a useful framework for integrating health literacy learning and teaching in adult basic skills classrooms (see Chapter 5, this volume, for a pilot project based on the Calgary Charter).

Nutbeam's (2000) definition of health literacy broadly interprets the meaning of 'social context' in healthcare, ranging from one's personal healthcare circumstances to the larger public health environment that shapes our access to resources. Nutbeam (2000, p 263) argues that 'the narrow definition of health literacy misses much of the deeper meaning and purpose of literacy for people…. One approach to classification simply identifies types of literacy not as measures of achievement in reading and writing, but more in terms of what it is that literacy enables us to do.' In this way, Nutbeam treats health literacy as a *resource* for healthy living, not an end unto itself. This view is particularly useful when working with adult learners whose skill deficits tend to be magnified if their health literacy is reduced to competency in English proficiency or reading comprehension.

Nutbeam's (2000) conceptualisation of health literacy includes three types of literacy – basic/functional, communicative/interactive and critical – a scaling that demonstrates 'different levels of literacy progressively allow for greater autonomy and personal empowerment' (2000, p 264; for more information see also Chapters 1, 11 and 14, this volume). Nutbeam's inclusion of *critical* literacy complements adult learning frameworks that value increased autonomy and self-empowerment as important literacy outcomes (cf Wallerstein, 1983; Auerbach, 1992; Nash et al, 1992). From a critical approach, adult educators are problem-posers who ask 'questions that … help students think more analytically about aspects of their lives that they may assume cannot be changed' (Degener, 2001). When students collectively reflect on their 'common sense knowledge' – for example, how much sugar is in a can of soda (fizzy drink) – they are able to identify the reasons behind their struggles to live healthy lives, and identify action steps. This is where Nutbeam's (2009) 'critical health literacy' becomes critical! Because adult educators work closely with students over the course of this discovery process, their influence on students' critical health literacy merits far greater attention in health literacy research and in proposed interventions to educate 'vulnerable' communities.

Health literacy in the US basic skills population: a brief history

The health literacy movement began in different countries via a variety of initiatives (Pleasant, 2013). In the US it was catalysed largely by the results of a large national study that showed a surprisingly low rate of functional literacy among adults. Two successive studies produced similar, equally discouraging results. The National Adult Literacy Survey (NALS) in 1992 found that almost half of American adults had marginal literacy skills. These findings prompted conversations about why so many people struggle to understand complex health information and, indeed, further studies revealed serious gaps between the reading skills of adults and the literacy demands of the healthcare system. This skills gap motivated adult literacy educators to ramp up the focus on health literacy in their classrooms to prepare their students meet these healthcare challenges. This ABE response to the health communication needs of their students was already underway before the public health field began addressing the problem on a widespread scale and adopted health literacy practices and policy goals (Sticht, 2002).

In 2003, a follow-up iteration of the NALS was administered under a new name – the National Assessment of Adult Literacy (NAAL) – and included 28 items that measured *health literacy* skills in addition to measures of document literacy, prose literacy and numeracy skills. A major finding was widely published in healthcare and other fields: 90 million Americans – almost half of the total population – did not have the skills to take care of their health (Nielsen-Bohlman et al, 2004). The NAAL further revealed that the demographic groups with the lowest levels of health literacy included people who had not finished high school and those whose primary language was not English. As we discuss later, these demographic characteristics also describe many adult learners in ABE programmes.

These distressing survey results sparked a movement to reduce the literacy-related demands of the healthcare system. New standards in plain language were applied to written materials, and new techniques for oral communication were created for healthcare providers. Now, there were focused efforts on both sides working to close the health literacy gap: providers were lowering barriers, and individuals were being educated in health literacy skills. Unfortunately, although the NAAL results generated this momentum, no plans were made to do follow-up surveys to see if these skills improved over time.

Starting in 2012, a new assessment platform, called the Program for the International Assessment of Adult Competencies (PIAAC), was administered in 24 developed countries. The PIAAC did not include a health literacy component, but assessed three categories of skills: (1) literacy, (2) numeracy, and (3) problem-solving in technology-rich environments. Since the PIAAC measurements and skill level categories did not match those of the NAAL, results could not be compared to see if US adult skills, particularly in the health literacy domain, had improved since 2003. The PIAAC results, however, did show that the US was poorly ranked in all categories, especially numeracy (Rampey et al, 2016). Another notable finding was that the US, along with Germany, had a significantly stronger association between literacy skills and self-reported health status than other countries. In other words, poor functional literacy skills appear to be a stronger predictor of health outcomes in the US than in most other countries. This finding further supports the need for a strong system of ABE and for incorporating health literacy skills into its curricula.

Adult basic education in the US

A focus on the ABE system in the health literacy field signals a commitment to supporting health literacy advancement where many adults are *already* invested in learning new skills. Adult education in the US is a loosely organised system of programmes that help adults to improve their skills in order to function more successfully in society. Funding comes from multiple government agencies, but primarily through Title II, Adult and Family Literacy, of the Workforce Innovation and Opportunity Act (WIOA). There is little federal oversight of how programmes should be structured or how programmes should articulate with one another. While the system is often viewed as an unarticulated 'patchwork of services' (Wrigley, 2007), this fragmentation also means that states and regional districts bear much of the decision-making responsibility for how to address the basic skills needs of local populations.

ABE programmes are run by a diverse array of providers, including adult learning centres, public schools, community colleges, regional multi-service centres, career development centres, employers, housing developments, religious organisations, correctional institutes and various community-based organisations. The adult education teacher workforce largely consists of part-time professionals or volunteer tutors. Although most states have set forth professional teaching standards, these do not always translate into ongoing professional development or training opportunities. These training opportunities, however, have been expanding, with more programmes addressing adult learning theory and English as a second language (ESL)/literacy instruction, thus deepening the pedagogical expertise of the ABE workforce. There is also an emerging practice of training ABE teachers to address health literacy specifically, which guides them in how to approach this topic, and links them to a growing body of health literacy curricula and other supports.

In 2015, the ABE system served over 1.5 million adult learners (US Department of Education, 2016), although the need for services is estimated to be much higher: about 4 per cent (over 12 million adults) of the US adult population report not speaking English well, and about 12 per cent (over 37 million adults) lack a high school credential. Most publicly funded programmes operate at capacity, so there are waiting lists for classes across all 50 states (National Council of State Directors of Adult Education, 2012).

While the contexts of delivery may vary, ABE programmes share a common curricular goal: to teach literacy, numeracy and digital literacy skills, and ultimately, to help adult learners use these new skills to improve their lives. These improvements may manifest in getting better jobs, continuing their formal education, participating more fully in community and civic activities and taking care of their families' health.

ABE programmes enrol learners from diverse ethnic, racial and linguistic backgrounds, schooling histories and learning goals. The ABE population includes demographic groups that overlap with those groups historically deemed 'at-risk' or under-resourced in healthcare, including adults who have low income or are un- or under-employed, immigrant and refugee adults who are not proficient in English, and elderly adults (US Department of Education, 2015, 2016). For several decades, the ABE system has supported the integration of adult education programming with early childhood education for parents or caregivers of young children (Clymer et al, 2017). Despite drastic cuts to family literacy programmes in recent years, large numbers of parents/caregivers continue to enrol, making the ABE system arguably one of the most significant contexts for addressing the health literacy needs of this population. The ABE system also serves an increasing number of youth aged 16-24 (Davis, 2014), a population that to date has received little attention in health literacy research (Manganello, 2008). The ABE system also serves historically hard-to-reach populations, such as immigrant and refugee adults without legal documentation, as well as English language learners with little to no print skills in the primary language, and limited formal schooling experience (one of the fastest growing sectors of English language programming; see Center for Applied Linguistics, 2010).

Adult educators are ideally positioned to speak to the diversity of the ABE population and their learning needs and goals. By tapping into this professional knowledge base, the health literacy field can help move adult educators into a position of greater visibility and influence in the health literacy field, and suggest strategies for cross-disciplinary partnerships. For more information on the link between adult education and health literacy see Chapter 2, this volume.

Evidence base

Many ABE programmes now integrate health literacy skills into their curricula, and in some cases offer stand-alone health literacy classes, which combine the standard goals for literacy, numeracy or language acquisition with health literacy goals. For far longer than the health literacy field has been around, teachers have found that using health as a context is motivating for students and helps them to master the competencies for literacy and language acquisition (cf Sticht, 2002).

A growing body of empirical literature demonstrates that health literacy instruction in ABE classrooms has a positive impact on adult learners' health literacy skills and, in turn, on their health behaviours. Studies have documented gains in the following areas for adult learners: knowledge of health topics and preventive health actions; confidence and self-efficacy to advocate for their needs; skills to find information and communicate with healthcare providers; and ability to navigate the healthcare system, make informed healthcare decisions and understand their rights and responsibilities (Kurtz-Rossi et al, 2006, 2007; Levy et al, 2008; Soto Mas et al, 2013; Santos et al, 2014). Other researchers have measured intention to act, and found positive gains as well. For example, learners have reported that they were more likely after the instruction to make a doctor's appointment, get a screening or change their lifestyle (Kurtz-Rossi et al, 2007). Another important finding concerns the diffusion of the new information and skills to learners' families and communities (Kurtz-Rossi et al, 2006; Hohn et al, 2010; Santos et al, 2014), which highlights the impact of classroom instruction on the broader community.

The ABE curricular focus of health literacy studies varies. Some studies focus on integrating a broad range of navigation and communication skills (for example, talking to healthcare providers, reading health labels) into the ABE curriculum (Soto Mas et al, 2013). Health literacy skills have also been addressed in the context of specific healthcare topics, including lead poisoning prevention (Handley et al, 2009), healthy eating (Santos et al, 2011; Duncan et al, 2012), type 2 diabetes (Santos et al, 2014), hepatitis B (Coronado et al, 2008; Taylor et al, 2008), and breast and cervical cancer (Kurtz-Ross et al, 2006). This list reflects the wide range of health content that ABE educators value as curricular themes. These findings demonstrate not just the acquisition of new skills, but also their practical use, and the civic engagement and social empowerment that results.

More research needs to examine the educational pedagogies that result in significant gains. As noted earlier, there is great variety in teaching methods and in professional development in the ABE system, but for the most part, ABE teachers employ a participatory approach that values the students' beliefs and experience, and provides ample time to discuss, process and practice the use of new skills and knowledge. Hohn et al (2010) investigated teaching methodologies, and found that the ABE class' 'collective efficacy' – the support of peers during the learning process – contributed to individual self-efficacy.

While this literature is growing, many successful models and partnerships do not make their way into leading public health journals. Thus the 'practitioner wisdom' of ABE teachers about the variation and dynamics in health literacy learning is rarely visible to public health scholars. For example, a recent white paper, *Adult basic education and community health center partnerships: Improving the health of ABE learners*, produced by the Open Door Collective, features several successful, sustained ABE–public health partnerships and curricular models that have not been fully documented in the scholarly literature.

Very few of the aforementioned studies measured the health literacy levels of the learners using conventional tools in the health literacy field. In fact, the most common available tools, like the Rapid Estimate of Adult Literacy in Medicine (REALM) or Test of Functional Health Literacy in Adults (TOFHLA) are designed to measure *health-related literacy* rather than the more robust concept of health literacy that is accepted today. Instead, several of the ABE studies used pre- and post-tests to tap into gains in health knowledge (for example, anatomy terminology, the difference between primary and emergency care), changes in self-care skills and knowledge (how to do a breast self-exam), and intention to change behaviours. Additionally, several of these studies used common standardised measures, such as the Test of Adult Basic Education (TABE), to track gains in programme-mandated curricular goals, and found that general literacy skills improved at least as much as in classes without the health literacy content. This finding signals a need to re-think health literacy measurement tools and to invest in sustained partnership with literacy educators.

An example: Health literacy learning in the HEAL:BCC programme

ABE classrooms are places where adults learn new skills and are given multiple opportunities to *talk* about their learning. Extensive adult learning theory has demonstrated that this metacognition, referring to a person's awareness and management of their own learning process (Oxford, 1990), plays a critical role in learning any new skill. By working with ABE teachers and learners, the health literacy field is better poised to gain more insight into health literacy learning as a metacognitive activity: when a learner expresses the need for more health information or seeks to take action to improve their health, the classroom responds by providing a meaningful context for goal-setting, identifying resources for problem-solving, reflecting on milestones or roadblocks, and applying new skills to future contexts. ABE classrooms provide a unique window into health literacy learning as a process of learning *how* to manage one's own goals for living a healthy life. We illustrate this promise with a discussion of the ABE-based health literacy programme called HEAL:BCC (Health Education and Adult Literacy: Breast and Cervical Cancer) (Kurtz-Rossi et al, 2006, 2007). Health literacy skills were effectively taught in these classrooms and contributed to gains in navigation skills, knowledge about cancer prevention, self-efficacy and changes in behavioural intention, including getting a wellness check-up and scheduling a mammogram.

HEAL:BCC was a collaboration between World Education, Inc and the US Centers for Disease Control (CDC), supported by a three-year demonstration grant. A partnership between ABE teachers, public health researchers and health educators, the project aimed to raise awareness and improve access to information about breast and cervical cancer to ABE learners. Implemented and evaluated in ABE programmes across eight states, the comprehensive curriculum addressed several topics, including: good health, risk assessment, cancer, preventive habits, early detection, communicating with healthcare providers and accessing services.

An over-arching goal of HEAL:BCC was to encourage more women in the ABE programmes – many of whom were low-income – to get pap smears and mammograms. Ultimately, the curriculum sought to help both women and men in the ABE classes 'better understand health information, take action for themselves, and advocate for their families and communities.' These goals are reflected in these teacher comments:

> 'As a language teacher, I saw my role more clearly as providing vocabulary and basic health information about breast and cervical cancer and providing opportunities to practice language skills that would help students access the health services available in the United States. I wanted to give the students the tools they needed to get a Pap smear and a mammogram, to know more about breast self-examination, and to talk with their health practitioners more about all of this…. One concrete goal was to get women students in my class to the clinic for Pap smears and if needed mammograms and to start doing regular breast self-exams. Most important for the men and women in the class, I wanted to bring these issues into their everyday consciousness.' (quoted in Hewitt, 2005)

HEAL:BCC incorporated a variety of learning tasks designed to support the students' individual and collective exploration of emotional and personal experiences of illness or healthcare:

- learning and practising new vocabulary related to cancer prevention (for example, mammogram) and preventive health more broadly (for example, risk, screening);
- role-playing scenarios, like a friend seeking out healthcare advice from a peer;
- oral presentations in which students have the opportunity to present information about cancer prevention to their peers; and
- a blend of small-group and large-group discussions in which students discussed cancer risk statistics or personal stories about cancer.

As suggested by this list, the HEAL:BCC teachers' integration of a variety of instructional approaches was significant because students were given multiple, meaningful opportunities to engage with the cancer content, check their comprehension, compare perspectives and ask questions, thereby increasing the likelihood of learner uptake and retention of new information. In contrast to efforts to 'simplify' health content in 'plain language' campaigns, the goal in HEAL:BCC lessons often focused on *message abundancy*, referring to the 'amplification and enrichment' of the learning context, 'so that students do not get just one opportunity to come to terms with the concepts involved, but in fact may construct their understanding on the basis of multiple clues and perspectives encountered in a variety of class activities' (Walqui, 2006, p 196).

While the curriculum addressed the literacy and language skills that were required by the ABE programmes, it was also geared toward taking action (for example, self-assessing one's own risk) and then processing these individual action steps as a group. Learners were encouraged to share stories of people they knew who were affected by cancer, and the teachers created a space for these conversations. Learners were also encouraged to share and process their own cultural views, beliefs and experience with health and healthcare. This personalised approach to instruction had a positive impact on the students' health behaviours and motivation to make changes. As one teacher observed, "it became clear that it is not necessarily just a lack of knowledge about Pap smears or mammograms that keep people from getting them: it is deeply rooted attitudes, experiences and health practices." Through multiple opportunities to compare their 'common sense' perspectives about cancer with that of their peers' experiences, and the information presented in the curriculum, the learners were able to incorporate the new information with their own beliefs and experiences. Throughout the course, students were encouraged – by their peers and teachers – to adopt healthy habits, make appointments with healthcare providers and share what they were learning with their families and friends. In this way, the impact went far beyond learning the literacy or language skills, and helped to support the use of these new skills to take action for the learners' own health, and to become agents of change in their communities.

The impact of the HEAL:BCC curriculum is captured in the voices of this teacher and students:

> 'Mary's story [about breast cancer] helped students look at their own health attitudes and behaviors. One student took it home and shared the story with her teenaged daughter. Her daughter's response was, "Mami, you have to take care of yourself, go to the clinic to make an appointment for a check-up. It's a serious problem." And in fact that student did go have a much needed check-up after we finished.' (quoted in Kurtz-Rossi et al, 2006)

> 'I learned that when I have some problem with the health I should go to the doctor. When I talk to the doctor I shouldn't feel shy to talk to the doctor all about my problem.' (quoted in Kurtz-Rossi et al, 2006)

> 'I learned that I have to pay attention to my mother and my sister because sometimes my mother doesn't go to her appointment. I don't know if she had a mammogram or Pap smear.' (quoted in Hewitt, 2005)

In sum, trained adult educators, like those who worked on the HEAL:BCC curriculum, have pedagogical strategies for creating safe learning environments where students feel free to admit confusion, share personal experiences and ask questions. They also have strategies for breaking down concepts that are hard to learn, and helping learners incorporate new skills into their daily lives. Each unit in the curriculum included opportunities for learners to share what they already know and want to know about cancer, and generate real-world goals. In this way, the teaching and learning strived to be authentically person-centred and participatory. These qualities – which emerge because there was a professional commitment to learner engagement in the HEAL:BCC project – demonstrate the ripe conditions needed for meaningful health literacy learning.

Final thoughts

We began this chapter with a question about the scope of work required to improve health literacy outcomes for adults with low basic skills. We hope our readers are convinced that the pursuit of answers will be most productive if viewed as a shared commitment between adult education and public health. We know that exploring answers to this question will likely test some enduring assumptions about literacy and literacy growth that guide health literacy policies and interventions. To effectively address the health literacy needs of adults with basic skills, we must embrace a broader understanding of literacy as both a cognitive skill and social practice, as well as foster a deeper appreciation for health literacy learning in adult education classrooms.

While we have focused on health literacy in US adult education contexts, we acknowledge that there is a critical need to share evidence, measurements, and intervention designs across international lines. These discussions will be particularly useful to have with countries that have extensive basic skills education systems, health literacy policies that specify a role for the adult basic skills education or similar shifts in immigration patterns (cf Pleasant, 2013). We also hope that the approach, methods and curricular resources used by US ABE programmes to address health literacy challenges can serve as a model for basic skills programmes in other countries.

Increased investment in partnership-building between the US adult education and health literacy researchers will go a long way in changing the landscape in health literacy interventions. And yet, expanded sources of funding alone will be insufficient. Effective partnerships will also require a serious interrogation of what we think health literacy is and a renewed commitment to interdisciplinary problem-solving.

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Part 3

POLICY PROGRAMMES TO PROMOTE HEALTH LITERACY

The health and wellbeing of a population are important contributors to the social and economic development of societies. However, recent studies have revealed that many people across the world face problems in accessing, understanding, appraising and applying information to manage their health. Health literacy can be a determinant of health outcomes, which is why we cannot neglect the public health challenge concerning the impact of limited health literacy. To build a health-literate society, we need a health-literate public, health-literate health professionals, and health-literate decision-makers. This requires collective efforts from all stakeholders in policy, research, education and practice to bridge the gap. It is the right thing to do because improving health literacy is evident, it is measurable, it is feasible, and it is for the public good. According to this reasoning, health literacy is about rights, access and transparency. It is about a new form of health citizenship, in which citizens take both personal responsibility for health and become involved as citizens in social and political processes that address the root causes of health inequalities as well as inequalities in access to care.

Notably, this part of this book aims to illustrate how more and more countries are actively engaging in promoting health literacy on the political health agenda. It provides concrete examples on how we can develop political goals, strategies and action plans to improve health literacy for all. From their policy study supported by the European Commission, in Chapter 27 Iris van der Heide and colleagues provide insights into policies and actions that have been put in place in EU member states at national and regional levels during the past years. Their analysis shows that the health literacy agenda still needs to mature in many European countries.

One of the countries in the lead concerning policy development is Scotland. In a case study in Chapter 28, Graham Kramer and colleagues share their experience on how the first and second Scottish health literacy action plans, *Making it easy* and *Making it easier*, were developed and implemented. The Scottish national action plans have given encouragement and inspiration to many health literacy champions who are making a real difference and working hard to help achieve the ambition in Scotland. Internationally they have contributed to the case for action on health literacy and helped other countries to follow suit.

Canada was among the first countries to embrace the concept of health literacy, and it forms a strong part of the health promotion agenda, as explained by Sandra Vamos and colleagues in Chapter 29. The journey continues with ongoing interest and contributions across a continuum of discipline, background and expertise ranging from tireless individual champions to those new to the field. They argue that while governments and policies can set important preconditions as enablers to move the health literacy agenda forward, people must still be empowered to participate in their health and learning and support the health and learning of others. The Canadian Action Plan remains a call to action to close divides, underpin policy and help make the vision for a health-literate Canada a reality.

In Austria, the results of the European Health Literacy survey had an impact on the discussions of a new health reform leading to the implementation of health literacy as one of 10 national targets. The Austrian lessons learned are introduced by Peter Nowak and colleagues in Chapter 30. They explain how it was a welcome coincidence that the survey results became available at a time when the health targets were developed and a fundamental reform process of the health system in Austria was about to start. These developments opened a window of opportunity that resulted in high-level political commitment to the creation of a health-literate Austria.

In Chapter 31 Anita Trezona and colleagues discuss the past, present and future directions for health literacy in Australia. In Australia, 60 per cent of the population face limited health literacy and means have been developed to manage the health literacy divide in the country. Notably, they highlight that a positive outcome of the reframing of health literacy as a shared responsibility of both individuals and healthcare organisations was the inclusion of actions in state and territory policies that seek to meet the health literacy needs of consumers. However, a negative consequence of the reframing has been a narrowing in the scope of health literacy policy priorities since the framing of health literacy as a quality and safety issue almost exclusively positioned it within policies related to clinical care and health service delivery. Essentially, their thorough policy analysis provides unique insights into the dynamics related to real-time agenda-setting and policy-making where some agenda topics win over other topics that are also relevant.

Policy dynamics are also described by Julie McKinney and R.V. Rikard in Chapter 32, who reveal an in-depth account of evolvement in the US. They explain how it began as a grass-roots movement and grew from real needs identified by a wide variety of social services and health professionals struggling to serve vulnerable populations. These needs, and the solutions that were created, were the driving force to guide the federal policies that later stepped in to provide the top-down support.

In Chapter 33 Susan Reid and Carla White highlight health literacy in New Zealand as the tale of serendipity, indigenous health and addressing inequalities and inequities. They describe how New Zealand has developed a framework that outlines expectations for the health system, health organisations and the health workforce to support health literacy being a core business at all levels of the health system. Essentially, they wish to embrace all population groups.

Finally, on a different note, Olli Paakkari and Leena Paakkari introduce the example of incorporating health literacy into the school curriculum in Finland in Chapter 34. The learning of health-related competencies in basic education has recently become a national-level right of every pupil. They outline examples of learning principles and content, and state that the developments will undoubtedly require new ways of thinking about teaching, learning and assessment. Also, a new health education curriculum, with its explicit emphasis on health literacy, imposes demands on health education teacher training.

It is the hope that this part of the book concerning policy programmes will inspire and motivate others to follow in the footsteps of the presented countries to engage in developing national targets, strategies and action plans. Health literacy is essentially a political choice.

27

Health literacy policies: European perspectives

Iris van der Heide, Monique Heijmans and Jany Rademakers

Introduction

Health literacy in Europe and the role of policy-makers

Health literacy can be defined as the ability to read, filter and understand health information in order to form sound judgements (European Commission, 2007). Health literacy enables individuals to make informed decisions, which makes health literacy an important public health goal that can potentially reduce health inequalities within societies (Nutbeam, 2000). Where the topic of health literacy has mainly received attention within the realm of research and clinical practice, it is increasingly being recognised that efforts are needed on a health policy level to enhance health literacy on a population level (Kickbusch et al, 2013). Health literacy is not just the responsibility of the general population or of a single sector: it crosses boundaries, professionals and jurisdictions (Mitic and Rootman, 2012, p 17). Policy-makers are important stakeholders in this, and enhancing health literacy should therefore be a target of (national) policies.

In recent years, the interest in health literacy has been growing in European Union (EU) member states. The number of scientific studies on the topic is increasing, various educational and care improvement initiatives are being undertaken, and some countries have developed a national policy or formulated specific goals regarding health literacy in their general public health targets. Many of these activities were inspired by the first European international comparative study on health literacy, the European Health Literacy Survey (HLS-EU) (Pelikan et al, 2012; see also Chapter 8, this volume). The HLS-EU study was conducted in 2011 and focused on the level of health literacy in the general population of eight European countries: Austria, Germany (Nord-Rhein-Westphalia), Ireland, the Netherlands, Spain, Greece, Poland and Bulgaria. Since then, other European countries have also used the HLS-EU instrument to measure the level of health literacy in their population (Espanha and Ávila, 2016; Palumbo et al, 2016).

In 2013 the World Health Organization (WHO) published a report describing the 'solid facts' on health literacy in Europe (Kickbusch et al, 2013), which was in part based on the outcomes of the HLS-EU study, indicating that nearly half of all adults in the eight European countries that participated in the survey had inadequate or problematic health literacy skills (Pelikan et al, 2012). The difference between countries in this respect was considerable. Of the eight countries, the Netherlands performed relatively best (28.7% poor/inadequate health literacy) whereas Bulgaria had the worst rates (62.1% poor/inadequate health literacy). Since the health status of a country's population is generally correlated with the health literacy levels of the population, the WHO report called for action among policy-makers and health professionals to put policy and strategies into place that could enhance the population's level of health literacy and thereby their overall health status (Kickbusch et al, 2013).

In the years following the HLS-EU study, initiatives have been undertaken by various stakeholders across the EU to advance health literacy on the European agenda (Sørensen et al, 2013). Furthermore, in the European Commission's health strategy, *Together for health* (2007), health literacy was included and linked to citizen's empowerment (Sørensen et al, 2013). During the years following the HLS-EU study, several initiatives at the national and regional level have been undertaken in different European countries to improve health literacy (Heijmans et al, 2015). Until recently, no overview was present of the health literacy activities within European countries. To obtain this, the European Commission financed a study on sound evidence for a better understanding of health literacy in the EU: the HEALIT4EU study.

The HEALIT4EU study

To get a comprehensive overview of the policies and activities regarding health literacy that were developed in EU member states, in 2014 the European Commission financed the HEALIT4EU study (Heijmans et al, 2015). In this study three activities were undertaken to gain an insight into health literacy research and policy in Europe: (1) a systematic literature review of existing knowledge regarding health literacy interventions (and their effectiveness) in EU member states; (2) a mapping of policies and actions aimed at improving health literacy in EU member states; and (3) the development of a prediction model of determinants of health literacy using publicly available information sources. This chapter is almost exclusively based on the second activity of the HEALIT4EU study, the inventory of policies and actions in EU countries. The objective of this subproject was to map existing policies in EU member states at the national, regional and local level that were planned or that were already in place to improve health literacy. In addition to that, any health literacy actions, which could include strategies, programmes or activities that were executed at a national, regional or local level, were mapped. Policies and actions directed at health literacy in general as well as policies and actions that focused on a specific target population, such as children, adolescents, older people, minority ethnic groups and people with a chronic condition were mapped. Information on policies and actions was obtained via country experts, literature review, desk research and via experts from the European Public Health Alliance (EPHA) (Heijmans et al, 2015). The report that was published on the HEALIT4EU study includes a detailed description of the methods that were used to obtain insight into policies and actions (see Box 27.1) at the national, regional or local level in EU member states (Heijmans et al, 2015).

Box 27.1: Applied work definitions of policy and action

Policy: A set of ideas, plans or rules of what to do in particular situations that has been agreed to officially by an organisation, a local government or a national government.

Action: Any activity, strategy or programme initiated by an organisation, local government or a national government that is designed to achieve a specific goal.

Aim of this chapter

In this chapter we provide an insight into policies and actions that have been put in place in EU member states on a national and regional level during the past few years. The distinction between these levels was made based on the initiator of the policy/action as well as the implementation level of the policy/action: whether these were national or regional. Since the local initiatives are more widespread and usually not centrally coordinated within countries, and therefore not all initiatives might have been captured in the HEALIT4EU overview, we decided not to include them. However, when local authorities or policies are part of a bigger regional or national policy, they will be mentioned.

Snapshot of health literacy policies and actions across the EU

Use of the term 'health literacy'

There appeared to be a huge variation in the extent to which the concept of health literacy is established within countries (see Table 27.1). In Germany, Ireland, Italy, Portugal, Spain, and especially the UK, 'health literacy' is a rather common term, both in policies and in health debates. In Austria, the Czech Republic and the Netherlands the term is used, but only recently. In Belgium, Croatia, Denmark, Malta, Slovenia and Sweden, the term is known but infrequently used. In most countries, including Bulgaria, Cyprus, Estonia, Finland, France, Greece, Hungary, Lithuania, Poland, Romania and Slovakia, health literacy is only referred to in the context of other terms, and in Latvia it is still unknown. It is important to note, however, that even though the term 'health literacy' might not be established in specific countries, this does not automatically mean that the topic does not receive attention. In part it could be a matter of definition (Sørensen et al, 2012; see also Chapter 1, this volume): there might be attention for vulnerable groups within countries but under a different denominator.

Table 27.1: Level of establishment of the concept of health literacy in policies across EU member states

Level of establishment	Country
Regular use in policies, policy documents or in discussions about health for a number of years	Germany, Ireland, Italy, Portugal, Spain, UK
Used in policies, documents or discussions about health, but in recent use	Austria, Czech Republic, the Netherlands
Term 'health literacy' is known but its use is very uncommon in policies, documents or in discussions about health	Belgium, Croatia, Denmark, Malta, Slovenia, Sweden
Not used as an independent term but in the context of other terms such as health education, health promotion or empowerment	Bulgaria, Cyprus, Estonia, Finland, France, Greece, Hungary, Lithuania, Poland, Romania, Slovakia
Term is unknown	Latvia

Aims of the identified policies and actions

In total, 82 health literacy policies or actions were identified in the HEALIT4EU project across 16 European countries (Heijmans et al, 2015). In 10 countries, no policies or actions regarding health literacy were found. The selected policies and actions have various aims. One of the aims considered important in all 16 countries is to identify best practices for enhancing health literacy. Another aim that seems to be considered important in quite a few of the countries is to provide support to vulnerable groups that are more likely to have lower levels of health literacy, including minority ethnic groups. A third aim that is considered important in multiple countries is gaining more knowledge about levels of health literacy (see Table 27.2 for more details on the aims of the identified policies and actions). Note that in the 16 countries in which policies and actions on health literacy were found, attention to health literacy mainly has an exploring character, focusing, for instance, on: determining how big the problem of low health literacy is; identifying vulnerable groups; and obtaining an insight into the consequences of low health literacy. Current policies and actions are mainly centred around awareness, and in some countries policies and actions are directed at agenda setting.

Implementation level of policies in EU member states

The HEALIT4EU study showed that six EU member states have already included health literacy in national policies – Austria, Ireland, Italy, Spain, Portugal and

Table 27.2: Aims of policies and actions across EU member states

Aims	Country
To gain knowledge about levels of health literacy	Austria, Bulgaria, Denmark, Germany, Ireland, Poland, Portugal
Instrument development	Ireland, Portugal, Austria
Improve or create collaboration between possible stakeholders within countries (eg, building working groups; platforms)	Austria, the Netherlands, Germany, UK, Czech Republic
Improvement of health education/self-management support	Ireland, Italy, the Netherlands, Spain, Ireland
Improvement of (the delivery of) health information, both oral and written	Portugal, Ireland, the Netherlands, Spain
Supporting vulnerable groups with low health literacy, especially minority ethnic groups	Austria, France, Germany, Greece, Ireland, Italy, the Netherlands, Sweden
Policy development and agenda setting for research	Austria, the Netherlands, Germany, UK, Czech Republic
Identifying best practices	All countries
Improving health literacy of professionals	Croatia, Italy, the Netherlands, Sweden, Ireland
Improving digital information by building websites	Germany, Italy, Ireland
Empowerment	Italy

UK. As illustrated in Table 27.3, most EU member states do not have a national policy or plans to develop national policies on health literacy.

Policies and actions to promote health literacy at a national level

National policies

At the time the data collection of the HEALIT4EU study was performed in 2015, Austria, Ireland, Italy, Portugal, Spain and the UK had developed a national policy regarding health literacy. The target group of these policies include the general population, or specific groups such as children, minority ethnic groups, older people, people with diabetes or people with mental health problems. The ways policies aim to improve health literacy vary and include, for instance, providing tailored health information, educating professionals and developing health education programmes or materials for people with lower levels of health literacy. Also, better prevention, stimulating research and intervention development are ways in which policies try to improve health literacy at a population level. In the

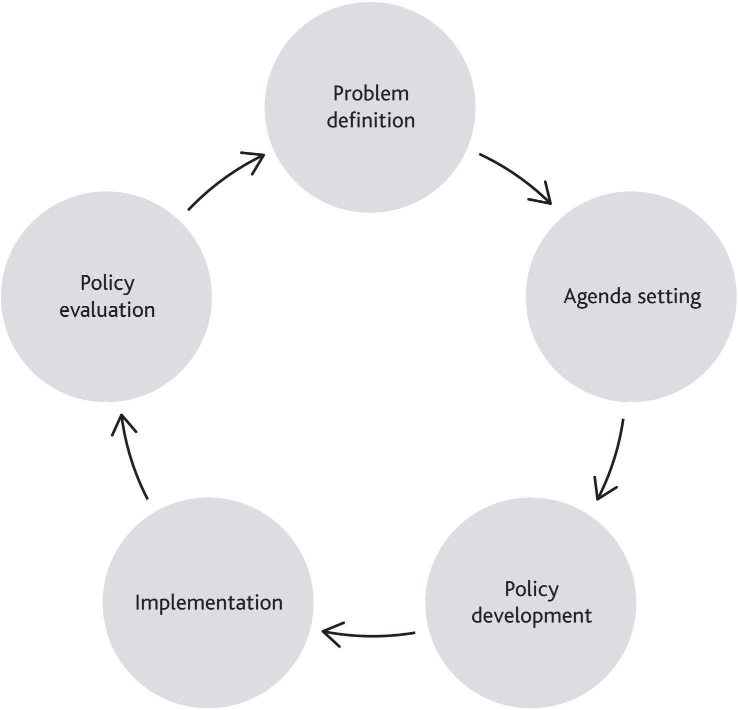
Table 27.3: Implementation of national policies across countries

Level of implementation	Country
No national policy and no plans to develop national policies on health literacy	Belgium, Bulgaria, Croatia, Cyprus, Denmark, Estonia, Finland, Germany, Hungary, Latvia, the Netherlands, Poland, Slovakia
No national policy but plans to develop national policy on health literacy in the near future	Czech Republic, Malta, Slovenia
No national policy on health literacy but national policies on health education and health promotion, so indirectly contributing to health literacy improvement	France, Greece, Romania, Lithuania
National policy on health literacy	Austria, Ireland, Italy*, Spain*, Portugal*, UK*

Note: * (Also) policy development and implementation at a regional and local level.

following we highlight six national policies and thereby describe at which stage of the policy cycle policies are. The policy cycle (see Figure 27.1) distinguishes between the following phases: problem definition, agenda setting, policy

Figure 27.1: Policy cycle



Source: Adapted figure based on Stake (1967) development, implementation and policy evaluation (Stake, 1967). Policies go through all of these five phases before starting a new cycle.

In some countries, policies were developed to be implemented at both a national and regional level, which was, for instance, the case in Austria. Austria was one of the collaborating partners of the HLS-EU project, which indicated that 56.4 per cent of the Austrian population had an inadequate or poor level of health literacy (Pelikan et al, 2012). This finding accelerated policy development, as illustrated in Box 27.2, and other related activities in the country. Policy development in Austria is advanced as it entered the last phase of the policy cycle, the policy evaluation phase. For more information on Austrian health literacy, see Chapter 30, this volume.

Box 27.2: Austria: Example of a national policy to promote health literacy

In 2011 the Austrian Ministry of Health (*Ministerium für Gesundheit*) set 10 new health targets for the next 20 years (*Rahmengesundheitsziele*). One of these targets was to enhance health literacy in the population (*Gesundheitskompetenz der Bevölkerung stärken*) and more specifically, to design target-group specific health information to improve health literacy. The Österreichische Plattform Gesundheitskompetenz (ÖPGK) was established to support and coordinate activities undertaken with respect to this health target. The 10 new health targets were to be implemented both at a national and regional level. In June 2013, the federal government, regional governments and the main insurance association (HVSV) signed a health target control agreement (*Bundes-Zielsteuerungsvertrag*, *Zielsteuerung-Gesundheit*) (BMGF, nd). This policy document is the legal basis for the implementation of the health targets at the regional level. The document includes strategic long-term objectives as well as operational short- and mid-term objectives that the contracting partners need to accomplish (see also Chapter 30, this volume).

In Ireland, health literacy has gained attention in Ireland's health debate during the last decade. Ireland was also one of the collaborating partners of the HLS-EU project (40.0% of the population had poor/inadequate health literacy). In 2007, the National Adult Literacy Agency (NALA) published a policy paper on the issue of health literacy, including a strategic plan for 2007-10 (Lynch, 2007). This document was based on the research report entitled *Health literacy, policy and strategy* (McCarthy and Lynch, 2002), produced by the NALA in 2002, which began the formal discussion of health literacy in an Irish context. The strategic plan for 2007-10 stressed the importance of addressing the issue of health literacy further through research, awareness and integration of health literacy in the Irish health system. In 2013 the Department of Health published their new policy, *Healthy Ireland: A framework for improved health and wellbeing 2013-2025* (see Box 27.3). As in Austria, in Ireland policy development entered the last phase of the policy cycle, which entails policy evaluation.

Box 27.3: Ireland: Example of a national policy to promote health literacy

The policy *Healthy Ireland: A framework for improved health and wellbeing 2013-2025* recommends action to 'address and prioritize health literacy in developing future policy, educational and information interventions' and to 'support and link existing partnerships, strategies and initiatives that aim to improve the decision-making capacity of children and young people through strengthening self-esteem, resilience, responses to social and interpersonal pressure, health and media literacy (including social media literacy).' These actions were listed under Theme 3, 'Empowering people and communities'. The goal of this policy theme is to foster the implementation of mutually reinforcing and integrated strategies and actions to encourage, support and enable people to make better choices for themselves and their families (DH, 2013). The partners that are involved in the proposed actions to enhance health literacy include the Department of Health, Department of Children and Youth Affairs, Department of Education and Skills, HSE directorates, statutory agencies, community and voluntary bodies and the private sector.

Italy was not a partner in the HLS-EU project, but researchers did assess health literacy in the Italian population a few years later using the HLS measurement tool (Palumbo et al, 2016). It was found that more than half of the population had limited health literacy: 37 per cent had problematic health literacy and 17.3 per cent had inadequate health literacy (Palumbo et al, 2016). Before these insights, health literacy was already being addressed in Italian policies. In general, Italian health policies are executed at a regional level, as the Italian National Institute of Health is a decentralised system giving the 20 regions political, administrative and financial responsibility regarding the provision of healthcare. Yet the Italian state retains (limited) supervisory control and continues to have overall responsibility for the National Health Service, to assure uniform and essential levels of health services across the country. The regions have significant autonomy and organise services that are designed to meet the needs of their specific populations, define ways to allocate financial resources to all the local health authorities (LHA) within their territories, monitor LHAs' healthcare services and activities, and assess their performance. Each region defines a regional plan that is in accordance with central government guidelines based on the national healthcare plan. Policy development in Italy is currently in the implementation stage of the policy cycle (see Box 27.4).

Box 27.4: Italy: Example of a national policy to promote health literacy

In the Italian national healthcare plan, health literacy is addressed within policies aimed at enhancing residents' empowerment, especially in terms of an educational campaign aimed at citizens and training for healthcare professionals. Most of the national policies in Italy are made through the Istituto Superiore di Sanità (ISS) on behalf of the Italian Ministry of

Health. The Italian Ministry of Health (2010) published guidelines on the web channel of the Ministry of Health called 'citizens', and encourages online education for citizens by any public healthcare institution.

Portugal did not participate in the HLS-EU, but like Italy, it did apply the HLS measurement tool later among the Portuguese population (Espanha et al, 2016). Based on the outcomes of the HLS, Portugal had relatively few respondents with inadequate health literacy (10.1%), which seems a positive outcome compared to other European countries. In Portugal, a national health plan was initiated by the government and with respect to policy development, the country has entered the policy evaluation phase (see Box 27.5).

Box 27.5: Portugal: Example of a national policy to promote health literacy

In Portugal the national health plan (DGS, 2013), approved for the years 2016-20, speaks about health literacy promotion at both national and regional levels. The strategy mentions that the national health plan presents 'instruments and actions that are intended for citizens to get involved with health institutions and systems, through: … Health literacy: its objectives, strategies and instruments for its promotion, in an intersectional perspective.'

In Spain, the outcomes of the HLS-EU study showed that 50.8 per cent of the Spanish population had problematic health literacy and 7.5 per cent inadequate health literacy, which gave cause for concern. Before the results of the HLS-EU study, Spain was already active with respect to the development of policies and actions at a national level. Since the 41/2002 law regarding a person's right to informed consent and to medical information, the Spanish government and autonomous regions create and promote health literacy programmes. Like Italy and Portugal, Spain has a national policy that is conducted at regional levels. Policy development is currently in the implementation phase of the policy cycle.

The UK did not participate in the HLS-EU study, but within the EU the UK can be regarded as the most active country in the field of health literacy, and policies on health literacy are most established in this country with the active involvement of government. Although there is no UK-wide policy on health literacy, extensive action plan documents are provided by the national governments to address the issue of health literacy and to move the agenda forward (see Box 27.6). Policy development in the UK is in the policy evaluation phase of the policy development cycle.

Box 27.6: United Kingdom: Example of a national policy to promote health literacy

In Wales, there is an action plan for reducing inequities in health (Welsh Assembly Government, 2011); for more information, see Chapter 28, this volume). One of the seven key actions to make progress in achieving fairer health outcomes for all is improving health literacy. In Scotland, the health literacy action plan (*Making it easy*; Scottish Government, 2014) has been developed with a national group, which has drawn on the expertise of front-line practitioners, policy-makers, academics and those with years of experience with NHS boards and the third sector. In England there is a Health Literacy Group that is funded by the Department of Health and the Department for Innovation, Universities and Skills. This group consists of those interested in building the evidence base for health literacy and its impact on people and their lives, and in supporting national policy to reduce inequalities.

National actions

Some EU countries, such as the Netherlands and Germany, do not have national policies on health literacy but do have a national working group or 'network' initiated by non-governmental organisations (NGOs): the German Network for Health Literacy and Health Education and the Dutch Health Literacy Alliance. In other countries, like the UK or the Czech Republic, national working groups are funded or initiated by the government. These working groups serve as a platform where insights from research and practice on health literacy improvement can result in joint ideas for projects and policy. Another important task of these networks is putting health literacy on the (national) agenda. Besides this, several EU countries undertake other actions at a national level to enhance health literacy, including the implementation of research or intervention programmes.

Table 27.4 provides an overview of all actions that take place at a national level, specifying the type of action and the initiators/stakeholders involved. The table indicates that Austria, Germany, Hungary, Ireland, the Netherlands and the UK are most active when it comes to actions at a national level. Furthermore, it shows that guidelines (n=17) are the most frequently implemented actions, followed by intervention programmes (n=15) and research programmes (n=8). NGOs, including, for instance, research institutes, are an important initiator or stakeholder in actions at a national level besides governments.

Policies and actions to promote health literacy at a regional level

Regional policies

The HEALIT4EU project found two policies at a regional level: one from France and one from Italy. In Italy, the policy was from the Tuscany region, a

Table 27.4: Type and number of actions at a national level and involved initiators/stakeholders

Country, time frame	Type of actions	Initiators/stakeholders
Austria, 2009-15	Research programmes (3) Guidelines (2) Advice (1)	NGO Government
Belgium, ongoing	Subsidy (1)	Partners from the Belgian health sector
Croatia, not provided	Intervention programme (1)	NGO
Cyprus, 2014	Intervention programme (3)	NGO
France, 2008-12	Intervention programme (3) Guideline (1)	NGO Government
Germany, 2003-13	Intervention programme (3) Advocacy network (1) Subsidy (2)	Healthcare researchers Government NGO
Hungary, 2006-20	Intervention programme (2) Programme (3)	Government
Ireland, 2003-11	Research programme (1) Intervention programme (1) Guideline (2) Subsidy (2)	NGO
Italy, 2011-13	Intervention programme (1)	Government
Malta, not provided	Research programme (1)	Government
The Netherlands, 2004-14	Research programme (1) Guideline (5) Advocacy network (1) Advice (2)	NGO Government
Romania, 2001-07	Intervention programme (1) Guideline (3)	Local authority Government
UK, 1997-2015	Research programme (2) Intervention programme (1) Guideline (4) Subsidy (1)	NGO Government Stakeholders from the health and education sectors

region that is actively involved in promoting communication exchange from care professionals to citizens in order to help citizens make informed decisions. The region also aims at reducing socioeconomic gaps such as gaps in information/education level for subgroups of citizens by means of targeted interventions/activities. The *Piano sanitario e sociale integrato regionale 2012-2015* (*Integrated regional social and healthcare plan*) was put into place between 2012 and 2015, initiated by the Regional Healthcare Government. In France, the *Pays de la Loire regional* was put into place in 2012, which includes programmes to promote access to disease prevention and healthcare for the most disadvantaged citizens, including illiterate people, in order to tackle social inequalities in health (Ministère du travail, de l'emploi et de la santé, 2011). In France regional health agencies (Agences régionales de santé, ARS) are responsible for ensuring a unified health policy at regional level, in order to better meet specific territorial needs and make the health system more efficient. The agencies contribute in health education/promotion policy development through their regional health plans that determine the main development directions.

Regional actions

Compared to national actions, less regional actions seem to be undertaken in the context of health literacy in EU member states. Table 27.5 summarises the actions at a regional level, indicating that the UK is also most active at a regional level, and that regional actions most often involve intervention programmes.

Table 27.5: Type and number of actions at a regional level and involved initiators/stakeholders

Country, time frame	Type of actions	Initiators/stakeholders
Austria	Intervention programme (1)	NGO
France, 2000	Intervention programme (1)	Government Community Local authorities
Germany, 2007-10	Intervention programme (1) Research programme (1)	NGO
Greece, 2013	Intervention programme (1)	NGO
Hungary, 2010	Programme (1)	NGO
UK, 2008-12	Guideline (4)	NGO

Discussion

Although health literacy is on the agenda in most of the EU member states, in many countries the efforts are not coordinated through a national (or regional) policy. This increases the risk of programmes and activities within a country being fragmented (both geographically and in time), which can result in less effective use of means and less exchange of knowledge and 'best practices'. National or regional policies could contribute to a more balanced distribution of programmes and activities directed at different phases of the lifespan, that is, childhood, adolescents, adulthood and older age. The policies as described in this chapter seem to focus most often on health literacy in general. It remains unclear if specific groups benefit more or are (un)intentionally targeted more than other groups by these policies.

A national policy does not seem to be a requirement for the development of programmes and activities regarding health literacy, as actions on health literacy were identified in most of the EU member states. The organisation and implementation of activities related to health literacy seem more dependent on other factors, including, for instance, a country's familiarity with the concept of health literacy, financial incentives, efforts made by NGOs, the organisation of the healthcare systems and conceptions of citizens' rights. For example, in countries with strong NGOs such as the NALA in Ireland or in countries where national working groups with many stakeholders are active, implementations of activities and initiatives to improve health literacy seem more feasible.

The concept of 'health literacy' can be considered a useful complement to more general health promotion and education policies, as it adds a better focus on individuals or populations that experience difficulties with accessing, understanding and applying health-related information for the benefit of their health. Making health literacy part of health promotion and education policies will, for instance, foster more attention for the development and offering of easy-to-read information. Some countries do not know or use the term health literacy in their policies or activities. Variation in the extent to which the concept of health literacy is established within EU member states might in part be attributable to the presence of national working groups or 'networks' that aim to put health literacy on the policy agenda. However, through other activities in the area of health promotion and health education, health literacy in a specific population could indirectly be increased as well. This raises the question as to how important it is that all EU countries embrace the term 'health literacy' in their policies and activities.

In theoretical models on health literacy (see, for example, Nutbeam, 2000) health literacy is a personal competency that influences health behaviour and outcomes and that can be influenced by health promotion and education. In order to be able to tailor these educational activities to the different needs of individuals (in clinical practice) or populations (in public health), the concept of 'health literacy' can be considered an asset to a more general health promotion and education approach, which are known to have fewer effects on low-literate individuals and populations. Therefore, it seems that using the concept of health literacy, or at least the notion that people have different needs and competencies and that the healthcare system should be tailored in that respect, has advantages. Tailoring to different levels seems especially important for improving the effectiveness of health promotion and education activities (and through that, they have a more positive effect on health behaviours and health outcomes) for people with lower health literacy.

An important limitation of the policies and actions that are currently in place in EU member states is a lack of monitoring and evaluation. Monitoring and evaluation are essential to obtain information on the feasibility and effectiveness of policies and actions. This information would be valuable for other EU member states or regions that aim to implement identical or comparable policies or actions directed at improving health literacy. Also, it would be valuable information for the initiators of policies and actions, since it could help them improve policies and actions and optimise their outcomes.

A limitation of the current chapter is that insights are based on the data that was collected in 2015 in the context of the HEALIT4EU study. We did conduct an additional limited search on policies implemented after 2015, which resulted in no additional policies. However, this was done without the use of country experts, as was done in the HEALIT4EU study, which means that any publications on policies that were not available in English or Dutch were not identified. Therefore, it could be that policies have been put in place in EU member states after 2015 without being described in this chapter. Another limitation is that the quality of the data as described in this chapter is largely dependent on the knowledge of the country experts who were consulted in the HEALIT4EU project. As the English term health literacy was used to ask country experts for policies and actions in their country, this might have influenced the amount and type of information provided by the country experts. Not every country is familiar with the English term health literacy and use this term in their own languages. The check by EPHA, however, contributed to the validity of the data.

Conclusion

The topic of health literacy has gained attention in several EU member states in recent years. The countries in which the concept gained most attention are Germany, Ireland, Italy, Portugal, Spain, the UK, Austria, the Czech Republic and the Netherlands. In other countries, however, such as Bulgaria, Cyprus, Estonia, France, Greece, Hungary, Lithuania, Poland, Romania and Slovakia, the concept is less common and often linked to broader concepts such as health education and health promotion. Six countries have a national-level policy – Austria, Ireland, Italy, Portugal, Spain and the UK. However, such a policy does not seem to be a requirement for the development of programmes and activities on health literacy: overall, actions on health literacy were identified in 16 EU member states. Many different stakeholders are involved in these actions, often including both government and NGOs. Current evidence does not enable us to conclude whether policies and actions are effective or not. Both on policy and on action level, evaluation and monitoring is an important gap. Besides that, a more programmatic and evidence-based policy for health literacy in EU member states could be beneficial to better coordinate efforts to improve health literacy within countries.

Acknowledgements

This chapter is for the most part based on work done in WP2 of the HEALIT4EU study on sound evidence for a better understanding of health literacy in the EU. This study was funded by the Health Programme of the EU. The full report can be downloaded at http://ec.europa.eu/health//sites/health/files/health_policies/docs/2015_health_literacy_en.pdf

The authors would like to express their thanks to:

- the country coordinators of the EPHORT consortium who provided input for WP2 (see Annex L of the full report for their names and affiliations);
- the EPHA colleagues/network partners who checked and supplemented the results of WP2;
- fellow researchers of the HEALIT4EU study and co-authors of the full report, based at Netherlands Institute for Health Services Research (Nivel), National Institute for Public Health and the Environment (RIVM) and European Public Health Alliance (EPHA).

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28

Developing health literacy policy in Scotland: A case study

Graham Kramer, Blythe Robertson, Phyllis Easton and Andrew Pearson

Introduction

In 2011, the Scottish Government convened a National Health Literacy Action Group (NHLAG) to prioritise actions that would raise awareness of the impact of inadequate health literacy for all parts of the population in Scotland and stimulate a responsive, enabling culture to address the problem. Addressing health literacy requires a societal response, with significant contributions from education systems and communities. However, it also requires a healthcare system that is responsive across people's entire lifespans. It was to this that NHLAG decided to devote its focus as a starting point.

This case study describes the approach, rationale and processes that NHLAG took to formulate Scotland's health literacy action plan, *Making it easy*. It describes the key actions that were developed and discusses the progress that has been made to implement these actions and the outputs that have been achieved. While much has been achieved, we also describe the learning that will help inform further progress.

Background

The provision of health and social care in the UK is a responsibility devolved to the four nations of England, Wales, Northern Ireland and Scotland. There is universal healthcare provision under the National Health Service (NHS) across the UK, although differences exist in the provision of social care. The Scottish Government, through its *Healthcare quality strategy* (Scottish Government, 2010) and *2020 vision* (Scottish Government, 2011), has held a quality ambition for a safe, effective and person-centred healthcare system, along with an integration of health and social care and support for self-management to enable people to live at home or in a homely setting. There is strong emphasis in Scotland's culture and political ethos of respecting and promoting people's human rights and addressing inequalities.

Within this context there has been a growing realisation that the issue of health literacy has been a significant factor in determining people's ability to safeguard their own health and to get the most from their health and care systems. While this has long been a public health concern in promoting health and preventing disease, it is now an increasing challenge to the wider health and care systems as people are living longer with multiple long-term conditions. The growing demands and expectations that modern medicine is placing on people often overwhelms their abilities, undermining the safety and effectiveness of healthcare. Those with the greatest health literacy needs face the greatest challenges and poorest outcomes.

A Scottish Government scoping study looked at the national and international evidence on the impact of health literacy (Scottish Government, 2009). It was clear *something* had to be done. However, it was less clear *what* needed to be done. The study concluded that, because the issue of health literacy was central to so many policy areas, a stand-alone health literacy policy may not be necessary. Instead, it recommended the establishment of the NHLAG to prioritise areas for further development and integrate these into existing and emerging policies and programmes (Scottish Government, 2009). This challenge represented an exciting new frontier for healthcare and in enterprising fashion an expert group of health literacy pioneers was convened to prioritise actions that could make a difference. The action plan, *Making it easy*, was published in June 2014 (Scottish Government, 2014).

Approach

The NHLAG was convened in 2011 bringing together a representative panel of people working in the field encompassing public health, policy, academia, clinical practice, rights and health equity and health and knowledge information. It was chaired by the Chief Executive of The Alliance, representing third sector organisations and people with disabilities, living with long-term conditions or providing unpaid care. In addition, the Scottish Government appointed a GP as a national clinical lead for health literacy. The group met approximately every four weeks for two years. It was a collaborative and evolutionary approach that traversed key milestones:

- defining the problem and concepts
- developing an overarching ambition
- defining the specific scope
- devising and prioritising specific actions.

Defining the problem and concepts

The first task of this diverse group was to get a coherence of understanding around health literacy and how addressing it was going to be of benefit. We realised that, while insufficient health literacy was a common problem that had a significant impact on people's wellbeing, there was little evidence for what could be done about it. On the one hand, this lack of evidence can inhibit health economies from addressing the issue, but on the other hand, it offers an opportunity to innovate and evaluate. Doing nothing did not seem an option.

We began by exploring the usefulness and limitations of the multiple definitions of health literacy. While they are helpful in explaining what health literacy is, we found they are perhaps limited for the following reasons:

- They locate the problem of health literacy with individuals rather than the complexity and unfamiliarity of the health and social care environment (Baker, 2006).
- They focus on people's abilities. While people with poor cognitive and social skills will be most affected, even highly skilled university academics can struggle with unfamiliar contexts (WHO, 1998; American Medical Association Ad Hoc Committee on Health Literacy, 1999).
- They overlook the impact of culture, socialisation and health beliefs.

It felt more pragmatic to define health literacy in terms of its impact on people's health, care and health outcomes (DeWalt et al, 2004; Paasche-Orlow and Wolf, 2007; Berkman et al, 2011). From the literature, studies seem to show that poor health literacy principally has an impact on people's confidence, knowledge, understanding and skills to:

- access and navigate healthcare (Williams et al, 1995; Baker et al, 1997, 1998);
- collaborate with their healthcare professionals (Easton et al, 2013);
- self-care and self-manage (Williams et al, 1998a, b; Schillinger et al, 2002) in order to live well, on their own terms, and with any health conditions they may have.

This was helpful to us as it allowed us to say that responding to people's health literacy needs is about enabling and building people's confidence, knowledge, understanding and skills. The key concepts that emerged to shape our approach are summarised in Box 28.1. We sought to find a working definition that:

- avoided a deficit approach;
- acknowledged the need for services to address the issues;
- took account of the wider population including, but not exclusively focused on, particular groups;
- captured aspects of health literacy beyond literacy and numeracy skills.

Box 28.1: Key concepts underpinning Scotland's health literacy approach

- Health literacy challenges are very prevalent.
- Health literacy is not just an individual attribute, but is socially distributed and affects all of us.

- Individual health literacy is a hidden attribute and in particular, the stigma associated with low health literacy leads to people actively avoiding disclosure of any difficulties they may be experiencing during contact with health services.
- Low health literacy undermines people's confidence, knowledge, understanding and skills to positively engage in their own health and healthcare, and the health of those they care for.
- Health and care systems unwittingly place demand, expectations and barriers that exceed people's capabilities through over-reliance on written information, complex oral information and low awareness among healthcare staff when those they have contact with are struggling to understand (social disability model).
- Addressing health literacy individually and socially will bring reciprocal benefits.
- Redesigning and delivering healthcare to remove barriers and make it easier, more engaging and enabling is a worthwhile universal response to insufficient health literacy.
- Responding to people's health literacy needs is central to programmes that focus on person-centred care, patient safety, effectiveness, shared decision-making, self-management support, health equity and human rights.

Developing an overarching ambition

Our next challenge was to describe an aspirational vision or ambition. With any journey, it is helpful to know where you are heading. This may have seemed a simple enough task, but it became a fascinating exercise in gaining a shared understanding. It was clear that while health literacy was, on the surface, an individual attribute, it has an impact on all of us, whether as an individual, carer, family member, teacher, employer, community worker, politician, health manager or healthcare professional. It was also clear it had a social dimension, because good health literacy benefits us all, and we all have a role in enriching each other's health literacy. Health literacy is therefore socially distributed. There are reciprocal enabling benefits of building collective health literacy as a society and in individuals – as long as we have positive social connection. This perhaps explains the interaction between social isolation, poor health literacy and health outcomes. The associated vicious and virtuous cycles are illustrated below, in Figure 28.1.

Our ambition therefore became: 'We want Scotland to be a health-literate society that enables all of us to have sufficient confidence, knowledge, understanding and skills to live well, on our own terms, and with any health condition we may have.'

Defining the specific scope

Developing a health literate society is a multidimensional task with significant contributions to be made from: (1) child and adult education systems; (2) responsive health and care systems; and (3) communities (both real and online). This is visually represented in Figure 28.2, where people's health literacy needs are met at the intersection of all these elements of a health-literate society.

Figure 28.1: Vicious and virtuous cycles of social isolation, health literacy and health outcomes

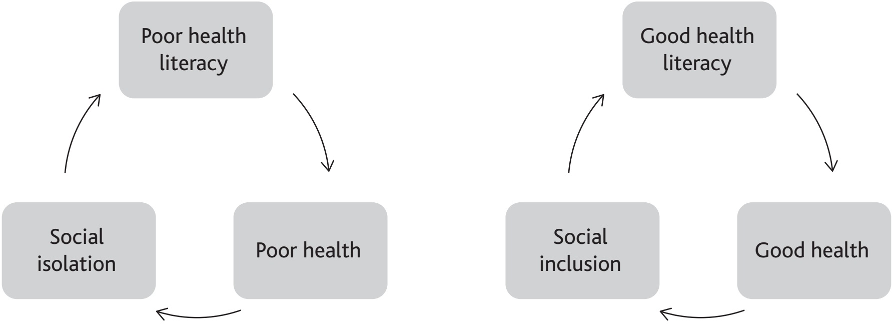
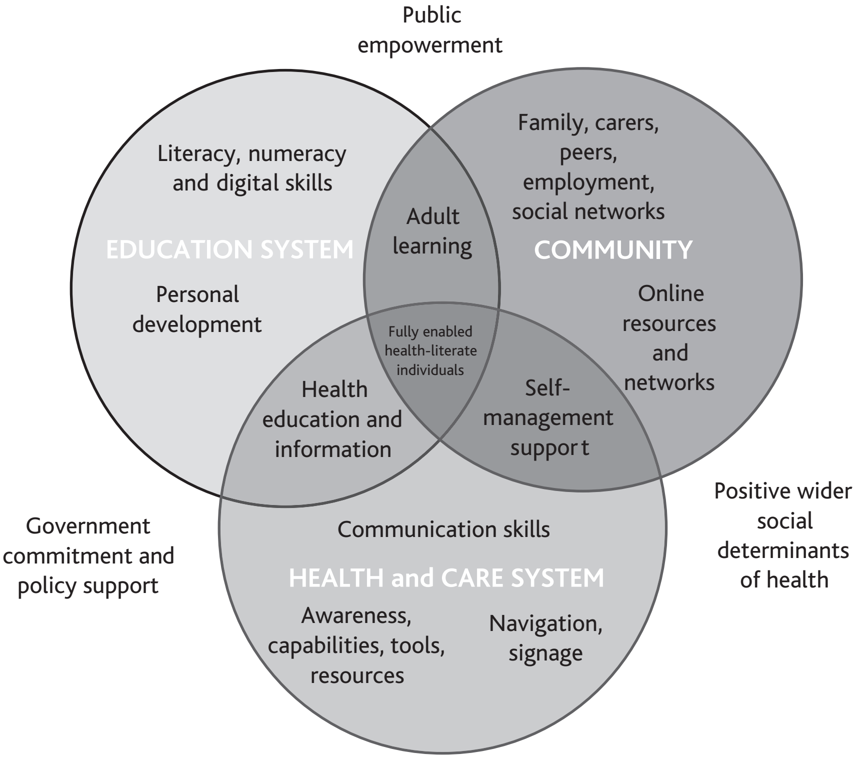


Figure 28.2: Attributes of an enabling health-literate society



We took evidence from educational experts and realised that Scotland's National Curriculum was addressing functional literacy and numeracy along with digital literacy, with a focus on health, wellbeing and personal development. We also realised that there was a vast amount of activity, support and advocacy within communities, both in people's neighbourhoods and online. While plentiful, the main challenges lay in making this support findable, accessible and networked with health and social care. However, significant work in Scotland was being done to address this (ALISS, 2017).

What struck us (and the public) as being of overwhelming concern was the lack of responsiveness by the health and care systems to the demands, expectations and obstacles it was unwittingly placing on its users. This would need to be our main priority and focus, not just to address health literacy in Scotland, but also as an urgent rights and equity issue. As a national health and care system, we needed to get our own house in order.

Devising and prioritising specific actions

This was a lengthy and in-depth process. It involved conducting a literature search of evidence on the effectiveness of health literacy interventions. We also looked at ongoing work in other countries with mature health and care systems, such as Ireland (NALA, 2017), the US and Australia. Based on our findings, our underlying concepts and ambition, we prioritised four areas of focus that we hoped would initiate and sustain a movement of health literacy responsiveness within our health and care system. We realised this had to start by raising awareness among professionals and administrators of the hidden issue of insufficient health literacy and its impact. We hoped to foster a health literacy culture and community of practice that would adopt and spread existing best practice, as well as generate innovation in new enabling approaches. This was particularly important at key learning and patient safety points within the system. From this starting point, four main objectives were developed:

- Raise awareness of the workforce and the capabilities of professionals to support improved health literacy responsiveness.
- Improve access to useful health literacy techniques and resources.
- Promote the development and spread of new tools and innovations.
- Enhance transitions of care, which are key learning and patient safety points in healthcare.

We were also mindful of the need to build in evaluation. Evaluating the impact of health literacy interventions is still a challenging and developing area. Since our main goal was to initiate health literacy action, our evaluative priority was to explore what possibilities would emerge and how, rather than focus on specific health, personal or economic outcomes. In order to meet our main objectives, we developed four strategic actions:

- Develop a workforce awareness and capabilities programme.
- Develop a ‘go to’ online health literacy resource.
- Embed health literacy practice into existing person-centred and patient safety improvement programmes.
- Establish a national health literacy demonstrator site.

Progress achieved from *Making it easy*

The learning and progress in implementing our actions from *Making it easy* is summarised below. A more detailed account of what has been achieved was published in *Making it easy – Progress against actions* (Scottish Government, 2017a).

A national health literacy resource for Scotland, The Health Literacy Place

The Health Literacy Place website (www.healthliteracyplace.org.uk) was developed by NHS Education for Scotland (NES) in 2015, and quickly became the principal resource for health literacy tools and support in Scotland. It was used to support the implementation of changes in the other action areas and to broaden awareness of the issues. An introductory video on the website and social media presence aided this. The web presence also supported a national network of health literacy champions, who, having attended central workforce educational events, would return to their local area to spread change.

Workforce skills and awareness

To achieve the broad task of raising awareness of health literacy and building the skills of the workforce, a range of methods was used between 2014 and 2017. Educational sessions in collaboration with NES were regularly held and covered 'Health literacy awareness raising' and 'Health literacy train the trainer' events. These were intended both to teach specific tools and techniques, and to equip staff to spread the message back to their local organisation. Remote learning was aided by the development of an eLearning module (see www.healthliteracyplace.org.uk).

The principles of *Making it easy* were encouraged to spread. Attendees from the sessions were encouraged to report back on how well local management were becoming involved and how local policies or literature were changing. Through the national demonstrator programme reported below, a collaboration with Dundee University also led to the inclusion of health literacy on their course for trainee nurses. This highlighted the importance of being aware of the issues and provided the skills necessary to improve patient care. NES also worked to improve the signposting to useful health information by working with other sectors, such as public librarians.

Promote and develop the spread of health literacy innovations

To ensure changes to practice were kept simple, educational efforts were focused on five main tools and techniques: teach-back; chunk and check; use simple language; use pictures; and always offer help with paperwork. These are summarised below, in Box 28.2. A key principle of the awareness raising taught to staff was the importance of avoiding making assumptions about people's abilities, and instead to consider using these tools and techniques routinely in their practice. The extent to which these have been adopted into practice is unknown and is a challenge for future evaluation.

Box 28.2: Five simple tools and techniques

Teach-back

This is a method to check information provided is being understood. The person is asked to 'teach back' what has been discussed. The emphasis of this is to check the professional's ability to explain information and not the person's ability to understand. This avoids the person perceiving it is their intelligence that is being questioned.

Chunk and check

Rather than providing a lot of information at once, 'chunk and check' breaks down information into more manageable parts. In between each 'chunk', methods such as teach-back could be used to check understanding before moving on.

Use simple language

Practitioners are encouraged to explain things to people as they would to a friend or family member, in a more relatable way.

Use pictures

The use of diagrams or photographs alongside verbal explanations is encouraged when explaining a task or problem and can help people understand. For example, it is much simpler to see pictures of someone giving an injection or caring for a wound than just reading or hearing an explanation.

Always offer help with paperwork

Routinely offering help reduces the pressure on people who may need to ask for assistance and reduces stigma. It also means the service gathers the correct information it needs.

A national demonstrator site

'Meeting the health literacy needs of people at transitions of care' was the working title for the national demonstrator programme. It was set up in a single health board region, NHS Tayside (population of around 400,000), to establish and evaluate best practice in meeting the health literacy needs of people as they are looked after by different parts of the system. Implementation made use of small tests of change and quality improvement methodology to acquire knowledge on what is most effective in practice. Learning was shared initially through established Health Literacy Place networks, and later through reports and events to inform innovation around the country. The demonstrator programme took a broad perspective on health literacy, as reflected in our working definition, which looks beyond written information and skills related to functional literacy. It focused on health service design and delivery, driven by a computer literacy analogy presented in *Making it easy*:

> Thirty years ago, IBM developed the first home computer. Most people, other than the very intrepid, were reluctant to learn how to use them. The IT industry could have provided us all with more information and education to increase our "computer literacy". Instead they set about making computers simpler and more engaging to use. Now five and 85-year-olds can do complex tasks on a tablet computer. This approach of simplifying the computer "interface" has dramatically reduced the barriers to using computers, opening them up to almost everyone. (Scottish Government, 2014, p 12)

The action plan, *Making it easy*, asserted that 'We must likewise simplify the healthcare "interface" and make healthcare more engaging' (Scottish Government, 2014, p 12). Our literature search of evidence presented us with many ways of addressing health literacy through the development of decision aids and health education interventions. However, these tended to be specific to particular clinical specialties or population cohorts. There is little evidence that these potentially valuable pieces of work have been disseminated beyond the academic community or implemented in a practical way. The demonstrator programme aimed to identify issues that could be scaled up. We then hoped to apply the principles and learning to broader clinical areas other than those participating in the programme and ultimately to other geographical (NHS Board) areas across Scotland. The aims of the programme were:

- to make more effective the interactions at 'transitions' of care such as outpatient appointments and discharge from hospital care;
- to improve methods of communication between patients/carers and their practitioners so it is tailored to their needs and circumstances; and
- to support staff to improve their practice and educational processes.

One of the key strands of the programme was a 'health literacy walkthrough'. This placed several different people – some adult learners, a Master's of Public Health student and the programme lead – in a hospital setting with an example appointment letter. They were then invited to find their way individually to their appointment in the paediatric neurology department, flagging any health literacy issues along the way. The exercise revealed some interesting insights, many of which were fairly simple to remedy and greatly improve people's experience of accessing the service.

For instance, the terminology on hospital signs was often inconsistent and the job of volunteer hospital guides made unnecessarily difficult. The appointment letters failed to highlight key information, contained confusing descriptions or missed the opportunity to include pictures or diagrams and other useful information about visiting the hospital. Additionally, some existing efforts to assist people were poorly implemented and too low-profile.

These findings were spread to other departments in the test area and, at the time of writing, work is ongoing to simplify and improve consistency in signage and direction information in departments. New information and appointment letters are being written in partnership with people accessing services to ensure they are easy to understand (see www.healthliteracyplace.org.uk).

Another strand of the programme focused on the need to be clear in communication before medical procedures. In some cases, the successful and safe completion of a procedure requires the person to follow very particular instructions. The quality and accessibility of relevant written information is therefore an important consideration in ensuring that people are appropriately supported to carry out any necessary preparation.

The demonstrator programme looked at endoscopy procedures as an example. It reviewed the suitability of materials relating to bowel preparation using both adult learners to test for comprehension, and specialist software to test for readability scores. The exercise highlighted that much of the mainstream language, not only the medical language, was needlessly complex. Adult learners involved in the exercise stated that they "would have signed the consent form but would have lied about understanding the information given."

This project also highlighted that relying solely on specialist software that estimates necessary reading ability levels is inadequate. The algorithms used do not assess comprehension or how information may be interpreted by different people. It was clear that, although there are several guidelines relating to the production of patient information, testing the final product must again involve real people from various backgrounds to ensure that instructions are clear and appropriate (see www.healthliteracyplace.org.uk).

Other projects in the demonstrator site explored the use of new technology, using tablet computers to share videos explaining how to self-manage some conditions, and reviewing people's understanding of their medication, prior to discharge from hospital. Work continues to further improve services and promote person-centred care through partnerships between academics and health service staff. While the findings of the demonstrator programme are not necessarily prescriptive or universally valid, they aim to give examples of common health literacy challenges and tips for local implementation. So, for example, the walkthrough can be replicated in any healthcare environment; many of the findings are likely to be the same but local issues can also be identified (see www.healthliteracyplace.org.uk).

Embedding health literacy into the shifting policy landscape

When the *Making it easy* action plan was published (Scottish Government, 2014), it was welcomed as a fresh approach. Since then, however, there have been further shifts in strategic policy for health and social care. The national action plan has been helpful in embedding the principles of health literacy into these policies, which, in turn, are giving energy and movement to addressing health literacy.

In January 2016 the Chief Medical Officer for Scotland published a novel annual report, *Realistic medicine* (Scottish Government, 2016a). In its chapter 'Sharing decision-making and informing consent: People and professionals combining their expertise' (2016a, p 16), it explored the case for change from the out-dated 'doctor knows best' culture to one where both parties can combine their expertise and be more comfortable in sharing the power and responsibility of decision-making. A key component of this is rebalancing the conversations and interactions between people and their practitioners that sit at the heart of our health and care system. The chapter identifies the need for system and organisational change to promote the required attitudes, roles and skills.

Scotland's Chief Medical Officer's next annual report, *Realising realistic medicine* (Scottish Government, 2017b), also looked to initiatives in health literacy as a specific means to implement the well-received approach outlined in *Realistic medicine* (Scottish Government, 2016a). *Realistic medicine* has therefore provided an important strategic context for progress on our actions to address health literacy.

In addition to the impact of *Realistic medicine*, 2016 also saw the integration of funding and commissioning for health and social care services at the level of local council authorities. This service restructure was to put people and not services at the centre of decisions,aiming to improve services, and to make them seamless and more responsive to the people who use them (Scottish Government, 2017c). Over the following 18 months, momentum in Scotland built further. Scotland's *Health and social care delivery plan* (Scottish Government, 2016b) specifically called for an updated health literacy action plan to extend the progress achieved since 2014.

Improving health literacy was also noted by other organisations reviewing what improvements services require, as expressed in the Scottish Public Services Ombudsman's report *Informed consent: Learning from complaints* (2017). The challenge had now become to capitalise on this momentum to encourage further innovations that would improve care and patient experience across the country. These helped develop the conversation around what the next steps and collaborations to meet this challenge should be.

The growing evidence base and future policy development

As we broaden our health literacy developments in Scotland in pursuit of our ambition, the evidence base supporting specific initiatives is growing. It is important to use this evidence to inform future policy development. For instance, studies are starting to demonstrate that interventions to improve how people think about their health and wellbeing needs to begin at an early a stage a possible in their lives. A recent paper has suggested that young people can be better supported to interpret health information (see Nsangi et al, 2017).

The Health Foundation in England, on their Making Good Decisions in Collaboration (MAGIC) programme (2017), provided lessons in respect to shared decision-making. This emphasised that shared decision-making is not confined to a single one-to-one interaction between a patient and clinician. Rather, it must be embedded across the whole healthcare team, between people and their families or carers, and their wider community. All these people will influence the process, especially for people living with long-term conditions. Approaches such as the *Ten attributes of health literate health care organizations* (Brach et al, 2012) or the work from Deakin University on the organisational health literacy assessment tool (Trezona et al, 2017) summarise this well.

The development of the Ophelia approach (OPtimising HEalth LIteracy and Access) uses health literacy needs and responsiveness to help design health and care services (Deakin University, 2017) and shows much promise. Importantly these approaches make it clear that identifying problems and implementing change in specific organisations or service areas requires the involvement of those trying to access and use the service.

Considering recent policy developments and emerging evidence, the Scottish Government has developed a second action plan on health literacy, *Making it easier.* This was published in November 2017 (Scottish Government, 2017d). It outlines three concurrent approaches to improve people's confidence, knowledge, understanding and skills in their health and healthcare. It intends to involve a public response on health literacy through Scotland's 'Our Voice' programmes, to include a citizens' jury focused on shared decision-making (Scottishhealthcouncil.org, 2017). The three areas of focus for the action plan are to:

- Spread the lessons and progress already made in *Making it easy* across the country, aiming to engage with all ages and abilities to reduce variation and unnecessary inequality.
- Support the development of new work and collaborations in areas beyond secondary healthcare, such as library services. Its focus is on embedding improved health literacy responsiveness across the full range of Scottish public policy.
- Shift the culture of organisations and communities towards 'health literacy by design'. Any planned strategic change or service development should consider the consequences for health literacy and what opportunity is present to respond and improve it. The aim should be to avoid barriers to health literacy being created in the first place.

We hope to expand beyond *Making it easy*'s initial focus, and support activity across the whole health and social care landscape, and associated services. Specific areas highlighted for attention are:

- primary care
- urgent care services
- mental health
- information about medicines
- supporting people with augmentative and alternative communication needs
- care and support planning
- community links worker relationships
- the role of librarians
- the integrated health and social care workforce.

There is also a need to specifically consider people with few social connections, as well as refugees and asylum-seekers.

Conclusion

Making it easy has given encouragement and inspiration to many health literacy champions who are making a real difference and working hard to help achieve our ambition in Scotland. Internationally it is contributing to the case for action on health literacy and helping other countries to follow suit.

Health literacy is now a global health promotion priority (Quaglio et al, 2017; WHO, 2017). At home, it now resides firmly at the heart of our person-centred care ambitions, *Realistic medicine*, and the transformation towards more enabling integrated health, social and community care services.

As we move towards achieving our ambition to become a health-literate society, assessing the impact and progress will always be a challenge. However, Scotland, with its spirit of innovation, community and commitment to rights and equity, is well placed to remain at the vanguard of this important agenda.

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29

Health literacy policies: National examples from Canada

Sandra Vamos, Irving Rootman, Linda Shohet and Lorie Donelle

Introduction

Canada is recognised as an international leader in the evolving field of health literacy. Drawing from many disciplines, health literacy efforts in Canada in large measure have been anchored in health promotion and education perspectives as opposed to being driven by the medical system. The Canadian health literacy path has been informed by noteworthy international landmark policy documents, such as the Ottawa Charter for health promotion, and by international adult literacy surveys (Statistics Canada, 2007, 2013), while leaving its own trail of significant reports and resources.

In Canada, health literacy is viewed as a determinant of health, public health issue and essential resource to promote and maintain good health across the life course. There are many pockets of innovative health literacy initiatives, activities and networks across the nation. Much of this work has been embedded in daily practice led by experts, local champions, universities, non-governmental organisations (NGOs) and associations. Yet many efforts tend to be project-based without being absorbed into practice, reinforcing the need for 'policy to underpin practice' (Shohet and Renaud, 2006). While promising national-level policy statements have been proposed, none is currently endorsed by policy-makers at any level of government to advance action.

In 2008, Canada's Expert Panel on health literacy produced *A vision for a health literate Canada* report, with a vision statement that: 'All people in Canada have the capacity, opportunities and support they need to obtain and use health information effectively, to act as informed partners in caring for themselves, their families and communities, and to manage interactions in a variety of settings that affect health and well-being' (Rootman and Gordon-El-Bihbety, 2008, p 23). This report recommended a pan-Canadian strategy for health literacy with policies, programmes and research to increase levels of health literacy and reduce health disparities. To date, there is still no official health literacy strategy in place. Nevertheless, many efforts have been guided by the Expert Panel's vision for a health literate Canada using a social justice lens, that 'All people in Canada can access, understand, evaluate and use health information and services that can guide them and others in making informed decisions to enhance their health and well-being' (Rootman and Gordon-El-Bihbety, 2008, p 23). Building on that report and vision, *An intersectoral approach for improving health literacy for Canadians* (Action Plan) was released in 2012 (Mitic and Rootman, 2012). While there is visible interest to continue to advance health literacy by many individuals, communities, institutions and organisations, government policies are needed to engage all players in a sustained intersectoral effort to realise this vision.

This chapter traces the pathway that has shaped Canada's vision and actions for better health and learning outcomes, highlighting the development of Canada's National Action Plan as an approach to promote health literacy and inform best practice and policy across provinces/territories. The chapter offers an update of the Action Plan's application across the country in different settings considering its relevance, potential, reach and shortcomings. It begins with a discussion of the concept of health literacy using a Canadian lens, followed by a snapshot of key developments in the health literacy movement in Canada. It outlines the relevance and role of the two key national milestone documents mentioned above, and analyses the relationship between the release of these documents, their respective policy recommendations and best practice examples. It also considers how future best practices building on progress to date can inform new perspectives and advance policy. The chapter concludes with a discussion of the need for practice and policy 'champions' to provide the needed public support and political will. Potential strategic directions are proposed identifying opportunities for government to act as a facilitator to advance a health literacy agenda in Canada.

Canadian context

The meaning of health literacy in Canada

In the Canadian context, health literacy applies to all individuals, providers and systems. The Expert Panel defined health literacy as 'the ability to access, understand, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across the life-course' (Rootman and Gordon-El-Bihbety, 2008, p 11). This implies that health literacy is the result of a complex interaction considering the various settings that individuals are in, the range of demands that might be imposed on them, the supports and systems available and the shared responsibility across the life course.

Health literacy is a health equity issue

As in other countries, many Canadians adults have low health literacy levels. The 2003 International Adult Literacy and Skills Survey (IALSS) included a subset of 193 questions on health literacy that has provided the data on Canadians used by researchers ever since. The first major reports based on those findings were two reports from the Canadian Council on Learning (CCL), stating that about 60 per cent of Canadian adults (ages 16 and older) and 88 per cent of seniors (over 65 years) lack the capacity to obtain, understand and act on health information and services and make appropriate health decisions on their own (CCL, 2007, 2008). Data showed that lower levels of health literacy are disproportionately distributed across segments of Canadian society such as seniors, Aboriginal people, immigrants, those with lower levels of education, those with lower English and French proficiency and those who are unemployed (CCL, 2008; Rootman and Gordon-El-Bihbety, 2008). Given these findings regarding vulnerable groups, it is important for Canadians to continue to address the links between health literacy and health equity (Hoffman-Goetz et al, 2014). Health literacy is recognised as a determinant of health, closely related to other determinants such as literacy, education, income and culture. The Expert Panel report was the first landmark report in Canada that called for a pan-Canadian strategy for health literacy as an important step towards reducing health disparities (Rootman and Gordon-El-Bihbety, 2008).

Health literacy is an asset

Interest in the evolving concept of health literacy around the globe has developed from three main perspectives: (1) healthcare; (2) health promotion; and (3) education (Vamos and Rootman, 2013). In Canada, where health literacy is viewed as an asset and anchored in the broader health promotion and education contexts, it means understanding the conditions that determine health, knowing how to change them and adjusting practices accordingly (Abel, 2008).

Today, the skill demands placed by society and the Canadian public health and healthcare system on individuals are very high. Both consumers and patients need to know more and do more to become partners in their own health. This means a wide range of health-literate professionals (for example, doctors, nurses, pharmacists, dentists, teachers) will need to communicate complex health issues and lifestyle instructions in user-friendly ways (Vamos, 2014). We know health-literate individuals have fewer emergency department visits, increased health knowledge and skills to make healthier lifestyle choices, manage chronic diseases better, communicate better with their health providers and participate more in health education and health promotion activities (Mitic and Rootman, 2012). We also know that health-literate providers, organisations and systems have greater effectiveness in caring for and supporting patients/clients. However, Canada as a federation of 13 provinces and territories with clearly defined federal/provincial jurisdictions, has 13 different healthcare and education systems that add to the complexity when considering the diverse individual and system factors shaping health literacy.

'Education for health literacy' is important

The education perspective is prominent in the Canadian pathway to health literacy and stems from researchers advocating the link between health and education (Vamos and Rootman, 2013). Health literacy is a 'key outcome of health education' and 'significantly broadens the scope and content of health education and communication', both of which are critical operational strategies in health promotion (Nutbeam, 2000, p 264). Building health literacy skills starts in early life, and participation in lifelong learning, both formal and informal, is one of the strongest predictors of health literacy among older adults (Wister et al, 2010; WHO, 2013).

Early childhood education, K-12 schools (pre-school; kindergarten to Grade 12), colleges/universities, community agencies, non-governmental and government organisations all play a role in building and applying skills throughout the life course. To improve health literacy in Canada, those working in the field advocate the need to improve the knowledge, capacity and skills of all who receive health-related information and skills, programmes and services, and of all who provide them. Milestone documents such as the Expert Panel report and Action Plan identify the important role of the education sector in the joint effort to improve a nation's health literacy. The Calgary Charter on health literacy (Center for Literacy, 2011), created at a meeting in Alberta by a group of individuals from Canada, the US, and UK, identified core principles to underpin health literacy curricula ranging from K-12 to adult education. More recently, the Okanagan Charter: An international charter for universities and colleges, created in British Columba as a call to action for all higher education institutions, further supports this notion (Okanagan Charter, 2015).

Unfortunately, there are a limited number of health literacy course offerings in university health-related degree programmes in Canada (Vamos and Yeung, 2016). The recent work of Vamos and Yeung is a unique Canadian example as it aligns with these Charters and Canada's two milestone reports that promote education for health literacy, focusing on higher education. In 2013, one of the authors of this chapter, Vamos, developed and currently teaches the first core undergraduate health literacy course titled 'Health Literacy and Systems Navigation' in the School of Public Health & Social Policy at the University of Victoria in British Columbia (Vamos and Yeung, 2016). This innovative course aims to help learners explore practices, tools and policies guiding health literacy efforts for diverse people across settings and the life course. It was recently adapted and used as a blueprint for a proposed introductory online European health literacy course for two German universities (Vamos et al, 2016). As another first, one of the authors, Donelle, co-authored a book titled *Health literacy in Canada: A primer for students* (Hoffman-Goetz et al, 2014), a timely resource to educate and inform students and practitioners using a Canadian perspective on health literacy with strong links to social justice and health equity. Two years earlier, a third author, Shohet, developed the first accredited online continuing education course for physicians for the Canadian Medical Association through Memorial University's MDCME (Medical Doctor Continuing Medical Education; website developed by Memorial University of Newfoundland's Faculty of Medicine which has partnered with the College of Family Physicians of Canada), highlighting the importance of health literacy in practice. It was well-received and re-accredited twice until funding stopped.

A glimpse into history

The Canadian path to health literacy began in 1986 when the Federal Government declared literacy a national priority. This was stimulated by the mass media raising concerns about the consequences of low literacy for Canadians, followed by surveys to determine the extent of low literacy in the population by the Southam Press in 1987 and Statistics Canada in 1989. The Federal Government responded by establishing the National Literacy Secretariat to fund initiatives across the country to address the issue of low literacy. The concerns and evidence also stimulated Trevor Hancock, a leader in health promotion and President of the Ontario Public Health Association (OPHA) at that time, to suggest that the Association initiate a project on the connection between literacy and health. This project, conducted in partnership with Frontier College – Canada's oldest literacy organisation – ran from 1989 to 1993.

The first OPHA report made the case that *literacy and health* was an important issue that needed to be addressed by public health and health promotion in Canada (Perrin, 1990). This conclusion was supported by a study that explored the relationship between literacy and health, examined what was being done to enable people with limited literacy skills to live healthier lives, and suggested the following potential solutions: (1) reducing inequities by teaching people to read; (2) increasing awareness in the health community; (3) working with communities needing health and literacy services; (4) providing health information in non-written form; and (5) simplifying written information (Perrin, 1990). The second OPHA project report documented the increasing collaboration between literacy workers, health service providers and learners across the country on issues related to literacy and health, some of which had been stimulated by the first report and the Perrin study (Breen, 1993).

In 1993, the first International Adult Literacy Survey (IALS) was conducted. Canada was a major player. Statistics Canada collaborated with the Organisation for Economic Co-operation and Development (OECD) and its US counterpart to refine the American methodology, and Canada had the largest population among participating countries (Center for Literacy, 2013). The impetus from that survey, and the OPHA/Frontier College project, led the Canadian Public Health Association (CPHA) to establish the National Literacy and Health Program funded by the National Literacy Secretariat. The CPHA programme involved collaboration with 27 national partners to try to improve health services for people with lower levels of literacy. The programme was intended as a resource for health professionals and students affiliated with partner organisations across Canada. It promoted and supported the use/creation of plain language material, planned and coordinated research projects, provided health professionals with resources to help them serve people with low literacy skills, provided a *plain language* service and offered plain language and clear verbal communication workshops. Working with its partners, it also organised two national conferences on *literacy and health*, which was the way the issue had been framed throughout the 1990s and still is used in the "Literacy" community.

The concept of *health literacy* was introduced at the first Canadian Conference on Literacy and Health in 2000 in a workshop by Rima Rudd (Harvard University), Scott Murray (Statistics Canada) and Irving Rootman (University of Toronto Centre for Health Promotion). Rootman presented a framework for health literacy (see Figure 29.1) based on a 1998 report (Perrin, 1998), and integrated ideas from health promotion (WHO, 1986) and population health (Federal, Provincial and Territorial Advisory Committee on Population Health, 1994). As seen in Figure 29.1, it included 'policy' as an *action,* as well as 'ageing' and 'early child development', which suggests a life course approach to health literacy.

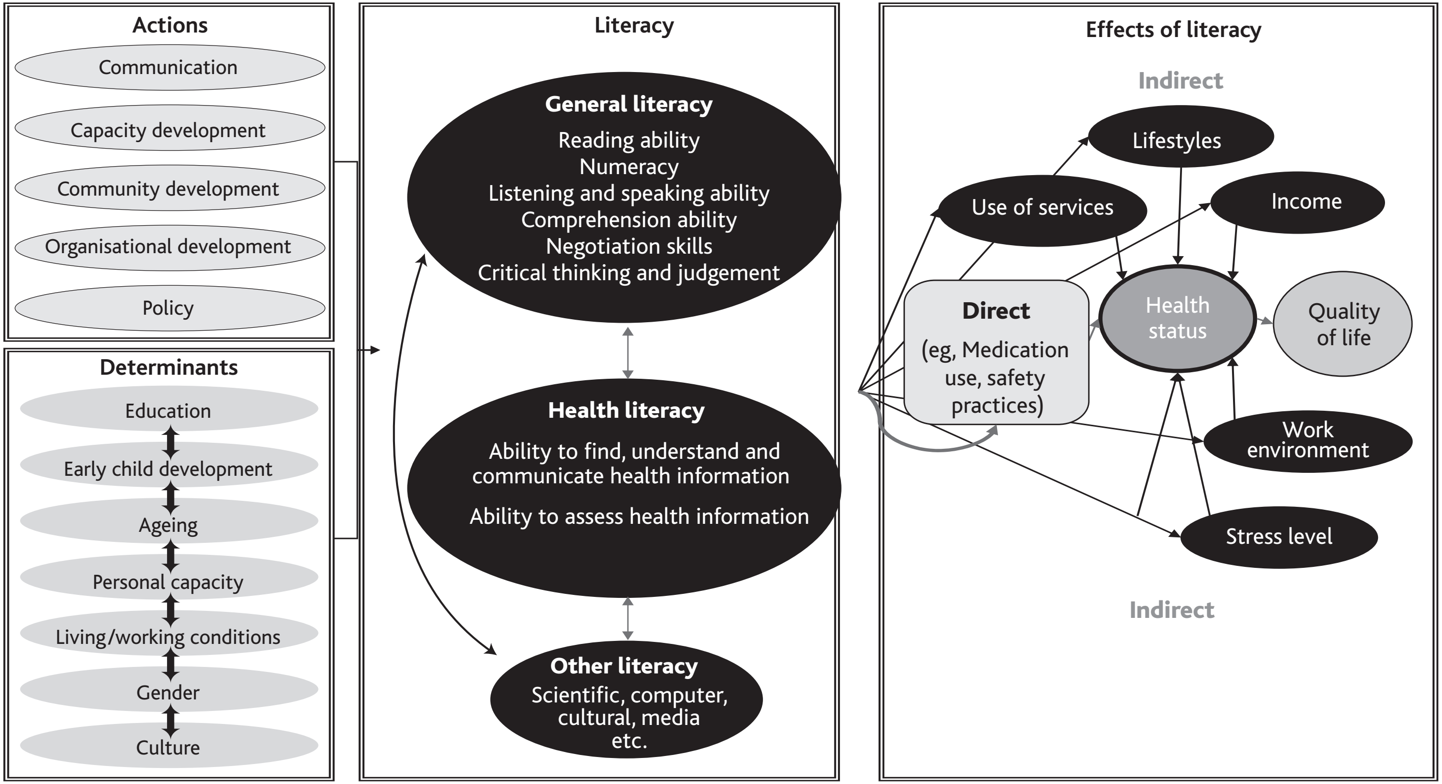
The IALSS pushed the health literacy agenda forward. The second of the OECD surveys, IALSS, included a subset of 193 questions on health literacy under five headings: health promotion, protection, prevention, healthcare maintenance, and system navigation. IALSS had a population sample of 23,000 Canadians. Although the data were not immediately available, the categories of study helped frame ongoing investigations and energised the sector. CPHA organised a second conference in 2004 that recommended establishing an Expert Panel similar to the US Institute of Medicine Expert Committee. By the time the Panel was set up in 2008, data from the IALSS were available and critical analysis by the CCL (2007) provided strong evidence to underpin the Panel's work.

Reaching two key pan-Canadian milestones

The Expert Panel report

The Expert Panel report called for a pan-Canadian strategy for health literacy and the development of policies, programmes and research to improve low health literacy levels as an important step toward reducing health disparities in Canada (Rootman and Gordon-El-Bihbety, 2008). It recommended that the Federal Government, including the Public Health Agency of Canada (PHAC) and Health Canada (HC), provide leadership to support the recommended actions and approaches. The Panel affirmed that 'a lack of awareness and understanding of the concept of health literacy' was impeding Canada's efforts to effectively promote and maintain public health (Rootman and Gordon-El-Bihbety, 2008, p 13). They reported that a survey of nearly 700 professionals and policy-makers found: (1) almost 30 per cent were unaware of the term 'health literacy'; (2) almost 60 per cent indicated the staff in their organisations did not know where to find resources to support health literacy efforts; and (3) only 7 per cent indicated that their organisations had policies on health literacy in place (Rootman and Gordon-El-Bihbety, 2008). This landmark report presented a call to action for

Figure 29.1: Framework for health literacy



Source: Rootman and Ronson (2005)

research, strategies, practices and policies needed to improve the health literacy and wellbeing of all Canadians.

The Action Plan

In 2009, the Centre for Chronic Disease Prevention and Control (CCDPC) at the PHAC invited Sandra Vamos as their first Senior Advisor of Health Education & Health Literacy to lead a national health literacy programme of research and practice. Building on the work of the Expert Panel, Vamos, in collaboration with others, proposed a health literacy Action Plan as a strategic approach encouraging stakeholders from different sectors to become involved to advance the national health literacy agenda.

Vamos created and led an internal PHAC Health Literacy Advisory Group, and Vamos and Rootman co-created and co-led an external National Health Literacy Advisory Group to gather multisector stakeholder input on a draft national action plan document. The initial draft document was prepared by Mitic in consultation with Vamos and Rootman. The final document, titled *An intersectoral approach for improving health literacy for Canadians* (Action Plan), was the culmination of feedback and advice from the multisector advisory groups from two national health literacy think tanks and one international workshop of health literacy experts, academics, policy-makers and practitioners (Mitic and Rootman, 2012). All meetings co-chaired by Vamos and Rootman were convened by the Public Health Association of British Columbia, supported by the PHAC.

The purpose of the Action Plan was three-fold: (1) to identify priorities and organise them into a comprehensive framework for improving health literacy in Canada; (2) to recommend a set of actions (that is, sample activities) at the national, provincial/territorial/local levels to improve health literacy among all Canadians; and (3) to facilitate conversations among stakeholders about health literacy and encourage cross-sectoral work around health literacy initiatives. Five key partners/settings were identified: governments; health sector; education sector; workplaces and businesses; and community organisations. Three action areas for the development of a comprehensive approach for improving health literacy were also identified: develop knowledge; raise awareness and build capacity; and build infrastructure and partnerships. The Action Plan included sample activities for all components and partners. Figure 29.2 depicts the logic model for the Action Plan.

The Action Plan has still not been endorsed by policy-makers at any level of government. It is important to note that due to federal budgets cuts, the National Literacy Secretariat that had funded early health literacy initiatives was replaced in 2007 by a new entity that saw literacy as a labour market issue. The CCL, that had supported a national centre of expertise, was closed in 2010. Finally, the health literacy arm of the PHAC, responsible for supporting the development of the Action Plan, was eliminated in 2012, terminating the federal health literacy position and unit that had been funding efforts associated with the Action Plan agenda. Table 29.1 provides an overview of pan-Canadian milestones in the health literacy movement. A discussion follows on the application of the Action Plan since its release.

Table 29.1: Milestones in the development of health literacy in Canada

Year	Canadian milestone
1989	Ontario Public Health Association Project on literacy and health
1994	International Adult Literacy Survey (IALS)
1994	Canadian Public Health Association Literacy and Health Program
2000	First National Conference on literacy and health
2003	International Adult Literacy and Skills Survey (IALSS)
2004	Second National Conference on literacy and health
2006	Canadian Council on Learning Research and Projects
2008	*A vision for a health literate Canada: Report of the Expert Panel on health literacy*
2008	Calgary Charter on health literacy
2011	*British Columbia Health Literacy Strategy*
2011	Online health literacy continuing medical education course for doctors
2012	*Intersectoral Approach For Improve Health Literacy for Canadians*
2013	Online core health literacy course for public health students
2014	*Health Literacy in Canada* book

Application and implications of the Action Plan

Two steps forward ... one step back

The Expert Panel report was a catalyst for Federal Government interest and funding for health literacy efforts for a few years, leading to the development of pockets of completed good work aligned with the Action Plan. However, these efforts are not all necessarily evident to others, particularly those new to the field. As noted, PHAC supported the development of the Action Plan with its three-pronged approach. Within this context, one specific federal project undertaken to inform the development and implementation of future health literacy activities was the Health Literacy Scan Project (Scan Project). The goal was to lay a foundation of shared knowledge as a prerequisite for PHAC to move forward on a vision and national plan to enhance the health literacy of all Canadians. The Scan Project led by Jim Frankish (University of British Columbia) and his research team worked with the PHAC lead. It was also informed by representatives from the Canadian Health Portfolio and community health literacy experts.

The Scan Project undertook three related *environmental scans* of available information and perspectives of key informants. Each scan addressed the questions of 'what examples exist of noteworthy health-literacy activities at a national level in Canada, and a set of comparable countries, and what have been the successes, areas of innovation and challenges of those activities?' (Frankish et al,

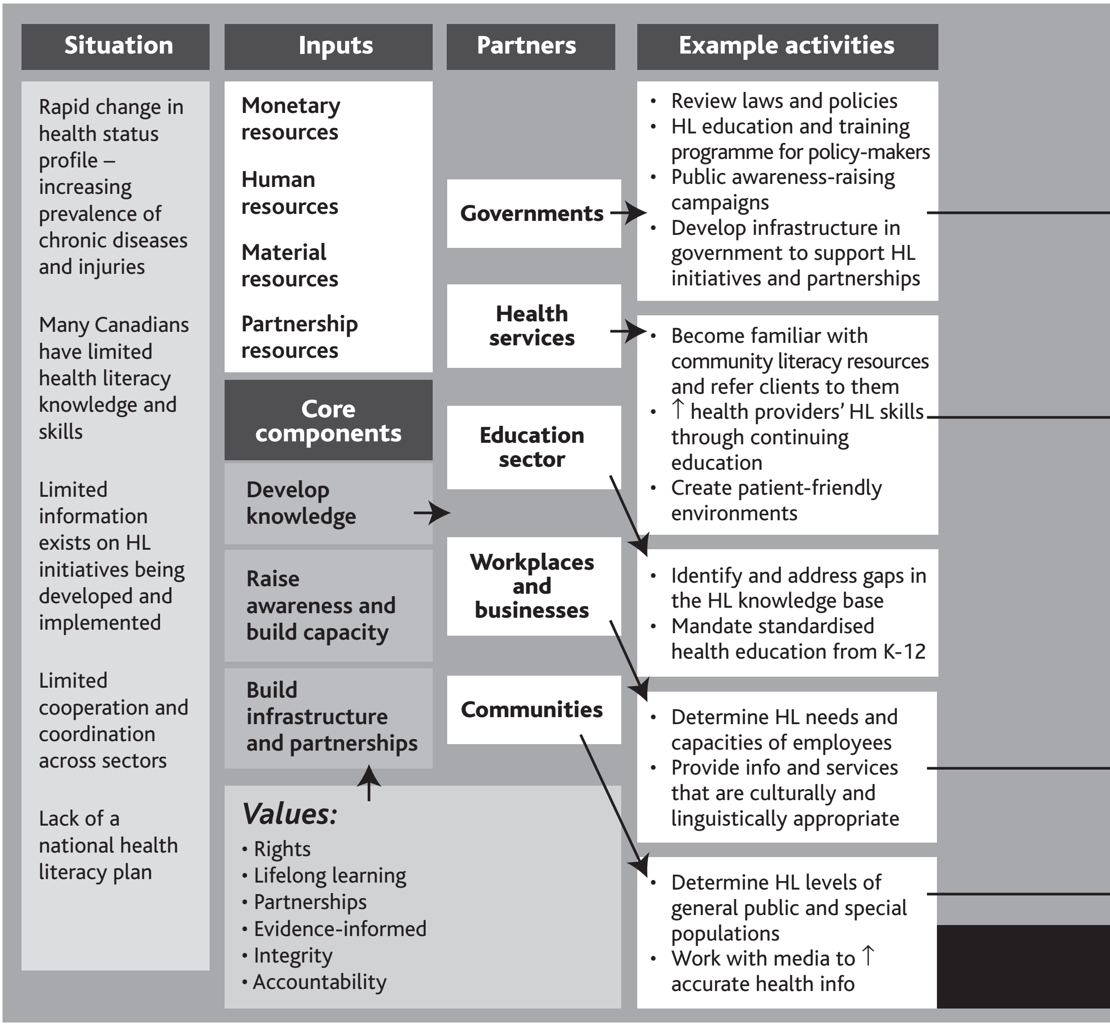
Figure 29.2: Logic model for the intersectoral approach to improving health literacy for Canadians

Vision

A Health Literate Canada in which all people in Canada can access, understand, evaluate and use health information and services that can guide them and others in making informed decisions to enhance their health and well-being.

Mission

To develop, implement and evaluate an approach that will support, coordinate and build health literacy capacity of the general public, and people and systems that deliver health information and services in Canada.



Situation

Rapid change in health status profile – increasing prevalence of chronic diseases and injuries

Many Canadians have limited health literacy knowledge and skills

Limited information exists on HL initiatives being developed and implemented

Limited cooperation and coordination across sectors

Lack of a national health literacy plan

Inputs

Monetary resources

Human resources

Material resources

Partnership resources

Core components

Develop knowledge

Raise awareness and build capacity

Build infrastructure and partnerships

Values:

- Rights
- Lifelong learning
- Partnerships
- Evidence-informed
- Integrity
- Accountability

Partners

Governments

Health services

Education sector

Workplaces and businesses

Communities

Example activities

- Review laws and policies
- HL education and training programme for policy-makers
- Public awareness-raising campaigns
- Develop infrastructure in government to support HL initiatives and partnerships

- Become familiar with community literacy resources and refer clients to them
- ↑ health providers' HL skills through continuing education
- Create patient-friendly environments

- Identify and address gaps in the HL knowledge base
- Mandate standardised health education from K-12

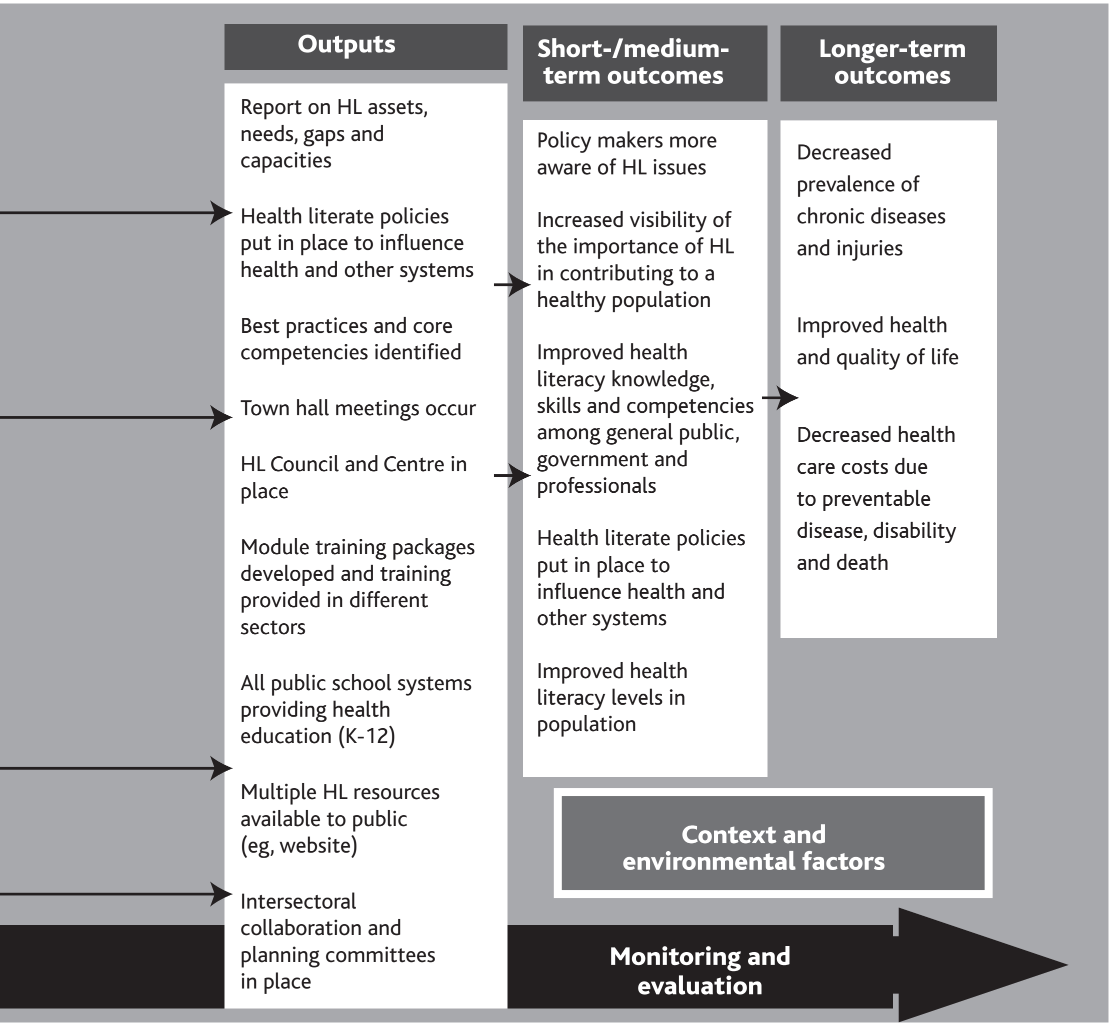
- Determine HL needs and capacities of employees
- Provide info and services that are culturally and linguistically appropriate

- Determine HL levels of general public and special populations
- Work with media to ↑ accurate health info

Figure 29.2: Logic model for the intersectoral approach to improving health literacy for Canadians (continued)

Goals: To improve health literacy abilities of all Canadians by:

- developing a sound knowledge base that provides access to the existing and most recent information as well as evidence on effective ways to improve health literacy
- raising the awareness and increasing the capacity of all Canadians to improve health literacy levels
- building the infrastructure and identifying the partnerships necessary to develop a coordinated approach to advancing health literacy initiatives



Source: Mitic and Rootman (2012, p 56)

2012, p 7). The results included a coded summary of initiatives related to health literacy (for example, actions, policies) using the Action Plan categories. Results were presented to PHAC designed to foster dialogue on the appropriate role of the federal sector in addressing needs, resources, skills, capacities and challenges to move forward on health literacy. They were intended to identify potential opportunities for training and capacity and useful examples of ongoing work from different jurisdictions. It was hoped that the information would be of value and interest to PHAC, other decision leaders, NGOs, practitioners and communities in Canada to inform policy and practice and beyond (Frankish et al, 2012). Unfortunately, similar to other federally funded health literacy work, this work was never published or disseminated to the public by government.

Following the 2012 PHAC health literacy cut, national literacy organisations, several of which supported health literacy initiatives, saw their federal core funding gradually reduced and ended in 2014, forcing further closures. Consequently, many important completed pieces of work and promising pilot projects aligned and driven by the Action Plan were shelved. Many players are not aware of the extent and range of past good work; the implication is that the work of tireless champions may not be used and built on. This increases the likelihood of duplicating past efforts due to a lack of awareness, knowledge uptake and transfer.

Nevertheless, Canada has great expertise spread across the country, although it is not currently formally connected; no national organisation has taken the lead. Of a number of model programmes highlighted several years ago by the PHAC, only a few remain in place after funding ended. Yet there are new initiatives of promise. Looking at the many health literacy research projects and practices currently underway or in place, it is clear that they could fit into the Action Plan (that is, the three-pronged approach and five sectors). Similar to the Scan Project findings, most ongoing efforts continue to neglect the 'Building partnerships and infrastructure' category and target 'specific' skills that support health literacy. Some selected current initiatives are categorised below, according to the Action Plan.

Knowledge development

Some research continues to be supported through the Canadian Institute for Health Research (CIHR) and Canadian Institute for Health Information (CIHI). Their databases show many projects in both medical and social science disciplines in which health literacy is a component. The range is broad, from studies on the impact of health literacy on specific diseases to cultural or digital dimensions of health literacy. The research seems to be concentrated in provinces where there has been historical engagement in health literacy promotion and practice, such as British Columbia and Ontario, and where there have been strong individual and institutional champions over the years, suggesting the importance of networks and peer support.

Building capacity and raising awareness

Aside from the core health literacy course in public health curricula mentioned earlier, little formal training has been integrated into core medical curricula. Regarding continuing education in health literacy for health professionals, the PHAC online health literacy module for public health practitioners developed in 2012 is no longer being offered by PHAC as they no longer support the delivery of the Skills Online modules, through which this module was offered. Moreover, accreditation for the Canadian Medical Association online training option for physicians and nurses has not been maintained due to lack of funding.

Countless practices in community and healthcare settings are more difficult to document, but a rapid scan of the country shows health literacy resources being offered in adult literacy and immigrant settlement organisations, and in hospitals and medical offices. For examples in the medical sector, the Canadian Pediatric Society promotes integrating literacy into early childhood paediatric practice through a website based on health literacy principles to support the practice (see www.cps.ca/issues-questions/literacy). Montreal Children's Hospital has sustained a model paediatric intervention called Lire/Imagine/Read that combines multilingual guidance on early literacy for families with training in health literacy for physicians and other healthcare professionals (see www.thechildren.com/search/site/Lire/Imagine/Read). The challenge is that there is currently little connection among the many practices.

However, technology offers ways to share through webinars and blogs that are beginning to be used more frequently. Patient educators networks have taken a lead. For example, the Canadian Health Literacy and Patient Education Network (CHLPEN) is a listserv created to share information and queries (see www.symplur.com/healthcare-hashtags/chlpen/). CHLPEN is supported by the University Health Network (UHN) in Ontario. UHN, through CHLPEN, has partnered with the Ontario Ministry of Health and Long-Term Care (MOHLTC) to organise a series of health literacy webinars in 2016-17 and to host a Symposium in May 2018, the first gathering on health literacy in several years. CHLPEN and similar networks have the potential to offer a virtual space to connect players studying and practicing health literacy into a community of practice.

Building partnerships and infrastructure

In British Columbia, a Health Literacy Network (BCHLN) established in 2011 continues to be active. The BCHLN is a unique dynamic network of networks of community literacy, education, librarian, seniors organisations, health authorities and public health partners that engage practitioners and researchers in initiatives around specific health issues. It depends on a core of committed expert individuals, working as volunteers, and a long history of engagement. They offer a possible model of using community–university–government networks to support embedded practice and carry out small-scale research and education while looking for sustainable funding.

These examples give us hope that policy may eventually develop from recognition within governments that the groundwork for a coherent health literacy approach has already been laid. The expertise developed over more than two decades is still vibrant and can be tapped to renew the vision for health literacy in Canada that was put forward a decade ago.

Strategic directions: the role of governments

While Canada's historical path of health literacy has been anchored in broad health promotion and education perspectives, tides may be changing due to our current government's targeted focus on healthcare. It is critical that we do not regress to silos as a result of political agendas, but rather create alliances between sectors. The Action Plan is useful to remind us that health literacy is a crucial component of the determinants of health, and to encourage collective actions across sectors to improve the wellbeing of all Canadians.

We can learn from several key factors that influence and limit the advancement of the promising intersectoral health literacy work of individuals, groups and organisations (Frankish et al, 2012). The primary limiting factors are funding and leadership. The lack of understanding of Canada's definition of health literacy and a formal policy or mandate to incorporate health literacy work into programmes and initiatives limit the 'type' and 'scope' of work being done. In many cases, health literacy is an 'add-on' to existing projects. Dollars are not available to carry out system-wide, multi-year programmes. Coordination of new initiatives across governments and agencies are especially challenging given the wide range of activities related to and needed to address health literacy, coupled with the often limited capacity and number of trained people to do and measure this work. Improved communication and partnerships are needed among groups to build on existing skills and valuable work, to improve human capacity and to reduce duplication of health literacy resources, thereby using limited funds as effectively as possible (Frankish et al, 2012). Framing health literacy as a national priority should include a formal funding vehicle for health literacy initiatives.

What governments are doing

There is no current formal government policy on health literacy at either federal or provincial/territorial levels. However, there are initiatives that incorporate health literacy inside government departments. For example, Health Canada, recognising that health literacy is vital to providing nutrition guidance to all Canadians, has conducted internal studies on what users found challenging to understand in past programmes, and is applying a health literacy lens in developing products for Canada's Food Guide. Another encouraging recent development is a health literacy initiative by the Ontario MOHLTC that includes conducting a public opinion provincial survey on health literacy, starting a webinars series for the sector, and working to connect, where possible, with practitioners and researchers in the field.

Presently, Canadian governments are seeking ways to transform 'healthcare' with an ageing population, a high prevalence of chronic disease, a strained healthcare workforce, multiple and competing economic priorities and evolving technologies for communicating health information and services. While challenging, these circumstances also create the opportunity to re-imagine how we can provide Canadians with the right care, at the right time, in the right place. In preparing for 'health system' transformation, notwithstanding our current healthcare context, the compelling evidence in this chapter creates an obligation on the part of the Canadian government(s) to re-visit the existing Action Plan.

The federal/provincial/territorial Ministries of Health and specifically the PHAC have an opportunity to demonstrate leadership and innovation in health system transformation in raising awareness of the impact of health literacy on the health of Canadians, and on both the education and healthcare systems working with other sectors, as proposed by the Action Plan.

Opportunities and responsibilities

Continued and sustained support of health literacy research in Canada is fundamental to inform best practices among healthcare providers/organisations, and to address the diversity of health literacy skills among Canadians to ensure equitable access to information and services in support of the current government focus on healthcare needs. Key healthcare and system indicators collected by Statistics Canada and CIHI are used by decision-makers to identify priority health issues, and for healthcare planning and resource allocation. An important policy initiative would mandate the systematic assessment of Canadians' health literacy as another key health status/system indicator.

There are multiple exemplars related to raising awareness about health literacy and building capacity. Endorsing and advocating for the Action Plan by policy-makers would facilitate conversations among educators, practitioners, researchers and policy-makers to enhance the work accomplished by the many isolated initiatives that exist across the country. The Action Plan offers an opportunity to take a wider focus and to coordinate existing and new knowledge.

Opportunities also exist for strategic policy in creating infrastructure and partnerships. As noted, important collaborations already exist among the health and education sectors and with the various national/provincial/territorial healthcare provider associations (for example, the Canadian Medical Association, Canadian Nurses Association) to integrate health literacy skills into health professional education and continuing education. A review and revision of elementary/secondary school curricula are needed to formally integrate health literacy in the areas of multiple literacies (for example, health literacy, digital literacy, media literacy) as prerequisite to equitable access to health information, services and supports. To help do this the Ministries of Education could mandate 'education for health literacy' whereby standardised health education classes are required in all schools from preschool to Year 12 integrating health literacy principles across curricula. As in other countries, mandated health education coursework and degrees should be offered and required for all health education teachers enrolled in teacher education programmes. These recommendations suggest tackling capacity building issues within and between the health and education systems.

Innovative occupational health services might consider a health policy that recognises literacy (for example, basic, health, digital) education as part of health promotion programming in the workplace. Models exist in partnerships among community organisations (for example, literacy groups, immigration/refugee groups) that address the learning needs of older adults and new Canadians by integrating multiple literacies, including health, into community-based literacy curricula/programmes.

Conclusion

Over the past 30 years, Canada has made progress toward becoming health literate. The journey continues with ongoing interest and contributions across a continuum of discipline, background and expertise, ranging from tireless individual champions to those new to the field. Health promotion and health education frames health literacy as a resource for life. We know health literacy is a major health and education investment, yet separate systems continue to compete. While governments and policies can set important preconditions as enablers to move a health literacy agenda forward, people must still be empowered to participate in their health and learning and support the health and learning of others. The Action Plan remains our national call to action to close divides, underpin policy and help make the vision for a health-literate Canada a reality.

Postscript

Please note: As this book went to press, there were a couple of encouraging developments in Canada related to Literacy and Health and Health Literacy. The first was a national forum on 'Literacy and Health' supported by the Public Health Agency of Canada organized by Frontier College and supplemented in Vancouver by a session on 'Health Literacy' in partnership with the BC Health Literacy Network. Another positive development was the formation of a national network on Adult Literacy with involvement of some Canadian leaders in health literacy. Thus, it appears as if government, the NGO sector and academia in Canada are beginning to work together again at the national level to improve the literacy levels of Canadians.

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Health literacy policies: National example from Austria – A unique story and some lessons learned from an ongoing journey

Peter Nowak, Christina Dietscher and Marlene Sator

Introduction and background: the Austrian story

Health literacy (HL) became a policy topic in Austria in 2011/12, initiated by expert discussions on the preliminary results of the first comparative European survey of population HL, known as the HLS-EU Survey (HLS-EU Consortium, 2012). The findings were widely communicated in Austrian expert communities. Leading experts, in particular Jürgen Pelikan, one of the initiators of the HLS-EU Survey, presented them with urgency to senior decision-makers in the Austrian health system. The data came as a shock to the national health authorities and the expert community, as the study results indicate that HL in Austria is one of the lowest in Europe. This seems problematic since a growing body of evidence (Berkman et al, 2011) suggests that HL and health status are significantly interrelated, as are HL and adequate usage of the healthcare system. Particularly in old age, people with better HL also report a better health status. A possible explanation might be that better HL is associated with better health-conducive decisions throughout the life course, which accumulate to better health outcomes in the long run. Against this background, it seems plausible that the low level of HL in Austria might very likely contribute to the comparatively low number of healthy life years in the Austrian population. However, since Austrians scored second best in the cognitive questions (NVS-UK) in the HLS-EU Questionnaire (HLS-EU Consortium, 2012, p 27), their low level of HL does not seem to reflect limited intellectual skills, but rather some specificities of the Austrian healthcare system and the prevailing culture of care. The system is highly fragmented and strongly shaped by Austria's federal structure. The national state has a rather modest influence compared to the Austrian provinces or 'Länder', so that there are numerous differences in service provision for the population in the different provinces. Furthermore, the system is strongly doctor-driven, hospital-centred, and has only very few participatory elements that allow the involvement of the people concerned; health promotion is not integrated into the healthcare system but is, as healthcare, implemented and performed in a very fragmented way so that it does not systematically reach the population.

It was a welcome coincidence that the HL data became available at a time when a broad development process of intersectoral, determinant-oriented national health targets was in progress (BMASGK, 2018) and a fundamental reform process of the healthcare system in Austria was about to start. These developments opened windows of opportunity that allowed moving HL high up the political agenda, especially in the health sector, resulting in an ongoing commitment to specific activities and interventions. In the following, we provide an overview of the Austrian journey, take stock of achievements so far, and present our lessons learned with regard to key success factors and obstacles.

Main steps of a unique story

In our experience, the following six main steps were crucial for establishing HL as a new health policy focus in Austria.

Providing and extensively communicating data to inform (health) policy

Austria was among the initiating countries of the HLS-EU Survey (HLS-EU Consortium, 2012) and had a lead role in the international data analysis. Therefore, there was prominent access to the findings. Accordingly, limited HL – that is, problematic or inadequate levels of HL – affects not only 56.4 per cent of Austrians, but is also more widespread in Austria than in the international average of all eight participating countries. Of these, the Netherlands has the lowest proportion of limited HL (less than 29%), while Bulgaria has the highest (62%). Austria's position in this survey came as a wake-up call to the national health authorities and expert community.

It is worth mentioning that the heavy national marketing of the data is also related to a lack of public funding for the national study and the resulting co-funding by a pharmaceutical company that had a strong interest in supporting broad public debate and establishing contact with political decision-makers. While the company's involvement is double-edged and also created some ambivalence about the study, it was essential for starting the Austrian journey.

The study results provided some directions for future strategies and interventions. Although they clearly demonstrate that limited HL is a relevant problem for the entire Austrian society, there are also clear indications that the HL of specific vulnerable groups is below the population average, with more than 76 per cent of problematic HL in some groups. People who consider their health as poor or very poor (for example, people with chronic diseases) and those who have frequent contact with the healthcare system are especially affected, as are people from higher age groups. Since chronically ill and older people use the healthcare system most frequently, these findings seem to indicate that the current healthcare system is not adequately meeting the information and professional communication needs of its main target groups.

In addition, HL is directly related to the socioeconomic status of people, especially to education, to the financial situation and to employment status. Data clearly indicate that HL is socially unequally distributed. While this is a general pattern in the HLS-EU Survey, the results for vulnerable groups are worse in Austria than for the European Union (EU) as a whole (Pelikan et al, 2013b).

In international comparison, Austrians seem to find it particularly difficult to understand medication leaflets, to assess the advantages and disadvantages of treatment options, to assess whether they should obtain a second opinion from another doctor or to understand what their doctor tells them. They also have difficulty assessing whether media coverage about diseases or health risks is trustworthy. Furthermore, it is difficult for Austrians to assess the availability of health promotion offers at their workplace, or to estimate whether political changes have an impact on their health. Understanding information on food packaging is also a challenge (Pelikan et al, 2013a). Overall, Austrians seem to have more problems with HL in relation to health promotion and disease prevention than with treatment-related HL (HLS-EU Consortium, 2012).

The causes for these poor results are still subject to ongoing analysis and discussion. Initially, parts of the public health community feared that the new focus on HL might lead to a renaissance of blaming the individual for adverse health outcomes (individual accountability) rather than concentrating on further developing the health system to meet population and patient needs (political accountability). Luckily, the data from the HLS-EU Survey became available at a time when Austria was just about to start two important national reform processes: the comprehensive and intersectoral Austrian health target process, and a new approach to the ongoing Austrian healthcare reform process ('management by targets'). These two strategies that comprise both the wider public health system and the narrower healthcare system enabled a balanced approach towards HL with a strong focus on the systems level, challenging the paternalistic doctor, hospital and illness-centred healthcare system in Austria.

Setting up an intersectoral approach towards HL as part of the comprehensive Austrian health target process

In 2012, 10 comprehensive targets that are based on a determinant-oriented understanding of health, and on an intersectoral approach to improve these determinants in the sense of Health in All Policies (HiAP) (WHO, 2015), were approved and launched by the Austrian Council of Ministers. Stakeholders from most ministries, organisations of civil society and non-governmental organisations (NGOs), that form the so-called health target plenary, had been involved in the target development.

Health target 3 is 'to enhance HL in the population'. It was prioritised by the health target plenary as it was understood as the most urgent and promising target. From 2012-13, a working group, consisting of 30 experts from public administration, social security, research institutions and other stakeholders, developed specific sub-targets, main indicators of success and concrete interventions to improve HL in Austria. The three sub-targets are as follows:

1. To make the health system more health literate through involving stakeholders and those affected (for example, by developing health-literate organisations in healthcare)
2. To strengthen individual HL in consideration of vulnerable groups (for example, by collaborating with the education system)
3. To embed HL in the service and production sectors (the economic system). (BMGF, 2017)

The development of these sub-targets followed a comparatively systematic process, highlighting determinants that can plausibly be related to HL improvements. In line with the overall health target approach, the resulting interventions to improve HL focused on HL for health promotion, disease prevention and healthcare, as well as on a life course perspective – from supporting health promotion and prevention-oriented HL in early childhood (nursery and schools), up to healthcare-oriented HL for (potential) patients of all age groups. However, as there was no specific budget available for intervention, their selection depended on offers made by participating experts and stakeholders who had the power and means to get action into practice. These stakeholders had to be convinced to invest in HL, either by new interventions or by (re-)shaping already planned interventions with an additional focus on HL. As a result, a rather arbitrary mix of comprehensive, longer-term initiatives by the Ministry of Health (MoH) (for example, 'Establishing a national HL coordination alliance') and by social security institutions (for example, 'Health-literate social security services'), and of rather local and often short-term initiatives by other partners, was implemented (BMGF, 2017).

As the selection of interventions is not guided by, for example, causal pathways to improve low HL, by available evidence or by a rational selection of priority target groups and institutions, it is difficult to assess their effectiveness for improving HL in the Austrian population. Furthermore, a number of strategic and HL-relevant initiatives by the MoH itself, namely, a national health information web portal, a low-threshold 24-hours telephone health information service and implementation of the Austrian electronic patient record system are not part of the health target process but are implemented under the ongoing national healthcare reform process. These parallel developments make it even more complicated to assess and attribute outcomes, which may well be taken as an indicator for the complex and fragmented Austrian health (care) system.

Now, four years after the publication of the original HL intervention plan, an outcome model that was systematically developed on the basis of the Swiss model for outcome classification in health promotion (Spencer et al, 2008) serves as the basis for strategically identifying white spots on the map of national HL interventions.

Defining HL-sensitive healthcare as a specific goal of the ongoing national healthcare reform process

As data from the HLS-EU Survey put specific concern on the HL of Austrian patients, it seemed important to address HL not only in the wider public health context, but also in the very core processes of the healthcare system. The national healthcare reform process, which started in 2013, served as an entry point.

Since then, the main partners of Austria's complex healthcare system – the MoH, which has responsibility for defining political frameworks, the Länder, that are responsible for concretisation and implementation, and social security, a major strategic and funding partner – have been engaging in the so-called 'management by targets' (Zielsteuerung Gesundheit) process. For given periods of time (4-5 years), they jointly agree on common goals and matching interventions.

In the agreement on the first period of this reform process (2013-16), HL was mentioned as follows:

- The introduction mentions HL as part of the vision of the agreement, and as a precondition for self-determination, citizen and patient participation and better health-related decisions.
- The strategic goals include communication and information to improve HL, as well as HL measurement.
- Four resulting interventions are listed: (1) the development of a national health information website (see www.gesundheit.gv.at); (2) the stepwise implementation of the HL interventions collected in the health target processes; (3) using the Austrian electronic patient record system to improve HL; and (4) participation in future European HL surveys.

This agreement triggered two important next steps for HL in Austria: initiation of the 'Austrian Health Literacy Alliance' (Österreichische Plattform Gesundheitskompetenz – ÖPGK; see https://oepgk.at/) as the national HL steering and coordination body for HL, and the development of a national strategy for improving the quality of communication in healthcare.

The second period of the reform process started in 2017 and is scheduled until 2021. It builds on the first reform period and specifically highlights three HL intervention areas:

- further institutionalisation and development of the ÖPGK;
- implementation of interventions for more HL-sensitive communication in healthcare, written or audio-visual health information and of organisational HL;
- participation in the next HL survey.

In addition, there are some ongoing attempts to systematically include HL and health promotion as part of the professional competencies of healthcare providers in primary healthcare (Rojatz et al, 2018), which is currently undergoing major restructuring in

Austria. Moreover, recent developments towards strengthening self-help organisations might bring about a better participation of patients and citizens in health policy decisions. According to the healthcare reform structure, these interventions have to be supported by all three reform partners (MoH, social security, Länder).

Capacity-building for a national coordination and support structure – who will lead and how will it be financed?

The Austrian HL landscape quickly became complex, with strong drivers from within the healthcare sector, while other sectors whose contribution seems indispensable for building up better HL in the population are still only loosely related to the process. One attempt to overcome this shortcoming and to engage other relevant sectors was to set up an intersectoral national coordination structure.

Inspired by a Canadian discussion paper (Mitic and Rootman, 2012; see also Chapter 29, this volume), the working group on the national health target on improving HL had identified a coordination structure as crucial for achieving a critical and lasting impact. In an attempt to raise funds for such a structure, leading figures of the MoH and of social security introduced the idea to the healthcare reform partners. While this provided an opportunity to gain political backing and raise financial resources, there was also a considerable risk to get stuck in the complex power play of the healthcare reform process, of losing the support and buy-in from stakeholders in other sectors, and the momentum for change.

In the end, a specific working group, consisting of experts from the three main healthcare reform partners, as well as from other sectors such as the social and the education sector, and the national Public Health Institute, set out to develop a concept for the coordination structure. Three questions were crucial during the negotiation process: (1) Who would provide the financial resources for the ÖPGK? (2) What structure or institution should it be linked to, or, in other words, how (in)dependent should it be? (3) What balance of power seems adequate for governing the ÖPGK between the main stakeholders in healthcare and the other involved sectors, and what would be the role and visibility of representatives of grass-roots initiatives and beneficiaries of the support structure? At one point differences about the questions on resources and independence nearly crashed the whole endeavour. Political interests took over what was until then a well-taken expert debate. The final political decisions were made behind closed doors and were in favour of an independent structure, financed by the Austrian Health Promotion Fund (see http://fgoe.org/).

It took a year and help from an external facilitator to draft and negotiate a recommendation paper that outlined what would from now on be called the 'Austrian Health Literacy Alliance'. This recommendation paper was passed by the highest decision-making body of the Austrian health system in 2014. It outlines a long-term vision and goals for 20 years of implementation, the tasks to be accomplished, the governance structure (see Box 30.1), and resources needed for the national coordination structure.

Box 30.1: The Austrian Health Literacy Alliance (ÖPGK)

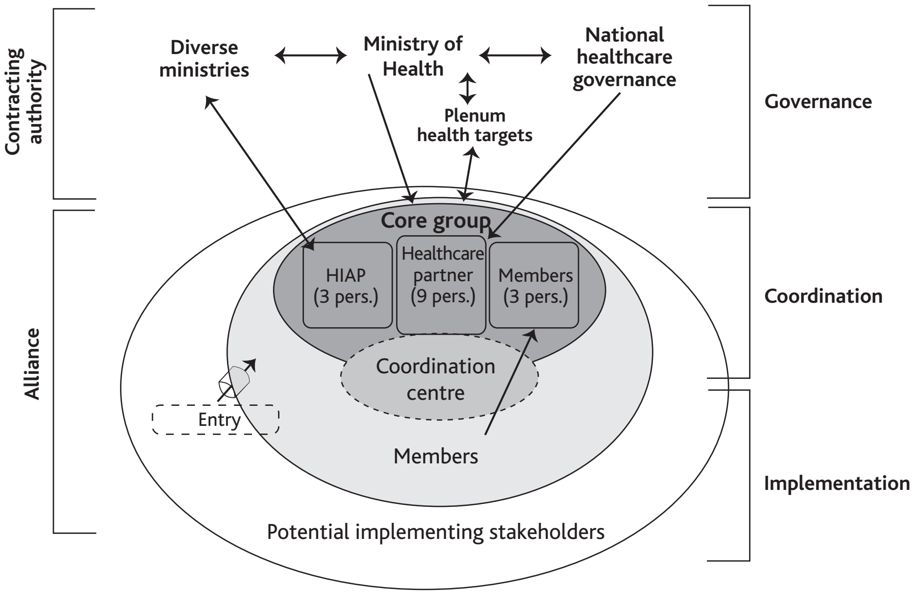
The ÖPGK is chaired by the Austrian MoH. It has a 'core group' with representatives from the MoH, the Länder and social security, as well as partners from currently four other ministries as so-called 'HiAP partners'. All types of organisations that run HL projects can be accepted as 'members' of the alliance, and representatives of these members can be elected into the core group that meets four to five times a year to take strategic decisions. The coordination centre of the alliance is run by the Austrian Health Promotion Fund (see Figure 30.1).

The main aims of the alliance are as follows:

1. Support the long-term development and establishment of HL in Austria.
2. Promote networking, cooperation, exchange of experiences and joint learning.
3. Enable and coordinate measures between policy areas and social areas.
4. Develop a common understanding, disseminate knowledge and facilitate innovation.
5. Establish monitoring and reporting, develop transparency and quality.

The alliance organises an annual national HL conference, encourages the implementation of HL measures by a membership process for organisations performing HL interventions, and recently started an exchange network on the quality of communication in healthcare.

Figure 30.1: Organisational chart of the ÖPGK



One of the ÖPGK's shortcomings until today is that there is no systematic patient or citizen involvement built into its governance structure. Some NGOs have become members, but the main governance and coordination processes are determined by professionals from public administration and healthcare.

Another shortcoming is the alliance's financing. Although the money from the Austrian Health Promotion Fund guaranteed some independence, the ÖPGK's financial source complicates longer-term planning since decisions on the Fund's resources are taken by a board of trustees who follow a rather puristic understanding of health promotion that does not extend to interventions in the healthcare field. Therefore, the Fund and the partners of the ÖPGK constantly have to convince the trustees to maintain investment in the ÖPGK.

Now, in the ÖPGK's third year of existence, the question of how to win the political and (potentially much higher) financial support of the core healthcare system is becoming crucial for the further development of HL in Austria.

Developing specific policies – the quality of personal healthcare communication in healthcare and of written health information

The ongoing developments of the ÖPGK and the 'management by targets' process provide a strong momentum for strategic change towards better quality of communication in healthcare. In 2016, the core group of the ÖPGK defined two priority topics to be supported by all media and initiatives of the alliance: (1) the quality of face-to-face communication in healthcare (see Box 30.2) and (2) evidence based and understandable written and audio-visual health information (see Box 30.3).

Box 30.2: A national strategy for improving the quality of personal communication in healthcare

Communication between professionals and patients is key to patient-centred and efficient healthcare and to HL (Sator et al, 2015). In 2015 a national strategy for improving the quality of personal, patient-centred communication in healthcare was developed. The strategy was passed by the main decision-making body for the Austrian healthcare system in 2016 (BMGF, 2016). It suggests a comprehensive intervention model and recommends action in four areas:

1. Human resources development for healthcare professionals

High-quality communication in healthcare is hampered by a considerable gap between classroom and workplace learning in Austria as well as in other countries. Students lack role models and reinforcement and have to handle contradictions between theory and practice (Rosenbaum, 2017). Clinical teachers lack the skills for facilitating communication skills training (CST). Therefore, a train-the-trainer certificate programme for facilitators of CST for practising healthcare professionals in Austrian healthcare organisations has been started in close cooperation with EACH: International Association for Communication in Healthcare (see www.each.eu).

2. Empowering patients and families

To attend to the asymmetry of power between patients and families on the one hand and healthcare professionals on the other, interventions have been started for:

- designing effective patient information and decision aids
- running evidence-based patient education programmes
- disseminating question prompt lists and campaigns.

3. Organisational development for healthcare institutions

High-quality communication needs organisational support. Pilot projects are in preparation, that include initial assessments (of organisational HL; see Dietscher and Pelikan, 2017 and Chapter 35, this volume; of the quality of healthcare communication and of local communication processes and challenges), organisational development interventions, and final evaluation of the quality of healthcare communication on an organisational level.

4. Health systems development for patient-centred healthcare communication

Healthcare communication is still widely understood as a nice-to-have, rather than a must-have. Interventions to raise attention for its importance include:

- communication to important stakeholders
- building a national network of practitioners, researchers and policy-makers
- developing incentives for high-quality communication.

Box 30.3: Manual for evidence-based, independent, understandable and gender-sensible health information

Good-quality, understandable health information in written texts and audio-visual media is a precondition for HL. Building on an Austrian adaption of the German standard for good health information (Deutsches Netzwerk Evidenzbasierte Medizin, 2016), a working group of the ÖPGK developed the manual *Good health information Austria* (ÖPGK and BMGF, 2017). The 15 quality criteria of the manual address people and organisations that publish, finance, write or disseminate written or audio-visual health-related information.

The 15 quality criteria for evidence-based and gender-sensitive health information address four main topics:

- Selection of relevant scientific sources and data to guarantee evidence-based information
- Provision of undistorted, clear information in words and pictures

- Adequately addressing, and involving, target groups
- Provision of transparent and neutral information, non-biased for users.

These criteria of 'Good Health Information Austria' were launched at the national HL conference in November 2017.

The two policies on personal and written or audio-visual communication and information present important first steps towards providing high-quality HL interventions. It will take years to implement them by training professionals, by new regulations and by public debate. The ÖPGK has already initiated a third main focus of its activities: the development of health-literate organisations (Brach et al, 2012; see also Chapter 35, this volume) in diverse sectors of public interest. First pilot approaches in hospitals (Dietscher and Pelikan, 2017) and in youth centres (Wieczorek et al, 2017) in Austria indicate promising results. Next steps in 2018 included identifying and disseminating models of good practice, assessment and implementation tools (ÖPGK, 2018).

Building realistic evaluation and monitoring – producing data for change

Data were key for Austria's journey towards HL from the beginning. The low ranking of Austria in the baseline data from the European HL survey started the whole movement. They were essential for getting HL on the political agenda, and for getting relevant experts and stakeholders involved.

Data were also important for establishing the ÖPGK. An independent evaluation was performed after the first year of activities (Gutknecht-Gmeiner and Capellaro, 2016). The evaluation report confirmed successful capacity-building for improving HL in Austria, and came up with some recommendations:

- to realise its potential, secure and further develop the ÖPGK in the longer term;
- to pursue strategic, broad-based interventions (lighthouse projects), while maintaining openness to a wide range of activities of member institutions from various fields;
- to further develop the ÖPGK's membership strategy, especially in relation to the strategic selection and recruitment of new members;
- to maintain and expand the existing range of information provision, advice and networking and strengthen systematic public relations;
- to secure professional support and a comprehensive approach to reach the various (heterogeneous) target groups.

These findings proved supportive for the ongoing negotiations on financing the ÖPGK. However, for sustained success, it will be important to be able to demonstrate that the activities of the ÖPGK actually contribute to improving population HL in Austria and that these improvements will bring about economic benefits for the Austrian healthcare system.

These complex issues will require further research. Currently, we do not know if HL in Austria has changed since the HLS-EU Survey. Therefore, the MoH and social security in particular are pushing the development of a new population-based HL survey. Still, it will be difficult to attribute changes in the HL of Austrians, if any, to the work of the ÖPGK and the 'governance by targets' process. Nonetheless, data on the distribution of (low) HL between different groups of the population, different settings and different regions in Austria would be essential for further steering a target-oriented development process. Austria and the other German-speaking countries convinced WHO-Europe, that already defined HL as a priority for health in Europe in the next years (WHO, 2013), to support the development of an Action Network under its patronage (M-POHL – WHO Action Network on Measuring Population and Organizational Health Literacy; https://m-pohl.net/), with the aim of starting the next European HL survey. More than 20 countries have already become network members and about 12 declared their interest in performing a harmonised survey in 2019. This would allow an assessment of Austria's development in international comparison, and to select outcome-oriented interventions for improving HL in Austria.

Also, potential costs and savings of the healthcare system through better HL can currently at best be estimated. The international literature (McDaid, 2017) on the economic impact of HL in relation to costs and savings is scarce, and data for Austria are not available at all. Future research in this field might be relevant to keep decision-makers engaged in HL policy and financing.

Taking stock: what has been achieved so far?

Since publication of the original implementation plan for health target 3 to improve HL in Austria in 2013, a lot of work has been done. HL has become part of the mainstream public discourse in Austria, and was even included in the government programme for the period 2017-22. Main professional bodies focus on HL in their conferences. Most education institutions in healthcare have started to work on new curricula to develop HL knowledge and skills in future healthcare professionals. The ÖPGK has a rapidly growing number of members implementing diverse measures to improve HL in a variety of fields.

So, on the one hand, the story of HL in Austria is quite impressive. But, on the other hand, we also see some shortcomings and potentials for further development:

- Most interventions still take place in the healthcare sector. From the perspective of healthcare, this can be considered an important contribution to improving healthcare quality. But other important sectors, especially the education sector, are still only marginally involved. For example, there is currently only a limited debate on what HL means for curricular developments in nurseries or schools.

Also, the economic sector is not yet on board despite its strong impact on (un)healthy lifestyles of the population. The HiAP approach is reflected in the governance structure of the ÖPGK, but in real life partners from outside the healthcare system participate mostly in observational roles.
- The involvement of patients and citizens is only indirect, and most interventions are planned and implemented by experts and public bodies. There is still no involvement strategy for the beneficiaries of the interventions, and we lack feedback on whether the chosen interventions actually meet their needs.
- The continuous financing of HL coordination and interventions remains a challenge on all levels and is vulnerable to political change. Austria's federal structure would require regional roll-out strategies, but only a few of the Austrian provinces have already started to invest in the field. Overall, it takes a lot of tactics, perseverance and charm to secure resources for each coming year.
- While the current 'hype' around HL triggered a lot of pioneer and pilot activity, long-term strategic implementation will also require formal regulations to support institutions to systematically orient their daily routines towards HL, using, for example, concepts like health-literate organisations.

Discussion: key success factors, obstacles and lessons learned

In this chapter we used six actions proposed by Holmes et al (2016) to change complex systems as an analytical framework to structure our observations and analysis on key success factors and obstacles for HL policy development and implementation at a national level.

Co-producing knowledge

The co-production of knowledge between engaged researchers, public administration, policy-makers and frontline professionals was essential for strengthening HL orientation in Austria. One example is the conceptualisation and adaptation of HL definitions for Austria, relating to the salutogenic approach (Eriksson, 2017) that focuses both on empowering people and on providing understandable, supportive environments, especially for vulnerable groups. This process created joint ownership and inspired an ongoing debate within the ÖPGK. Over the years, we have observed an impressive development of a 'community of practice'. Long-lasting trustful interprofessional relationships guard HL developments in the complex HiAP context.

One shortcoming already mentioned is the lack of involvement of the 'target populations'. Although this is a complex and resource-intensive endeavour, it seems necessary to avoid drifting off towards a purely expert-driven movement that loses ground contact and its initial targets.

Establishing shared goals and shared interventions

Supported and driven by the Austrian health target process, key decision-makers from the MoH, social security and other fields jointly discussed, developed and shared data, goals and partly also interventions, adopting the transformation logic of the public health action cycle (Rosenbrock and Hartung, 2011). This joint ownership proved essential to engage key stakeholders, to sustain their support and to realise the 'kairos' of the situation – that is, to make use of the unique window of opportunity at a national level.

However, this approach is hardly mirrored at the level of the Austrian 'Länder'. Due to a lack of funding, good-quality data to compare the HL levels of the Länder are inexistent. As first limited results suggest big differences between their HL levels, reliable data might motivate more of the provinces to put HL higher up on their agendas.

Another lesson learned was that, in jointly owned processes, it is important to constantly strive for the right balance between aspiration (such as high-quality and evidence-based international standards, for example, for training multiplicators) and actual capabilities, so as not to discourage interested people and organisations to start change processes in the reality of their everyday contexts.

Enabling and supporting leadership

Leadership is key to any change process but takes a lot of energy for strategic planning, persistence and constantly motivating oneself and others. Luckily enough, leaders from different levels, sectors and institutions had enough backing (or independence) from their home organisations to support the Austrian journey towards HL. During this journey, ways to facilitate exchange, mutual information, inspiration and motivation between these leaders were developed. These include the ongoing administrative and scientific support provided by the coordination centre of the ÖPGK. Another instrument is an annual two-day reflecting and planning workshop of the ÖPGK core group that functions as a catalyst for knowledge and expertise and enables participants to act as change agents in their own organisations and contexts, in the sense of 'engaged scholarship' (Holmes et al, 2016) and translation of expert knowledge into practice.

The ÖPGK core group also provides peer support that can be essential to maintain stamina and determination, especially when long-lasting open processes have to be endured and patience is needed until the public, political and scientific discourse has been sufficiently developed to enable the next steps of implementation.

One shortcoming is that leadership for HL still has not yet sufficiently reached beyond the healthcare sector. It might help to convince leaders from other sectors to demonstrate the co-benefits of HL for their sector – especially in relation to better reaching their own goals. As a first step, we developed a policy brief on the co-benefits of HL in the education sector together with the European Observatory on Health Systems and Policies (McDaid, 2016).

Ensuring adequate resourcing

In times of scarce public resources, the question of ensuring adequate finances is essential, but also difficult. This also remains an ongoing issue for Austria in light of changing political power situations. The currently stable and midterm provision of financial and human resources helps to hold the momentum at the level of the whole movement, of single key organisations and of engaged people. But the development and implementation of clear quality criteria that support a long-term transformation process is equally important.

Therefore, the ÖPGK aims to develop such criteria, and has already done so in relation to the quality of communication in healthcare and the criteria for good health information. For the future, the development of HL-related legislation may also be considered, since a legal basis might support ongoing provision of implementation resources for HL.

For some interventions, such as attempts to improve quality of communication in healthcare, developed human resources are another important precondition. Accordingly, the national strategy on communication in healthcare supports trainers to become multiplicators, disseminators and change agents for HL. As the example of this strategy shows, international partnerships like cooperation with EACH: International Association for Communication in Healthcare are most helpful in obtaining the knowledge resources needed at the national level.

Contributing to the science of knowledge-to-action

Enabling the transfer from knowledge to action is part of the core goals of the ÖPGK. For this purpose, the platform runs a knowledge centre on its website, publishes a newsletter, organises annual conferences and facilitates specific exchange networks, working groups and international knowledge exchange. These offers are open to members of the ÖPGK and also to the interested public.

A further development of the ÖPGK's exchange structures is already at the planning stage. The platform plans to create specific sub-networks for HL in specific settings such as schools or youth centres. We hope that in the long run this strategy will also help to get HiAP partners more on board.

Being strategic with communication

The national public debate on HL is only partly due to strategic communication. Currently, the different partners of the ÖPGK act very independently with regard to their HL-related communication, so that some of the communicated messages may even appear contradictive as they are not counterchecked with other players in the field.

One of the problems in this field is a lack of resources – professional strategic communication can be quite expensive. But it is also difficult to engage the different players in HL, many of whom are not linked by hierarchy or formal agreements, to pursue a joint communication strategy. To find ways around these issues, the ÖPGK core group implemented a temporary working group to develop a joint communication strategy.

While there is currently no joint strategy on the content and tools of communication, one of the outstanding achievements of the ÖPGK and its partners is a pervasive and palpable culture of friendly 'human' communication across sectors and hierarchies that is shared and spread throughout the national alliance.

Conclusion and implications for change at a systems level

One of the major learnings from our experiences is that major developments need strong drivers. In the case of Austria, the availability of internationally comparative data on population HL was such a driver.

At least for the Austrian healthcare sector, it proved successful to use existing strategic change processes governed by the health sector, such as the health target process and the 'governance by targets' process, to support HL. However, in hindsight, the resulting strong role of the healthcare sector may have hindered a stronger involvement of other sectors. Through the ÖPGK, we were able to establish at least good cooperation with some HiAP partners, but were not yet sufficiently able to support them to identify, and successfully use, strategic processes within their own domains to contribute to better HL.

At least four ways towards this end seem possible from here. The first is to seek personal contacts to bridge the gaps between the sectors. This resulted, for example, in a consultative involvement of the health sector in updating a decree of the Ministry of Education on health promotion (including HL) as an educational principle. Another way would be a whole-of-government approach, making HL everybody's business, which, however, seems unrealistic for the near future. A third way would be the development of legislative bases for HL, which might, for example, make sense in relation to regulating food packaging. However, this will, if envisaged, take years to develop. The fourth option is to clearly indicate the co-benefits of investments in HL for other sectors.

This may relate to synergies between HL and specific targets of a HiAP partner, but also to other desired effects such as visibility. Therefore, the ÖPGK supports communication about successful activities of its partners in a number of ways (website, newsletter, conferences). For the future, new tools to support visibility, such as a national HL prize or social media, might be envisaged.

Last, but not least, in order to maintain resources and to keep momentum it will be important to get new data on population HL in Austria. The M-POHL action network, led by Austria, is currently building up together with other countries under the patronage of WHO. The WHO will also support our aim of collecting and transferring HL data into evidence-based policy-making.

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31

Health literacy policy in Australia: Past, present and future directions

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Introduction

Health literacy now appears in health policies in a number of countries around the world (USDHHS, 2010; Scottish Government, 2014; Heijmans et al, 2015; New Zealand Minister of Health, 2016), and has been incorporated into several regional and global policy statements (European Commission, 2007; WHO, 2009). In some contexts, policies have focused on empowering consumers through health promotion and health education, with the aim of improving the health-related knowledge, skills and capabilities of individuals. In other contexts, policy has emphasised improving patient safety and reducing clinical risks and incidents within healthcare settings. This has included efforts to make health services and systems more person-centred, to enhance self-management and increase the participation of service users in decision-making about their own health.

Momentum for the development of health literacy policy continues to build, as evidenced by the World Health Organization's (WHO) recent positioning of health literacy as one of three key pillars for achieving sustainable development and health equity (WHO, 2016). The *Shanghai Declaration on promoting health* sets a strong mandate for health literacy globally, emphasising the role and responsibility of governments to address it. Countries and regions are already responding to this call to action (Budhathoki et al, 2017), and policy responses to health literacy are likely to be rapidly forthcoming in coming years. Improving health outcomes and reducing the health inequities that arise from health literacy limitations will require effective leadership and stewardship by governments and policy-makers at country and regional levels (CSDH, 2008; Solar and Irwin, 2010). It is therefore timely to examine current public policy approaches to health literacy across countries, with a view to strengthening policy development and implementation into the future. This chapter examines public policies approaches to health literacy within the Australian context.

Overview

This chapter presents an overview of health literacy policy in Australia, covering populations across the whole lifespan, from children and adolescents, through to adults and older people. It details the context in which health literacy first emerged as a national policy issue, describes the way early policies framed and approached it, and the changes that have occurred in the way health literacy is now positioned within public policy at a national level, as well as across state and territory jurisdictions. It concludes with a discussion of the ways in which health literacy policy can be strengthened in Australia.

Health governance in Australia

In order to understand the policy landscape in Australia, it is important to first understand its health and political systems. Federal and state and territory governments have a shared responsibility for health governance in Australia, including policy development and implementation, and the management of healthcare systems. Their respective roles are specified in the *National healthcare agreement* (Council of Australian Governments, 2012). The federal government has responsibility for the three core elements of Australia's universal public health system. The first is the national public health insurance scheme (Medicare), which provides free or subsidised benefits for most medical, diagnostic and allied health services. The second is the Pharmaceutical Benefits Scheme (PBS), which provides subsidised prescription medications (AIHW, 2016), and the third is the private health insurance rebate, which covers private hospital services and many out-of-hospital services not covered by Medicare.

The federal government also maintains responsibility for the development of policies that set a national agenda for population health outcomes, including for health promotion and prevention, health protection, primary and mental healthcare. State and territory governments set the agenda for their jurisdictions in the above areas, as well as develop the programme and funding guidelines that mandate the way services are expected to operate, including specific targets for service delivery. National advisory and regulatory bodies also play a significant role in shaping the priorities and direction of healthcare in Australia, and in monitoring the performance of the healthcare system. For example, the Australian Commission on Safety and Quality in Health Care (ACSQHC) develops and maintains national quality standards, while the National Health Performance Authority (NHPA), and Australian Institute of Health and Welfare (AIHW) play key roles in reporting on health system performance.

The Australian healthcare system

Federal and state and territory governments also share the role of designing and managing the public health system. Federal government provides the funding for public hospitals across Australia, but the state and territory governments are responsible for the management and administration of public hospitals, ambulance and emergency services, and patient transport services. Public hospital treatment is free for public patients, but care is often subject to long waiting times. For those who can afford to pay, private health insurance provides health consumers with greater choice of providers and allows them to avoid waiting lists in the public system.

Primary care services are delivered largely by privately operated general practice (GP) clinics. The availability of GP and ancillary primary healthcare services varies across the country, with those living in outer urban, rural and remote areas experiencing the most difficulties in terms of health service access. Community health facilities in most jurisdictions also offer low-cost basic services such as maternal and child health, cancer screening, immunisations, mental health and allied healthcare. These sit alongside community-based services for specific population groups, such as women's health and Aboriginal health services.

Hence, while Australia has one of the highest performing health systems in the world, and provides universal coverage for its citizens, the mixed-system and shared responsibility for its implementation means it also suffers from significant complexity and fragmentation. This can make it difficult for people to access and navigate the system, particularly marginalised and vulnerable groups (Morgan et al, 2011), and people living in rural and remote areas (AIHW, 2016).

Emergence and evolution of health literacy policy in Australia

Health literacy first appeared in public policy in Australia in 2009 at a time when it was gaining prominence within public health policy internationally. Also released in 2009 were the results of the first population study on health literacy in Australia, which revealed that an estimated 60 per cent of Australian adults lacked sufficient functional health literacy to meet routine health demands (ABS, 2009). The first policy to note health literacy was the *Fourth national mental health plan* (Department of Health and Ageing, 2009), which advocated for a health promotion approach to improving mental health literacy through the implementation of health promotion programmes in schools, workplaces and community-based settings. The aim of these programmes was to increase individuals' knowledge of mental health, their ability to recognise specific mental illnesses, to seek mental health information and services, and promote attitudes that support appropriate help-seeking.

In the years following publication of the *Fourth national mental health plan* (2009-13), there was a surge in the number of national policies discussing health literacy (see Table 31.1). These policies varied in the extent to which they prioritised and operationalised health literacy, in that some only mentioned the term, whereas others positioned health literacy as a key policy priority, and set out concrete actions to strengthen it. Policies with a focus on specific population groups, for example, the *National women's health policy* (Department of Health and Ageing, 2010b), *National male health policy* (Department of Health and Ageing, 2010a),

Table 31.1: Early national policies containing health literacy (2009-13)

National policies	**Year published**
Fourth national mental health plan, 2009-14	2009
National preventive health strategy – The roadmap for action	2009
National women's health policy 2010	2010
National male health policy	2010
Third national Aboriginal and Torres Strait Islander blood borne viruses and sexually transmissible infections strategy 2010-2013	2010
Second national sexually transmissible infections strategy 2010-2013	2010
Sixth national HIV strategy 2010-2013	2010
National ageing and aged care strategy for people from culturally and linguistically diverse (CALD) backgrounds	2012
The roadmap for national mental health reform 2012-2022	2012
National strategic framework for rural and remote health	2012
National Aboriginal and Torres Strait Islander health plan 2013-2023	2013
National primary health care strategic framework	2013
Veteran mental health strategy 2013-2023	2013

and *Third national Aboriginal and Torres Strait Islander blood borne viruses and sexually transmissible infections strategy* (Department of Health and Ageing, 2010c) gave health literacy a greater level of prominence, and set out actions that aimed to address the specific health literacy needs of the target populations.

These early national policies tended to promote a health promotion approach to addressing health literacy issues, emphasising the importance of health information provision, resource development, health education and communication to improve individual knowledge, skills and capabilities. This is illustrated in Table 31.2, which provides a summary of the health literacy-related actions or strategies proposed in policies published between 2009 and 2013.

Alongside these national policies, during this period health literacy also began to appear in state and territory government policies. For example, the Victorian Government developed and implemented the *Victorian public health and wellbeing plan 2011-15* (Department of Health, 2011c) and the *Metropolitan and Rural health priorities frameworks* (Department of Health, 2011a, b). The Tasmanian Government launched its first *Communication and health literacy action plan* in 2011 (Department of Health and Human Services, 2011), and the Western Australian Government included health literacy as a key principle within its 2011 *Primary health care strategy* (Department of Health, 2011d). These policies also adopted a health promotion approach, emphasising the need to build the health literacy of individuals by providing information and education, although they tended to emphasise this more specifically within the context of healthcare settings.

Table 31.2: Proposed actions/strategies within national and state government policies developed prior to 2014

Policy	**Proposed actions/strategies**
National women's health policy 2010 (Department of Health and Ageing, 2010b)	• Develop gender-sensitive resources, and programmes that support health education and literacy
National male health policy (Department of Health and Ageing, 2010a)	• Generic programmes for providing health information
National Aboriginal blood borne viruses and sexually transmitted infections strategy 2010-2013 (Department of Health and Ageing, 2010c)	• Implement social marketing campaigns • Deliver school-based and other youth education programmes • Deliver health education linked to treatment and testing access
National strategic framework for rural and remote health (Department of Health and Ageing, 2012a)	• Provide education on health prevention and early intervention • Provide information on services and programmes • Promote understanding of the health system • Implement strategies to reduce service access barriers
Fourth national mental health plan 2009-2014 (Department of Health and Ageing, 2009)	• Work with schools, workplaces and communities to deliver programmes that improve mental health literacy and enhance resilience
Veteran mental health strategy 2013-2023 (Department of Veterans' Affairs, 2013)	• Maintain a mental health literacy website for veterans and returned service people • Develop online programmes and tools • Use online media and mobile applications to engage the community
The roadmap for national mental health reform 2012-2022 (Department of Health and Ageing, 2012b)	• Support people to better understand and recognise their own and other people's mental health needs • Identify the early signs and symptoms of mental health issues • Know the appropriate action to take in these situations
Victorian health priorities framework: 2012-22: Metropolitan plan (Department of Health, 2011a)	• Generic actions regarding information provision and improving patient knowledge
Victorian health priorities framework 2012-22: Rural and regional plan (Department of Health, 2011b)	• Generic actions regarding information provision and improving patient knowledge
Communication and health literacy action plan 2011 (Department of Health and Human Services, 2015)	• Raise awareness of the importance of effective communication and health literacy • Help people to access, understand and use our services and our information • Help staff, volunteers and service users to be more health-literate
Western Australian primary health care strategy (Department of Health, 2011d)	• Use information and communication technology, including for providing services to reduce the burden of travel and waiting times • Encourage online and electronic information and support for consumers and carers • Provide education and resources to deliver effective health promotion

The appearance of health literacy within a number of national and state government policies between 2009 and 2013 is indicative of an increasing awareness of the concept among policy-makers in Australia over this period, as well as increasing understanding of its relationship to health and wellbeing outcomes. However, despite this early proliferation of policies containing health literacy, the concept has not been incorporated into a national policy developed since 2013 (although some of the early policies remain current public policy in Australia).

Australian health literacy policy development between 2014 and 2018

While the first wave of policies to discuss health literacy put the issue on the policy agenda, it was the release of the ACSQHC's (The Commission) *National statement on health literacy* (2014), coupled with its broader health literacy agenda, that has had the most significant influence on the health literacy policy landscape in Australia over the past decade.

The role of the Commission is to ensure safe and high-quality health systems in Australia, including through the establishment of national safety and quality standards and the ongoing accreditation of certain healthcare services (namely, hospitals, dental services and some primary care services). The Commission developed the *National statement on health literacy* (see Box 31.1) in order to increase understanding of health literacy across relevant sectors and to promote a coordinated and collaborative approach to systematically addressing it nationally. While the statement does not constitute a formal government policy, it was endorsed by all federal, state and territory health ministers, signalling at least an in-principle commitment to addressing health literacy across Australia.

Health literacy was also incorporated into the *National safety and quality health service standards*, specifically in relation to 'partnering with consumers' (ACSQHC, 2012). The National Standards mandate the performance requirements of healthcare services in Australia, and have influenced a general shift towards health literacy being positioned as a quality and safety issue on the policy agendas of state and territory governments. For example, health literacy is a key component of the *South Australian framework for active partnership with consumers and the community* (Department for Health and Ageing, 2017), and the *Victorian partnering in health care framework* (Department for Health and Human Services, 2017), as summarised in Table 31.3.

Box 31.1: *National statement on health literacy*

Background

The *National statement on health literacy* was released by the ACSQHC in 2014. It was informed by extensive research and consultation into health literacy activities across Australia, and is one of a number of initiatives by the Commission to improve health literacy nationally.

Purpose
The statement aims to:

- raise awareness about health literacy;
- highlight the importance of addressing health literacy to ensure safe and high-quality care and reduce health inequities;
- promote a coordinated and collaborative approach across relevant sectors to systematically address health literacy;
- highlight actions that can be implemented across health sector organisations.

Target audiences/stakeholders
- Individuals and organisations working within the health sector
- Individuals and organisations working within education, welfare and social services sectors

Proposed action areas/strategies
The National Statement outlines three action areas for achieving sustainable system change and a more coordinated approach to addressing health literacy in Australia:

- *Embed health literacy into systems:* To ensure that strategies are coordinated and sustainable, they need to be embedded into policies, procedures and practices of organisational systems, as well government legislation, policies and plans, standards and funding mechanisms.
- *Ensure effective communication:* Supporting effective partnerships and communication between consumers and the health workforce, and ensuring communication is tailored to the needs of consumers.
- *Integrate health literacy into education:* This includes formal education and training for healthcare providers and consumers including population health programme, health promotion, education and social marketing campaigns.

Source: ACSQHC (2014)

Keeping with this quality and safety approach to health literacy, a key feature of current state policies is their focus on increasing the responsiveness of health and social service organisations to the health literacy needs of individuals and communities, such as in the *Northern New South Wales health literacy framework* (Northern NSW Local Health District, 2016) (see Box 31.2), and the Tasmanian *Communication and health literacy action plan* (see Box 31.3). This emphasis on responsive health services and systems is consistent with developments in the health literacy field more broadly, which in recent years has increasingly focused on health service reform, largely influenced by the US Institute of Medicine's (IOM) work describing the 10 attributes of 'health-literate organisations' (Brach et al, 2012; see also Chapters 26 and 35, this volume).

A positive outcome of the reframing of health literacy as a shared responsibility of both individuals and healthcare organisations has been the inclusion of actions

Table 31.3: Current state government policies that incorporate health literacy

State	Policy	Purpose/aim
New South Wales	*Northern New South Wales health literacy framework*	To improve person-centred care by providing health information that is easy to understand and supports knowledge, empowerment and self-management of conditions; developing the skills and capabilities of the health workforce to improve communication (Northern NSW Local Health District, 2016)
South Australia	*Framework for active partnership with consumers and the community*	To articulate the South Australia Department of Health's position on the importance and value of consumer and community engagement and strengthen the way it is undertaken across South Australia. The framework sets out the responsibilities of all South Australia health employees, and the standards they must adhere to. Health literacy is strongly featured across the standards within the framework (Department for Health and Ageing, 2017)
Tasmania	*Communication and health literacy action plan 2015-2017*	To outline the role of health and human service organisations in supporting people to access, understand and use the health and human services systems. The Action Plan aligns with the Tasmanian Department of Health and Human Services *Strategic framework for health workforce 2013-2018*, which articulates the role of the health workforce in promoting patient and consumer-centred care, and creating a culture of safety and quality (Department of Health and Human Services, 2015)
Victoria	*Partnering in healthcare framework*	The Victorian Government is in the process of developing its *Partnering in health care framework*, which forms part of the Victorian Government's quality and safety agenda. The framework is comprised of five interdependent domains, one of which is health literacy, information and communication. It aims to strengthen consumer, carer and community participation, diversity, and equity by identifying and developing priority areas and strategies across the five domains (Department of Health and Human Services, 2017)

in state and territory policies that seek to involve consumers in programme, service and health information design and delivery; build the knowledge, skills and capabilities of the health workforce; and improve the policies, procedures and practices of healthcare organisations to ensure they are better able to meet the health literacy needs of consumers. However, a negative consequence of the reframing has been a narrowing in the scope of health literacy policy priorities. That is, the framing of health literacy as a quality and safety issue has seen it positioned almost exclusively within policies that seek to improve clinical care and health service delivery. This has occurred at the expense of health promotion-oriented policies that seek to build individual health literacy capabilities through effective health education and capacity-building activities. Current policies also largely fail to address health literacy across key life stages and in key health-promoting settings such as in schools, workplaces and other social/community environments, despite the wide acknowledgement that health literacy is content- and context-specific. Further, current policies give very little attention to the health literacy needs of specific population groups, or the need to consider factors such as culture, language, gender, sexuality and disability.

The deepening conceptual understanding of health literacy emerging from the literature, an improved understanding of the health benefits of engaged populations, the need to address health literacy across a range of contexts and a more sophisticated understanding of the complex interplay between individuals' health literacy and healthcare systems, structures and practices now lay a useful foundation for a next phase of health literacy policy development in Australia.

Box 31.2: *Northern New South Wales health literacy framework 2016-17*

Background

The *Northern New South Wales health literacy framework* was developed by the Northern NSW Local Health District (NNSW LHD) and the North Coast Primary Health Network (NCPHN). At a state level the Framework aligns with the NSW State Health Plan, and the Business Plan of the Northern NSW District of the NSW Department of Health. At a national level it aligns with the *National statement on health literacy* and the National Standards.

Purpose

The Framework aims to improve person-centred care in Northern NSW by:

- providing health consumer information that is easily understood and supports people's increased knowledge, empowerment and self-management of their own conditions;
- developing the skills and capabilities of the health workforce to improve communication with people in their care.

Target audiences/stakeholders

- Consumers with chronic conditions and complex care needs, including people with mental illness
- Health professionals working across Northern NSW

Proposed action areas/strategies

The Framework proposes a range of actions across five focus areas:

1. Establish an online health literacy library
2. Recruit, train and support health professionals to be 'health literacy champions'
3. Train health professionals in how to support health consumers to engage in self-management
4. Increase consumer participation in health consultations
5. Identify opportunities to embed

Source: Northern NSW Local Health District (2016)

Box 31.3: Tasmanian *Communication and health literacy action plan 2015-17*

Background

The Tasmanian *Communication and health literacy action plan 2015-17* was developed by the Tasmanian Department of Health and Human Services following consultation with departmental staff and their clients, other government agencies, community sector organisations and the University of Tasmania. The Action Plan builds on the *Communication and health literacy action plan 2011-13*, and is supported by several state-wide policy frameworks and initiatives. The Action Plan also aligns with the *National statement on health literacy*.

Purpose

The Action Plan aims to ensure that:

- staff in the healthcare and human services sectors have the skills and resources to communicate effectively with clients;
- organisations put policies and systems in place that support effective service delivery and communication with clients;
- organisations reduce literacy-related barriers for vulnerable groups;
- the health literacy of the Tasmanian population is improved.

Target audiences/stakeholders

- Staff at all levels working in healthcare and human services public, private and non-government sectors
- Education sector and tertiary institutions

Proposed action areas/strategies

The Action Plan outlines 30 actions that will be implemented across the following four strategic themes:

1. Health literacy awareness: Improve understanding of health literacy
2. Workforce development: Improve the skills and knowledge of staff
3. Organisational development: Improve system responses
4. Partnerships: Improve education and research opportunities

Source: Department of Health and Human Services (2015)

Future directions for health literacy policy in Australia

Health literacy is now part of public policy discourse at national, state and local levels in Australia, and there is significant momentum towards continued evolution of health literacy policy and practice. This provides a strong platform on which to build health literacy policy in Australia; however, for future policies to be effective and comprehensive in addressing health literacy, policy development and coordination will need to be strengthened, and the scope of public policies will need to be expanded to ensure they: (1) seek to strengthen health systems and build the capability of health and social care organisations to respond to the health literacy needs of consumers; and (2) seek to build the health literacy capabilities of individuals, families and communities across the range of everyday settings in which they make health-related decisions. Five key areas for strengthening health literacy policy in Australia are proposed: leadership and governance; monitoring and evaluation; strengthening the health service and system capability to respond to health literacy needs; improving workforce capability; and building the health literacy capability of individuals, families and communities.

Leadership and governance

Given the complexity of the Australian health system, and the multiple layers of government and governance structures, a whole-of-government approach to health literacy will be required to ensure that policies, approaches and systems are integrated and coordinated. While the absence of a national health literacy policy is not necessarily a limitation in itself (indeed, incorporating health literacy into a broad range of relevant public policies is likely to be more appropriate and effective), there is currently a lack of stewardship at the national level to guide effective action on health literacy, and as a result local, regional and state and territory approaches to it are inconsistent and fragmented. Leadership and governance for health literacy in Australia would be enhanced by: (1) establishing a clear mandate for improving health literacy, linked to stated national health priorities and Australia's commitment to the 2030 Agenda for Sustainable Development; (2) setting concrete health literacy goals, objectives and targets; (3) implementing accountability mechanisms at all levels of government; (4) strengthening intergovernmental and intersectoral partnerships (including engaging citizens in the policy process); (5) allocating sufficient resources to health literacy activities; and (6) using the full range of policy instruments available, including legislation, strategies, standards and funding mechanisms.

Monitoring and evaluation

Monitoring and evaluation of health literacy in Australia is currently inadequate, which extends to government policies, interventions and programmes and broader system performance. More reliable information and data on health literacy is required to support needs assessment and inform public health planning and policy development. Likewise, interventions, programmes and policies need to be evaluated for evidence of their effectiveness in achieving health literacy outcomes. Ensuring adequate monitoring and evaluation capability in Australia will not only require the establishment of health literacy goals, objectives and targets, but also the development and implementation of monitoring and evaluation systems. Effective connections will also need to be established between health literacy goals, targets and monitoring and evaluation systems, and those relating to national health priorities and national Sustainable Development Goal (SDG) reporting. Appropriate technology must also be available to support accurate and efficient data collection, and that relevant stakeholders are equipped with the necessary skills, resources and support to undertake monitoring and evaluation activities.

Strengthening the health service and system capability to respond to health literacy needs

Due to the leadership and policy agenda of the ACSQHC, there has been an increasing focus within Australian policy in recent years, on health service and system responsiveness to health literacy. However, while the *National safety and quality health service standards* mandate the performance requirements of hospitals and dental services, quality standards do not universally apply across all health and social care organisations. Further, health literacy indicators are only applied to improving consumer participation and engagement. Strengthening health service and system responsiveness to health literacy will require all organisations to make improvements across a range of organisational systems, process and practices. The organisational health literacy (Org-HLR) framework (Trezona et al, 2017) (see Table 31.4) provides a useful guide for developing policies and guidelines in this area, and could be utilised as the basis for a more robust and comprehensive set of accreditation standards for health and social care organisations, as well as the means by which organisational performance could be monitored and evaluated.

Table 31.4: Org-HLR framework domains and descriptions

Domain	Description
1. External policy and funding environment	Governments and other relevant bodies provide adequate programme funding, flexible service agreements, incentives (for example, through accreditation), and health literacy-specific policy frameworks and standards
2. Supportive leadership and culture	Organisations value inclusion, person-centred care and equity and have leaders, managers and decision-makers who drive and support effective financial management, service planning, change management and continuous quality improvement
3. Supportive systems, processes and policies	Organisations implement systems, processes and policies that enable effective service and programme planning, internal and external communication, performance monitoring, evaluation and continuous quality improvement
4. Supporting access to services and programmes	Organisations ensure that its services and programmes are accessible to all people and implement strategies that support people to access and fully engage with health services and programmes, as well as navigate their way through the health system
5. Community engagement and partnerships	Organisations undertake meaningful community consultation, and involve service users, communities and stakeholders in all aspects of service planning, delivery and evaluation. They also work in partnership with other health and social service organisations to ensure an integrated and coordinated approach to service and programme delivery
6. Communication practices and standards	Organisations ensure that all written and verbal communication is accessible, inclusive, respectful, and tailored to the needs and learning preferences of clients and communities, and utilise a broad range of strategies, techniques and approaches to provide health information
7. Recruiting, supporting and developing the workforce	Organisations ensure an appropriate and competent workforce by recruiting staff with the necessary experience, skills, knowledge and attitudes, and by providing a supportive working environment, practice resources and ongoing professional development opportunities

Source: Trezona et al (2017)

Improving workforce capability

The health and social care workforce plays a crucial role in addressing the health literacy needs of individuals and communities, particularly consumers of health and social services. Workforce capability is a key component of organisational health literacy responsiveness, but also represents an important public policy issue in its own right. The health literacy-specific capabilities and training needs of the health workforce have not been articulated in public policy in Australia, and health literacy specific competencies are not currently embedded within health professional education or workforce accreditation requirements (Naccarella et al, 2015, 2016). Developing and implementing policies that strengthen workforce planning and incorporate health literacy into health professional education, training and accreditation is likely to strengthen health literacy practice and improve health literacy outcomes in Australia.

Building the health literacy capability of individuals, families and communities

The importance of health promotion approaches to health literacy have been overshadowed in recent years by the increasing focus on the need for healthcare organisations to reduce barriers to service access and the health literacy demands placed on individuals. However, improving health literacy outcomes in Australia requires a combination of health service and systems reform and health promotion and capacity-building approaches. As such, there is a need for policies at all levels of government to promote opportunities to build health literacy in everyday settings (that is, schools, workplaces, early childhood centres) and build the health literacy capabilities of individuals, families and communities at key life stages (that is, childhood, adolescence, pregnancy/parenthood, ageing). Further, policies that address the specific health literacy needs of marginalised and vulnerable people are needed to ensure the inequity in health outcomes experienced by these groups is minimised.

Implications for the development of health literacy policies in other countries

While this chapter has focused on the evolution of, and current approaches to, health literacy policy in Australia, the examples described, and the recommendations outlined for improving future policies, have implications for the development of health literacy policies in other countries. There is growing interest in health literacy policy globally. In countries where health literacy policies have already been developed, such as Austria, China, New Zealand, Scotland and the US, two distinct policy approaches can be observed: one that emphasises improving the health literacy responsiveness of health services, and one that emphasises improving the health literacy of individuals through health promotion and health education. However, the trend in recent years has been towards the development of policies with an emphasis on health service improvement. From a policy content perspective, both approaches will be necessary to encourage effective healthcare participation in populations. From a policy process and accountability perspective, policies will need to establish clear health literacy goals, objectives and targets, as well as comprehensive monitoring and evaluation mechanism. Further, policy implementation is likely to be enhanced by ensuring sufficient financial resources are allocated.

To conclude, this chapter has provided an overview of health literacy policy in Australia and its evolution over the past decade. Since health literacy first appeared in policy in 2009 it has become firmly part of public policy discourse across jurisdictions. As health literacy discourse has evolved to highlight health literacy as a shared responsibility of both individuals and healthcare organisations, a swing in the emphasis in policy from health promotion to health system reform approaches has also been observed. A balance between these approaches is now needed at the policy level in Australia, as are coordinated efforts to strengthen national monitoring and evaluation of health literacy, to build workforce and health systems capacity, and to implement effective programmes to promote participation in health and build the health literacy capabilities of individuals, families and communities.

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32

Health literacy policies: National examples from the United States

Julie McKinney and R.V. Rikard

Introduction

Health literacy as a concept, a research topic and a field of practice has steadily grown since the beginning of the 21st century in the US. There is also a growing acknowledgement that health literacy is a key tool to promote better health among entire populations, *perhaps even the most important tool.* The evolution of health literacy has responded to different influences and taken different paths in multiple countries, as we see in the other chapters of this book. Since health literacy is such a multifaceted concept, involving a wide range of types of organisations, levels of leadership, community populations and strategies for improvement, it is intriguing to see the paths taken by different countries to build awareness and incorporate health literacy into their healthcare systems and support activities.

There is often a question of whether an initiative should be top-down or bottom-up. Top-down is when policies and guidance are given from the top levels of leadership, then interventions are implemented by the layers of hierarchy until they reach down to the individual community members. The policies are the catalyst that starts the change. A bottom-up approach is also referred to as a *grass-roots* process where individuals identify a need and create solutions to implement in their own area of influence. Over time the isolated solutions gradually become a larger movement.

How has it worked for health literacy? In the US, health literacy started as a bottom-up, grass-roots movement. However, top-down support for health literacy initiatives was also a need, and this support has grown over the years to strengthen the movement. While there are few federal mandates for specific health literacy interventions, there are some government policies that provide very useful guidance to support training, education and overall attention to health literacy.

We often hear from other professionals working on health literacy interventions that they are ‘working in silos’. In many cases, one or two dedicated people will shoulder the burden of incorporating basic health literacy practices into their organisation’s activities. For example, one patient education coordinator at a large hospital will pull together a review team to ensure that written materials are in plain language. One nurse manager will create and teach a *Health Literacy 101* training module for newly hired providers. One adult literacy teacher will integrate health literacy skills into the curriculum and take students on a field trip to the local health centre. We are aware of many innovative and successful projects to improve health literacy skills and lower barriers to healthcare.

We highlight the important federal policies that either directly or indirectly mandate and support grass-roots health literacy initiatives. In general, there are only a few federal policies that *mandate* specific health literacy solutions, but there are some others that directly address health literacy. Moreover, some policies have indirectly created such an acute need for solutions that they effectively spurred the health literacy movement into action. Guidance, rather than policy, is perhaps the most important support from federal government agencies. This includes resources, information and tools to help health professionals learn about health literacy and implement health-literate solutions. We first focus on federal policy, but also discuss federal initiatives and institutional guidance in other sectors. Most federal policy and guidance focus on the general population across the lifespan, although we highlight those aimed at specific age groups. While we highlight the important federal policies and resources, we are unable to include an exhaustive analysis of every initiative that exists in the US.

2010: A landmark year for health literacy

In 2010, there were four major initiatives from the US government that supported health literacy efforts throughout the country:

- Patient Protection and Affordable Care Act (ACA)
- *National action plan to improve health literacy*
- Plain Writing Act 2010
- *Healthy people 2020*

The release of each initiative in the same year provides some weight that the government sees health literacy as a critical factor to improve Americans' health and the system of healthcare in the US. It was at this point that the federal support rose up to try to meet the needs of the grass-roots efforts.

Patient Protection and Affordable Care Act (ACA)

The ACA is one of the most significant federal laws to promote health literacy since the creation of Medicare in 1968 (Quadagno, 2005). Also known as 'Obamacare', the ACA is a complicated law, which was passed in 2010 after much debate and revision (Quadagno, 2010). Its main purpose is to provide more Americans with health insurance, but in the process the law continues to have an impact on many other areas of healthcare delivery, such as patient-centred care and the payment structure for healthcare services. In effect, the ACA had positive effects on health literacy promotion as newly insured people, many of whom had poor health literacy, flooded into the healthcare system (Somers and

Mahadevan, 2010). Healthcare providers and hospitals quickly realised that they were unprepared to effectively serve this newly insured population (Angel et al, 2011; Blumberg, 2012; Clemans-Cope et al, 2012). In turn, increasing attention focused on health literacy barriers and the need to improve policies and training in the healthcare sector (Koh et al, 2012, 2013a, b).

While the ACA explicitly mentions health literacy in a few places, the majority of legislation indirectly points to the rationale for promoting health-literate practices (Koh et al, 2013b). By including policies for health insurance enrolment, improved patient care, patient-friendly written materials and improved communication, the ACA indirectly required health literacy practices in many areas of outreach and service (Somers and Mahadevan, 2010).

Health insurance and the US healthcare system

The US healthcare system does not include universal care, and is thus intricately tied to health insurance coverage (Quadagno, 2005). Although there are options for free or low-cost care for people with a low income, people with health insurance are healthier and receive better healthcare services (Rikard, 2013). There are many reasons for this disparity. Those without insurance are more likely to be elderly, poor, unemployed and foreign-born, all of which are groups likely to have poor health literacy skills and poorer health outcomes (Fiscella et al, 2002; Hadley, 2003; Kutner et al, 2006; Angel et al, 2011; Blumberg, 2012; Clemans-Cope et al, 2012; Lavelle and Smock, 2012; Sentell, 2012).

But the most significant reason may be that people with health insurance are much more likely to receive primary care and have a medical home, which is a regular doctor and a place where they go for coordinated care. People with health insurance are more likely to get regular health screenings and manage chronic conditions that could lead to worse health outcomes down the road (Clemans-Cope et al, 2012; Sentell, 2012). By comparison, many people who are uninsured tend to avoid seeing a doctor unless it is an emergency and chronic health conditions, like high blood pressure or pre-diabetes, go unnoticed until there is a significant health event (Hadley, 2003).

There exist 'safety net' services for people who are uninsured or underinsured. 'Underinsured' means that a person has health insurance for catastrophic events, but not a good enough plan to cover primary care and other important services to keep them healthy (Dickman et al, 2017). Federally qualified health centres and public hospitals serve people who cannot pay for services and who do not have health insurance. Yet not everyone who needs healthcare knows about or uses the services, especially primary care.

Basics of the ACA

While the main goal of the ACA is to provide health insurance for more Americans, there are parts of the law that specifically address health literacy in the context of improving patient-centred care and communication (Koh et al, 2012, 2013a, b). The ACA essentially made health insurance coverage mandatory for all Americans. This meant that employers were required to offer health insurance plans to employees, and each state was required to offer subsidised health insurance plans, offered through a 'marketplace' where people could compare plans and sign up. The enrolment process alone was immensely complicated and revealed a huge need for clear communication and health literacy (Koh et al, 2012, 2013a, b).

Health literacy components of the ACA

There are four subsections in the ACA that mention health literacy (Somers and Mahadevan, 2010):

- *Accessibility of quality and improvement and patient safety research:* The law states that this research must be made 'available to the public through multiple media and appropriate formats to reflect the varying needs of healthcare providers and consumers and diverse levels of health literacy.'
- *Shared decision-making:* The law provides grants to develop decision-making aids to help providers educate patients, and states that 'decision aids must reflect varying needs of consumers and diverse levels of health literacy.'
- *Prescription drug benefit and risk information:* The law calls for consulting with 'experts in health literacy' when making decisions about standardised drug labelling and advertising.
- *Training of healthcare providers:* Preference is given to award grants for provider trainings that 'provide training in enhanced communication with patients … and in cultural competence and health literacy.'

These call-outs to health literacy may have helped to create an awareness of health literacy for the healthcare systems and provide some incentive to address it in their activities. But the reasons why the ACA had the most effect on health literacy programmes may have been more related to the need to serve a new population of patients in a more effective and accountable way.

Medicaid expansion

As part of the ACA, most states could also opt to expand Medicaid and increase their portion of federal Medicaid funding. Medicaid is a government-administered healthcare programme for families with low income and people with disabilities. The expansion allowed millions more people to take advantage of Medicaid and obtain basic primary care along with many other health benefits. The population of new Medicaid members share many of the demographic characteristics as those with low health literacy, such as low income, immigrants and people with disabilities (Kutner et al, 2006).

Patient-centred care

Perhaps anticipating the influx of new patients with health literacy challenges, the ACA also includes policies to support patient-centred care and communication practices of healthcare providers (Koh et al, 2012). In addition to the explicit support for training providers in cultural competence and health literacy, the law created other incentives to create patient-centred medical homes. These are hospitals or health centres where a person has doctors who know them and a coordinated set of primary care and specialty services. Standards must be met in order to be certified as a patient-centred medical home. The standards include providing services and care that patients can understand, which requires a level of communication that is impossible without addressing health literacy (Koh et al, 2013a).

This element of the ACA incentivised healthcare systems across the country to improve their communication practices, and many used health literacy interventions as key tools in this process. In fact, the Agency for Healthcare Research and Quality (AHRQ) created a health literacy universal precautions toolkit and specifically mapped out which health literacy tools could be used to achieve each element required to become a patient-centred medical home (Brega et al, 2015). This toolkit has been widely used by healthcare organisations to help assess their practices, train providers and work towards a standard of clear communication in order to meet the needs of all patients.

Results of implementing the ACA

Before the ACA, 16–18 per cent of Americans were uninsured or underinsured (Kaiser Family Foundation, 2017). This meant that there was a huge pool of people who were not routinely connected to the healthcare system, were less healthy than others and had poor health literacy skills. During the first few years of the ACA, 15.8 million people enrolled in health insurance or Medicaid, many of them for the first time. During the enrolment process, health literacy principles were adopted out of necessity. Health insurance companies started to create plain language materials, and special navigators were trained to help people through the enrolment process, which meant explaining complicated information in a way that was easy to understand. Workshops and curricula were created to help people through this process of learning about health insurance and making informed decisions. One example is the Smart Choice Health Insurance programme from the University of Maryland Extension Program (Bartholomae et al, 2016). The programme includes a series of workshops and educational materials that were designed with health literacy principles and created to help people with low literacy skills learn about and use their insurance options. To date, over 2,000 people have benefited from the Smart Choice Health Insurance programme (Bartholomae et al, 2016).

To date, we are unaware of any efforts to quantitatively track the health literacy-related benefits resulting from the ACA (Gurley-Calvez et al, 2017).

Yet, anecdotal evidence suggests that many key stakeholders across the country responded with specific programmes aimed at reducing health literacy barriers in order to increase health insurance access and patient-centred healthcare. These programmes include training and support to improve the communication practices of healthcare providers; the development of easy-to-understand written materials about health insurance and Medicaid; and the provision of trained navigators to help people face-to-face as they enrol in health insurance and navigate the complicated healthcare system.

A recent study tracked the amount of professional discourse about the ACA as it relates to health literacy activities (Kurtz-Rossi et al, 2017). The 'Health Literacy Discussion List' is a longstanding community of practice with over 1,500 members from many different fields of practice, including healthcare, education, public health, research and others. A recent analysis of common topics of interest showed that one of the most popular discussion topics was the ACA and health literacy interventions, with about 30 per cent of over 2,000 posts between 2012 and 2014 focused on this (Kurtz-Rossi et al, 2017). This level of activity reveals that health literacy advocates were actively addressing ACA components.

Limitations of the ACA

However, many stakeholders agree that there is still much work to be done and that the ACA did not go far enough in requiring more health literacy training of professionals and education for communities. In one US state, Colorado, a state-wide *Health literacy environmental scan* (JSI, 2017) assessed the status of health literacy activities and progress. Since Colorado was particularly successful in enrolling new members in health insurance plans under the ACA, much of the discussion centred around those efforts and other health literacy activities that stemmed from the ACA. Interviews were conducted with community groups, patient navigators, providers, educators, public health officials and health literacy advocates to find out what health literacy practices were in place, and how well they were filling the needs of diverse communities. The interviews revealed that while there were many great ACA-related policies around practice transformation, payment reform and data tracking systems, there was not enough effort to educate the public. People who were newly enrolled in health insurance still did not understand the 'culture' of relating to healthcare in the way that people with insurance are used to. Not enough new enrollees were taught how best to access care or how to use their insurance benefits effectively. To make it worse, the insurance information was so complex and varied that even healthcare providers and staff did not understand it well enough to explain to patients how much their care may cost or what benefits were covered.

One public health professional described it this way: "There is a disconnect between those creating the policies and the people in the communities. Policy folks and administrators put in these great systems, then wonder why people still show up in the ER" (JSI, 2017).

National action plan to improve health literacy

The *National action plan to improve health literacy* was released in May 2010 by the US Department of Health and Human Services (USDHHS) (Office of Disease Prevention and Health Promotion, 2010). While the ACA was focused on the healthcare and insurance sectors, the Action Plan involved a much broader group of organisations. The Action Plan 'seeks to engage organisations, professionals, policymakers, communities, individuals, and families in a linked, multisector effort to improve health literacy' (USDHHS Office of Disease Prevention and Health Promotion, 2010, p 1).

The Action Plan contains seven goals, each with identified strategies that will enable a variety of organisations and fields to improve health literacy from their particular angle (see Box 32.1).

Box 32.1: Goals of the *National action plan to improve health literacy*

1. Develop and disseminate health and safety information that is accurate, accessible, and actionable
2. Promote changes in the healthcare system that improve health information, communication, informed decision-making and access to health services
3. Incorporate accurate, standards-based and developmentally appropriate health and science information and curricula in childcare and education through the university level
4. Support and expand local efforts to provide adult education, English language instruction and culturally and linguistically appropriate health information services in the community
5. Build partnerships, develop guidance and change policies
6. Increase basic research and the development, implementation and evaluation of practices and interventions to improve health literacy
7. Increase the dissemination and use of evidence-based health literacy practices and interventions

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This inclusive approach encouraged other sectors outside healthcare to address health literacy. Notably, the Action Plan described *how education across the lifespan can contribute to a more health-literate population* by including objectives for early childhood through university-level education, and even adult literacy education and English language instruction. It also focused on creating partnerships between sectors, which has been a successful overall strategy for addressing health literacy.

While the Action Plan did not dictate any specific policy or mandate any activities, it contained two important components. First, by addressing health literacy from many angles with multiple stakeholders, it shows that health literacy is an important national priority. Advocates from diverse organisations from healthcare to education to research could use the Action Plan to leverage support and buy-in from leadership and funders. Second, it provides a framework and instruction for organisations to create health literacy policies and interventions. In addition to detailed guidance to implement each of the seven goals, the Action Plan offered a template that organisations could use to create their own internal action plans.

The 'Health Literacy Discussion List' hosted three nationwide discussions about the Action Plan between 2010 and 2012. All discussions revealed extensive and varied activity spurred on by the Action Plan. We heard from many different organisations about what exactly they were doing to implement the goals, including state-wide health literacy coalitions, adult education programmes, community health centres, advocacy agencies, primary care providers, researchers and others (LINCS, 2010, 2011, 2012). The activities were just as varied and geared toward educating audiences throughout the lifespan and improving health system capacity to serve diverse communities. Here are some examples: maternal and child health organisations created pregnancy and baby care books written in easy-to-read language; programmes for children in day care centres addressed early health literacy skills through nutrition education units; universities created health literacy courses for health professionals; adult education programmes created health literacy curricula to integrate into adult education and English language instruction; hospitals implemented techniques such as brown bag medication checks to help patients – especially older adults – to manage their medication regimes; and government agencies put out more requests for research proposals related to health literacy.

As mentioned, there were several grass-roots state-wide health literacy coalitions and initiatives forming at this time. Their goals were to bring together a variety of state and local stakeholders to increase health literacy awareness of and use it to improve health in their state. The Action Plan became a common framework for the goals and activities of these coalitions, and many new ones were formed since its release. Now, about half of the 50 US states have formal health literacy coalitions, which continue to support health literacy efforts in their respective regions. So, while the Action Plan was neither a law nor a policy, it lent both government support and specific guidance that catalysed a huge number and range of health literacy interventions.

Plain Writing Act of 2010

The Plain Writing Act of 2010 requires all federal agencies to follow plain language guidelines in their communications. The goal is to 'improve the effectiveness and accountability of Federal agencies to the public by promoting clear Government communication that the public can understand and use.' This Act includes provisions for training staff in plain language writing and overseeing the process of creating or revising all communication to meet the standards. While the Act sent a strong message about the importance of plain language and clear communication, and it was in fact a mandate, it does not seem to have had as big an impact as other programmes on lowering health literacy-related barriers for most citizens. While many government websites and documents improved a great deal, there are still many federal websites that are difficult for most Americans to understand (Politi et al, 2016).

Healthy people 2020

Since 2000, *Healthy people* has provided science-based objectives for improving the health of all Americans (USDHHS Office of Disease Prevention and Health Promotion, 2014). It establishes national benchmarks for each decade and monitors progress over time to encourage community collaborations, empowers people to make informed health decisions, and measures the impact of prevention activities. *Healthy people 2020* includes an objective for improving health literacy for the second decade in a row, to be measured by how many healthcare providers give instructions to patients in an easy-to-understand format. Other health literacy related objectives in *Healthy people 2020* measure increases in:

- providers who have good communication skills
- shared decision-making
- personalised health information resources
- easy-to-use health websites.

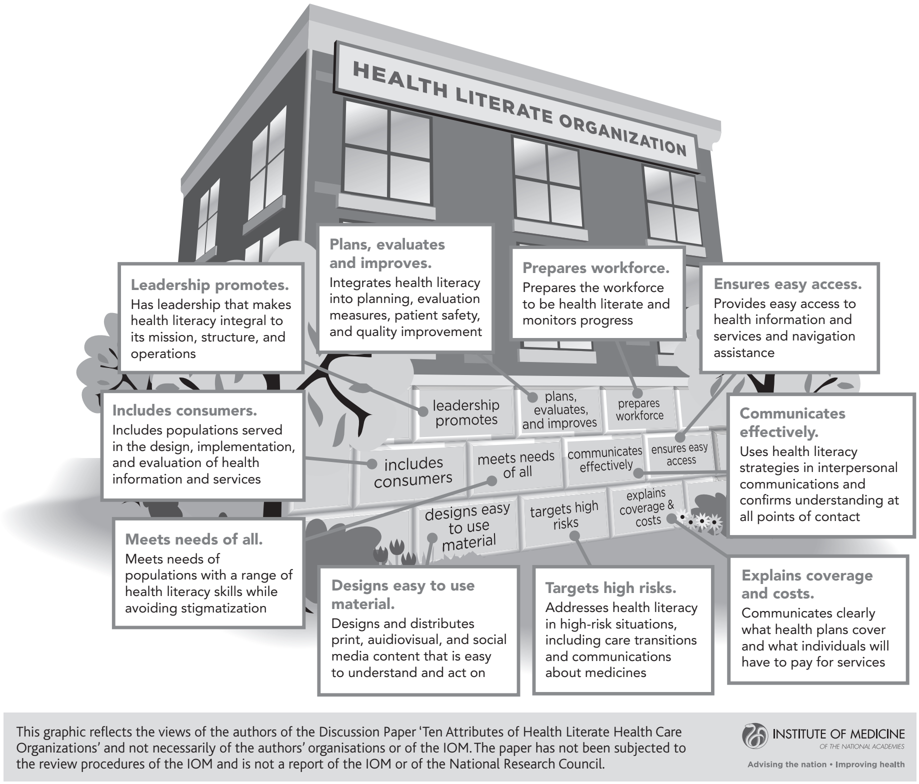
The *Healthy people 2020* objectives lend public health policy support to the ACA, the Action Plan and the Plain Writing Act 2010. Specifically, *Healthy people 2020* objectives on health communication and health information technology (IT) offer measures and targets for tracking progress on population-level health outcomes and hold healthcare systems accountable to improve patient health literacy.

Health literacy: a prescription to end confusion, and the Ten attributes of health literate health care organizations

The National Academy of Science Engineering and Medicine (formerly the Institute of Medicine, IOM) has been a key player in health literacy advocacy for many years. In 2004 they created the Roundtable on Health Literacy, and commissioned the seminal report, *Health literacy: A prescription to end confusion* (Nielsen-Bohlman et al, 2004). The report was one of the first big wake-up calls for healthcare systems and providers to address health literacy, and catalysed significant progress in the following decade. The most commonly cited definition of health literacy came from this report, which called on providers to take ownership of their role in lowering barriers to care for people with literacy challenges. The report described the role of healthcare providers in communicating clearly with patients, and providing written information that is easy to understand (Nielsen-Bohlman et al, 2004). Up until this point, health literacy was mostly framed as a deficit of knowledge and skills of individuals (a ‘blame the patient’ model) rather than a lack of providers’ capacity to present information in a way that people could understand and act on. This report opened up many new avenues of improvement by framing health literacy as more of a *two-way street*. Ironically, the definition of health literacy from the report did not reflect this dual ownership, only the skills of the individual. Since then, other definitions have included the skills of providers and systems as well as those of individuals (Coleman et al, 2009).

The Roundtable on Health Literacy has convened a diverse group of health literacy researchers and advocates for annual meetings and quarterly workshops for over a decade. They have written and commissioned several white papers on topics such as informed consent, numeracy, communicating with immigrants and refugees, and health literacy's role in public health. Perhaps the Roundtable's largest achievement and source of impact is the *Ten attributes of health literate health care organizations* (Brach et al, 2012; see also Chapters 31 and 35, this volume). This report identified 10 standards that a healthcare organisation must meet to provide effective, understandable care to all people, regardless of their health literacy level (see Figure 32.1).

Figure 32.1: Elaborations on the foundations of a health-literate organisation



This graphic reflects the views of the authors of the Discussion Paper 'Ten Attributes of Health Literate Health Care Organizations' and not necessarily of the authors' organisations or of the IOM. The paper has not been subjected to the review procedures of the IOM and is not a report of the IOM or of the National Research Council.

Source: Reprinted with permission from Nielsen Bohlman et al (2004) by the National Academy of Sciences, Courtesy of the National Academies Press, Washington, DC

Like the Action Plan, the Ten Attributes provides not just proof of federal support for health literacy standards, but also a framework to help organisations know where and how to instil new policies and interventions. This document has supported many healthcare organisations in their efforts to promote health-literate practices and better serve patients and communities. In fact, a companion guide was written to help organisations implement the standards described in the Ten Attributes – *Building health literate health care organizations* (Abrams et al, 2014).

Other federal agencies

Some of the most effective support for health literacy efforts has come not from specific federal policies, but from government agencies that adopted health literacy as an important area of focus. These agencies created workgroups, wrote white papers and developed practical guidance, tools and courses to help organisations lower health literacy barriers and better serve people with low health literacy skills (Pleasant, 2013a, 2013b). While we cannot describe all the useful and effective work done by these agencies, we will highlight a few key projects here.

The following federal agencies have all played important roles in championing health literacy efforts in the US: the Agency for Healthcare Research and Quality (AHRQ), the Centers for Disease Control and Prevention (CDC), the National Academy of Science Engineering and Medicine (formerly called the Institute of Medicine, or IOM), the Health Resources and Services Administration (HRSA), the Office of Minority Health (OMH) and the National Library of Medicine (NLM). Many departments have well-developed and informative health literacy sections of their websites that have been useful for educating professionals and consumers and building awareness. Notably, the CDC has an extensive health literacy section that includes information and guidance about improving organisational health literacy capacity, a listing of state-wide health literacy coalitions, research summaries and a series of free online courses that they developed for healthcare providers and public health professionals. The CDC also developed a Clear Communication Index that helps organizations, governmental departments, and developers of health materials to assess public health messaging to ensure that it is easy to understand and actionable.

The National Network of Libraries of Medicine (NNLM) has also had a big impact. They created a variety of health literacy training programmes for and by librarians, who then implement training for health professionals and communities. NNLM also created a widely used consumer health information website, MedlinePlus, that provides easy-to-understand health information for the public.

The Office of Minority Health (OML) recognised its role in advocating for health literacy as a tool to ensure that access to health information and services be improved for minorities. This is important because minorities of all kinds have been found to have greater health literacy challenges, especially those with limited English proficiency (Nielsen-Bohlman et al, 2004; Kutner et al, 2006; Rikard et al, 2016). This agency developed the *National standards for culturally and* *linguistically appropriate services (CLAS)*, which was modelled after the *Ten attributes for health literate health care organizations*. The CLAS standards provide similar guidelines for healthcare organisations to adopt practices to better serve patients from diverse cultures. The overarching standard is: 'Provide effective, equitable, understandable, and respectful quality care and services that are responsive to diverse cultural health beliefs and practices, preferred languages, health literacy, and other communication needs' (USDHHS, 2012). These have also been used widely, especially in the growing numbers of communities with large populations of new immigrants.

Conclusion

In general, the field of health literacy in the US began as a grass-roots movement. This was an important way to begin, as it grew from real needs identified by a wide variety of social service and health professionals struggling to serve vulnerable populations. These needs, and the solutions that were created, were the driving force to guide the federal policies that later stepped in to provide the top-down support. This support has grown significantly over the past decade and has served in several ways to strengthen the efforts that improve health literacy throughout the US. While the laws, mandates and strict policies, like those stemming from the ACA, have pressed organisations to adopt health-literate practices, it has largely been the practical guidance that has helped them to create the programmes and interventions that put these practices into action. The support for health literacy from so many diverse agencies and sectors has helped the US to address this issue from the many different angles that are needed to have widespread impact. Furthermore, the fact that several of these agencies stepped up with guidance around the same time, in 2010, helped to create a 'splash' of awareness that put health literacy firmly in our national consciousness.

Our hope is that localised programmes continue to respond to the needs of their communities, and that federal agencies and departments continue to play the supportive role that we have described here. We have seen that by combining top-down support with grass-roots efforts, we can make better progress towards improving the nation's health through health literacy.

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Health literacy in New Zealand: A tale of serendipity and indigenous health

Susan Reid and Carla White

Introduction

This chapter discusses the emergence of health literacy, including policy development, in New Zealand (NZ), through the lens of the authors' involvement in the initial health literacy development projects, and in light of international perspectives. New Zealand has a small population, centralised government and a single Ministry of Health responsible for health outcomes. A lucky series of chance encounters generated interest in the relationship between recently published adult literacy data about New Zealanders, including the indigenous Māori population, and poor health outcomes for Māori. This resulted in the publication of NZ's first health literacy research report for the adult population (Ministry of Health, 2010), showing the widespread need to address health literacy as a nation.

Health literacy in NZ over the past 10 years has been driven by the need to reduce health inequalities and inequities for Māori, NZ's indigenous population. Starting work in the health literacy field more recently than other nations, NZ has been able to take advantage of research and experiences generated by others who have worked in this area for much longer, in particular, the US. This supported health literacy to be positioned as a system and health equity issue, rather than as a problem of patient-deficit.

The Ministry of Health's *He Korowai Oranga – Māori health strategy* (Ministry of Health, 2014a) supported a systemic approach to improving health outcomes for Māori, with health literacy identified as a key enabler to improving health outcomes. This Strategy supported the creation of NZ's *A framework for health literacy* (Ministry of Health, 2015a), outlining expectations for the health system, health organisations, health professionals and consumers in addressing health literacy. The Framework and other health literacy initiatives reflect the contribution and engagement of indigenous communities in actively managing their health and wellbeing.

New Zealand context

How government operates

New Zealand is a small country of 4.75 million people. As a member of the British Commonwealth, NZ operates a stable, democratic system with national parliamentary elections every three years. Government ministers are selected from the elected members of Parliament. New Zealand has no states or federal government structure.

The relatively small population of NZ enables the vast majority of social, education, health, infrastructure, environment and economic policy to be managed by centralised government departments (also known as the public sector). Schools, hospitals, welfare, roads, conservation and so on are designed and funded by government departments. The departments are politically neutral while being answerable to a minister, the Government and the public. Ministers with high-profile portfolios such as health, social welfare, education and finance, are well known and accessible to the public. By international standards, the NZ public sector is seen to be transparent and free of corruption.

The policies and decisions of the Government and public sector affect the daily lives of New Zealanders, directly influencing their access to health services, education and social and income support if needed. By design, and partly due to population size, policy-writers, planners, decision-makers and funders can be accessed in both formal and informal ways through official channels and personal networks. Back in 2008, when NZ's health literacy journey started, NZ had recently elected a new right-of-centre coalition government, following nine years of a left-of-centre coalition.

New Zealand recognises the rights of the indigenous population

The Treaty of Waitangi signed in 1840 is the founding document of NZ. The Treaty is an agreement entered into by representatives of the British Crown and the indigenous Māori people. The Treaty is a broad statement of principles on which a government could be built, a legal system introduced and the settlement of the British could be managed. The Treaty is not a constitution or stand-alone statute, and while the principles of the Treaty are referred to in some statutes, the interpretation of the Treaty continues to be a topic of debate.

Despite the Treaty, from 1840 onwards laws and regulatory decisions saw Māori dispossessed of land and other natural resources. Since the 1970s, successive governments have recognised the unjust nature of the treatment of Māori and have tried to address past and current grievances, as well as remove prejudice from the system of government. There has also been acknowledgement of the right of Māori to be provided with the conditions that create equitable outcomes. Exactly how this might be achieved remains a challenge. It does mean that in key government portfolios, such as health, expertise, resources and policies are focused on improving equity and outcomes for Māori.

The health system

The Ministry of Health has overall responsibility for the management and development of NZ's health and disability system (Ministry of Health, nd, a). The Ministry develops national health policy, plans and strategies such as government health targets and the Māori Health Strategy, as well as designs and funds the majority of health delivery in NZ. The Ministry of Health has approximately 800 staff and is led by the Director General of Health.

The provision and funding of health services is geographically divided across 20 district health boards (DHBs). Funding is provided to the DHBs by the Ministry, and performance is measured against government health targets and other output measures. The DHBs are expected to show a sense of social responsibility, to foster community participation in health improvement, and to uphold the ethical and quality standards (Ministry of Health, nd, b). Public hospitals are owned and funded by DHBs in each district and are the main providers of secondary care in NZ, with care being free for NZ citizens and residents.

Primary health organisations (PHOs) are funded by DHBs, and occasionally directly by the Ministry of Health. PHOs arrange or provide primary healthcare services through general practices to NZ citizens and residents. PHOs are not-for-profit organisations and vary widely in size and structure. Visits to primary care are free for children up to age 13. After this age people pay to visit primary care; however, these charges are subsidised by DHB funding and vary significantly by practice, with greater subsidy directed to unemployed people and older people and those living in low socioeconomic communities.

Statistics and the adult literacy sector

In 2008, the full results of the Organisation for Economic Co-operation and Development (OECD) Adult Literacy and Lifeskills (ALL) Survey were published by the Ministry of Education following the Survey's administration in NZ households in 2006 (Satherley et al, 2008). The results showed that 42 per cent of adult New Zealanders aged 16-65 had inadequate literacy and numeracy to manage the daily demands they were likely to face. The results also showed some improvement has been achieved in adult literacy and numeracy since the 1996 International Adult Literacy Survey (IALS). In the Survey appropriate sampling of smaller population groups, including Māori, was undertaken to produce valid and representative results for these groups. These results showed Māori, Pacific and Asian groups had lower literacy and numeracy skills than people of European ancestry. This caused a misconception that Māori and Pacific and Asian groups were the largest populations with low literacy and numeracy skills in NZ, when, in fact, the issue was much more widespread, with the largest single group being

NZ Europeans as they made up 68 per cent of the adult population (Satherley and Lawes, 2009).

At the time of publication of the ALL Survey results, the authors of this article were both working in the adult literacy sector at Workbase, a not-for-profit trust, based in Auckland. Workbase provided long-term workplace literacy and numeracy programmes within companies, funded by the companies themselves, and later by government subsidies. Workbase's programmes used a system analysis approach to identify training needs. This involved initially identifying and resolving business issues that create unnecessary literacy and numeracy 'demands', such as unclear processes, poor quality instructions and unneeded complexity, in order that the eventual literacy and numeracy training programme could focus on both reducing these demands as well as building the skills and knowledge essential to a workplace.

As a result of using the system analysis approach with a large number of companies, we found employees were often unable to apply to work environments the literacy and numeracy skills they already possessed, mainly due to overly complex workplace systems, and poorly communicated, incomplete or incorrect instructions and documents creating unnecessary literacy and numeracy demands. We later used a similar approach to inform health literacy work with the health sector.

The health literacy picture emerges from adult literacy research

As part of managing the New Zealand Literacy Portal and specialist literacy library for the sector (while at Workbase), we actively identified and disseminated new international research and information about literacy, language and numeracy. This included research and articles about health literacy and health literacy statistics.

In 2008 NZ had no health literacy data but we were aware that nearly 200 questions in the recently released ALL Survey results related to using literacy and numeracy in health contexts. This health context data had not been separately analysed as the Ministry of Education did not have the mandate or budget to do so, and was not intending to seek further funding for such an analysis. The lead author Susan Reid casually mentioned this matter at a family gathering to a family member who is a highly regarded indigenous public health researcher. As a result, Susan was introduced to the Director of Te Kete Hauora, the Māori Health Directorate in the Ministry of Health. The role of Te Kete Hauora was to undertake and fund research, develop policy and help design and deliver a health system that better responded to the needs of Māori and addressed the significant health inequalities and inequities experienced by Māori. The Director immediately recognised the strong alignment between health literacy, health equity and health outcomes for Māori.

As a result, Te Kete Hauora funded the analysis of the ALL Survey health literacy data, and subsequently published the research report, *Kōrero Mārama: Health literacy and Māori* (Ministry of Health, 2010), describing the health literacy skills of adult

Māori compared to the adult non-Māori population by gender, rural and urban location, age, level of education, labour force status and household income.

Kōrero Mārama showed that 56 per cent of the adult population in NZ had low health literacy, equating to 1.8 million people. As non-Māori make up 85 per cent of the population, the report provided evidence of health literacy needs across the whole population, as well as specifically for Māori (who make up 15 per cent of the population).

Within the adult Māori population, 72 per cent had low health literacy. Very low health literacy for Māori in the 50–65 and 16–24 age groups was particularly concerning because Māori have lower life expectancy than non-Māori, older age groups have higher levels of health need, and over half of the Māori population is under 25 years of age.

The publication of *Kōrero Mārama* was a defining moment for health literacy in NZ. *Kōrero Mārama* gave the Ministry of Health and health providers an idea of the size and scale of the health literacy challenge. The results suggested health literacy needed to be taken into account in every decision about service design, delivery, access and communication. *Kōrero Mārama* also included a definition of health literacy for NZ, taken from international literature:

> Health literacy is the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions. (Ministry of Health, 2010, p iii)

This broad definition of health literacy includes many aspects of information gathering and use for decision-making. However, on the face of it, the definition emphasises health literacy as an individual skill or capacity that does not reflect the system-wide aspects of health literacy. Like adult literacy, the adequacy of a person or population's health literacy is determined by the health literacy 'demands' faced by a person or population. Health literacy demands are created by health information, services and systems. Providing accessible information, services and health systems is an important system response to improving health literacy, as is supporting the upskilling of patients, families and communities. Other definitions of health literacy describe health literacy as having both system and individual components rather than as a personal (patient) skill set, for example:

> Health literacy is an interaction between the skills of the patient, and the demands of the health system. (Institute of Medicine, 2004)

Exploratory research

Following the publication of *Kōrero Mārama*, the Ministry, through Te Kete Hauora, contracted three exploratory research projects to determine whether and how health literacy affected health outcomes for three health conditions where

Māori had historically poor health outcomes as well as at the present time. These three projects were the following:

- Skin infections in children: Māori children have high numbers of hospitalisations for skin infections and associated illnesses that could be prevented by timely treatment in primary care.
- Prevention and effective management of gout: Gout affects Māori at a much earlier age than the general population, and Māori are far less likely to be prescribed urate-lowering medicines to prevent and manage gout.
- Timely identification of gestational diabetes mellitus (GDM): Māori women were less likely to be tested for GDM, despite free testing being offered to all pregnant women, and Māori women being more likely to develop GDM.

The research methodology for all three projects focused on talking with health professionals and families about these conditions, what was important to them, how and why families access health services, what and who helped, what was difficult, and what might assist with the prevention and management of these conditions.

At the time Workbase was growing consulting services in health literacy, building on experience advising workplaces, organisations and government agencies on adult literacy. We submitted tenders to carry out each of the three research projects and were selected to undertake the projects. Each of the research projects found different health literacy facilitators and barriers, and identified potential solutions to improve health outcomes for Māori.

Skin infections and health literacy

While Māori make up 15 per cent of the general population, Māori under the age of 15 make up 26 per cent of children in this age group. This research project found parents and families were confused about skin conditions in children because many skin conditions seemed to be harmless and often resolved with no primary care intervention, while others with similar symptoms quickly led to hospitalisation if not treated in primary care. Parents wanted to build health literacy in order to know what to do before seeing a health professional, as well as identify the circumstances under which to seek treatment in primary care.

Families' experiences in primary care were not frequent enough or sufficient to build a wide understanding of what to do if similar or other types of skin infections developed. Families wanted credible, clear, easily accessible photographic information to help them identify *why* and *when* a child needed to be taken to primary care. Parents had found online material of little value as it often showed advanced cases of a disease, used drawings rather than photographs, relied on parents knowing appropriate search terms or was focused on promoting and selling remedies or services. Parents also described informal, but highly regarded, sources of health advice, such as friends and grandparents, as being unsure or out of date about managing infections especially in light of confusing public health messages about antibiotic overuse and resistance (White et al, 2013). From a health literacy perspective, this meant there were difficulties accessing information, including people to talk to for reliable up-to-date advice prior to visiting primary care, as well as issues with the accuracy and relevance of information available at the early stages of a skin infection.

As part of the research, resources were developed and trialled with families to use at home, with photographs of the warning signs and progression of common skin conditions, identifying when and why to seek treatment in primary care, as well as how to prevent and treat various types of skin infections. The resources were designed for people to access before seeing a health professional as this is when crucial decisions need to be made within families. Parents identified that the resources were very helpful, as did health professionals who used them with families to build understanding of managing infections. The resources are freely available for download on the Ministry of Health website (Ministry of Health, nd, c) and other credible websites, and are often used in primary care as the basis of discussion with parents about what they can do. Ideally, access to these or similar resources would be available at schools and early childhood centres, in primary care waiting rooms and in public places such as supermarkets and pharmacies.

Gout and health literacy

Gout is much more prevalent among Māori, particularly Māori men, and affects Māori at a much earlier age. This leads to a loss of employment and income. In the gout project the researchers identified that men with gout believed their gout was caused by eating too many purine-rich foods and beverages rather than understanding that for a large number of Māori men, high uric acid levels are caused by genetic factors that stop the kidneys excreting uric acid. Little was understood about the long-term implications for joints and kidneys of repeated gout attacks and long-term use of pain relief medicines. Primary care health professionals were aware of the genetic link, but did not discuss this or gout prevention with patients as they thought men with gout would neither comply with the titration of uric acid medicines nor reduce their consumption of purine-rich food and beverages (Reid et al, 2014). With little discussion about gout prevention or long-term management in primary care, and with patients feeling ashamed or blamed for having gout, discussion usually focused on pain management for gout attacks. From a health literacy perspective, people were not involved in discussions with a health professional which, over time, can build a comprehensive understanding of gout and the long-term implications of the condition. In light of this, it was understandable that patients preferred to manage gout attacks with short-term pain medication rather than use urate-lowering medicine, which was complicated and at times painful to introduce as well as being a long-term or permanent regime.

As part of the research, researchers co-designed gout resources that explained the importance of reducing uric acid levels, how genes prevent the clearance of uric acid for many Māori, that urate-lowering medicines were the most effective and efficient way to reduce uric acid levels and how different urate-lowering medicines work. Researchers also developed guidance for health professionals about how to use the resources with patients as a way of addressing the biases health professionals had about people with gout. The resources focus on discussing gout in primary care settings as gout is a long-term condition that benefits from expert advice and ongoing monitoring. The resources are used in primary and secondary care and are freely available on the Ministry of Health and other health websites (Ministry of Health, 2015b).

Gestational diabetes mellitus and health literacy

Māori women have more children, and start having children earlier, than the non-Māori. Researchers in this project found the majority of Māori women who had not been tested for GDM during pregnancy had agreed in principle to be tested, and intended to have a test but had not prioritised the test and 'ran out of time' as they did not think the test was very important or of themselves as at high-risk of developing GDM. These women had been offered the test and voiced objections to testing, other than it being time-consuming (taking approximately three hours) and therefore inconvenient. This reflects that some women need to understand why testing is important for them, in order to prioritise the testing process. A few women who had been diagnosed with GDM in previous pregnancies attributed not being tested during subsequent pregnancies to not liking the diabetes services provided after diagnosis. A small number of women disagreed with medical tests being carried out during pregnancy.

Significantly, the health professionals offering the test to women had mixed views about how to offer testing, as well as the value of testing. A small group saw testing as over-medicalising pregnancy. Most often, women were told the purpose of the test (as being to identify diabetes that develops during pregnancy) and where the test could be taken, with little supporting discussion. Some health professionals did not want to jeopardise their relationship with women by 'nagging' women if they did not carry out the test as initially agreed. There was also a view that having all women receive the same offer of testing, in the same way, was providing an equitable service. This view did not recognise that in order to prioritise testing for GDM, some women may need more or different information than others, as well as assistance with transport and childcare. Some health professionals had very high rates of GDM testing among the Māori women they worked with. They described using more in-depth discussion to support the testing decision, particularly explaining the risks of GDM to women and babies and benefits of managing GDM if present, as well as giving timely reminders if a woman agreed to testing but had not completed the process (White et al, 2014).

It became clear that how GDM and testing were discussed with women, and encouraging completion with those who agreed to be tested, affected testing rates. A booklet explaining gestational diabetes and reasons for testing was developed for women and health professionals to support more discussion about GDM. However, the booklet was sometimes added to the information pack for women rather than being discussed and as such, had little impact on testing rates. In addition, there were complex reasons why organisations were not often able to deal with issues affecting access to testing such as transport and childcare.

Research results

The three exploratory research projects demonstrated the complexity of health literacy and that health literacy was relevant to health outcomes for Māori. The projects highlighted that health literacy issues can stem from difficulty accessing people with knowledge and health expertise, to a lack of credible, appropriate information being available at the right time, to assumptions being made by patients and health professionals that ultimately lead to poor health outcomes.

The differences between the information needs and sector responses in each project helped highlight that health literacy skills are not a fixed skill set that can be pre-learned by a child or adult, and are not the same as general literacy and numeracy. For example, someone with strong literacy and numeracy skills can have low health literacy in relation to gout. The health literacy relevant to a health condition is often detailed and involves specific knowledge about how the body functions and responds to particular medicines as well as how health conditions progress and can be managed. Until a health condition becomes relevant to a person or family, there is little need or motivation to learn about it.

The projects also identified a commonly held belief that health literacy is an individual or patient issue, with little recognition that health services and systems often create health literacy barriers and do not support people to build health literacy when opportunities arise. The need to address the health literacy barriers created by the complexity, culture and accessibility of the health system, services and information was identified in each project, with the answer often involving both process improvement in health services, as well as health professionals identifying appropriate opportunities with patients and families to build skills and knowledge.

Growing interest

For the Ministry of Health, the exploratory projects demonstrated how health literacy was integral to achieving the outcomes sought in the Māori Health Strategy, *He Korowai Oranga* (Ministry of Health, 2014a), and aligned with other frameworks in Māori health such as health equity (Ministry of Health, 2014b), person and family-centred care and cultural competence. The challenge became how to get the wider health sector to build awareness of and capability in health literacy and make much-needed service improvements. Te Kete Hauora and other Ministry teams funded further health literacy projects in relation to key health issues for Māori, such as childhood asthma (Māori children are more likely to be hospitalised with poorly managed asthma) and palliative care (Māori are far more likely to provide palliative care services at home to extended family but are far less likely to be offered access to or seek assistance from funded palliative care providers).

In addition, some academic institutions were carrying out health literacy research projects, for example, the University of Auckland's project on cardiovascular disease medicines and the University of Otago's follow-up project on asthma for Māori children and their families. A number of students were also completing doctoral studies in health literacy.

In 2012 the Ministry published *Rauemi Atawhai: A guide to developing health education resources in New Zealand* (Ministry of Health, 2012), setting out the main steps for developing health education resources, including understanding the health literacy demands placed on audiences and the health literacy development needs of those audiences. In 2012 another government agency, the Health Quality and Safety Commission, undertook a health literacy project as part of the Partners in Care initiative about engaging consumers in decision-making, particularly around medicine use. The Commission contracted Workbase to work with health professionals, initially community pharmacists, to develop workforce development material that could be used by pharmacists working directly with patients and families to build the health literacy of these groups.

The workforce development materials were based on applying the universal precautions approach to health literacy (AHRQ, 2010) and employed a strengths-based approach. Along with background information on health literacy, a training resource was developed called the *Three steps to better health literacy*, centred on a community pharmacy context. The authors used reading and schema theory and other adult literacy strategies to inform the content of the resource. The three steps described were as follows:

1. Ask – focused on eliciting a person's existing knowledge and beliefs.
2. Build – focused on building new knowledge by linking to what had been uncovered in Step 1 and using a mix of teaching and learning strategies.
3. Check – focused on checking whether the health professional has helped a person build new understanding (Health Quality and Safety Commission New Zealand, 2014).

The project also identified the health literacy demands placed on patients and families. For example, pharmacists used a considerable amount of unfamiliar language and abbreviations that had an impact on patients and families' understanding of medicines. The three steps were designed to help pharmacists think more about the way they provided information to patients and families as well as to check whether a pharmacist had been clear and effective in their communication.

In 2014 the Commission asked Workbase to redevelop the workforce development material, so it was applicable to all health professionals (Health Quality and Safety Commission, 2014). At the same time, other Ministry of Health-commissioned projects required health literacy demands to be identified and addressed, such as in the Ministry's Rheumatic Fever Prevention Programme. Rheumatic fever is still present in Māori and Pacific youth populations and those living in areas of high deprivation. Significant government investment had been made in producing national media campaigns to build awareness of rheumatic fever risks, as well as providing additional free health services in schools and communities to encourage the identification and treatment of streptococcus bacteria sore throats.

When looking at the issues of timely access to healthcare and medicine adherence from a health literacy perspective, it was identified that families were sometimes unsure of the connection between sore throats and rheumatic fever, the consequences of rheumatic fever and the rationale for continuing to administer antibiotics for a sore throat after a child appeared to be symptom-free.

Rheumatic fever is a complex condition requiring parents to understand the role of the immune system and how it can attack the heart and joints. There is no obvious connection between heart damage and a sore throat. Parents were also hearing conflicting messages about antibiotic use, with over-use and resistance warnings in the public arena, while personally being told to start children on antibiotics immediately for sore throats (and not wait for a streptococcus infection to be confirmed), and to continue antibiotics after all symptoms had cleared. This reinforced the need for the health workforce and media campaigns to engage with families about their understanding of sore throats, discussing *why* antibiotics are needed in this situation as well as *what* to do, in order to support healthy behaviours and good outcomes from improved access to health services.

Associated initiatives, such as work in the public housing sector, also needed to take a health literacy approach when discussing healthy home environments in order to make the link to and support prevention and management of streptococcus throat infections and rheumatic fever.

Other health literacy projects funded by the Ministry included resources for people considering live kidney donation, as well as resources for recipients of live donor transplants and resources to support people's enrolment in national screening programmes, for example, bowel screening, breast screening and cervical screening.

Big-picture thinking

In 2011 Dr Rima Rudd, an internationally renowned health literacy researcher from the Harvard School of Public Health in the US, visited New Zealand to speak at the first health literacy conference, and was asked to meet with the Ministry of Health and DHBs to discuss health literacy. Her visit was influential, particularly as her description of health literacy as a system issue rather than an issue of patient-deficit resonated with the Ministry, as their analysis of health disparity had led to a very similar perspective for achieving health equity in New Zealand. For those DHBs working with populations living in significant socioeconomic deprivation, this framing of health literacy matched the DHBs' concerns that the inequities and poor health outcomes experienced by these populations were due to far more complex issues than the individual efforts of patients and families.

In 2013 and 2014 the Ministry decided to develop guidance for healthcare organisations, particularly DHBs, about reviewing services from a health literacy perspective, and again sought contestable bids for the project. Workbase was the successful bidder working with three DHBs and Dr Rima Rudd as an expert reviewer.

The project involved developing a process by which large healthcare organisations could self-review their services and models-of-care from a health literacy perspective. The review process would result in a healthcare organisation developing an action plan for providing health-literate services, becoming a health-literate organisation and providing health literacy leadership in their region or service area (see Chapters 31 and 35, this volume). The guide, *Health literacy review: A guide*, and supporting website were made available by the Ministry at the end of 2015 (Ministry of Health, 2015c).

A critical foundation document for the Guide was the Institute of Medicine's discussion paper, *Ten attributes of a health literate health care organization* (Brach et al, 2012). This described what healthcare organisations could do to reduce the barriers to accessing and using health information and services. Many of these attributes seemed relevant to the NZ health system.

Eventually, six dimensions of a health-literate organisation were found to be significant and relevant to NZ and the self-review process. These were: governance and management; access and navigation; consumer involvement; meeting the needs of the population; the health workforce; and communication. These dimensions helped to reinforce the system and service design aspects of delivering health-literate healthcare, reducing unnecessary complexity and finding opportunities to build patient and public understanding of health and healthcare.

The Guide was also informed by health literacy toolkits, guides and projects that had been developed in the US, for example, the *Pharmacy health literacy assessment tool* (Jacobson et al, 2007); AHRQ *Health literacy universal precautions toolkit* (AHRQ, 2010); and *The health literacy environment of hospitals and health centers – Partners for action: Making your healthcare facility literacy-friendly* (Rudd and Anderson, 2006).

As health literacy was very much an emerging concept in NZ, the Guide needed to help reviewers and their organisations understand and support the concept of health-literate healthcare organisations, as well as provide a straightforward process for undertaking a review. A balance needed to be struck between providing standardised, reusable review tools, such as an exemplar review plans, observation checklists and interview questions, and ensuring a review team would be able to design and adapt the review process to best suit the services, issues and parties involved in a review.

An extra challenge in NZ was the self-administered nature of the review, given that health literacy experience and expertise was not widespread within the sector. The expert feedback from Dr Rudd focused on what could reasonably be expected of healthcare organisations, when carrying out a review would be the start of the health literacy journey for most organisations.

At the same time as the Guide was being developed, Te Kete Hauora was working on developing a health literacy framework for NZ. Te Kete Hauora drew on learning from local health literacy projects and analysis, as well as current international research and responses to health literacy. Te Kete Hauora consulted widely with a large range of national healthcare organisations and health professionals. In 2015 the Ministry released *A framework for health literacy* (Ministry of Health, 2015a). The Framework identifies the leadership and management actions, knowledge and skills needed by the health workforce and public, as well as system and service changes that build a health-literate health system.

New Zealand is the only country to have developed a framework that outlines expectations for the health system, health organisations and the health workforce to support health literacy being core business at all levels of the health system. The Framework identifies that effective health literacy practice contributes to improved health outcomes and reduced health costs.

The Ministry described the Framework as key to creating a health-literate health system which:

> builds health literacy skills of its workforce, and the individuals and whānau (families) who use its services. It provides high-quality services that are easy to access and navigate and gives clear and relevant health messages so that everyone living in New Zealand can effectively manage their own health, keep well and live well. (Ministry of Health, 2015a)

The current situation

At the end of 2015, Te Kete Hauora was disestablished as part of a major restructure of the Ministry of Health. The functions and responsibilities of the directorate were spread across the wider Ministry. Some DHBs and other large healthcare organisations are using the *Health literacy reviews: A guide to better understand health literacy in service design and delivery*. One DHB carried out a high-level health literacy review of healthcare provision across its entire region. They were able to look at whether the health services within their region were understood and coordinated from a user perspective. Some specific projects were identified that would benefit most from health literacy interventions, such as access to and outcomes from bariatric surgery. Two other DHBs have a series of health literacy reviews underway and some have developed or are developing strategic-level plans for health literacy.

New health sector initiatives, particularly those undertaken by DHBs, are using the six dimensions of a health-literate organisation described in the Guide to plan new services in order to build engagement with and understanding of these services. This involves looking at new services from a service user perspective, helping people to better understand the health journey, to anticipate the next steps in their healthcare and weigh up their treatment or other options. This is not about producing written information for service users, but rather focusing on the health delivery and management workforce – ensuring they have skills and resources needed to design, promote and discuss services, as well as coordinating the messages provided across all of the information points. Increasingly, health literacy is recognised as an essential building block in other projects, such as a project about creating workforce development resources to encourage and improve the provision of self-management support in primary care practices.

Future challenges

While there has been some clear leadership shown in the work carried out by the Ministry, one of the ongoing challenges is moving the health sector's and communities' framing of health literacy from being an issue of patient-deficit to being an issue of system response. The health system and services, treatment pathways and health conditions are often complex. Some of the complexity can be removed, but a significant part of helping people manage their health is helping them understand the health conditions and journeys they may be facing. In an age of increasing demands on healthcare services, and where self-management of multiple long-term conditions is becoming a necessity, it is essential that every health interaction and message is building health literacy as needed.

Primary care is increasingly inviting service users to participate in patient portals to improve time management for health professionals and giving people greater access to information and services. This increased access is a significant improvement for many, but there is the potential for people unable to operate in digital environments to become even further isolated unless they are upskilled and provided with equipment or offered alternative ways to access their information.

Many of the developments and changes in the health sector add to the health literacy demands people face when managing their health and navigating the health system. There is a continued need to consider how to reduce these demands and resulting complexity, and create health organisations, services and a health workforce that takes every opportunity to build health literacy when and where it is needed by individuals, families and communities.

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Health literacy and the school curriculum: The example of Finland

Olli Paakkari and Leena Paakkari

Introduction

The education system has been recognised as a central arena for developing children's health literacy (Nutbeam, 2000; St Leger and Nutbeam, 2000; Begoray et al, 2009; Paakkari and Paakkari, 2012). Schools reach almost all children, and there is a link between high health literacy and positive health outcomes (Volandes and Paasche-Orlow, 2007; Berkman et al, 2011). Thus, there are good grounds for anticipating that the acquisition of health-related competencies at school can decrease health disparities among children. This would be a clear public health benefit, but above all, it is a question of ethics (Paakkari and George, 2018). If health literacy becomes part of the school curriculum, it has the potential to guarantee that *all* school-aged children will be able to learn the competencies they need to take care of their own health and the health of others.

Health literacy has been adopted into the school curriculum of several countries, including the Czech Republic (Hrivnová, 2016), Australia (Macdonald, 2013), and Finland (Finnish National Board of Education, 2014). One of the first countries to adopt such a curriculum was the US. There, the introduction of *National health education standards* in 1995 meant that health literacy was seen as a competence allowing the individual to be a critical thinker and problem-solver, a responsible and productive citizen, a self-directed learner and an effective communicator (Joint Committee on National Health Education Standards, 1995; see Chapter 2, this volume). This set of competencies corresponds well with the most recent health literacy definitions (see, for example, Paakkari and Paakkari, 2012; see also Chapters 1 and 3, this volume), and with the key competencies identified and defined by the Organisation for Economic Co-operation and Development (OECD, 2005), with a view to ensuring that citizens can meet the demands of society. According to the OECD (2005), in order for a competence to be considered 'key', it has to 'contribute to valued outcomes for societies and individuals; help individuals meet important demands in a wide variety of contexts; and be important not just for specialists but for all individuals' (2005, p 4). Following this line of argument, one can readily view health literacy as an important competence for citizens: after all, it contributes to positive health outcomes both at the individual and societal level, helps people to cope with and modify the factors that influence their own and others' health, and is relevant for every citizen. Moreover, as also argued in this chapter, the establishment of school-based learning standards for health literacy may assist in tackling health disparities (Parker et al, 2003).

The identification of health literacy learning standards – which can be regarded as criteria for a qualification in health literacy – responds to the qualification function of education (see Biesta, 2010). It can be argued that one of the main purposes of education is to qualify pupils with the competencies they need in a particular society; indeed, this function is 'one of the major functions of organised education and is an important rationale for having state-funded education in the first place' (Biesta, 2010, p 20). This function is clearly linked to assessments of how far pupils meet the criteria defined in a given curriculum.

This chapter focuses on how health literacy is addressed within the current Finnish national basic education core curriculum. A particular focus is on describing health education as a school subject, its learning objectives and its assessment principles.

Evolution of Health Education as a subject

The move towards a stand-alone subject

The teaching of health issues has always had a central place in the Finnish school curriculum. Over 100 years ago (in 1913) the subject called 'Hygiene and temperance education' was officially introduced in schools, although health issues had been taught long before that (Korhonen, 2007). Until 2001, Health Education was taught as part of Physical Education, although it formed a separate entity in terms of content. Health topics were also integrated with other school subjects, notably Civic Education, Home Economics and Biology (Korhonen, 1998, p 35). In addition to curriculum-based Health Education activities, whole-school approaches were applied in schools, especially during the late 1990s (under the title of 'Health-Promoting Schools'). These offered possibilities for pupils to learn and experience health issues in a holistic manner.

In 2001 two acts were ratified, namely, the Act on Basic Education and the Act on the Upper Secondary School. Now, Health Education became an independent and obligatory school subject in basic and upper secondary schools. In the Government proposal (Hallituksen esitys) of 2000, two main justifications were given for this educational reform. In the first place, negative changes in pupils' health and health behaviours had been observed. These included an increase in various ailments and disorders (for example, neck and shoulder pain, daytime sleepiness, depression) and in the use of alcohol. Within the proposal it was argued that since the school is an educational institution that can reach nearly all children at their most impressionable ages, it could help to decrease health inequalities. Second, current health teaching was seen as inadequate for developing pupils' skills regarding their own safety, and insufficient for promoting life management and citizenship. The integration of health issues with other subjects had not been successful. In addressing these problems, it was proposed that there should be teaching on various distinct entities, and that relevant teaching objectives should be clearly defined. Only then, it was argued, could teaching in this domain become more effective (Hallituksen esitys, 2000).

At the time when the Government proposal was set out there was favourable momentum for such an educational initiative. Large-scale surveys had reported parallel findings in terms of pupils' health and health behaviour (see, for example, Lintonen et al, 2000). Furthermore, various stakeholders such as the Ministry of Education, universities and health institutes had arrived at a consensus on the current state of pupils' health and wellbeing, and on the teaching of health issues in schools. The time was ripe for the ratification of the law, and for the introduction of a new school subject.

In August 2004, schools at a basic level were able to introduce Health Education as a new, independent school subject. Now, in grades 1-6, it was taught as an independent component of Science, and from grades 7 and upwards, it was taught as a stand-alone subject. Furthermore, the status of Health Education was strengthened in upper secondary education.

Development process of the national core curricula

The most recent Finnish national curriculum for basic education was introduced in 2016. The reform process took four years. It started in 2012, when the Finnish government confirmed the subjects to be taught, and the overall distribution of lesson hours, both in basic education and in upper secondary education. The drafting of the core curriculum – including the Health Education curriculum – was organised by the Finnish National Board of Education. It was set up to be partnership-based and highly transparent. The draft of the core curriculum was created by several multidisciplinary working groups, supported by online consultation groups. In 2012, general guidelines for the entire curriculum were created, and in the following year the subject-specific groups started their work. The group that outlined the Health Education curriculum consisted of health education subject teachers, school principals, scientists and educational experts. During the curriculum reform process the National Board of Education asked for feedback three times. The feedback was collected via a website, and was open to everyone. Education providers and parents were particularly encouraged to provide their comments on the draft of the curriculum.

During the autumn of 2014, various key stakeholders (for example, teacher associations, municipalities, universities, health associations) were able to give their official opinions. This open and participatory reform process ensured that the voices of the various parties were heard, the overall aim being to share power in deciding the content of the curriculum. However, the final decisions were made by a select group of people, based on their visions of what the focus should be in the subject of Health Education. Hence, the Health Education curriculum is not (and never will be) based on a purely neutral agglomeration of knowledge (see Apple, 1993). The new national core curriculum was accepted in December 2014. It includes the objectives and contents of different subjects, the underlying learning concept, plus guidelines to promote the welfare of students. It also encompasses assessment principles and education for special needs.

Starting in August 2016, the new core curriculum has been implemented in schools for grades 1-6. Between 2017 and 2019, the new curriculum will be put into operation for grades 7-9, on a step-by-step basis. Schools can decide how they will divide the lessons per year between the various grades. However, it has been shown that if the lessons are evenly distributed, this produces better learning on health issues (Summanen, 2014).

Towards a competence- and phenomenon-based curriculum

Many factors made it necessary to revise the core curriculum in Finland. These included rapid changes in society and the world, relating to environmental issues, ever-increasing globalisation and rapid technological development. The goal of the curriculum reform was to ensure that the pupils could achieve competencies that would meet the requirements of present and future society, both nationally and internationally. This called for a shift away from a focus on specific contents towards a focus on broader phenomena, and the competencies relating to these.

In Health Education, one intention was to identify phenomena that would not merely be broad, but also complex and tightly rooted in real-life contexts and challenges. For grades 7-9 the following three phenomena were identified: (1) individual growth and development; (2) key resources for health; and (3) the contribution of the community and society to health. These broader phenomena were linked to certain corresponding competencies. Here, health literacy served as a theoretical framework for defining and describing the set of competencies (described in more detail below). Furthermore, the new national core curriculum stated that in the teaching of various subjects it was necessary to take into account the following cross-subject competencies: thinking and learning to learn; cultural competence, interaction and self-expression; taking care of oneself and managing daily life; multiliteracy; ICT competence; working life competence and entrepreneurship; and participation, involvement and building a sustainable future. These were to be addressed in the teaching of subjects such as Health Education. Cross-curricular activities were required here also. In line with this, the national curriculum required schools to describe in detail 'multidisciplinary learning modules'. These are larger projects or courses, focusing on a selected phenomenon or theme, and connecting the key objectives of the different subjects (Finnish National Board of Education, 2014). In line with this, the current Health Education curriculum represents a competency-based curriculum since it is designed around a set of cross-curricular and subject-bound competencies and not round a list of contents (see UNESCO IBE, 2013, pp 12-13).

Health literacy as a theoretical framework for the Health Education curriculum

At the time of the recent curriculum reform, *health literacy* was adopted as the term covering the teaching objectives and learning criteria for the subject of Health Education. In fact, the concept had also been identified in the previous basic education curriculum (Finnish National Board of Education, 2004), but it was now more explicitly described and applied. A theoretical framework for the conceptualisation of health literacy was developed by Paakkari and Paakkari (2012). According to their view, health literacy develops through learning. They define that health literacy comprises a broad range of knowledge and competencies that people seek to encompass, evaluate, construct and use. They argue that health literacy enables people to understand themselves, others and the world in a way that will enable them to make sound health decisions, and to work on and change the factors that constitute their own and others' health chances (cf Zarcadoolas et al, 2005; Abel, 2007; Paakkari and Paakkari, 2012, p 136). Health literacy does not focus merely on information located 'out there'; it also concerns information situated within oneself as an individual. Hence, health literacy enables us to 'become literate about ourselves and the broader context we are part of' (Paakkari and Paakkari, 2012, p 136).

According to the core curriculum (Finnish National Board of Education, 2014), the overall aim of Health Education in grades 1-9 is to support the development of health literacy in a versatile manner. The teaching objectives, and the learning criteria, are divided according to the core components of health literacy, namely, theoretical knowledge, practical knowledge, self-awareness, critical thinking and citizenship (Paakkari and Paakkari, 2012) (see Box 34.1). These components are to be addressed in grades 1-9 (see Tables 34.1–34.3). This implies that they are equally important for pupils, regardless of age; they can and should be developed throughout the school system, but in an age-appropriate manner.

Box 34.1: The core components of health literacy

The five core components of health literacy

The *theoretical knowledge* of health issues encompasses a range of principles, theories and conceptual models. Knowledge is viewed as something explicit, factual, universal, formal and declarative. It includes lower levels of thinking skills, such as remembering.

Practical knowledge (that is, procedural knowledge, skills) can be seen as a competency that allows one to put theoretical knowledge into practice. Whereas theoretical knowledge is something applicable to many different situations, practical knowledge can be regarded as usable only in specific contexts. It is partly rooted in the individual's experiences, and thus it includes tacit, intuitive or implicit knowledge. Practical knowledge covers basic health skills such as the ability to find health information, the ability to seek health services and the ability to give first aid.

Individual critical thinking can be understood as the ability to think clearly and rationally. It is based on possession of an investigative attitude towards the world, and a desire to understand health issues in a deeper way. In practice, critical thinking includes higher-level thinking skills, such as an ability to analyse, evaluate and create something new; this could include, for example, the ability to search for logical connections between health ideas, to solve problems, to argue, to draw conclusions or to assess the validity of health information.

Self-awareness is the ability to reflect on oneself, and it makes possible the personal contextualisation of health issues. Through self-reflection, the individual becomes conscious of his/her own thoughts, feelings, needs, motives, values, attitudes and experiences, and is able to consider how these relate to ways of behaving in an individually health-enhancing way. An important part of self-awareness is the ability to reflect on oneself as a learner.

Citizenship involves the ability to take social responsibility, and to think of the probable consequences of one's own actions on others. The ability to act in an ethically responsible way means that individuals are able to consider health issues beyond their own perspective: they may thus become aware of their own rights and responsibilities, and the effects that their actions or thoughts may have on other people, or on the environment. This component further includes the ability to identify (and to work on) factors that influence possibilities to achieve or maintain good health, both for oneself and for others.

Source: Paakkari and Paakkari (2012), according to Paakkari et al (2016)

At the time when most recent curriculum development was taking place, the Finnish National Board of Education published a report on the national assessment of Health Education. The findings indicated that pupils' competence in Health Education was at a satisfactory level, and clear challenges were identified regarding pupils' higher-order thinking skills (Summanen, 2014). Hence, the new curriculum aimed at strengthening the role of such higher-order competencies.

Objectives of instruction in grades 1-2 and 3-6

In grades 1-6, Health Education is to be taught as a component of integrated environmental studies, and this clearly influences the content of Health Education. In total, 532 hours are allocated for environmental studies; these are to be divided between Health Education, Biology and Geography, Physics and Chemistry. In grades 1-6, instruction in environmental studies should support pupils in knowing and understanding themselves and other people; it should further address the importance of health and wellbeing, nature and the constructed environment and related phenomena. Attention should be paid to the development of critical thinking, with efforts to improve pupils' ability to acquire, process, produce, present, evaluate and appraise information in different situations. An essential element in Health Education is an understanding of environmental factors and human activities that support health, wellbeing and safety. Table 34.1 gives some examples of the specific objectives of environmental studies in grades 1-2.

In grades 3-6 the objectives of environmental studies are slightly more demanding than in the lower grades, but still focus on a range of aspects of health literacy (see Table 34.2). To support teachers' assessments, the core curriculum contains the assessment criteria for 'good' knowledge and skills (corresponding to numerical grade 8, scale 4-10).

Objectives of instruction in grades 7-9

In grades 7-9 there are 114 hours of Health Education. The instruction should expand and deepen the themes studied at lower levels, and the learning requirements are thus more demanding.

The main idea in the instruction is to build up a holistic picture of health and its constituents (see Dahlgren and Whitehead, 1991). Health, wellbeing, and safety-related phenomena are to be observed in an age-appropriate way, via different components of health literacy. The core curriculum is built up from three broader phenomenon (that is, key content areas), namely: (1) growth and development supporting health; (2) factors supporting and harming health and prevention of illness; and (3) health, communities, society and culture (Finnish National Board

Table 34.1: Examples of objectives in grades 1-2, divided into health literacy components

Objectives of instruction	**Health literacy component(s)**
To guide the pupil in reflecting on factors that support growth, development, health and wellbeing, and the basic necessities of life	Theoretical knowledge
To guide the pupil in practising (1) teamwork skills and (2) emotional skills, and to strengthen their self-respect and respect for others	Practical knowledge, self-awareness
To encourage curiosity about the world, so that pupils ask questions, and use collaborative discussion as a basis for small research assignments and other activities	Practical knowledge, critical thinking
To encourage pupils in expressing themselves and in justifying their opinions To guide pupils in describing, comparing and classifying organisms, habitats, phenomena, materials and situations in diverse ways, applying names when possible	Practical knowledge, self-awareness, critical thinking
To support the development of pupils' environmental awareness, guiding pupils so that they act sustainably in their surroundings and the school community	Citizenship, critical thinking

Source: Finnish National Board of Education (2014), modified

Table 34.2: Examples of objectives in grades 3-6, with health literacy components and assessment criteria for 'good' knowledge at the end of grade 6

Objectives of instruction	Health literacy component	Assessment criteria for 'good' knowledge and skills/ numerical grade 8
To guide pupils in understanding aspects of health and the importance of everyday health habits; also people's life courses, plus individual growth and development in children and teenagers. To encourage pupils to practise and apply their health literacy in daily life	Theoretical knowledge	Pupils should be able to describe aspects of health and to give examples of how they can promote their own good health in daily life Pupils should be able to describe life course stages and to explain key characteristics of growth and development in puberty, plus individual variations
To offer pupils opportunities to practise acting in a group in different roles and interactive situations; to inspire pupils to express themselves and to listen to others; also to support pupils in recognising, expressing and regulating their emotions	Practical knowledge	Pupils should be able to describe practices related to, for example, acting in a group and polite behaviour; also practices for expressing and regulating emotions, and for applying them in different roles
To guide and encourage pupils in setting personal study goals and in making persistent efforts to achieve them; also in recognising their own competence in environmental studies	Self-awareness	Pupils should be able to set goals for themselves in small study units, and to work towards common goals
To guide pupils in obtaining reliable information, expressing and justifying different views and interpreting and critically evaluating information sources and viewpoints To guide pupils in recognising causal relationships, and in arriving at conclusions from results obtained	Critical thinking	Pupils should be able to search for information from different sources of information and select some reliable sources of information Pupils should be able to justify various views and to identify dissimilarities in different viewpoints Pupils should be able to identify causal relationships through guidance, and draw simple conclusions from results obtained
To support the development of pupils' environmental awareness and to guide pupils in acting and becoming involved with their surroundings and community, with the aim of promoting sustainable development and appreciating the importance of sustainable development for themselves and the world	Citizenship	Pupils should be able to describe factors that support and threaten the building of a sustainable future, using examples Pupils should be able to describe different methods of protecting, developing and influencing their surroundings and communities; also to act jointly in projects, under guidance

Source: Finnish National Board of Education (2014), modified

of Education, 2014). There are in total 12 objectives for Health Education, and more specifically, four objectives relating to a single broader phenomenon. All the objectives related to one phenomenon are then assigned to various health literacy components (theoretical knowledge, practical knowledge, self-awareness, and critical thinking and citizenship). These components should be related to the relevant larger phenomenon, which forms the context. Critical thinking and citizenship are grouped together to form common objectives. Table 34.3 shows some of the instructional objectives for each health literacy component. In addition, learning criteria for the level of 'good' are set out. A final assessment, based on these criteria, should take place on completion of studies.

Assessment of health literacy as a learning outcome

In Finland, learning assessments are based on the Basic Education Act 1998. This states that 'the aim of pupil assessment is to guide and encourage learning and to develop the pupil's capability for self-assessment' (1998, p 10). In the Finnish national core curriculum, a special emphasis has been placed on defining what assessment is, and how it should be carried out in schools. It clearly states that at all assessment should: (1) take place in an encouraging atmosphere; (2) use various assessment practices; and (3) be conducted in a dialogical and interactive manner (pupil–teacher, pupil–pupil, home–school). The assessment should further (4) support pupils so that they become aware of their own learning; (5) be ethically sound and fair; and (6) be used to develop teaching further (Finnish National Board of Education, 2014). All assessment should take into account the age and capabilities of the pupils.

Health Education assessment should focus on the different components of health literacy. Furthermore, pupils should have the opportunity to demonstrate their competence in different phases of the instruction. The assessment and feedback should support learning, and should encourage the pupils to develop their health literacy. A pupil-oriented learning culture will also challenge schools to renew their assessment culture. Thus, rather than having a culture of measuring and controlling, schools should move towards a learning-based assessment culture in which the pupil is an active participant (Black et al, 2004). This means that pupils should have opportunities for both self-assessment and peer assessment. Such self-assessment should give pupils a view of their own level of knowledge. This will encourage learners to consider reasons for learning, support them in adopting an in-depth learning method and promote their ability to self-regulate their learning processes (Prosser and Trigwell, 1999; Ozogul and Sullivan, 2007). In a similar manner to self-assessment, peer assessment directly involves pupils in the learning process, and in addition, allows pupils to learn from others (Vu and Dall'Alba, 2007).

The assessment should be based on pre-published criteria (derived from learning objectives). This increases the transparency and openness of the assessment. Criterion-based assessment supports reliability and fairness, since

Table 34.3: Examples of objectives in grades 7-9, health literacy components and final assessment criteria for 'good' knowledge

Objectives of instruction	Health literacy component(s)	Assessment criteria for 'good' knowledge and skills/numerical grade 8
To guide pupils in understanding the broad nature of health, plus health promotion, life courses, growth and development, in a resource-based manner	Theoretical knowledge	Using examples, pupils should be able to describe aspects of health, plus the interaction between the various aspects, and to describe what health promotion means Pupils should be able to describe different stages of life courses, particularly development during adolescence, and to describe with examples the significance of health, growth and development as a resource for life
To guide pupils in developing their emotional and interaction skills, and the ability to act in different conflict and crisis situations	Practical knowledge	Pupils should be able to identify various emotions and give examples of the interaction of emotions and behaviour, linking this also to regulation of behaviour Pupils should be able to find solutions to conflicts and to present ways to manage stress and crises
To guide pupils in recognising and evaluating habits and choices related to health and safety; also to encourage pupils to reflect on the resources that are important for their health To guide pupils in understanding the ways of learning that are most personally suitable for them	Self-awareness	Not used as a basis for grade formulation. Pupils are guided to reflect on their own experiences as an element in self-assessment Pupils can use examples to analyse factors that support their own learning
To guide pupils in recognising and critically examining phenomena related to health and safety, plus the values and norms connected to these; also to evaluate the reliability and significance of information To support pupils' ability to analyse rights, responsibilities and means of individual involvement, in matters of health, the learning environment and local communities	Critical thinking and citizenship	Pupils should be able to analyse factors affecting the adoption of health habits, and to explain the formation of phenomena related to health habits Pupils should be able to describe ethical questions related to ways of life; using examples, they should be able to evaluate the consequences of choices related to ways of life Pupils should be able to evaluate the reliability of health-related information, on the basis of multiple factors affecting the reliability of information Pupils should be able to analyse the consequences of various ways of life on other people, and on the health of the environment; also to give examples of measures affecting health in their surroundings

Source: Finnish National Board of Education (2014), modified

pupils' competencies are compared only to the criteria in question, and not, for example, to the level of other pupils. Pre-defined criteria give information to pupils on the kinds of competence (quality, scale, depth) that are expected, and on the purpose of an assessment. This can guide pupils' learning and support comprehensive health literacy.

Health literacy as a learning outcome will be explicitly assessed from grade 7. At lower levels (grades 3-6), it will be implicitly assessed as part of environmental studies. Numerical grading will begin no later than in grade 8. Before that, it will be possible for verbal assessment to be used alone, or applied in conjunction with numerical grading. Pupils are to be assessed in how well they have fulfilled the criteria for grade 8 ('good') as defined and described in the national curriculum (see Tables 34.2 and 34.3).

Health Education aims at developing pupils' self-awareness in addition to other core components. However, this competence cannot be included into the grading (see Table 34.2). This decision was taken to avoid a situation in which assessment would focus on pupils' ways of behaving, or their attitudes, or their values, rather than on their knowledge and skills. It should be noted that this decision was linked to a particular cause for concern. In fact, about 20 per cent of Health Education teachers in Finland have reported that they do include health behaviour within their assessment (Summanen, 2014). Considered from the point of view of curriculum objectives, this is a basic fault. Teachers should be able to distinguish individual ways of behaving, values, and attitudes from the pupil's ability to reflect on them. The national curriculum obliges all teachers to follow the instructions it provides, regarding the focus and practices relating to assessment. Thus, the criteria for the assessment of learning in Health Education set bounds on the kinds of aspects of health literacy that can and should be assessed.

The arguments above are linked to the question of where health literacy actually ends. Paakkari and George (2018) reflect on the ethical perspectives that may be relevant here. They argue that health literacy ends when we move from learning outcomes to the probable consequences of these outcomes on one's personal characteristics, ways of behaving and health. In fact, opinions along these lines underline certain elements of the Health Education curriculum. There, one can see that the learning criteria do not include motivation and attitudes, even if these have been included in the OECD (2005) discussions of key competences. In taking this decision, the Health Education curriculum explicitly emphasises that one's health literacy level cannot be assessed on the basis of a pupil's 'values, attitudes, health behaviour, sociability, temperament, or other personal characteristics' (Finnish National Board of Education, 2014, p 432).

Final remarks

To sum up, in Finland, the learning of health-related competencies in basic education is a national-level right of every pupil, and the curriculum aims to secure this right. It remains to be seen how far the general principles set out in the national core curriculum are manifested in schools, since they will undoubtedly require new ways of thinking about teaching, learning and assessment. Also, the new Health Education curriculum, with its explicit emphasis on health literacy, imposes demands on Health Education teacher training.

In Finland teachers of Health Education must have the teaching qualifications required for a subject teacher (that is, a teacher specialising in and teaching the content of one particular school subject). The studies must consist of at least basic-level (25 ETCS) and intermediate-level (35 ECTS) multidisciplinary university-level studies in Health Education. In addition, if Health Education is to be the *main* teaching subject of a teacher, then she or he must include advanced-level studies (60 ECTS) into the study programme as well. Health literacy is clearly approached and focused on during the teacher training programme in all areas of expertise of a teacher. Health Education teacher training has been built around seven areas of expertise, which are the teacher's grasp of research, content knowledge, pedagogical content knowledge, and interactive skills, ethical awareness, knowledge of the pupils as learners, the teacher's self-knowledge, and knowledge of the school as an operational environment. The aim has been to form a coherent teacher training programme that will emphasise the linkage between educational and health phenomena, rather than presenting an 'atomistic' view that would tend to blur the connection between education and health – as has been reported to be the case in England (Speller et al, 2010). It is easy to agree with the statement made almost two decades ago, that 'education for health literacy for the provider (teacher) should be as important as for the consumer (student)' (Peterson et al, 2001, p 144). In Finland, to a certain degree this has be secured by the law: both the subject Health Education focusing on health literacy and teacher training are law-based.

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Part 4

FUTURE DIALOGUE AND NEW PERSPECTIVES

The aim of Part 4 is to look at health literacy through the lens of further scientific disciplines and to foster future dialogue and thereby introduce new perspectives to widen the field of health literacy. Health literacy is still an evolving concept that is undergoing dynamic changes on all levels. Learning from other scientific fields and their theoretical considerations, empirical results and practical implications is a key to move health literacy forward while it is still evolving. The following chapters view health literacy from the perspectives of literacy studies and education, childhood studies, nursing science, sociology, palliative care and inclusion and special needs. Further approaches focus on public health capacity building and improving system-level organisational structures, discuss health literacy in the context of digital worlds and eHealth literacy linked to sociocultural perspectives, and bridge between health literacy and the health promotion health model of salutogenesis.

Today, successful improvement of health literacy and associated health communication are widely accepted to be systems efforts on multiple levels rather than approaches isolating action to the individual level. In this context, the health-literate organisation is an evolving concept and is critically discussed in Chapter 35 by Jürgen M. Pelikan.

Chapter 36 by Paulo Pinheiro connects current approaches to health literacy with approaches that have been used in literacy research to understand the nature of literacy. This contribution provides an overview of major perspectives that have shaped the literacy debate, contrasts them with the currently dominant definitions of health literacy, and discusses implications for further research on health literacy.

This social interaction-oriented discussion is taken up by Ullrich Bauer in Chapter 37, who, from a sociological point of view, highlights the social embeddedness of health literacy and how social factors and the interplay of compositional and contextual factors affect health literacy-related health practices, and therefore should be considered accordingly.

In their chapter on children as active participants in health literacy research, Chapter 38, Emma Bond and Vanessa Rawlings introduce several unique ideas to the field. In doing so, they especially draw on the social studies of childhood, participatory research, and highlight a rights-based perspective to challenge issues of power relations, tokenism and adultist agenda-setting in the context of child and adolescent health literacy research approaches.

In Chapter 39, Evelyn McElhinney introduces her novel qualitative study on how multiple social skills, cultural competencies and social resources influence the health literacy of children, adolescents and adults, which she has conducted in the context of 3D social virtual worlds. Her study provides first evidence of the multi-literacies used by adults in areas of new media, and shows similarities with those used by children and adolescents, suggesting a more intergenerational lifespan approach be applied to new media literacies.

In her chapter on health literacy and the healthcare participation of adults, Chapter 40, Melanie Messer asks the question as to whether the concepts of health literacy and participation are compatible or rather incompatible approaches. In this context, she describes the possible links and relationships between these, and discusses future challenges for healthcare development, considering health literacy and patient–provider interaction.

Although older people have been the focus of health literacy since the very beginning of research in this field, there is little research on ageing in the context of end-of-life issues in relation to health literacy. In Chapter 41 Barbara Kondilis understands that this sensitive topic is best addressed by going beyond the individual-level perspective. She suggests that addressing end-of-life issues should always include social or community-level action, and considers the constant interplay of the involved micro and macro levels.

When examining the scientific discourse around health literacy, it becomes well clear that the one term, 'literacy', of the composite term 'health literacy', has been extensively discussed among scholars worldwide. However, when seeking for research on the other term, 'health', it becomes clear that it had not received similar attention as literacy. Therefore, Chapter 42 by Luis Saboga-Nunes and colleagues focuses on the health element of health literacy and introduces the concept of salutogenesis and to what extent health literacy could be utilised as a resource in the asset-based health approach, or in other words, asks the question, what makes people healthy?

Chapter 43 by Ruth Pitt and colleagues provides a meta-narrative review, which is a relatively new method for evidence synthesis, to explore the diversity of research approaches to the social context of health literacy in different populations across the whole life course. By providing a deeper understanding regarding global research evidence around social health literacy and diverse conceptualisations of health literacy and social context, and how these two concepts intersect, the authors address a critical research gap and provide new evidence to inform future research protocols.

In Chapter 44 Uwe H. Bittlingmayer and Diana Sahrai provide a meaningful introduction to the concept of inclusion as proposed and ratified by the United Nations. At its core, inclusion serves the purpose of addressing barrier-less participation in a whole society for all, particularly including a systems perspective. With participation and the systems perspective, inclusion shares at least two intersections with health literacy that are both discussed critically, including associated challenges health literacy research may face when addressing people with disabilities.

In times where the meaning and scope of health literacy have expanded to include more complex and interconnected abilities, an important precondition to successfully addressing the challenges of limited health literacy is to ensure that the health system has sufficient capacity to do so. To stress the relevance of sustainable capacities for health literacy, and taking into account the knowledge and competencies that are required to meet the complex demands of modern society, in Chapter 45 Stephan Van den Broucke transforms a conceptual public health capacity framework to the field of health literacy in order to address some of the future challenges, when strengthening health literacy-related capacity building is the focus of interest and action.

By addressing these topics, this part of the handbook analyses recent trends that, if valued and weighted sufficiently, could support future directions in health literacy. The chapters take a multidisciplinary approach and deal with priority issues, policy implications as well as research and action opportunities.

35

Health-literate healthcare organisations

Jürgen M. Pelikan

Introduction

There has been a rapid increase in the number of publications on health literacy in general, but also specifically on organisational health literacy, health-literate healthcare organisations (HLHCOs) or health-literate organisations (HLOs). The discourse on HLOs, like the one on health literacy, started in the US, but has increasingly been taken up, adapted and further developed in other countries such as Australia, Austria, Belgium, Canada, Germany, Italy, Israel, Norway, Taiwan and New Zealand, and there are already several literature reviews or overview articles on organisational health literacy (Palumbo, 2016; Brach, 2017; Meggetto et al, 2017; Farmanova et al, 2018; Lloyd et al, 2018) that support orientation about this rapidly evolving field of research, practice and policy.

While from its beginning health literacy was introduced as a measurable and modifiable concept, based on the long tradition of measuring and teaching literacy, instruments for HLO measurement and modification are still being developed. Measurement of the functional health literacy of patients had already begun in the US in the 1990s, and produced empirical evidence that health literacy matters for healthcare: first, a considerable number of patients have low or limited (functional) health literacy, and this proportion is likely to increase (Parker et al, 2008). Second, patients with low (functional) health literacy have higher use and worse outcomes of healthcare services (Berkman et al, 2011; Brach et al, 2012). And third, low health literacy in healthcare also has considerable consequences for the costs of health care (Eichler et al, 2009).

These facts, taken up by the former Institute of Medicine and supported by the health policy of the US government, led to a focus by practitioners and researchers on the limited health literacy of patients within the healthcare system. Different single strategies were tried out, such as measuring patients' health literacy to take low health literacy into account in communication; improving the readability of written health materials; improving oral communication by enhancing the communication of health professionals; using specific techniques such as the teach-back method in the clinical encounter; and improving access to services and navigation among facilities. Step by step these strategies were integrated into more systemic, holistic frameworks (Nielsen-Bohlman et al, 2004; Paasche-Orlow et al, 2006; Rudd and Anderson, 2006; Andrulis and Brach, 2007; Schillinger and

Keller, 2011), resulting in the *Ten attributes of health literate health care organizations* (see Brach et al, 2012).

A precondition for defining the concepts of HLHCO, HLO or organisational health literacy was the evolving understanding of health literacy as relational or interactive (Pelikan and Ganahl, 2017), individual vs system-related (Baker, 2006; Rudd and Anderson, 2006), contextual (Nutbeam, 2008) or dual (Parker, 2009), which partly resulted from interpreting the low health literacy of patients in the US healthcare system. This understanding acknowledges that an actual individual's health literacy does not depend on their personal skills or competencies alone, but also on the complexity, that is, the demands and resources, of the situations in which health-literate decisions or actions have to be taken. By this understanding, not only can personal health literacy be measured and improved, but also situational, organisational or settings and systems-specific health literacy or health literacy sensitivity.

The meaning of 'health' and 'literacy' in health literacy has broadened in parallel, from focusing just on disease in clinical healthcare to also including positive health and wellbeing as understood in public health, disease prevention and health promotion, and from just understanding health-related information to also accessing, appraising and using it (Sørensen et al, 2012; Pelikan and Ganahl, 2017). Thus, health literacy and organisational health literacy are relevant for people in many roles besides being patients, such as, for example, for workers, consumers and citizens in all kinds of organisations, settings and systems in late modern society (Kickbusch and Maag, 2008). Therefore, the concept of a health-literate organisation or organisational health literacy is now also used for cities, schools, workplaces etc. While the limited space of this chapter does not allow to expand on these conceptual expansions, the World Health Organization's (WHO) *Health literacy: The solid facts* (Kickbusch et al, 2013) gives some overview on this ongoing development.

The leading questions for this chapter are: (1) How is OHL in relation to health services, or specifically HLHCO, defined and conceptualised? (2) What instruments have been developed to assess and improve organisational health literacy/HLHCO? (3) What are the experiences of implementing the concept and using the tools in different healthcare contexts? And what are the barriers and facilitators for implementing organisational health literacy/HLHCO?

Development of a holistic, systems-oriented concept of health-literate healthcare organisations

In the US the organisational health literacy/HLHCO concept was developed in parts by different authors (Adams and Corrigan, 2003; Nielsen-Bohlman et al, 2004; Rudd et al, 2005; Paasche-Orlow et al, 2006; Rudd and Anderson, 2006; Andrulis and Brach, 2007; Schillinger and Keller, 2011) before being integrated into a more comprehensive framework by a task force from the Institute of Medicine of the National Academies in the US, which proposed the *Ten attributes* *of health literate health care organizations* (see Brach et al, 2012). Following this conceptual breakthrough, instruments to assess the organisational health literacy of healthcare facilities and tool boxes of best practice interventions to improve it have been further developed, and hospitals and healthcare organisations have begun to implement the concept. In the US, the concept has also been differentiated for specific organisations of the healthcare system, for example, hospitals, pharmacies or other PHC (primary healthcare) facilities.

Terminology and definitions of organisational health literacy

'Health literacy' is still an evolving concept (Nutbeam, 2008), and for 'organisational health literacy' this is even more so. For health literacy, at least in the English language, there is a fixed commonly used term, but variation in defining its meaning. In contrast, for organisational health literacy, several different terms have been proposed, and not always explicitly and clearly. Therefore, they may or may not also signal differences in the intended meaning of the concept. In a recent article 'What's in a name? An overview of organizational health literacy terminology', Meggetto et al (2017) gave an overview of the terms used and definitions proposed, as well as analysing the underlying dimensions and discussing the pros and cons of the existing variety of terms. They identified 19 different terms or phrases to describe organisational health literacy: environmental health literacy, health literacy environment, health literacy friendly, health literacy practice/s, health literacy responsiveness, health literacy system-level infrastructure, health literacy universal precaution, health-literate healthcare organisations, health-literate health service, health-literate organisation, health system health literacy, health-literate workplace, improving health literacy in services, organisational capacity to address health literacy, organisational health literacy, organisational health literacy responsiveness, provider health literacy, workforce health literacy, and workplace health literacy. This list does not yet take into account some further terms used in the literature, such as 'health-literate settings', 'health literacy-friendly settings', 'health literacy-friendly organisations' (Kickbusch et al, 2013), 'health-literate society' (Paasche-Orlow et al, 2006) or 'health-literate America' (Nielsen-Bohlman et al, 2004).

For further analysing the differences in terminology of organisational health literacy the linguistic aspects and differences in use of language in different communities have to be taken into account. Underlying the concept of organisational health literacy is the difference of people vs situations or personal vs situational, as proposed by Kurt Lewin (1982). For organisational health literacy for the 'situation', as the object referred to, different kinds of specifications are offered – either more abstract nouns like 'environment', 'organisation', 'workplace', 'setting', 'service', 'system', 'society', or also a process like 'practice'. Also, further specified composites by prefixing additional terms have been used, like 'healthcare' or 'health', for example, most prominent 'healthcare organisation', or other functional or institutional concepts like 'education', or also quite concrete ones like 'America'. Instead of 'situational', other adjectives like 'environmental' or 'organisational' were also used. But these kinds of differences in terminology are not a problem. Partly they reflect an affiliation to different scientific or practice discourses, for example, 'health-literate settings', to the health promotion discourse. By choosing a specific term, an author just indicates to which objects other than people they want to relate health literacy. And usually these terms denote clearly enough which kinds of objects are focused on (just a specific healthcare organisation or the all-embracing health system or the whole of society).

More critical is the use of the terms 'health literacy' or further developed 'health literacy responsiveness' as nouns or as adjectives 'health-literate' or further developed 'health literacy-friendly' or 'health literacy-responsive' or 'health-literate healthcare organisation' to denounce the way a non-personal object puts demands on or deals with the (personal) health literacy of the people it affects. What is meant by the 'health literacy' or 'health-literate' component is much more open to interpretation, since health literacy is an evolving concept (Nutbeam, 2008) with limited consensus on its meaning. Therefore, an author has to make explicit what they mean by organisational 'health literacy'. For example, in the context of healthcare, is it only about the health literacy of patients or also of staff and of citizens in the community served by an organisation? Or is it just taking differences in the given health literacy of patients adequately into account, or does it also intend to improve their personal health literacy to empower them to effectively self-manage chronic conditions? Or is it just about making information and communication more understandable or also more accessible, appraisable and usable? Or is it just limited to clinical interaction, or does it concern all aspects of a healthcare organisation? These possible conceptual meanings of 'health literacy' in organisational health literacy must be explicitly stated by an author, to indicate what they intend by the term.

But the different terms used in the organisational health literacy discourse must not automatically indicate a different understanding of the content or scope of organisational health literacy; often they just relate to different reform discourses or try to be linguistically more correct or specific. Meggetto et al (2017), in relation to the three most commonly used terms – 'health system health literacy', 'organisational health literacy' and 'health literacy practice' – also came to the conclusion, 'it is evident that the three dominant terms … are not mutually exclusive but rather interrelated' (Meggetto et al, 2017, p G).

Concerning explicit definitions proposed for organisational health literacy or HLHCO, just three are presented here. First, an early one for 'health literacy environment': 'The health literacy environment of a healthcare facility represents the demand side of the equation suggested by the IOM (2004) – the expectations, preferences, and skills of those providing health information and services' (Rudd and Anderson, 2006, p i). Second, the probably most quoted definition for 'health-literate healthcare organisations' is: 'Health care organizations that make it easier for people to navigate, understand, and use information and services to take care of their health' (Brach et al, 2012, p 1). Third, a rather cumbersome but more extensive and up-to-date definition that tries to explicitly integrate the content of the Brach et al (2012) definition with the comprehensive definition of health literacy of the HLS-EU Consortium (Sørensen et al, 2012, p 3) is:

> A health literate healthcare organization makes it easier for all stakeholders (patients/relatives, staff/leadership and citizens) to access, understand, appraise and use/apply disease- and health relevant information and tries to improve personal health literacy for making judgements and taking decisions in everyday life concerning healthcare (co-production), disease prevention and health promotion to maintain or improve quality of life during the life course. To achieve this comprehensive concept systematically and sustainably, a healthcare organisation will have to apply principles and tools of quality management, change management and health promotion and to build specific organizational capacities (infrastructures and resources) for becoming more health literate. (Pelikan and Dietscher, 2015b, slide 16)

Concepts, models and frameworks of organisational health literacy

An up-to-date overview article (Farmanova et al, 2018, based on Farmanova, 2017) on the theories, frameworks, guides and implementation issues of organisational health literacy identified 15 conceptual papers that focus either on the 'what', that is, creating a vision, and/or on the 'how', that is, proposing operational frameworks to support action. These conceptual papers have also been presented in a complex conceptual and chronological map of organisational health literacy. For the 'what', seven theories have been identified (Paasche-Orlow et al, 2006; Andrulis and Brach, 2007; Coughlan et al, 2013; Kickbusch et al, 2013; Frosch and Elwyn, 2014; Pelikan and Dietscher, 2015b; Trezona et al, 2017) and discussed in some detail. Of the seven, two recent frameworks (Pelikan and Dietscher, 2015a; Trezona et al, 2017) and also one by Kickbusch et al (2013) have been highlighted as visioning organisational health literacy as a more complex phenomenon. The Vienna concept of health-literate hospitals and healthcare organisations (V-HLO) (Pelikan and Dietscher, 2015a) 'present a broader understanding of health literacy as coproduction of health, quality, and safety; health promotion; and "healthy settings".' Similar to Kickbusch et al (2013), the authors of V-HLO also call for the wider application of health literacy beyond health care' (Farmanova et al, 2018, p 4). In contrast, 'Trezona and colleagues (2017), in their empirically developed Organisational Health Literacy Responsiveness (Org-HLR) framework, "conceptualize health literacy as an issue of healthcare responsiveness"' (Farmanova et al, 2018, p 4). But 'both V-HLO and Org-HLR focus on developing organizational capacities, structures, and processes to support action on health literacy' (Farmanova et al, 2018, p 4).

For the 'how' of organisational health literacy, nine operational frameworks were identified (Andrulis and Brach, 2007; Schillinger and Keller, 2011; Brach et al, 2012; Hernandez, 2012; Parker and Hernandez, 2012; Koh et al, 2013; Rudd et al, 2013; ACSQHC, 2014; Frosch and Elwyn, 2014; Palumbo and Annarumma, 2014; Dietscher and Pelikan, 2017; Trezona et al, 2017) and integrated into the conceptual map of organisational health literacy. For these, the underlying disciplines used for operationalisation, such as 'organisational behaviour, healthcare management, implementation science, and quality improvement' (Farmanova et al, 2018, p 4), or frameworks they relate to, such as the Balanced Scorecard, the Chronic Care Model or the Health-Literate Care Model (Koh et al, 2013), were described. Due to limitations of space, only two frameworks are highlighted in somewhat more detail here – the Institute of Medicine's *Ten attributes* and the V-HLO.

Institute of Medicine's model of a health-literate healthcare organisation

The discussion paper, *Ten attributes of health literate health care organizations* (Brach et al, 2012, p 19), published by the Institute of Medicine of the National Academies, proposes a list of attributes 'that health literate health care organizations can adopt and invest in to help everyone benefit fully from the nation's health care system' (see Box 35.1).

Box 35.1: Ten attributes of health-literate healthcare organisations

A health-literate healthcare organisation:

1. Has leadership that makes health literacy integral to its mission, structure and operations
2. Integrates health literacy into planning, evaluation measures, patient safety and quality improvement
3. Prepares the workforce to be health-literate and monitors progress
4. Includes populations served in the design, implementation and evaluation of health information and services
5. Meets the needs of populations with a range of health literacy skills while avoiding stigmatisation
6. Uses health literacy strategies in interpersonal communications and confirms understanding at all points of contact
7. Provides easy access to health information and services and navigation assistance
8. Designs and distributes print, audiovisual and social media content that is easy to understand and act on
9. Addresses health literacy in high-risk situations, including care transitions and communications about medicines
10. Communicates clearly what health plans cover and what individuals will have to pay for services

Source: Brach et al (2012)

For each of these attributes a description and rationale are given and a list of more detailed characteristics – including already available assessment or intervention tools – is provided.

A closer look at the ten attributes reveals that these relate to different underlying dimensions. Only attributes 5-8 define the specific health literacy content of a healthcare organisation, that is, the accessibility and design of all its channels and materials for information and communication. Attributes 1-3 define general organisational preconditions that are necessary for systematically integrating a quality aspect or quality criterion into the totality of an organisation. These aspects therefore have to be observed in change management and organisational development generally. Attribute 4 relates to the value of participation, which is a core principle in person-oriented healthcare, in quality management and in health promotion. Attributes 9 and 10 highlight specific aspects of healthcare where adequate information and communication is specifically important or relevant in the US healthcare system.

In its conclusion, the discussion paper (Brach et al, 2012, p 19) wisely summarises:

> The concept of "health literate health care organizations" will profit from further discussion and refinement. The many examples in this paper, however, demonstrate that health care organizations can immediately take concrete, practical actions to close the gap between individuals' health literacy skills and the demands of complex health care systems. The transformation to a more person-centered health care system provides opportunities to redesign health information and services, integrating principles of health literacy into organizational objectives, infrastructure, policies and practices, workforce development, and communication strategies. If health care organizations adopt most of the 10 attributes in even a modest way, they will not only be more responsive to individuals' needs, and especially those with limited health literacy, they will also make a substantial contribution to improved population health.

The discussion paper (Brach et al, 2012) started a new phase in the organisational health literacy discourse.

Vienna concept of health-literate hospitals and healthcare organisations (V-HLO)

In the US the *Ten attributes* were taken up in different ways by practitioners and researchers (Brach, 2017). In Europe a team in Vienna/Austria (Pelikan and Dietscher, 2015a; Dietscher and Pelikan, 2017) started to develop a more comprehensive framework for a HLHCO with a focus on hospitals (V-HLO). In comparison to the *Ten attributes*, the V-HLO explicitly relates to the health promotion settings approach by using a simplified model of the 18 health-promoting hospitals strategies (Pelikan et al, 2005). Instead of a list, a matrix model was used to define the content of organisational health literacy in V-HLO. The scope of included stakeholders was also extended from patients and their families to the staff and citizens in the catchment area of the hospital. The scope of content was widened from taking the given health literacy of patients adequately into account for better healthcare to also improve the personal health literacy of all stakeholders for disease management and prevention, and for lifestyle development. The V-HLO also uses the comprehensive definition of health literacy of the HLS-EU Consortium (Sørensen et al, 2012), by which health literacy is about finding, understanding, appraising and applying health-relevant information for judgement and decisions in everyday life concerning healthcare, disease prevention and health promotion.

But in V-HLO health literacy is not only understood as a core concept of health promotion, but like health promotion, also as a core aspect of quality in healthcare. Therefore, to make the implementation of health literacy in healthcare more acceptable and compatible for management and health professionals, and to support systematic implementation, the quality methodology of the International Society for Quality in Healthcare (ISQua) was applied to develop and define nine standards, with 22 sub-standards and 160 indicators for self-assessment of organisational health literacy, as a first step for improving it. This tool was piloted and validated in nine Austrian hospitals (Dietscher and Pelikan, 2017). In the meantime, the tool was translated into English, French, Italian and Mandarin and an international Working Group within the Network of Health Promoting Hospitals and Health Services (HPH) is further improving and validating it for use in different languages and healthcare systems (see Box 35.2).

Box 35.2: The nine standards of a health-literate organisation

The nine standards of a health-literate organisation are to:

1. Provide (organisational) capacities, infrastructures and resources for health literacy in the organisation
2. Develop and evaluate materials and services in participation with users
3. Qualify staff for HL communication
4. Develop a supportive environment – provide navigation assistance
5. Apply HL communication principles in all routine communications – in spoken, written, audio-visual and digital communication and by providing interpreting and translation support
6. Improve personal HL of patients and significant others by learning offers
7. Improve personal HL of staff by learning offers
8. Improve HL in the organisation’s community and catchment area
9. Share experiences and be a role model for HL in the healthcare community

Sources: Pelikan and Dietscher (2015b); Dietscher and Pelikan (2017)

Guides and toolkits for assessing and improving organisational health literacy

In their overview, Farmanova et al (2018) identified 20 health literacy guides and described these in a table, ordering the guides chronologically and giving information relating to the country, the objective, the healthcare sector, the focus, health literacy elements included and scoring possibilities of the guides. Furthermore, the guides were evaluated based on six health literacy dimensions (access and navigation, communication, consumer involvement, workforce, leadership and management, and meeting the needs of the population) and on eight quality improvement characteristics (form team, set aims, assess, establish measures, communicate and raise awareness, develop action plan, test changes, and track progress/sustain efforts). Summing up, Farmanova et al (2018, p 6) found:

> Guides vary in their scope (single- to multiple-issue) and context to which they apply. The majority of guides were developed for healthcare organizations in general; 6 are specialized for primary care practices, hospitals, and pharmacies, and one is designed to support health-literate nursing practices…. Most guides combine an assessment of health literacy barriers and an action plan for improving OHL.

In summary it can be said that a great variety of tools already exist to support the implementation of organisational health literacy for different kinds of health services, but for practitioners it might be beneficial to further map, integrate and standardise these tools.

Empirical research on implementing organisational health literacy concepts and guides

Farmanova et al (2018, p 12) summarise their findings: 'Thirteen reports published in 2008–2017 described the use of health literacy guides (Barrett et al, 2008; Groene and Rudd, 2011; Weaver et al, 2012; Callahan et al, 2013; Shoemaker et al, 2013; R.O. White et al, 2013; Zanchetta et al, 2013; Batterham et al, 2014; A. Johnson, 2014; Palumbo and Annarumma, 2014; Briglia et al, 2015; Adsul et al, 2017; Brach, 2017). The majority of these reports described the use of assessments of health literacy barriers (Groene and Rudd, 2011; Weaver et al, 2012; A. Johnson, 2014); few reports detailed implementation of organisational health literacy (Callahan et al, 2013; Briglia et al, 2015; Brach, 2017). Although these studies do not allow us to comprehensively assess evidence of the effects of organisational health literacy and the application of the guides, they demonstrate that the guides can facilitate action to remedy health literacy barriers (Groene and Rudd, 2011; Weaver et al, 2012; Brach, 2017; Dietscher and Pelikan, 2017), to adopt specific health-literate practices (Callahan et al, 2013; Briglia et al, 2015; Brach, 2017), and to understand the complexity of organisational health literacy and the factors influencing health-literate practices (Weaver et al, 2012; Batterham et al, 2014; Brach, 2017). Organisations commonly modified existing guides to local context (Callahan et al, 2013; Brach, 2017), and used two or more health literacy guides (Weaver et al, 2012, Briglia et al, 2015) at the same time. A health literacy universal precautions toolkit (DeWalt et al, 2010; Brega et al, 2015; Cifuentes et al, 2015) was favoured in chronic disease management (Callahan et al, 2013), health promotion and disease prevention interventions (M. White et al, 2013), and to inspire the adoption of system-wide policies and procedures across healthcare organisations (Brach, 2017). The use of assessment tools provided with the guides was regarded as a useful and feasible exercise to provide direction for improvement (Groene and Rudd, 2011; Weaver et al, 2012; M. Johnson, 2014); it required few organisational resources, and caused little to no interference with patient care (Groene and Rudd, 2011). A particular guide, however, was perceived as complex and with limited value (Shoemaker et al, 2013). The use of health literacy guides could be enhanced if the guides had a clear relative advantage, were simple and adaptable, and if support with implementation was provided or barriers to organisational health literacy removed (Shoemaker et al, 2013)'. This appraisal is mostly supported by another systematic review (Lloyd et al, 2018).

From the reviewed studies Farmanova et al (2018) have extracted a list of 13 common key barriers (or facilitators) for implementing organisational health literacy. These include, specifically related to organisational health literacy, the *lack* of awareness of, of seeing the advantages of, of commitment to, of priority of, of support from leadership for, of training for, of resources for, of time for, of procedures, policies and protocols for, of change champions for, of a culture of change and innovation for, of not too complex tools and guides for organisational health literacy. Critical for successful implementation is the presence of advocates for change, support from leadership and of a supporting management structure and culture for innovation and quality improvement. But these identified barriers and facilitators are not specific for implementing organisational health literacy; they hold true for all change management in healthcare facilities and far beyond. Therefore, it makes sense to integrate HLO into quality management in healthcare. More implementation research is definitely needed, but this research should focus on the specifics of organisational health literacy, and not just on the common challenges and problems of changing healthcare organisations.

Furthermore, as argued by Brach (2017) for the US, Lloyd et al (2018) for Australia and Pelikan and Dietscher (2015a) for Austria, for successful implementation at the organisational meso level it is important to have adequate support by health policy at the societal macro level. One way to do this is to include organisational health literacy standards or indicators in health service accreditation systems (Meggetto et al, 2017).

Summary and conclusion

Low health literacy is more widespread in patient and general populations than expected by health professionals, but it has detrimental impacts on the use and outcomes of healthcare for patients. Since there is a social gradient for health literacy, as a determinant of health it also contributes to creating the health gap. Therefore, taking the low health literacy of patients better into account in healthcare by decreasing the demands of health services and improving health literacy by offering patient and health education can enhance the quality of healthcare and the health of people, and also contribute to lowering the health gap.

To realise this, a number of single interventions and measures are available that can be implemented by healthcare facilities. But for more comprehensive and sustainable results, an integrated, complex, whole systems approach is recommended. The concept of HLHCO, available in different, but overlapping, versions, provides such a model. A number of different tools are available to systematically assess organisational health literacy in healthcare as a necessary precondition for starting organisational development, learning or change processes towards a more health-literate organisation. But, as the limited and already existing research literature confirms, implementing a complex concept into the existing structures, processes and culture of an organisation is quite a demanding challenge. Therefore, more and better research on furthering and hindering factors for implementing the specific concept of HLHCO or organisational health literacy is needed.

The experience in the US and in some other countries like Australia, Austria, Canada and Germany shows that widespread and effective implementation at the meso level of healthcare organisations needs supportive regulations, incentives and resources from the societal macro level of health policy. Health policy should include organisational health literacy in national health targets or action plans and integrate organisational health literacy standards or indicators into healthcare accreditation systems. To better enable take-up by politicians and practitioners and comparability of research, more consensus on the terminology, concepts and definitions, models and measurement would be welcome, while allowing some lee-way for variety and internal differentiation of the concept and its tools. The newly founded Action Network on Measuring of Population and Organizational Health Literacy (M-POHL) under the umbrella of the European Health Information Initiative (EHII) of WHO-Europe will contribute to achieve this (https://m-pohl.net/).

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Future avenues for health literacy: Learning from literacy and literacy learning

Paulo Pinheiro

Introduction

A definition of health literacy that has become widely used suggests that 'health literacy is linked to literacy' (Sørensen et al, 2012, p 3). The screening of literature, however, reveals that this link to literacy remains vaguely described in many of the attempts to define health literacy. Explicit references to literacy or a broader discussion and integration of core perspectives addressed in literacy research can be found only to a limited extent in the health literacy debate. Expecting new insights from the examination of literacy perspectives for the further understanding and development of health literacy approaches, it thus seems promising to grasp the current discussions about the topic of literacy, and to contrast core perspectives of literacy with the ongoing discussions about health literacy. This is what the current contribution aims at. This chapter first provides an outline of current conceptualisations in health literacy and highlights similarities of the most commonly used health literacy definitions. This is then followed by an overview of perspectives that currently shape the discussions about literacy. Finally, core perspectives in literacy are contrasted with main approaches to health literacy, and implications for further research on health literacy discussed.

Current conceptualisations of health literacy

Malloy-Weir et al (2016) performed a systematic review of definitions of health literacy published between 2007 and 2013 in journals indexed in MEDLINE. Of the 250 different definitions of health literacy, they identified six as most commonly used definitions; 133 definitions were modified versions of these six definitions, and another 111 were classified as 'other' because they differed in wording. The analysis of similarities and differences across definitions showed that 'each of the most commonly used definitions treated a person's abilities (or skills) as central to the concept of health literacy' (Malloy-Weir et al, 2016, p 338). Differences across definitions were reported to be in terms of the 'number and types of abilities (or skills) and/or actions believed to comprise health literacy;

the context and/or time frames in which the various abilities and/or actions are believed to be important; and thus, what each implies a health literate person is' (Malloy-Weir et al, 2016, p 338). The term 'knowledge' appeared – with different types of knowledge mentioned – in some of the definitions of which the wording was not related to the six most commonly used definitions. A critical analysis of the most commonly used definitions of health literacy showed that these definitions are open to multiple interpretations and incorporate basic assumptions that are not always justifiable.

Malloy-Weir et al (2016) articulate several concerns about the scope for interpretation allowed by the definitions of health literacy due to the wording and/or underlying assumptions. They highlight that the most common definitions implicitly include the assumption that information or health information can be used to promote or maintain health, or to reduce health risks and increase quality of life. They exemplify their concerns with people whose health is negatively impacted by structural features of society. They further point out that some definitions incorporate the assumption that there are relationships between (1) the health literacy or the capacity to deal with health information and (2) the making of appropriate or sound health decisions in the context of everyday life. They question this assumption by arguing that health-related decision-making is influenced by a much broader set of factors, such as personal values and beliefs, or life context. In addition, they argue that the terms *sound* and *appropriate* when used to describe decision-making are open to assessments by use of different criteria. Some definitions, for example, do not rule out the possibility that assessments of health literacy could be based on normative judgements about the appropriateness of people's choices. Finally, the critical analysis showed that the wording used in the most common definitions does not preclude the interpretation that the burden of responsibility of achieving health literacy falls on the individual. The authors highlight that this can turn out to be a pitfall because such wording 'leaves scope for the neglect of non-modifiable individual-level factors…, structural features of society … as well as features of health care provisions' (Malloy-Weir et al, 2016, p 342). They further argue that although the importance of social considerations beyond individuals is recognised in the contemporary discourse on health literacy, this has not been reflected by definitions that seem to promote more individualistic ideas and obfuscate barriers that individuals may face.

Another systematic review of the international literature was performed by the European Health Literacy Survey (HLS-EU) with the objectives (1) to identify core characteristics of definitions and concepts of health literacy and, building on that, (2) to develop an integrated definition as well as a conceptual model of health literacy (Sørensen et al, 2012). This review revealed 17 definitions and 12 conceptual frameworks of health literacy. A content analysis of the definitions allowed a grouping of the terms and notions used in the definitions into six clusters: (1) competence, skills, abilities; (2) actions; (3) information and resources; (4) objective; (5) context; and (6) time. These results were used to subsequently develop a new and integrated definition of health literacy that has since then become a key reference in the field of health literacy. According to the HLS-EU definition, health literacy 'is linked to literacy and entails people's knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course' (Sørensen et al, 2012, p 3).

The analysis of the 12 conceptual models showed various shortcomings such as the lack of theoretical foundation, empirical validation or pathways outlining causes and effects of health literacy. Based on the findings from the content analysis of the conceptual models, Malloy-Weir et al propose an integrated model of health literacy. They highlight that the integrated model combines the main dimensions of health literacy with proximal and distal factors impacting on health literacy as well as with the pathways linking health literacy to health outcomes. The main dimensions of health literacy are represented and visualised as a matrix that combines knowledge, motivation and competencies related to four tasks in the processing of health information (namely, access, understand, appraise, and apply health-related information) with the three domains of healthcare, disease prevention and health promotion. They conclude that the integrated model can be used as a conceptual basis for the development and validation of measurement tools as well as for the development of health literacy-promoting interventions. For more information on the HLS-EU model, see Chapters 1 and 8, this volume.

The overview of current conceptualisations of health literacy based on two comprehensive systematic reviews of literature allows for the identification of some common features in the current understanding about health literacy. First, health literacy addresses how people deal with health-related information. The definitions offer a broad range of actions and usually link those actions with purposes or goals such as the management of diseases or the improvement of wellbeing. Second, there is a strong emphasis on the acquisition and performance of skills and knowledge. An individualistic approach is prioritised and reflected by a focus on mental processes. Third, the impact of social or environmental determinants on the activities is acknowledged but remains obscured or unmentioned in many of the influential definitions.

A tailored view on the target groups of children and adolescents seems to be a promising undertaking to gain further insights about health literacy constructions. Children and adolescents can be distinguished from adults by several characteristics (see, for example, Rothman et al, 2009). They differ, for instance, in their development potentials, have different disease, risk and disability profiles, as well as a higher vulnerability to unfavourable sociodemographic factors. Further, their dependency on adults for social and healthcare is significant and highlights a particular relevance of questions that address intergenerational and power relationships that are per se unequally distributed between children and adults. It is thus to be expected that social contexts, interactions and agency are more pronounced in perspectives on health literacy when children are targeted.

Current conceptualisations of health literacy in childhood and adolescence

This section basically refers to findings from two systematic reviews of literature recently conducted at our institution to identify common trends within current constructions of health literacy in childhood and adolescents. One literature review focused on definitions, concepts and models (Bröder et al, 2017), whereas the other addressed measurement methods of health literacy (Okan et al, 2018). The findings of our analyses revealed the following common features of current social constructions of health literacy within childhood and adolescence.

There is a strong focus on personal attributes such as knowledge and skills, and on individual rather than on social conditions that are required to respond to societal or situational demands. These demands – briefly summarised – concern the gathering, understanding, appraisal and use of health information in terms of minimum standards within children's health. The conceptualisation of health literacy in childhood based on the surveyed literature is thus fairly similar to the majority of definitions and conceptualisations for adults as outlined before. Social and cultural conditions or environments are widely acknowledged to be relevant. Related discussions, however, were less pronounced than the elaborations on the individual prerequisites. The issue of the social or cultural context is usually addressed when internal abilities of children and adolescents are contrasted with external demands and minimum information-handling requirements to benefit health. Health literacy is understood as a relational concept in which the social or cultural context defines the demands on a child or an adolescent to handle information for the purpose of health. The systematic reviews, in addition, indicate that childhood and adolescence are distinguished from adulthood, usually through reference to developmental issues and tasks (see, for example, Borzekowski, 2009). Most of the articles draw on concepts from developmental psychology rather than on sociological approaches. As a result, this prioritisation might have also contributed to the promotion of individualistic ideas of health literacy. Finally, the review of the measurements of health literacy in childhood and adolescence showed that the assessments of health literacy in children and adolescents usually rate personal attributes and involve distinctions between high and low or adequate and inadequate levels of health literacy. The dominance of rating systems of health literacy in childhood and adolescence reflects the normative notion of the underlying current conceptualisations of health literacy that results in the identification of populations at risk. Such assessment procedures, however, disregard a perspective that addresses multiple health literacy practices to which quantified ratings cannot be applied.

Overall, our systematic reviews of literature also revealed that current conceptualisations of health literacy in childhood and adolescents have mainly evolved in the fields of health research, notably within healthcare and public health, and thus within disciplines in which there has traditionally been an emphasis on individualistic ideas. Given the significant bias in current constructions of health literacy towards perspectives originating from health research, it is therefore obvious to assume that there has been a neglect of other important points of reference originating, for example, from childhood or literacy research that might provide opportunities to rethink and, where reasonable and appropriate, reframe and further develop the existing conceptualisations of health literacy.

Theoretical perspectives of literacy and literacy learning

There are contrasting views of the nature of literacy that can be closely linked to the purposes of literacy that are, according to Hamilton (2010, p 8):

- a set of functional skills, helping people to meet the demands made by the society on them, especially in terms of employment;
- a civilizing tool, allowing people to access a literary culture that is part of their cultural heritage;
- a means of emancipation, enabling people to control their lives, challenge injustice and become autonomous, participating citizens in a democracy.

Historical overviews of the research on literacy highlight that the subject has been underpinned by a broad range of theoretical perspectives that have evolved over time, shaped the understanding, use and assessment of literacy, and informed priority setting in education policy-making. Kennedy et al (2012) provide a comprehensive presentation of the various theoretical approaches to literacy development since the 1950s. Their overview of theoretical perspectives on literacy include cognitive, psycholinguistic, cognitive apprenticeship, metacognitive, sociocultural, constructivist/social constructivist, sociolinguistic, critical theories, multimodal and digital approaches. Kennedy et al (2012), as well as Gaffney and Anderson (2000), provide some guidance to capture the many perspectives when they highlight that the historical trends in literacy research have had three major paradigm shifts, moving from behaviourist to cognitive to sociocultural perspectives.

The contemporary discourse on literacy is shaped by cognitive and sociocultural perspectives. While cognitive approaches view literacy development as a succession of different reading and writing skills, sociocultural approaches view literacy as socially and culturally embedded. Both approaches have largely been considered incommensurable given their underpinnings and differences. Street (1984) referred to the cognitive perspectives as *autonomous* because they imply that literacy consists of decontextualised skills that are learned independently from social or cultural influences. Street's theoretical and empirical work is inextricably linked to what has come to be known as New Literacy Studies (NLS), in which the focus on literacy is not on a set of autonomous skills, but on a social practice that is embedded in social, political, economic and cultural power relations. Street called this alternative view *ideological* to highlight the context-dependent and power-laden nature of literacy. To structure the overview of the major perspectives on literacy, we use Street's distinction between autonomous and ideological perspectives on literacy. The autonomous views of literacy are first summarised and followed by an overview of ideological views of literacy exemplified by sociocultural and sociolinguistic literacy perspectives.

Autonomous views of literacy

Autonomous views of literacy are associated with cognitive and psycholinguistic perspectives of literacy, both of which have been influential in literacy programmes and policies. Cognitive approaches to literacy and literacy development are rooted in the premise that the acquisition of reading and writing skills follows predefined developmental patterns and distinct milestones for generally everyone. The Oxford Dictionary defines cognition as 'the mental action or process of acquiring knowledge and understanding through thought, experience, and the senses.' Cognition encompasses a range of processes such as knowledge, reasoning, problem-solving and decision-making, and includes mental processes that affect the acquisition, formation or use of language. The differentiation of cognitive from behaviourist perspectives is grounded in the understanding that human behaviour is more than just a stimulus–response pattern. From a cognitive perspective, acting is determined by mental processes rather than exclusively by external conditions or stimuli. Development is seen as an active process of a subject who is equipped with cognitive functions such as recognition and awareness. Knowledge is, for example, built through the active engagement of a subject with the environment, and human responses to an external stimulus are poorly controlled or driven by the external impulse. Other key characteristics of cognitive perspectives are accommodation (which refers to processes in which an individual adapts the internal with the external world) and assimilation (the individual who adapts the external world is incorporated into the internal word), both of which are complementary processes of adaptation through which awareness of the outside world is internalised. Davidson (2010, p 247) provides a collection of priorities when addressing the development of reading and writing from a cognitive perspective:

> Cognitive researchers are interested in normative behavior, for example, the learning-to-read process, and their emphases are on operations that take place in the head.... Cognitivists believe that literacy is largely taught and learned.... Cognitive theorists, in addition, believe that stages of reading or writing development are necessary to guide teaching; the stages illuminate the competence that is optimal for specific purposes, and they identify and explain the inadequacies exhibited by certain groups.

Cognitive perspectives of literacy are concerned with mental processes that take place while words, structures and grammar of a text are recognised, information or meaning are retrieved from text, processed during the reading process and stored in the memory for future retrieval (Lyytinen, 1985). A cognitive theory of reading development can be exemplified by the work of Chall (1983), who postulated that all individuals progress through stages of reading acquisition in characteristic ways, in certain age limits and following the same sequence. Based on this, Chall developed stages of reading and recommended norm-referenced tests to diagnose a reading problem.

Another autonomous perspective of literacy is that of psycholinguistics that focuses on how written words and symbols are decoded, and how meaning is assigned to words and sentences for the purpose of language production in oral communication processes (see, for example, Goodman, 1967; Perfetti et al, 2001). Psycholinguistic perspectives see reading as a constructive process by which the reader uses their previous knowledge of language to predict words and retrieve meaning (Kennedy et al, 2012). Psycholinguistic and cognitive perspectives have demonstrated that there is a strong relationship between phonological awareness and literacy development (see, for example, Ehri et al, 2001). Phonological awareness refers to the awareness that language is composed of sounds and the ability of a person to detect sounds in speech and to associate sounds with words and letters. It is considered as critical for learning to read any alphabetic writing system and a strong predictor for reading proficiency. These findings have translated into now well-established recommendations and current policies that promote shared reading opportunities between children of pre-school age and their parents or other literate adults.

As outlined above, autonomous views of literacy value and emphasise the identification of specific reading and writing skills to target and measure. Critical literacy theory positions have questioned such views, and argue that a focus on cognitive processes implies that individuals outside prescribed stages or standard norms are deficient in their literacy skills (Davidson, 2010). Davidson (2010) refers to Tracey and Morrow (2006) who raise the question as to whether adherence to autonomous views systematically disadvantages children from non-mainstream backgrounds who have poor access to education in the home and, therefore, out-of-school literacy practices that conflict with predefined reading and writing stages of development. Others have raised concerns that the autonomous views of literacy are limited in understanding how individuals learn to read and write because they fall short in considering the impact of social and cultural environments on the individual's literacy development (see, for example, Street, 1984).

Ideological views of literacy

Ideological views of literacy are rooted in the premise that sees literacy as a social practice and always embedded in social, historical, cultural and political contexts of use (Kennedy et al, 2012). Accordingly, literacy is constructed in the specific social practices of participants and in particular contexts for particular purposes that give reading and writing meaning (Street, 2005). Kennedy et al

(2012) suggest thinking about autonomous and ideological definitions as being points on a continuum of definitions rather than being two opposing views. Ideological views of literacy emphasise the social nature of literacy learning. They refer to cognitive apprenticeship models coined by the work of Vygotsky (1978) that have demonstrated the impact of the interaction between a learner and an expert on learning.

Proponents of sociocultural and sociolinguistic perspectives argue based on the premise that literacy is always interrelated and interdependent with the context in which it is performed. Within sociocultural and sociolinguistic literacy perspectives, the focus shifts away from technical skills and their acquisition to the underlying contextual and cultural processes, individual capabilities and dispositions as well as to the impact of collective (social) structures on the multiple ways literacy is practiced (see, for example, Street, 2003; Papen, 2005). Reading and writing are hence regarded as social processes and cultural constructions (Pearson and Stephens, 1994). Sociolinguistic theories of literacy are closely associated with sociocultural theories. While both share a social perspective that is concerned with the use of literacy in interactions between people, sociolinguistic approaches emphasise linguistic aspects that focus on how language is used to establish a social context, and vice versa, how the social context influences language use and the communication of meaning (Kennedy et al, 2010). Perry (2012) summarises that sociocultural perspectives relate to sociolinguistic conceptualisations as they address the ways in which language instantiates culture, the ways in which language use varies according to contexts, the relationship between language use and power, and the ethnography of communication. Perry (2012) also highlights that it is more appropriate to speak of sociocultural perspective as a collection of theories, and suggests a selection of some major theoretical perspectives to oversee the sociocultural paradigm. These include literacy as a social practice, multiliteracies and critical theories of literacy.

Literacy as a (situated) social practice, multiliteracies and critical literacy

Scholars endorsing literacy as a social practice emphasise that literacy is 'what people do with reading, writing, and texts in real world contexts and why they do it' (Perry, 2012, p 54), and that 'in the simplest sense literacy practices are what people do with literacy' (Barton and Hamilton, 2000, p 7). According to this line of thought, practices involve more than actions with texts. They connect to, and are shaped by, values, attitudes, feelings and social relationships. The notion of literacy as a social practice has been coined by work of Brian Street and then been promoted by the NLS. Literacy as a social practice questions the premise favoured by autonomous views that texts have meanings independent of their context of use. As the NLS locate reading and writing in the social and linguistic practices that give them meaning, they claim that literacy is more than acquiring content (Street, 2005), and that texts do not have uses independent of the social meanings and purposes people construct (Barton and Hamilton, 1998).

Hence, such perspectives aim to describe how literacy is practised in everyday life, recognising that this practice is not neutral, but dependent on the context in which it takes place, embedded in social relationships and power relations hidden in the nature of this context (Barton and Hamilton, 2000). Street raises concerns that if literacy is seen as a decontextualised set of skills, as suggested by the autonomous perspectives, it fulfils the purposes of those in power to maintain a position of superiority by marginalising other forms of literate knowledge (Street, 2005). Literacy as a social practice draws on two key ideas that are interdependent: literacy events and literacy practices (see, for example, Barton and Hamilton, 2000).

The idea of a literacy event refers back to the work of Heath (1983) on early literacy experiences of preschool-aged children, and can be defined according to Street (2003, p 78) as 'any occasion in which a piece of writing is integral to the nature of the participants' interactions and their interpretative processes.' According to Barton and Hamilton (2000), who see a literacy event as an observable activity involving print and written text, many of such literacy events are regular, repeated activities or even established routines that are formed by social structures and procedures.

The key idea of literacy practices is broader and refers to people's behaviour and understanding of the uses of reading and/or writing. Literacy practices incorporate not only literacy events but also the ways people understand, feel and talk about those events (Hamilton, 2000). Hamilton (2000) proposes some wider aspects of context that should be addressed when analysing teaching and learning activities from a social practice view:

- what people do with texts rather than focusing simply on the texts themselves;
- how reading and writing are embedded in everyday activities, formed by cultural convention and reflect and support social relationships;
- how literacy is changing;
- the diversity of different languages, scripts, cultural conventions and modalities used in reading and writing;
- the existence of 'funds of knowledge' that reside in communities and individuals.

Hamilton (2000), in addition, proposes a set of building blocks to document and analyse literacy practices and events:

- participants who are involved in an interaction with a written text;
- activities in that interaction;
- formal or informal settings where literacy takes place physically;
- domains, describing the different areas of social life, and its purpose and values;
- resources, referring to intangible ones within the individual (for example, cognitive skills and knowledge) and tangible or material ones (for example, paper, computer, pens).

Perry (2012) highlights the distinction between literacy events and literacy practices when used as framework to approach literacy as a social practice. She argues that literacy events are observable and thus allow for seeing what people do with texts. She continues that, in contrast, literacy practices must be inferred because they connect to unobservable beliefs, values, attitudes and social structures. Perry (2012) also indicates that people working with the framework on literacy as a social practice focus on print and written texts, and argues that this perspective has been challenged by theories relating to multimodality. Proponents of multiliteracies or multimodality argue that communication has always been multimodal as humans make meaning through various modes of language (oral, written, body language as well as symbols). They have pointed to the inappropriateness of conceptualising literacy in the digital age as a single, uniform form with the exclusive focus on print or text. Instead, they recognise sociolinguistic perspectives on language and the multiple communication channels and media that come with new technologies. Meaning is hence not only derived from written information, but meaning-making also occurs in flexible forms and through a variety of communication channels (Cope and Kalantzis, 2000; Kress, 2000).

Critical literacy theories, to complete the ideological views of literacy, have contributed to the understanding of literacy with perspectives focusing on power relationships and aiming at understanding how texts try to influence and change people as members of society. There are several broad perspectives related to critical literacy (Kennedy et al, 2012): a Freireian perspective that draws on the pedagogy of Paulo Freire focuses on the use of literacy to empower the disempowered and views literacy as a process of consciousness. In defining literacy as reading both the word and the world, Freire emphasises understanding literacy as the relationship of learners to the world (Freire and Macedo, 2001). The so-called Australian perspective emphasises the interpretation of language and text as a social construct and the recognition that a text is never neutral but designed to inform, entertain, persuade and manipulate (see, for example, Freebody and Luke, 1990). Other perspectives relate to the writings of Bourdieu on language and on the relations among language use, power and politics (Bourdieu, 1991). They connect the concept of habitus, which is the set of dispositions by which we perceive, think and act in certain ways, to that of cultural capital, and conclude that language should be viewed not only as a means of communication but also as a medium of power through which the social uses of language and literacy reproduce power relationships and social differences. For more information on the significance of Bourdieu's theory in the context of health literacy, see Chapter 37, this volume.

Contrasting current conceptualisations of health literacy with autonomous and ideological views of literacy

Based on the information provided by thoroughly conducted systematic reviews of literature that summarise and analyse the large body of theoretical and empirical literature on health literacy, it is most likely to conclude that the current understanding of health literacy is shaped by a strong notion on skills that is sometimes complemented by concepts of knowledge. Another striking finding from the analysis is that although skills can be identified as a commonality among many approaches to health literacy, there is a wide – and hard to oversee – range of descriptions and specifications of those skills that are considered to be fundamental when using health-related information. There is heterogeneity in the many theoretical approaches to health literacy, but a closer look into the literature suggests that there is heterogeneity in homogeneity because most of the approaches are closely linking health literacy with skill approaches. The emphasis on skills that is reflected by the most commonly used definitions and concepts of health literacy promotes a rather individualistic idea of the concept. It was argued that this view of health literacy is biased, especially when combined with a neglect of social considerations that are well known to effect health and the use of health-related information. The current notion of health literacy, however, focuses on a set of personal characteristics, howsoever defined, that are considered necessary when using health-related information, materials or communications.

A subject-centred perspective and the ability to act are clearly prioritised in the current understanding of health literacy. Considerations on the context are frequently made in the current debates on health literacy, but are shaped by a perspective that postulates that health literacy is a relational concept. The interpretation of health literacy as a relational concept usually establishes and stipulates that the use of health-related information can and should be targeted in order to adequately meet requirements arising from or in different social contexts in which the individual is embedded. The rating of adequacy results from the comparison of the individual action with standards that are defined and established for the management of diseases and risk factors as well as for healthy lifestyles or quality of life. Such an approach is obviously supported and advocated because it matches well with notions of empowerment in which self-control and self-management are emphasised. However, the analysis of the literature also reveals that this is a one-sided consideration of contexts that gives little attention to contextual perspectives that (1) take social structures and backgrounds in which individuals are embedded into account and (2) provide information about the impact of living conditions and structures for the development and performance of health literacy. Such perspectives have been taken up so far sporadically rather than systematically in the discussions and conceptual definitions of health literacy (see, for example, Parikh et al, 1996; Fairbrother et al, 2016; Sentell et al, 2017), and have not yet been included in many of the descriptions of health literacy. Interestingly, this also applies to conceptualisations of health literacy for children and adolescents where extrapolations of adult models that are usually enriched with references to concepts from developmental psychology are more likely to take place than target group-tailored specifications.

The concerns about definitions and conceptualisations of health literacy voiced by Malloy-Weir et al (2016) highlight that the most common definitions include a series of assumptions that can be considered problematic because they are empirically either poorly verified or questionable. Data from other studies might stimulate a reconsideration of the strong individualistic notion of health literacy. Alexander et al (2014), for example, have provided illuminating evidence on the robustness of the reproduction of social conditions and the transmission of the sociocultural legacy from one generation to the next. They tracked in a longitudinal study the lives of a significant number of schoolchildren living in Baltimore as they made their way through school, joined the workforce and started families. The unfolding of the children's life trajectories and the contrasting of urban children with different family backgrounds revealed that the overwhelming majority found themselves with the same socioeconomic status as their parents when they were nearly 30 years old. The study highlighted that there are strong effects of inertia affecting the dynamics and scale of both up- and downward social mobility. Interestingly, social deprivation was even more unlikely than social advancement.

The current understanding of health literacy shows several analogies to the understanding of literacy that dominated the debates and programmes on literacy and literacy education up to the 1990s. The collection of theories called by Street 'autonomous perspectives' relies on skills, similar to the current understanding of health literacy, and is often linked to the premise that individual skills are developed in a context-independent way. The bundle of cognitive and linguistic approaches to literacy is based on such a perspective and has continuously been prone to discussions addressing the learning environments. The vague consideration of contexts has then systematically been taken up in the literacy debate some 30 years ago and promoted by the NLS. The NLS viewed literacy as something people did inside society and argued that literacy was a sociocultural rather than a mental phenomenon and needed to be understood and studied in its full range of contexts. In line with this, the sociocultural approaches to literacy have addressed the impact of social conditions on the development and practice of literacy. The strong orientation towards social contexts and structures is supported by empirical findings and suggests that literacy is understood as a set of social practices rather than a set of skills. It was then suggested that the social practices of literacy could be inferred from so-called literacy events in which written texts or other visualisations of language are involved. According to such approaches, there are always different literacies that are purposeful and always embedded in broader sociocultural goals and practices. Literacy practices are thus always shaped by social structures, institutions and power relationships, and therefore change and are acquired through processes of informal learning and sense-making.

When one agrees that health literacy is linked to literacy, it is obvious to suggest that the current debates about health literacy should take up and systematically explore the sociocultural approaches to literacy. There are certainly analogies between health literacy and literacy when we refer to health literacy as those dimensions of literacy that address health information or messages. A first preliminary step would be to demand clarification on how the very different interpretable concept of health can be combined with literacy.

Health can be related to literacy in different ways. It can specifically address the management or prevention of diseases. In such biomedical or pathogenic approaches, health is about treatment and risk management of diseases in order to restore health or to avoid disease, and health literacy processes instruct how to avoid life-threatening situations and justify rating health literacy practices in terms of ranking systems. Health can also be addressed in a way that is decoupled from any specific disease, through social models of health that address the social determinants of health and the impact of the social environment on individual health and wellbeing. Social models of health overlap with pathogenic health models but also connect to salutogenic approaches that are basically concerned with the origins of health and wellbeing and address factors and processes that support individuals in dealing healthily with stimuli from internal and external environments. Salutogenesis is grounded in comprehensibility, manageability and meaningfulness of internal and external demands (see Antonovsky, 1983), and assumes that any balance between internal and external environments results from an inherently critical appraisal of internal or external stimuli. Social and salutogenic approaches to health therefore support the use of descriptive, non-rating assessments of literacy practices that are probably more appropriate to health promotion issues than the use of rating systems. The salutogenic approach can also be used as an analytical matrix for literacy practices as such (that is, that are not explicitly about health-related information) and their contribution to health and wellbeing. For more information on the salutogenic model and its relationship to health literacy, see Chapter 42, this volume.

If we then contrast health literacy with those perspectives of literacy that take a sociocultural view, it is first of all obvious to question that health literacy is basically the individual processing of health information. The review of current health literacy definitions and models finds, at their core, an emphasis on individual functioning in order to meet prescribed standards that are set for particular situations. Such a focus tends to underline strongly individual skills, abilities and competencies while disregarding the social practices of health literacy that reflect the processes whereby meaning is created from the given health information. Such an approach also does not address questions such as individual needs for health literacy or the effects on health literacy of the sociocultural structures in which a person is embedded.

Following a sociocultural approach would call for shifting the focus from a skill-based view of the use of health information to perspectives focusing on the processes at work when meaning is created within multiple forms of language. Meaning-making in health literacy highlights how people understand and make sense of health-related messages. Shifting the focus of health literacy towards meaning-making processes then has implications for methodological approaches within health literacy research, including alterations in the unit of observation. Following sociocultural perspectives on literacy, health literacy could benefit from a framework that is shaped by literacy events and related social practices. Accordingly, the unit of observation would shift from the personal attributes of a person – which is the current mode in health literacy research – to health literacy events and practices that a person is involved in. This connects to the NLS where the research framework is organised around the notion of literacy events and practices.

A health literacy event can be defined as any occasion in which any form of language (spoken, written or body language) that is used to transmit a health-related message is integral to the nature of the participants' interactions and their interpretative processes. Analysing health literacy in terms of literacy events illuminates literacy practices, here defined as a set of social practices that can be observed in and inferred from a literacy event, and that represent what people actually do when they are exposed to language. Social practices inform us about an individual's set of skills and knowledge and also provide insights into beliefs and dispositions as well as values, attitudes, feelings and social relationships. Disposition, for example, is an individual attribute that in this context is defined as a state of readiness or a tendency to act in a specified way. Dispositions are influenced by the social milieu in which a person is embedded and reflect the impact of social structures on the processes of meaning-making. Analyses of health literacy as framed by literacy events and practices connect to meaning-making and also to questions related to willingness and readiness to act. Using health literacy events and practices as the main analytical framework allows for at least three domains of research as follows:

- Personal attributes (skills, knowledge and understanding, beliefs, dispositions as well as values, attitudes, feelings and social relationships) of the people who act in the health literacy event and who code or encode health information by using multiple forms of language. Such an approach addresses the personal characteristics of both the person who is usually considered to be the receiver and the person who acts as the sender.
- Attributes of the forms of language that are used in an event and attributes of the health-related content of language (for example, multimodality, signs and symbols, content and evidence of health information, purpose).
- Attributes of the context in which the interaction takes place or within which people are embedded (cultural and social attributes of the context, interrelationships and power relationships between the people who act, their social agency).

In summary, we can conclude that the current understanding of health literacy is closely associated with an understanding of literacy that relies on perspectives that have been questioned and subsequently replaced or expanded. In this contribution, only a sketchy and experimental attempt was made to connect health literacy with the sociocultural approaches that are prioritised in the current literacy debate. It clearly shows, however, that such a connection can provide new impetus for the further development of the current understanding of health literacy. The future conceptualisation of health literacy should therefore take into account a more pronounced systematic review and, where appropriate, transfer of the approaches that currently coin the literacy debate.

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37

The social embeddedness of health literacy

Ullrich Bauer

Introduction

Health literacy has received great attention as a risk factor or as an asset for health as well as being a powerful mediator of the social determinants of health (Nutbeam, 2008; Kickbusch et al, 2013). Whereas the aspect of mediating social determinants is quite familiar in the recent health literacy discussion, the question of how health literacy itself is mediated, and especially by social environments, is far less the focus of attention. It is helpful, however, that health literacy has already been described as a 'complex social construct', which refers to a phenomenon that is not directly observable but shaped by the way it is socially practised (Pleasant, 2014).

Social practice can be seen as an indicator of direction for further debates concerning the conditioning of the social factors of health literacy (see Chapters 36 and 39, this volume). Using social embeddedness as a superior concept, this term encompasses social factors in general and the interplay of compositional and contextual factors in particular (groups, social milieus and material environments). Interestingly, the integrated health literacy definition by Sørensen et al (2012, p 3) highlights 'people's knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course', but does not include a wider perspective concerning non-individual factors. Despite the fact that there are heterogeneous health literacy concepts available focusing not only on the knowledge and abilities of the individual but also on the relatedness of health literacy to the individual and communities' socioeconomic and socio-cultural context (Parker and Ratzan, 2010; Kickbusch et al, 2013; Sørensen et al, 2015; see also Chapter 18, this volume), the importance of the discussion on social embeddedness has not yet been fully captured. This previously omitted question is an interesting starting point for the following.

Macro-level conditions, for instance, such as a market liberal or neoliberal order, may have an impact on the increasing discussion on health literacy (Bell and Green, 2016). Since, there is reasonable evidence that health literacy is linked to personal health behaviour, health outcomes and health service use as well as healthcare costs at societal level (Kickbusch et al, 2013, p 47), one may expect that health literacy as a key concept in health promotion is triggered by the interest of cost savings in the health sector. Whether this is so or not, the ideology at macro level is a crucial determining factor that is related to the social embeddedness of health literacy. In this context, the social embedding of health literacy refers to a macro level as well as to micro- and meso-system impacts on the way health literacy is performed.

This way of arguing was already being considered early on by Kickbusch (2001, p 295), but yet to be implemented in the research discussion. This chapter tries to fill this gap. In the subsequent argument, the perspective of social milieus, which directly follows Bourdieu's social theory, is provided as a missing link in the health literacy debate. This theory import is also linked to the updating of a socio-structural orientation in sociology. This further frame of reference refers to different forms of mentalities and lifestyles, without which we have no understanding of social embedding. A discussion about health literacy cannot do without such an extended understanding of social embedding that refers from the very beginning to an involvement of the social sphere. This applies to the entire lifespan, as illustrated below. The first question is whether health literacy has so far taken sufficient account of social embedding factors in order to subsequently introduce a sociologically oriented perspective of inequality, and to outline the perspective of health literacy research oriented towards social embedding.

Health literacy as an evolving concept: growing into the social sphere

From a bird's-eye view, health literacy can be seen as part of a discussion concerning health promotion. The common goal of both health literacy and health promotion is the maintenance and improvement of health. However, it is important to state that health promotion is the larger unit in the sense that health literacy is a means to promote health and is therefore a component of health promotion. Obviously, they share similar frameworks, but are easy to distinguish regarding aim and range: health promotion's goal is to promote, maintain or restore health, whereas health literacy's concern is to access, understand, appraise and apply information to acquire one's own health or that of others. For a perspective of conceptual differentiation this means that we do not replace or occupy the area of health promotion. The point is that we add a puzzle piece – namely, health literacy – to the overriding framework of health promotion. Finally, health literacy is not an old-wine-in-new-bottle-concept, as previously discussed (Tones, 2002), but its aims and means are differentiated from health promotion (Wills, 2009). Later on we may see that old bottles are still able to absorb new wine.

Despite the fact that health literacy might be seen as the smaller concept in comparison to health promotion, the ongoing development of the framework suggests an extension of the discussion. Initially focused on care and patient–provider relationships, the concept is now entering a new stage aiming at different goals that encompass conceptual and theoretical innovations. With regard to an ongoing exceeding of the biomedical and clinical context, this innovative process within the paradigm encompasses first, combining health literacy with the theory of action, which means that health literacy depends on personal agency and environmental factors; and second, understanding the social background plays a crucial role. Emphasising the social embedding and social background of health literacy seems to be evident since health literacy is seen as an ongoing process of capacity building. The latter takes place in a lifelong interaction with the social and material environment, producing substantial abilities, knowledge and skills in individuals:

- Has this reference to the perspective of social embedding been sufficiently reflected in the discussion on health literacy so far?
- Is the health literacy discussion sufficiently referring to the social embeddedness factor?

If we try to approach the issue by asking if a health literacy discussion is referring to the impact of social embeddedness, the answer is, in a real sense, undecided. There are several hints of going beyond the narrow focus of patient–provider relationships, but clearly there is no coherent discussion going on that might be able to feature the whole variety of social science-driven research focusing on social embeddedness. Remarkably, Don Nutbeam (2017) summed up the complexity of health literacy with regard to different environments that require decisions that may be or become health relevant:

> Literacy is not a fixed asset. It is both content and context specific. Although the possession of generic literacy skills in reading, writing and understanding text improves the ability of an individual to access, understand and act on new information, it is no guarantee that a person can consistently apply their skills in situations requiring specific content knowledge, or in unfamiliar settings. In this context, more specialist knowledge and more specific skills may be required. This has led to the recognition of different specialist "literacies", such as financial literacy, science literacy or media literacy. Health literacy can be considered in this context as the possession of the specific literacy skills that are required to make health related decisions in a variety of different environments. (Nutbeam, 2017, p 5)

Mentioning 'different specialist literacies' is pointing out that different environments play a role at least if we talk about the performative aspect of health literacy. But what does it mean if we define health literacy hereafter 'as an observable set of skills that will vary from individual to individual' (Nutbeam et al, 2017, p 2)? Is that a sufficient specification of individual-to-individual differences? It is not, of course. Considering the existing debate on health literacy's contexts ('collective health literacy'; cf Sanders et al, 2009), public health literacy (Freedman et al, 2009) or context variables are considered as antecedents, influencing factors or determinants of individual health literacy (see, for example, Sørensen et al, 2012). Sociological approaches to describe the interaction of the individual with their environment are used within a health literacy socialisation model (Paek et al, 2011), a socio-ecological model of health literacy for adolescents (Wharf-Higgins et al, 2009) and finally, the health literacy sensitivity of the systems is postulated and a new health literacy flow, the health-literate organisation, was first developed for the healthcare system context and then applied to other health literacies (see, for example, Pelikan et al, 2013; see also Chapters 31 and 35, this volume).

In addition, other approaches occur. A focus sensitive to misinterpretation is highlighted by emphasising the fact that health literacy is part of behaviour change paradigms in public health that focus on persuading individuals to change their habits in an effort to reduce disease propensities. This is not unproblematic, because it is an individualistic understanding of the cause of inadequate health literacy. Above all, the focus on the significance of social inequalities seems to be invisibilised as a result. Blue et al (2016) offer a public health perspective on inequalities that suggests that social theories of practice may provide an alternative access to pressing challenges in dealing with health issues. They still try to avoid a too broad social factor perspective and as an alternative, they focus on social practices in everyday lives:

> We highlight the potential and the practical relevance of an alternative social-theoretical tradition: one which views the patterning of daily lives (and their implications for health) as outcomes of the coordination and synchronisation of social practices which persist over time and space, and which are reproduced and transformed by those who "carry" them. (Blue et al, 2016, p 38)

This appears to be an astonishing example for a perspective on social embedding since social practice is not understood as a synonym for individual behaviour, but suggesting that enacting social practices involves 'the active integration of generic "elements", including materials/tools/infrastructures, symbolic meanings and forms of competence and practical know-how' (Blue et al, 2016, p 41). The social practices perspective highlights interactional processes that include a competition and collaboration between practices as well. In Blue et al's words, it is a position against the individual as a 'decision-maker' (2016, p 4). Many approaches do not apply such a social practices perspective (see, for example, Cusack et al, 2017), and consequentially lack complexity in combining the phenomenon (health literacy) with an etiological perspective. Edwards et al (2013) use the term 'distributed literacy' to describe how literacy is dispersed throughout a group, and that 'social support is one of a number of broader factors that influence health literacy, leading to participation in health-care processes and subsequently to altered health outcomes' (Edwards et al, 2013, p 1182; cf Hamilton, 2010; Sentell et al, 2013). A network perspective (here referred to as long-term care) is undoubtedly a feature of a social embedding, and this can be shown particularly well by the example of immigrant populations and their networks (Fernández-Gutiérrez et al, 2018).

In *The solid facts* Kickbusch et al (2013) argue that communities will benefit from the health literacy of their members, and Rowlands et al (2017, p 131) add that 'health literacy shows strong associations with education, poverty, employment, first language other than the national mother tongue and deprivation of the area of residence.' Thus, a mutual dependency can be seen while a perspective on the way social factors do influence health literacy is not developed consistently. Sentell et al (2017) were the first arguing in a PRISMA-guided review concerning the context dependence of health literacy that the object in question is defined by a certain multiperspectivity. The latter encompasses different perspectives on the intersection between health literacy and embedding social contexts. Concerning the most common misinterpretation of health literacy as an individual trait independent of social contexts, they argue that most common are association studies combining health literacy and social context variables. The less common studies focus on social context as the ability to leverage a social network to achieve health-related goals. Finally, the least common studies in this area of research encompass health literacy as an aggregated property at a group or network level as well as in a caregiving dyad.

Social embedding, social inequalities and the individual: more of a social science perspective

The question as whether the health literacy discussion is sufficiently referring to the social embeddedness factor cannot yet be answered unambiguously. First, we can state that social context factors highly interact and do not only influence the health-related practices and practice of health literacy. Second, even those approaches that are sensitive to the subject matter (Parker and Ratzan, 2010) still speak of contexts with one focus on medical care and clinical contexts. However, this means a desideratum in the current discourse, and provokes the challenge of an extended concept of context, which should rather focus on the entire range of social embedding.

A social science perspective nowadays encounters a much slower pattern of change in modern societies and their social structures than is commonly assumed by theories of pluralisation, postmodernity and individualisation. Fundamental convictions in the formation of theory, which accept constant change, turned out to be unsuitable. This applies particularly to the subject of social inequality, the structures of social embedding and the assumption of a high degree of autonomous self-control ability of individuals over the dominance of structural effects. The reception of the social theory of the French sociologist Pierre Bourdieu (1932–2002), which is still extensively practised internationally to this day, points the way for social science perspectives in research on the effect of social structures on individual action. Bourdieu developed a synthesising approach, the specificity of which is not to understand the production and reproduction of social inequalities either purely mechanically, that is, without the involvement of the social actors themselves, or as a result of an arbitrary, almost autonomous, practice. One of Bourdieu's (1984) major works, *Distinction: A social critique of the judgement of taste*, makes this the starting point of empirical analysis. Bourdieu focuses here on the analysis of objective structures of living conditions (income, educational attainment, etc) as well as on the formation of perceptual, thought and action dispositions of the individuals, and thus on the analysis of subjective (meaning) constructs, motivations for action and individual knowledge. According to Bourdieu, both of these objective structures and dispositional arrangements and the dispositions and modes of action condensed in the habitus form a homology (symmetry) that leads to the stabilisation of inequality and power relations. The underprivileged then form dispositions that hardly allow the questioning of an order recognised as legitimate – even though it discriminates against them.

Habitus and the social milieu perspective

For the first time, Bourdieu extensively examined the hierarchical distribution of social power on the subject of everyday aesthetic phenomena such as etiquette, value preferences and mentalities. And today it is abundantly clear that such an extension of the perspective for health issues applies (Dubbin et al, 2013; Blue et al, 2016), especially within social epidemiology (O'Campo and Dunn, 2012), but has not yet been prepared for a connection to health literacy issues. The concept of unequal individual habitus is particularly relevant here. Habitus is considered a product of accumulated, individually experienced and inscribed history in the socialised bodies (in Bourdieu's sense of internalisation and embodiment of social influences). They are thus in a relationship of equivalence to understand the individual dispositions. The basis for the creation of a habitus is the conditions of social embedding, or spaces of experience, as Bourdieu calls it. Bourdieu describes habitus acquisition in a general sense as a conditioning process in early childhood. Habitus patterns depend on the degree of development and solidification or resistance, depending on the time of their development. The biographically earliest structures, however, have the greatest impact on their lifelong practical application and enforcement.

The perspective of social milieus, which directly follows Bourdieu's social theory, is linked to the updating of a socio-structural orientation in sociology, which refers to the different forms of mentalities and lifestyles, without which we can have no understanding of social inequality. Interestingly, there is a connection with much older works that refer to the connection between socioeconomic differences and expressions such as language. Thus, the sociolinguistic studies of Basil Bernstein (starting in 1971), in an initially very specific line of research on literacy socialisation, formed one of the most important cornerstones in explaining inequalities, which are reflected both in the social structure and in the mentalities, habits, norms and habitus of different social groups. It was only through the fact that the Bourdieu analysis categories received a lot of attention in the social science discussion that this discussion was revived. The link with research on divergent educational arrangements is a highly relevant point of contact, and something similar applies to the milieu-specific differentiation of educational styles.

One of the most important attempts to describe lifestyles and literacies in different social structures was made by Annette Lareau (2003). She focuses on educational practices and patterns of parent–child interaction in socially differentiated environments ('unequal childhoods'). Lareau's ethnographic method, the comparison between poor, working- and middle-class families from a participating perspective, shows clear differences in mentality, which are reproduced in the practices of bringing up children. This makes it particularly relevant to those inequalities in educational behaviour and the acquisition of different literacies that involve different, mostly symbolic, practices (such as language). Lareau describes, for example, the instinctiveness, the social sense, in dealing with the school, the doctor and authorities in the upper echelons of society, and the shame and even the fear and renunciation of the underprivileged milieus when it comes to strategic planning or the assertion of one's own interests. Lareau thus empirically confirms a traditional pattern of milieu-specific socialisation research, but further differentiates at the level of describing different styles of childrearing. In the upper class she identifies an overarching style pattern of education, which she calls 'concerted cultivation'. This covers a specific type of parental educational practices aimed at the targeted preparation of children for examinations, preparation for competition and practices that provide social recognition (for example, enough self-esteem to communicate with teachers in school). Lareau's research and subsequent research approaches thus theoretically come close to Pierre Bourdieu's theory of inequality and milieu research, because with the mentalities and lifestyles she places the importance of the appropriation of symbolic goods (language, expertise, rules of conduct, incorporated cultural capital, etc) at the centre of the analysis of the impact of unequal life worlds. This sheds light on an important black box in the current discussion, namely, the question of the effects of a different social embedding on individual resources, language, action or motivation patterns.

Embedding social embeddedness into health literacy research

Although the question of the determinants of health literacy necessarily arises from the current debate, there is a rather underdeveloped focus on family settings, peers, communities or other forms of contextual and compositional factors. As a consequence, the current discourse does not cover the whole range of the debate. It is overlooked, for example, how in different contexts and depending on social group affiliation, the rationality of action strategies can vary widely. Social milieu research shows impressively how such differences arise under conditions of differentiated social embedding. That also means that the meaning of health literacy can vary highly from one person, group or geographic (and even historical) setting to another. This is referring to social context factors in general and those concerning social embeddedness in particular. Although the growing of the concept into the social sphere means a more intensive consideration of the social framing of health literacy, it still neglects the contexts health literacy is embedded into in many different ways. Therefore, health literacy has, first, to be understood as a construction that is always socially and culturally embedded into specific practices and events in the everyday life of people, and during the processes of socialisation. Second, analysis and conceptualisations should include the close participation of health literacy users and providers, as these are the main actors with an impact on health outcomes. However, debates within socialisation, literacy and equity research shed light on the significance of differences between people and populations and how these differences lead to different understandings of specific concepts, such us developmental tasks, literacy concepts, educational teaching and learning methods or behavioural aspects in the context of uptake or non-uptake of interventions.

This does not mean that we already have sufficient knowledge to describe the forces of social embedding on the emergence of health literacy. But it is not like we do not know anything, and we cannot ignore related findings from research on learning, habitus, action or motivation. And this also means: neglecting to draw on these related dispositions that are in various ways responsible for the emergence of health literacy may increase the stigmatisation and exclusion of disadvantaged groups who are well known to be the under-achievers in health-related attitudes, knowledge and practice. The following argument includes describing in particular the social embeddedness of health literacy, to show how far social relatedness is important at theoretical and practical levels in the context of health literacy. Therefore, a proposal for an ongoing process of embedding social embeddedness into health literacy research is to use a threefold-oriented approach. This concerns the relationship between social embeddedness and health literacy and includes in brief overview:

- Micro-level of social actors:
  - learning processes and basic skills such as linguistic competence
  - development of basic dispositions (or habitus) of action, including self-efficacy or locus of control beliefs but also lifestyles, resources for action and the availability of capital in the sense of Bourdieu.

- Structural level of organisations and communities:
  - milieu-specific strategies for action, including the priority of embedding health issues into everyday life, parenting styles and knowledge transfer in the family (that is, the knowledge that health can be actively produced)
  - sense of shame in dealing with health or the ability to formulate one's own health needs vis-à-vis health service providers or facilities that are relevant to health.

- Level of health literacy interventions:
  - knowledge that mistakes can be made in face-to-face communication (including cognitive, motivational or linguistic overload) because subjective barriers are not recognised correctly
  - sensitivity to target group-specific needs and limits on the accessibility of different groups.

Previous Bourdieu reception in the health literacy-related discourse

Differentiation of different levels can only allow a first, heuristic approach. Here, I would just like to point out the extent to which these different levels can be combined with findings from social science research. This applies in particular to Bourdieu's explanations that are especially relevant for the perspective of the micro and structural level outlined here. In Bourdieu's social structure model, the space of unequal social positions is structured primarily by the unequal distribution of material and immaterial resources. The differentiation between three primary forms of capital is crucial. Bourdieu distinguishes between: *economic capital*, characterised by the availability of financial resources; *cultural capital*, which is (1) in an incorporated (internalised, body-bound) state of skills and competences, (2) institutionalised, that is, mostly legitimised by the educational title, and finally (3) objectified – in short, an objectified form of cultural consumption (goods); and *social capital* refers to the network of contacts and relationships that can be exploited for personal purposes.

Interestingly, there has been a timid, but perceptible interpretation of Bourdieu's analysis categories. Adkins and Corus (2009), for instance, try to reconceptualise health literacy as a social and cultural practice. Yang et al (2013) provide a more limited but not uninteresting social capital approach, and Cortelyou-Ward et al (2012) use Bourdieu's concepts of field and habitus for analysing provider–patient relationships. Dubbin et al (2013) also focus on patient-centred care but give a good starting point for conceptualising what they call 'cultural health capital' (as interesting as work by Nduka Uzoma, 2016). Only a few of the younger works (Pinxten and Lievens, 2014) adopt a Bourdieu-based approach in a broader sense of capital differentiation as conditions for action, which seems even more fruitful when it is directly linked to health literacy. In a rather unknown presentation, Smith and McCaffery (2010) try to apply a Bourdieu perspective even in the clinical situation (that is, doctors providing less information to patients with lower education). The most comprehensive approach in this respect is Shim's (2010) work. This defines cultural health capital as a variety of competencies, attitudes and behaviours, and interactional styles that are responsible for barriers to successful interaction regarding health literacy. Shim focuses on both sides, the culture capital of users and providers, which seems to be well adaptable for the logic of health literacy interventions mentioned in the brief overview of the heuristic approach above. It serves as an indication of the mechanisms of a social dilemma of health promotion, which presumably also affects strategies to promote health literacy and is associated with the diagnosis of unequal social embedding. In health promotion, the social gap of health inequalities continues in this way: reactive stress syndromes, which accumulate precisely in the lower social situations, do not only have an impact on vulnerability to unhealthy lifestyles that can damage health. At the same time they are also responsible for reducing the responsiveness to an offer of resource reinforcement aimed at increasing invulnerability. The 'Inverse Care Law' formulated by Tudor Hart (1971), which is intended to describe the drifting apart of medical care provision from the actual treatment of underprivileged groups, finds its current counterpart in the area of health promotion and highly likely within health literacy promotion itself. If this problem is not recognised and therefore no elaborate understanding of the social embedding of health literacy exists, a development of effective target group-specific strategies cannot take place.

Context matters – but how?

Against this background and by discussing health literacy today, no one would contradict the statement 'Context matters'. But still, to the question 'What does it mean exactly?' no one can give an adequate answer that tells us how context becomes really relevant. With what effect do we have to understand contexts, inequalities and structures or, more generally, social embedding as determinants in the discussion about health literacy? Investigations into the context have so far often been understood as a demand of structures. In other words, contexts function as a structure that makes demands. Also, according to the Parker model, structures are understood as demands while on the individual side there are skills and abilities. However, structures and questions of social integration have so far played little role here. This approach does not seem appropriate to empirical reality.

Recent works, including Bourdieu's socio-theoretical input, suggest an alternative. Such an alternative approach that also takes into account the structural peculiarities at the individual level could be as follows. Based on a well-known distinction in migration research, the structural level associated with focusing on demands could also be described as 'pull' factors. While on the structural level associated with focusing on skills and abilities, 'push' factors act. 'Pull' means that there is an offer that is unequally attractive or can be connected to one's own needs, competences or abilities. 'Push' means one's own needs, sensitivities, resources or abilities with which one relates to an offer. Immediately understandable to many, much of this argument reminds to understand literacy as literacy practices. In the tradition of NLS, this may indeed be the decisive indicator of why the relationship between health information on the one hand, and the practices of access and use on the other, is not a relation of a rational interaction relationship. The idea that an offer can be used by all users in the same way would correspond to what Bourdieu would call a typical scholastic fallacy – the rational overestimation of social actors or conversely, the confusion of one's own rationality with that of the objects of observation.

On the other hand, the perspective of social embedding refers to these different conditions under which resources are used or their own rationality of action is applied. From the perspective of a narrow axiomatic logic, one could say that whoever can read and does not adhere to what health-relevant information recommends is incapable. This is perhaps true from such a normative standpoint. However, it overlooks the fact that 'deviant' behaviour also follows its own logic of action, which is tied to the rationalities and demands (the push factors) of different social environments. Could one possibly even make from this perspective that there is no inadequate health literacy, but only different forms? An answer to this question is not easy. It provokes a debate on cultural relativism and the no less provocative consequence of *laissez faire* in health promotion. But is that what we want? The answer to this more far-reaching question can only be one that distinguishes between two levels: analytical and political. Analytically, we have to state that we must first understand the different rationalities of action that arise from different forms of social embedding (and associated barriers and limitations). Politically, we can think about how we respond to these insights.

Conclusion

As a conclusion and aside from an ideologically overloaded discussion, one must keep sober in argument for a further development of the debate. Who deals with health literacy and does not refer to the social embedding of strategies to act with health issues is widening the health inequality gap. Neglecting the social rendering of dispositions is the first step that leads to the unilateral dissolution of accessibility to good care provision in favour of privileged groups. On the other hand, no matter how rigorously upstream-oriented health promotion is, it is certainly not possible for a society's health promotion policy to turn its back on the imbalance in the distribution of goods and resources. This level of determinants of health and also that of good practice in health promotion concerning health equity is unattainable. But the possibilities of an at least egalitarian promotion of health literacy must be exhausted. According to Michael Marmot's 'proportionate universalism' ideas, interventions aiming at enhancing health literacy have to address the whole population while putting particular emphasis on people from the most vulnerable social groups (Marmot et al, 2008).

The presented distinction between research activities that refer to the concept of social embedding can be a first step towards integrating social embedding more precisely into the research process. It is clear that the social embedding as a determinant of health literacy has not yet found sufficient space in the discussion so far. Future activities should be focused on the development of health literacy dispositions with a broad analytical focus that includes social embedding and contextual factors. In addition, there is the structural level of embedding in different social environments as well as the independent meaning of the social embedding of interventions that address the behaviour of target groups. All three levels can be an introduction to the clearer consideration of a significant development perspective of the health literacy concept. The latter refers to exceeding the narrow limits of a research concept mainly focused on the healthcare situation, which has more potential than has previously been unlocked.

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Children as active participants in health literacy research and practice? From rhetoric to rights

Emma Bond and Vanessa Rawlings

Introduction

This chapter highlights recent developments in health literacy research in childhood and adolescence. It draws on the debates framed in the social studies of childhood and feminist approaches to research in order to critically consider contemporary child health literacy research. Article 24 of the United Nations Convention on the Rights of the Child (UNCRC) states: 'children have the right to good quality healthcare – the best healthcare possible – to safe drinking water, nutritious food, a clean and safe environment, and information to help them stay healthy' (UNICEF, 2004). This chapter considers health literacy approaches to research in childhood and adolescence, and considers their appropriateness from a rights-based perspective. It also highlights the important role of Article 12 UNCRC (UNICEF, 2004) – that children have the right to be listened to and have their views respected – to argue that there is a significant dearth of children's voices in health literacy research, which urgently needs to be addressed: 'Despite the potential for children to make meaningful contributions to research, many projects continue to displace children on the basis of inferiority, dependence and vulnerability' (Velardo and Drummond, 2017, p 7).

Much of the research in the health literacy arena is adult-centred, and this chapter explores methodologies that confront the dominance of scientific positivistic approaches. We argue that there needs to be a conceptual shift away from simplistic research approaches that attempt to measure health literacy towards rights-based research approaches in order to improve understanding of health literacy in childhood and to challenge issues of power relations, tokenism and adultist agenda-setting. We contend here that the ideology of meaningful participation in current policy development is often, at best, tokenistic or at worst, completely overlooked in research practice due to both the ethical and practical complexities of undertaking research with children and young people. Paakkari and Paakkari (2012) have argued that there is a need for research that focuses on what it means for a child or young person to be health literate in different contexts (see Chapter 34, this volume). To this end, we suggest, that creative and respectful approaches for researching sensitive topics that include verbal and non-verbal communication provide methodological frameworks that acknowledge the complexities of doing participatory research with children and young people and celebrate the diversity of children and young people's everyday lives. The chapter concludes with some suggestions for moving future dialogues for undertaking research with children and adolescents towards new horizons in health literacy research.

Understanding health literacy

Academic interest in health literacy has recently increased (Paasche-Orlow et al, 2010). 'As a field of research, an approach to improved healthcare, and an important area of policy work, health literacy has experienced significant growth and considerable evolution' (Pleasant et al, 2015, p 1176). As already discussed elsewhere in this volume, health literacy has attracted considerable attention as a goal of public health and has both impacted on and influenced policy in healthcare settings and healthcare systems (Levin-Zamir and Peterburg, 2001). According to Kickbusch (2008, p 104), 'health literacy should be and needs to be, an active part of a person's citizenship and it is a key component of social inclusion.' Health literacy skills have been defined by the World Health Organization (WHO, 2015, p 12) as: 'the personal characteristics and social resources needed for individuals and communities to access, understand, appraise and use information and services to make decisions about health.'

While mother's literacy was previously afforded to children's health and indeed survival (Sandiford et al, 1995), the development of health literacy in childhood is well acknowledged as an important vehicle for reducing health inequalities in vulnerable groups and in tackling preventable health problems and diseases. It is important that researchers have a clear understanding of what health literacy means (Levin-Zamir et al, 2011) and, although various definitions and models of health literacy in childhood and adolescence exist, all depict it as a complex and multidimensional construct (Bröder et al, 2017; see also Chapter 3, this volume). In relation to children and young people, health literacy is viewed as a powerful mechanism in overcoming health inequalities. According to Velardo and Drummond (2017, p 5), 'meeting children's specific needs arguably includes the delivery of information that can be easily accessed and understood by younger age groups.' Paakkari and Paakkari (2012, p 146) suggest health literacy as a competency 'includes a blend of theoretical and practical health knowledge, critical thinking, self-awareness, and citizenship.'

The focus of health literacy interventions in childhood and adolescence is not confined to the healthcare arena but extended to schools and the educational curriculum in the policy agenda (Wu et al, 2010; see also Chapters 2 and 34, this volume). Thus, schools have become a setting for health prevention interventions and also for health education and the development of health literacy skills. The WHO (1999, p 7) goes so far as to highlight schools as settings that are key to children's health and also to adults in that: 'healthy children who become healthy adolescents are more likely to become healthy adults.' Interventions focus on health literacy as a learning outcome and an individual competency (Paakkari and Paakkari, 2012). Nutbeam (2000) highlights the key elements of functional, communicative and critical health literacy important for children's health over the life course, and Sharif and Blank (2010) suggest that higher levels of health literacy are associated with higher levels of self-efficacy in childhood. Bröder et al (2017) further outline the three core dimensions of health literacy in childhood as cognitive attributes, behavioural attributes and affective/conative attributes.

Velardo and Drummond (2017, p 6) argue that 'the delivery of information that is easily accessible and understood by younger age groups, is likely to play a role in shaping subsequent attitudes and behaviours that typically endure into adulthood.' Thus, health literacy research to date has, arguably, been underpinned not by conceptualisations of child health per se but actually by adult health or more accurately by preventing adult ill health. Thus children in such contexts have been conceptualised not as *beings* in their own right but unhelpfully as *becoming* adults (James et al, 1998), which has dominated approaches in the limited research to date on health literacy in childhood. This point is exemplified by Driessnack et al (2014, p 165) who argue:

> Researchers are beginning to explore health literacy in adolescents; however, no research is being done directly with children, which is a critical oversight because health-related knowledge, attitudes, and behaviors developed during childhood are increasingly being recognised as foundational, deeply rooted, and resistant to change later, when children become adults.

The social studies of childhood has been instrumental in challenging negative conceptions of childhood for over a decade, and it is well acknowledged in other fields that children and young people need to be seen as citizens in their own right (Hill, 2006), citizens with agency and as active participants rather than objects of research (Greene and Hogan, 2005). Acknowledging children as rights-holders has significant implications for research processes (Lundy and McEvoy, 2011, p 129), and we suggest that it is time that these perspectives also underpinned health literacy research.

Researching health literacy in childhood and adolescence

As outlined above, there is a growing interest in the field of childhood health literacy (Ormshaw et al, 2013), yet most research focuses on measuring health literacy and, just as there are differences in health literacy and conceptualisations of health literacy, there have been varying measures of health literacy (Paakkari et al, 2016, p 752). There are a growing number of tools that measure health literacy (Cooper Bailey et al, 2016), as exemplified by the Health Literacy Tool

Shed (see https://healthliteracy.bu.edu), which includes questionnaires that purport to measure the health literacy of children and young people. While it is not our intention here to provide a detailed review of the childhood health literacy literature, as these are available elsewhere (see, for example, Ormshaw et al, 2013; Bröder et al, 2017), it is helpful to consider a few examples and there are various studies undertaken to date.

Sharif and Blank (2010) adopted the use of a Short Test of Functional Health Literacy in Adults (STOFHLA) to ascertain the relationship between health literacy and body mass index (BMI) in childhood with 9- to 12-year-old children. While their findings suggest that there is a significant correlation between higher health literacy and lower BMI, they propose that any measure of health literacy needs to be sensitive to children's cultural context and developmental stage. Driessnack et al (2014) explored the use of the Newest Vital Sign (NVS) (an evidence-based health literacy screening tool; see Weiss et al, 2005) questionnaire and a single Home Literacy Environment (HLE) question to assess health literacy in children. They concluded that children as young as seven were able to complete the questionnaire in a similar time frame and with a similar distribution of results as adults, and that the tool provided a mechanism for identifying which households are potentially at risk of inadequate health literacy. Trout et al (2014) used both the Rapid Estimate of Adolescent Literacy in Medicine (REALM-Teen; see Davis et al, 2006) and NVS to assess the health literacy of 229 young people in a care setting, and suggest that such a measure may be useful in service planning for young people in care and as a baseline measure for youth health literacy knowledge. They do suggest, however, that these scales were limited in that they do not 'provide a comprehensive overview of youth health literacy' and 'do not provide information on youth's ability to navigate the healthcare system or specific health knowledge related to prevention and treatment' (Trout et al, 2014, p 42).

Guntzviller et al (2016, p 155) also used a survey to examine health literacy in 100 young people with Spanish-speaking parents in the US, and found that levels of health literacy were 'remarkably high' and that age, self-efficacy and self-reported English language fluency were positively associated with health literacy. They suggest, however:

> having an "adequate" health literacy score does not mean that the individual will fully understand health information in all medical conversations – especially if the health information is complex and difficult. (Guntzviller et al, 2016, p 158)

Thus, we need to consider how children access, navigate and make sense of health-related information in their everyday worlds when the research on health literacy that does include children has, to date, been limited to studies that try to objectively measure health literacy (Velardo and Drummond, 2017). There is considerable methodological pluralism (see Hammersley, 2008), with Cooper

Bailey et al (2016, p 4) proposing that 'the proliferation of tools has been useful in many ways. But at this point, we have a bit of a mess. One of the key justifications for a lot of the instrument development activity was to spur the field to move beyond the limiting aspects of the older instruments.'

Pleasant et al (2015) argue that there is a need in a paradigm shift from measuring health literacy to identify those outcomes of best practice health literacy interventions. They suggest that 'a more viable approach to increase the utility and use of health literacy research is to better understand the positive effects that health literacy can have on the health and wellbeing of individuals, families, communities, nations and the world' (Pleasant et al, 2015, p 1177; see Chapter 5, this volume).

We suggest that, drawing on Pleasant et al's suggestion above, such a paradigm shift also needs to be driven across the field of child health literacy, but is one that is respectfully based on children's rights rather than hollow academic debate. In order to achieve such a shift and for children's rights to be acknowledged in research, we need to use 'methods that make it easy for them to express their opinions, views and experiences' and ensure that they are 'protected from harm that might result from taking part in research conducted by researchers who use quality, scientific methods and analysis' (Beazly et al, 2009, p 370). Therefore, if we are to fully understand the role that health literacy plays in childhood and adolescence, we need to have a broader range of research tools rather than the blunt instrument of the questionnaire. We need to consider how we can enable, empower and support children and young people to develop and critically employ health literacy knowledge and skills in their everyday lives in the present.

From rhetoric to rights

As outlined above, the importance of health literacy in childhood is well recognised and evidenced in World Health Organization (WHO) policy, national health agendas and educational interventions, yet this is arguably rhetorical as there is a dearth of research on children's perceptions of health literacy (Bröder et al, 2017; Okan et al, 2018), even though it is acknowledged in research that even very young children are involved in their own self-care (Chari et al, 2014):

> adult experts to define a concept for children and young people without consulting them to understand there meaning of health literacy, what health-related skills and knowledge, or health behaviours and practices may be important for them in their everyday lives. Moreover, while new perspectives from childhood research consider children and adolescents as active citizens, social agents, and co-constructors of their social worlds, they are a social minority living in a "childhood" with unequal power relations, uneven distribution of rights, and that is mainly constructed by adults. (Okan et al, 2018, p 13)

Velardo and Drummond (2017, p 5) argue for 'investing in children's health literacy by working *with* children to encourage meaning contributions in research and practice.' Bhagat et al's (2016, p 1) study provides a good example of how, through involving children (in this case young children) in health literacy research, we can gain a better understanding of children's own conceptualisations and, as such, 'address health literacy skills when designing and communicating health messages such that they resonate with children.' Using open-ended interviews and drawing, Bhagat et al's (2016) research supports Nutbeam's (2000) model of different types of health literacy, but more importantly illustrates how health literacy has an impact on how children construct meaning in relation to health information and that, through drawing on their own personal experiences, they are able to engage in critical analysis.

Fairbrother et al (2016) adopted the use of qualitative interviews with 9- to 10-year-old children in the UK, and suggest that this approach enabled a better understanding of how children access health information and the diversity of sources that children interact with. They conclude:

> Mobilising and bringing together insights from the Social Studies of Childhood, health literacy and New Literacy Studies also offers exciting possibilities for exploring diverse experiences. How children's interactions with health messages might vary according to ethnicity, socioeconomic position, gender, digitisation and indeed the globalisation of children's everyday lives represents fertile ground for future research. Further, while this study has honed in on how children access and understand health information, more work is now needed which explores how the ways in which children make health information meaningful relate to how they use this information in the context of their everyday lives. (Fairbrother et al, 2016, p 483)

Focus groups have been effectively used in health-focused research empowering participants to frame their own experiences in their own terms and for investigating deeper knowledge and understanding about aspects of the topic being researched (Green, 2013). Focus groups are also popular research tool with children, and Hernán-García et al (2015), for example, successfully used focus groups to examine the use of the internet by primary school pupils in Spain.

Using child-centred approaches can open up possibilities and opportunities for children to meaningfully participate in research (Clark and Moss, 2001; Barker and Weller, 2003; Greene and Hogan, 2005; Christensen and James, 2008; Bond, 2014), which includes online and digital methods (Barbovschi et al, 2013; Bond and Agnew, 2015). This includes their participation in research into topic previously deemed too sensitive for them to be included in. Coombs (2017), for example, recently used everyday material objects – *stuff in a box* – in order to facilitate a range of conversations with children about death; Renold (2017) used art-based methods to explore gender-based violence and bullying with teenage girls, and Fournier and Bilash (2016) document the use of photography in giving voice to children who are HIV positive in research in Uganda.

> When children are viewed through the children's rights paradigm, using the CRC [Convention on the Rights of the Child] as a framework for implementation, there are distinct implications for research methods: it requires that children are not only entitled to have their views given due weight in research studies but that the adults working with them ensure that their participation is compliant with the CRC. (Lundy and McEnvoy, 2011, p 140)

In order to enable and engage children and young people in respectful and meaningful ways, there is a need to consider the methodology, methods and approaches that create appropriate spaces and opportunities for engagement (Barker and Weller, 2003; Kellett, 2009). If this is to be achieved, the importance of the UNCRC needs to be more widely and better understood in the health literacy field. In health-focused research dominant organisational structures remain (Holloway and Wheeler, 2013), thus power relations is a key factor to address in the methods and ethical conduct of health literacy research, especially with children and young people. Therefore, although methodological approaches are centred within theoretical assumptions and beliefs about the social, it is important in ethically sound social science research for all contexts and influences to be acknowledged and evaluated (Christians, 2011). Thus, we argue that adopting a rights-based approach in health literacy research is essential if we are to uphold the principles set out in the UNCRC especially in relation to Article 12, the right to be listened to and have their views respected; the right to information – Article 17 and their right to guidance from adults – Article 5 (UNICEF, 2004). Future research directions in health literacy, we suggest, should additionally be based on the principles of a feminist ethic of care (Gilligan, 1982) in that they should actively embrace the moral activity of care, valuing children and young people as more than just recipients of care but also as participants within a social context, and engage in respectfully listening to participants' views and experiences and in a feminist ethic of rights (Tronto, 1993). Feminist research has been applied extensively to explore health and illness, medical knowledge, the body, health and social movements, shifting the focus onto subject matters once considered private sphere issues, so the feminist ethics of care becomes crucial in challenging the complexity, diversity and contentiousness of research topics (Olesen, 2011). If the research culture in the health literacy field is going to finally embrace children and young people, we suggest published research should evidence how it has valued meaningful relationships with participants to explore feelings and opinions and had engaged in a 'rights-based discourse within the framework of an ethic of care' (as outlined by Cockburn, 2005, p 73).

Previously overshadowed by scientific, positivistic approaches to research, Pleasant et al (2015, p 1177) argue that the field of health literacy reflects the dominance of 'other scientific endeavours that have strived to gain priority and credibility in society. However, that approach is insufficient to meet the needs of society, as well as being relatively useless to the healthcare professions.' There is some resistance towards qualitative enquiry perceived of as lacking 'scientific rigour' (Erickson, 2011, p 55), and all too often research is subject to the 'discourse of regulation' (Hesse-Biber, 2014, p 99), thus the dominance of positivism and scientific approaches have influenced the control and direction of funders, research governance and ethics committees, and significantly undermined children's rights to fully recognised as participants. However, unlike quantitative methods, qualitative methods incorporate a flexibility that enables researchers to be adaptable to the context of the research situation and to respond to the uniqueness of participant contributions (Silverman, 2006; Melia, 2010). A new toolkit for health literacy research *with* children and young people needs to be compiled that is based on respectful engagement: 'Tapping into the child's perspective is irrefutably valuable, in the sense that children's own unique social worlds, experiences, opinions and understandings are acknowledged and respected, which can inform supportive healthcare practices and meaningful health promotion interventions' (Velardo and Drummond, 2017, p 7). Therefore, rather than seeking data that validates theory, interpretivist research should be inductive and explore social phenomena through engagement and interactions to consider 'if empirical material can encourage the challenging and rethinking of established theory and thus inspire novel lines of theory development' (Alvesson and Kärreman, 2011, p 5).

Conclusion

There has recently been 'a significant and steady expansion of health literacy research over the past decade' (Cooper Bailey et al, 2015, p 1), which has included health literacy research in childhood and recognition that there is a need to focus on health literacy in younger children (Paakkari et al, 2016). However, much of this research has been focused on measuring health literacy (Pleasant et al, 2015), and it predominantly fails to include the views, experiences and perspectives of children and young people. While there is a limited, but admittedly growing, body of health literacy research related to children and young people, it is relatively very small when compared to the considerable interest accorded to that with adult populations (Bröder et al, 2017). The health literacy field needs to include more child-centred research approaches based on the principles of the UNCRC, adopt a more robust ethic of care towards children and young people and ensure that children and young people are viewed as knowledgeable about their lives (Mills, 2000; Back, 2009):

> There needs to be shift in definition and measurement of health literacy from a healthcare orientation to an educational point of view, encompassing knowledge, skills, motivation, attitudes and a sense of

> morality, and a shift in health literacy measurement from a simplistic, screening foundation to a more context specific, comprehensive nature. (Ormshaw et al, 2013, p 452)

Article 17 of the UNCRC states that children have the right to information that is important to their health and wellbeing (UNICEF, 2004). Future research endeavours to open up the research toolkit in health literacy in childhood needs to include 'the potential benefits of emergent digital health technologies' (Velardo and Drummond, 2017, p 9), and the role that mainstream social media can play in exploring and listening to children's everyday experiences in the knowledge economy (Bond and Agnew, 2015). 'The world is well into an era where technology is transforming how we conduct research, practice medicine, develop evidence-based public health interventions, and engage in our health and healthcare' (Pleasant et al, 2015, p 1177), as such 'we might consider how health literacy information seeking is influenced by the proliferation of media messages that convey sociocultural norms throughout the childhood years, or digitized, individualized "health promotion" technologies' (Velardo and Drummond, 2017, p 7). Media health literacy is becoming an important concept for health promotion among young people (Zamir et al, 2011; see Chapter 18, this volume). Concerns have recently arisen that, although the proliferation of IT and access to the internet is potentially very positive in enabling people, including children and young people, access to health-related information online (Bickmore and Paasche-Orlow, 2012), it may simultaneously exacerbate existing inequalities and reinforce digital divides (Bond, 2014). The importance of critical digital literacy to help children navigate the wealth of information online is crucial to informing future research (Sonck et al, 2011) and also how children can develop resilience towards the unhelpful and potentially harmful 'health'-related information online, especially in relation mental health and body image (Bond, 2018).

Borzekowski (2009) and Bröder et al (2017) conclude that health literacy can be empowering for children and young people who may be marginalised and potentially vulnerable:

> Future efforts must target the redesigning of systems to be more inclusive and friendly towards children and young people, the adjustment of curricula and training of health professionals, teachers and other relevant stakeholders in order to better meet the challenge of the health literacy deficit, and the recognition of children and young people as active partners in their health decision making. (Bröder et al, 2017, p 23)

Previously children and young people's views have not been valued in health literacy research, yet it is clear from other fields of enquiry that when they are given the opportunity to actively engage and participate in research, their voices can be heard and they can make powerful contributions to knowledge and understanding, policy and practice (Davey et al, 2010; Tisdall, 2013, 2015; Rawlings and Coombs, 2016). Furthermore, by drawing on a 'multiplicity of voices', media and opportunities to engage with social actors in more ethnographic ways, researchers can actively engage within postmodern contexts and reflexively construct meaning of and within the social realities (Delamont, 2003, pp 150–1). Issues around children and young people's health and wellbeing are highlighted in policy discussions and research (DfE, 2015; DH, 2015; Law et al, 2015), yet there remains a significant lack of health literacy research engagement with children and young people themselves as to what they want, need or have found works for them (Couldry, 2010).

As Velardo and Drummond (2017) have argued previously, it is important that policy-makers understand the diversity of health literacy capabilities in different communities. The findings presented here emphasise the importance of undertaking health literacy research with children and evidences the very valuable contribution that children themselves can make to current understandings and future directions for health literacy research.

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Health literacy practices of adults in an avatar-based immersive social virtual world: A sociocultural perspective of new media health literacies

Evelyn McElhinney

Introduction

The continued development of avatar-based immersive technology such as 3D social virtual worlds (VWs), games and virtual reality – that can be used to provide ‘places’ where communities can create and socially interact with health information through simulation, games, peer support groups and with healthcare practitioners via the virtual self – require a new perspective on new media health literacy.

This chapter discusses how new media children and adolescents’ social skills and cultural competencies were reflected and adapted in the context of adults and health, through findings from a qualitative interview based study carried out in a 3D social VW with 25 adults aged 18-70 across 10 countries. The study was carried out during September 2011 to June 2012.

3D social virtual worlds

3D social VWs are online multi-user virtual environments (MUVEs) that people can globally access using an avatar as the virtual self. Avatars can be modified to represent humanoid, fantastical, animal or anthropomorphic beings.

The avatar can also be animated to show facial expressions or movements to enhance non-verbal communication and can ‘chat’ to, and interact with, other avatars, the environment and objects in the VW. Communication with other avatars is initiated via either private instant messaging (IM) or with other avatars near them (not private, but can only be seen/accessed by avatars in close proximity to each other), or collectively across a group of users of the VW (not private, seen/accessed by all avatars in the group), using text or voice (Wagner, 2008). However, importantly the avatar in these worlds is driven by a human, and not artificial intelligence. Therefore, in VWs the avatar represents the person driving it from the physical world (PW). In this chapter the use of the term ‘real world’ is not used as this may infer that the experiences, relationships or learning in the VW have no bearing or influence on behaviour in the PW. The interactive, visual and auditory nature of VWs that react to the users' movements (objects are closer as the avatar walks closer, noises increase or decrease) creates a psychological state of immersion, presence (being there) and social presence (being there interacting with others) (Witmer and Singer, 1998; Biocca et al, 2003; Schultze, 2014), which differentiates it from other areas of the social web.

Health literacy, the ability to search for, appraise, understand and use health information and social resources to make health decision, is important to people's ability to maintain health or self-manage a health condition (Nutbeam, 1998; Dodson et al, 2014). Health literacy is considered a modifiable social determinant of health that can be improved or strengthened through interventions (WHO, 2017). However, models or measurements of health literacy often focus on individual skills or capabilities and ignore the social resources that are important to individuals and communities' collective knowledge and skills that can promote a distributed model of health literacy (Edwards et al, 2015). When these communities are online, in emerging new media and social areas of the web, information, skills, knowledge and sense-making can collectively contribute to improvements in health literacy through a network and sociocultural model of health literacy (McElhinney et al, 2018).

New media literacies

Previous studies of new media literacies (New London Group, 1996; Gee, 2010a; Lankshear and Knobel, 2011) and the new media informal learning practices of children and adolescents have discovered the multiple social skills and cultural competencies (multiliteracies) that are required to learn to become literate in the 21st century (Jenkins et al, 2006, 2009). The highly cited White Paper (Jenkins et al, 2006) and the report, *Confronting the challenges of participatory culture: Media education for the 21st century* (Jenkins et al, 2009), argued that children and young people require specific social skills and cultural competencies for 21st-century learning and literacy (see Chapter 18, this volume). This report set out the multiple literacies that moved literacy beyond reading, writing and numeracy. These were discovered through numerous reviews of new media literacies studies and the new media informal learning practices of children and adolescents, and included characteristics related to performance, play, simulation, negotiation, networking, multitasking, distributed cognition, collective intelligence, appropriation, judgement and transmedia navigation.

In the study discussed in this chapter, it is argued that many of the social skills and literacy practices enacted by adults, for example, mentoring, negotiating, networking, playfulness, judgement, problem-solving, collective intelligence and sharing resources, are similar to the literacy practices of children and young people found by Jenkins et al (2006, 2009) and other researchers of avatar-based 3D online games and VWs (Gee, 2003; Black and Steinkuehler, 2009; Elliot, 2014). In quantitative and qualitative ethnographic studies, researchers in 3D avatar-based massively multiplayer online games (MMOGs) (Steinkuehler, 2008) and 3D VWs (Barab et al, 2007; Gillen, 2009; Marcon, 2013; Merchant, 2013; Pellicone and Ahn, 2015) found several social skills, cultural competencies and literacy practices were being used by children and young people.

This chapter discusses how these new media health literacy practices influenced individual and community health literacy and health behaviour change in the PW. The socially constructed mechanisms discussed in the findings maximised the health literacy resources available, meaning improvements to individual or group health literacy was not only reliant on individuals' skills, but also on the health literacy practices of their social connections. Therefore, the use of others within participants' social networks as proxies, mediators or mentors who shared knowledge, information and skills with each other, to access resources and learn new ways to improve health literacy, reflects a social approach to health literacy discussed by (Papen, 2009; Chinn, 2011; Edwards et al, 2015; Rowlands et al, 2016). This also represents a sociocultural approach to literacy discussed by experts in new literacy studies and new media literacy studies, where literacy is seen as a situated social practice and a community resource realised in social relationships, and is shaped by cultural and social constructs (Barton et al, 2000; Gee 2010b; Mills, 2010; Street, 2014; see also Chapter 36, this volume). Hence understanding these multiliteracies in adults makes a unique contribution to enhancing understanding of the literacies required across the lifespan in modern online social environments, particularly those that are avatar-based.

Equally important is the unique contribution this study's findings make to understanding the importance of the avatar as the virtual self, the immersive VW environment and other people, to how VWs can be used to increase attraction to, and engagement with, health information to increase health literacy. Findings show evidence of concepts of Bandura's social cognitive theory (1998), such as mastery, which he regarded as the most powerful to influence self-efficacy and vicarious experiences, which relates to the involvement of social models to influence self-efficacy. Bandura argued 'seeing people similar to oneself succeed by sustained effort raises observers' beliefs that they too possess capabilities to succeed' (Bandura, 1998, p 626). However, in this study it was the use of an avatar as the virtual self to master or experience behaviour as opposed to others that influenced behaviour change. There was also evidence of the Proteus effect (based on Bem's 1972 theory of self-perception) discussed by Yee et al (2009), where the appearance and behaviour of the avatar influenced behaviour in the PW. Additionally, through 3D simulation and discussion perspective-taking theory was evident (walking in others' shoes) (Selman, 1975; Gehlbach et al, 2015). These findings are similar to, and supported by, several researchers of VWs and other immersive environments (virtual reality) who have reported evidence of positive changes to participants' behaviour, attitude and empathy to others. Examples include interacting as a person with a disability (Ortiz, 2009), dementia (Wijma et al, 2017), through simulated virtual hallucinations (Yellowlees and Cook, 2006) or by taking on a different gender (Yee and Bailenson, 2006) or race (Groom et al, 2009; Gutierrez et al, 2014).

Overview of the study

The study received ethical approval from Glasgow Caledonian University School of Health and Life Sciences (A11/001) and was undertaken in the social VW Second Life®; all participants were recruited in the VW and with consent, and interviews were undertaken via the VW private IM function, with interviews taking place in a private area of the VW. The ethical considerations involved in the study, recruitment methods and data collection methods have been reported in more detail (see McElhinney et al, 2014). Interviews and field notes were analysed following the principles of thematic analysis (Braun and Clarke, 2006).

Findings

Themes from the analysis of the data included those that were related to the study context and environment and are discussed in the thesis (McElhinney, 2015). For the purposes of this chapter themes related specifically to health literacy practices and behaviour change are discussed.

Theme: Accessing health information in the VW

This theme discusses and describes how accessing health information and healthcare practitioners in the VW was achieved through individual and social methods, and how the affordances of the VW influenced participants' ability to make sense of and use health information to decide to change their behaviour in the PW. Particularly important to those who had health conditions or low disposable income that prevented them from attending local health meetings or events in the PW was the instant access of the environment. The psychological feeling of VW presence (being there) and social presence (being there, interacting with others) was reported as different to other online forums:

> [Researcher: 'So do you think the avatar and the environment is important?'] 'Yeah to have avatars, in world experiments, and lectures which I couldn't otherwise attend, well, it's cool. It's the wow factor that also keeps me coming back…. Yeah, I think it saves gas, has the cutting edge and latest info, and it presents it at times I can attend. For example, some lectures here would be in another state or even country which I can't attend that way. Virtual means there's no transportation limitations. So basically, I save money and I spend less time traveling and more time recuperating.' (Avatar 23, male, aged 41–50)

Interestingly the immersive environment was also important to generating a feeling of an informal egalitarian environment; this was particularly important when the subject was difficult or emotional:

> 'I'm also less shy and reserved on this than in person. It's easier to ask questions. In real life I'm a bit more shy and reserved and I get a little nervous and forget what I wanted to ask.' (Avatar 23, male, aged 41-50)

However, navigating health information was difficult using the search function. This was further complicated using different software to access the VW (known as a viewer):

> 'The SL [Second Life] search is notoriously poor, so sometimes your search has to be pretty general to catch what you want.' [Researcher: 'When you do search, how confident are you about searching for health information in the virtual world? As in, you will find what you are looking for?'] 'About finding a result?' [Researcher: 'Yes.'] 'Not that confident, like I said, SL search is pretty poor.' (Avatar 6, female, aged 51-60)

Due to the challenges of search, participants used other strategies to find VW health information such as joining groups and communities. This led to group connections and, if desired, individual friendships. Communicating with groups could be achieved via group chat online at the time of posting, via notices of events created by the owner of the group received by members while in-world or via email when 'logged out'. The decision to pass this information on was often decided with others, therefore reflecting a social appraisal and judgement regarding the trustworthiness of the information and whether to share it. This network approach to searching increased the health resources of individuals and groups:

> 'If you have friends in here a social network that you start asking about something, someone has a friend, who has had a friend that has found something that they had a lot of benefit from a particular program or found a particular island.' [Researcher: 'So was it like a recommendation?'] 'Yes, very much so for lots of things in Second Life, but especially with healthcare.' (Avatar 14, male, aged 51-60)

> 'The big kicker is mingling with people and getting invited to join groups. Then in the group chat people announce other groups and that's more resources. Works better than just searching, it's networking like if I was looking for work but I'm looking for info and even help.' (Avatar 23, male, aged 41-50)

These unique in-world communication and information-sharing strategies were used to distribute information between infinite amounts of connected, interconnected or random people allowing information to be distributed to friends while 'online' or 'offline' via IM sent to email or even by leaving a 'box of information' in the VW that could be clicked by other avatars to deliver the information to their inventory (where they could access it later). Although some of these in-world strategies are similar to how information can be shared in web participatory social media, it was often the feeling of synchronously connecting with an avatar and places as opposed to 'flat' text that was seen as different and more intimate:

> 'The thing that is different is that on the web you are alone, even if there is a chat room, you know, even, because things are asynchronous … and because it is flat … so you don't have the sense of being "in" the environment.' [Researcher: 'Right, so?'] 'I am a very big reader but I think, yeah, virtual worlds offer a higher level of immersion that is important to our wellbeing.' (Avatar 4, female, aged 61-70)

The difference from Web 1.0 was the ability to experience information synchronously with others. Participants referred to 'journeying', 'stumbling upon' or 'walking through' the information with friends, a significant other or health groups, and this increased understanding and recall of the information. This was specifically relevant when one person had a health condition as they reported that this had helped their friends, family or partner understand their condition better through experience and discussion:

> 'I brought a loved one to the PTSD [post-traumatic stress disorder] simulation and I usually go to presentations with the same loved one we discuss the information a LOT.' (Avatar 18, female, aged 41-50)

> 'I can also explore interactive exhibits and network with people such as Survivors of TBI [traumatic brain injury] group and the Virtual Ability one…. I've got friends and they mostly know I've got a TBI and some even go to these events with me.' (Avatar 23, male, aged 41-50)

Interestingly, social connections and gatherings were discussed as they would be in face-to-face PW meetings, 'bumping into people' or 'sitting talking'. However, the ability to teleport to a health event or piece of health information and synchronously experience it, discuss it or walk through it together differentiates it from web sites, other participatory social media and indeed, the PW.

Theme: Understanding health information

This theme discusses the way in which participants made sense of information and how this influenced their understanding in the VW. The VW presentation style of information, through notecards of text, slideshows, 3D representations of anatomy, interactive simulations and healthcare practitioner seminars influenced understanding and recall. A number of key health literacy VW skills and practices were evident in the participants' appraisal of the information such as discussion with others, asking questions, navigating and judgement of trustworthiness, comparing information and social skills.

Healthcare seminars from practitioners or researchers were particularly popular as they allowed access to talks that participants believed they could not access in other media or in the PW. The ability to ask questions and discuss the subject with practitioners and others at the time of the talk was seen to aid understanding by increasing or sharing knowledge, clarifying information and affirmation.

Some of the key features afforded by 3D VWs are the feeling of being in a place that allows the avatar to walk around or interact through objects. Interactive, multimodal (visual, audio) objects and simulated scenarios were reported as interesting, attractive and engaging, which helped to increase knowledge and understanding:

> 'The most powerful one that I have ever been to was that exhibit on schizophrenia, it was, ummm, disturbing because it was so real and so visceral and others on stomach cancer and eye cancers, umm, they were very visual and very good, a combination of notecards you could pick up, signage you could read um, and, eh, pictures that you could see. The thing for me that is so powerful is going through an exhibit like that with someone else in real time, rather than by myself, in which case the web would do a fine job.' (Avatar 14, male, aged 51–60)

> 'Several of them were interactive and that, if it's a really good interaction … we had a great time at the nutrition simulation at Idaho.' [Researcher: 'Mmhmm.'] 'I don't know if you have seen the blizzard disaster and emergency preparedness simulation. That is another great one. You get totally involved and totally immersed in it. Um, those were both really great. Same thing with the nursing simulation at the University of [name removed] I watched while [name removed] went through the process of reviving the baby [both laugh] – you learn better when you are engaged.' (Avatar 11, female, aged 51–60)

Participants reported several helpful factors that aided understanding: anonymous avatars, the environment, access to healthcare practitioners and discussion with others. Discussion led participants to multitask, searching and comparing information in other areas of the web, to increase depth, compare or share information:

> 'Discussion does help as it allows you to consider different perspectives and ask questions specific to the situation that drove you to go looking

> in the first place. This often enhances the search process as well as expanding your horizons from the narrow starting point. It can also help keep one focused as the direct feedback and interaction provide strong impetus.' (Avatar 17, female, aged 51-60)
>
> [Researcher: 'Okay, so when you were talking to the healthcare practitioners, did you find that a good way to get information?'] 'Yes, definitely at the end of each talk that the healthcare professionals do, I … at the events, everyone will always say are there any questions, so this gives access to someone who normally I probably wouldn't be able get to and ask any question you want to. It's much better than you get in real life, you'd have to go a long way in real life to be able to do the same.' (Avatar 16, male, aged 31-40)

Regarding trustworthiness, participants referred to several methods to check the credibility of the avatar delivering the information, the 'place' in which it was delivered or the content of the information. This included multitasking through various sources, asking VW 'friends' or groups, and checking the credibility of the avatar by searching profiles or 'Googling' the avatar 'real name' when available.

When specifically discussing the identity of healthcare practitioners, participants were asked if the appearance or name of the avatar mattered to their ability to trust the VW practitioner or the information provided. There was no consensus, although for some names an appearance were important:

> 'I would like to say no, but yeah, it does and so does the name. Don't call yourself "silly little booboo" and claim to be a psychiatrist [both laugh] because I think you need to get on your own couch next then, and I am all for fantasy and being who you want to be in Second Life but if you want to be professional you need to kind of look it, and be it, and have an alt [alternative avatar] – who cares, it doesn't instil confidence if you have an idiot name.' (Avatar 11, female, aged 51-60)
>
> 'now that I think about it, I think yes, it does matter if they have a goofy looking avatar, then I think I would start to question their intent or their information I'm not sure why. Prejudice I guess, lol, no seriously, I have tacit expectations of professionalism in Real Life which carry over here into SL they don't have to be all buttoned up in a suit but there is what I would consider to be unprofessional appearance. I never really thought about this before!' (Avatar 18, female, aged 41-50)

For others the focus was instead placed on behaviour or content of information provided:

> 'Ohhh, that is a fantastic question but, eh, for me, no, not at all, they could be a flying toaster oven, they could be a Dragon, … I find it ridiculous that the appearance in SL is linked to the qualification…. So I find this throwing away of these norms, of these naming norms, and the appearance and the likes very refreshing. Going back to the white coat Dr syndrome,… if someone appears with the white coat in SL then, mmmm, maybe they would be better as a toaster oven [both laugh].' (Avatar 25, male, aged 41-50)

Theme: Changing behaviour, taking action

When participants discussed changes to health behaviour they referred to bi-directional behaviour changes (that is, changes in both worlds) as well as changes to PW health behaviour only. The bi-directional changes included: changes to attitudes, reduced stress and anxiety, improvement in social skills and increased confidence or positive influence on self-management of long-term conditions. PW changes included: health lifestyle changes such as losing weight, stopping smoking, changing diet and increasing exercise.

Changes in attitude were particularly evident in non-disabled participants who reported changing their attitude to people with disabilities after interacting with simulations or people with disabilities in the VW. This was exemplified in the VW by the ability to 'walk in others' shoes', with non-disabled participants being able to experience symptoms of a specific condition or disability:

> 'Em … the interaction I have received from Second Life … with disabled people, has made me look at disabled people in a new light in the real world. I think before I used to look on disabled people as people who need help, now I see them as just the same as me but disabled … when I got to Second Life I started to meet the people who were disabled and that made me want to find out all about them.' (Avatar 16, male aged 18-30)

> 'They had a rather compelling autism experience and they told you how to set your camera and your sounds and all and it was a cacophony of sounds and motion and things we felt like we were spinning round, I said to [name removed]…. I had to get out, which was a really good lesson on what people with autism faced.' (Avatar 11, female, aged 51-60)

What emerged from many participants' accounts was a feeling that after a period of social interaction in the VW, VW and PW self-efficacy and self-confidence increased and social skills improved. This was particularly evident in participants who had social anxiety or social isolation, an existing health condition or a disability. This increase in self-efficacy, confidence and improved social skills was often attributed to the ability to 'rehearse' or 'master' behaviour in the VW via the avatar before attempting it in the PW:

> 'I have mental health issues, major depression … etc. I have very little income so I have very little social activity so I came to SL, it was more for the social aspect but it is helping me work on some of my … stuff.… I consider my avi to be my inner self, and as she gains confidence, so do I and I have felt the difference in myself, it is good.… I notice a change in just the way I walk down the hall, the way I stand it feels good, and more confident.… I try to build on that a little, I am beginning to recognise possible triggers. I recognise more how much my anxiety is caused by my frustration with my difficulties.' (Avatar 7, female, aged 51-60)

> 'My social skills for sure improved, communicating and how to act around people improved drastically. I am aware that it is nowhere near "normal", but at least it's huge leaps ahead from what it was. I can also do more unplanned things now, which often is a problem for people with autism. So yeah, VW can be a great tool used properly in the right environment.' (Avatar 20, male, aged 18-30)

Eight participants who had sought out or 'stumbled upon' information or simulations that were aimed at modifiable lifestyle behaviour change used this information to take action and change their behaviour in the PW. Watching their avatar's shape change automatically or by manipulating their avatar to appear slimmer in the VW in response to the level of exercise or due to food choices inspired some participants to modify their behaviour in the PW, again, reflecting Bandura's (1998) previously discussed mastery and vicarious experiences concepts:

> 'Yeah, it did, I will take the nutrition information into the real world … the nutrition one has changed how I look at food, what shall I eat [laughs] or is it just what I wanna eat [laughs] … when we took a break later for dinner, ha, we came back and [name removed] says well I.… changed my mind about what I was having for dinner because we learned so much [laughs] and that is the point!' (Avatar 11, female, aged 51-60)

For others it was the availability of healthcare practitioners and the VW environment that led to greater trust in VW practitioners than those in the PW, reflecting positive reinforcement:

> 'I met, very early on a woman at the University of [name removed] that was running a project that has to do with weight loss and the health benefits of weight loss, and I got very interested in what she

> was doing because I had just started to lose weight.' [Researcher: 'Mmm, right….'] '… and I … found a lot of positive reinforcement because they knew what they were talking about…. So, I'll give you the really best example is that except for days like today when it is pouring out, I walk 40 minutes a day now and I thank among other people the woman in the University of [name removed] who I met in here for helping me with that. For the reinforcement that allows me to do that now. I have lost 30 pounds and I credit SL for a lot of that.' (Avatar 4, female, aged 61-70, suffering from rheumatoid arthritis)
>
> 'I spent ages soaking it all up, and then decided to have a complete lifestyle overhaul, in fact checked out what I was doing against what I should be doing.' [Researcher: 'So, did it help to motivate you, do you think?'] 'Yeah stopped smoking after 35 years, 14 months ago I stopped completely never had another since. Lost weight, I was amazed!' [Researcher: 'Excellent and you think the information helped?'] 'It was the ageing sim that did it; also I looked further into some of the advice. I was ripe for change, I was in the mood for change, the ageing sim laid it all out for me and let me look as long as I wanted to all I had to do was change.' (Avatar 8, female, aged 51-60, suffering from high cholesterol)

Discussion and challenges

These findings are important to our understanding of what people do and want from the social web in the context of health. They also reflect many of the concepts within Nutbeam's (2000) interactive and critical levels of health literacy. They add to our understanding of the expectations of adults who use immersive avatar-based virtual environments, particularly with reference to design principles that promote attraction and engagement with health information that can influence health literacy and behaviour change. However, it remains a challenge for healthcare practitioners to design information in these areas that requires multiple skills and a time commitment. Additionally, these platforms are often inappropriately labelled as games. However, the social skills and competencies (multiliteracies) discovered in this study differ from the health literacy skills and practices required for accessing other areas of the web, particularly Web 1.0, where people passively access static web pages and information is accessed with no or little interaction. The health literacy practices are more akin to social Web 2.0 tools that facilitate collaboration and are found to be popular for seeking health information and affirmation (Fox, 2011; Higgins et al, 2011; TNS Political & Social, European Commission, 2014). However, uniquely, they add an understanding of the psychological importance of avatars as the virtual self and an environment that is immersive, with multiple auditory and visual communication tools and interactive objects.

Conclusion

This chapter has evidenced the multiple social skills, competencies and social resources that influence health literacy in the context of adult social avatar-based immersive environments. Importantly, the social skills and literacy competencies in this study did not need to be achieved by all participants, allowing distribution of knowledge and skills throughout networks supporting the concept of a 'network' approach to improving individual and community health literacy. Additionally, this is the first study to explore the multiliteracies used by adults in these emerging areas of new media, and show the similarities to those used by children and adolescents promoting a move away from compartmentalisation of age groups to a more intergenerational lifespan approach to new media literacies. Thus, placing people with different levels of health literacy in intergenerational groups, or people who are socially isolated in VW communities, other online networks, or offline communities who have different social and cultural literacy competencies may help improve individual and community health literacy. The importance of understanding these multiple literacies requires a change in how healthcare practitioners, researchers and policy-makers review the design of health information that is accessed or presented in avatar-based social environments or other areas of the social web, and moves the focus of literacy as an individual process to a situated sociocultural model of health literacy.

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Health literacy and participation in the healthcare of adults: (In)compatible approaches?

Melanie Messer

Introduction

The rise of the health literacy movement has coincided with a demand for more patient participation in their own healthcare. Both represent different strategies assigning patients a new role in the responsible management of their own health and involving them in health-related decisions. For both concepts there is no commonly accepted understanding available; instead, the scientific literature provides various concepts and definitions (see Chapter 1, this volume). However, while health literacy basically focuses on the competencies and abilities of patients, participation focuses on patient involvement in the healthcare process.

Some prominent health literacy models conceptualise health literacy as a prerequisite for participation (Sørensen et al, 2012; Squiers et al, 2012), and empirical studies suggest that low health literacy is associated with reduced patient participation and less engagement in shared decision-making, or a rather passive role in health-related decision-making (Collins et al, 2004; DeWalt et al, 2007; Kripalani et al, 2010; Barton et al, 2014; Seo et al, 2016). In this context, a low general health literacy is associated with low socioeconomic status, lower education, migration background, lack of social support and an older age bracket (HLS-EU Consortium, 2012; Toci et al, 2016). However, the localisation of health literacy as an outcome or consequence of the participation process is rarely found (Malloy-Weir et al, 2015; Kamei et al, 2017). Participation is usually exclusively seen as a mediator between health literacy and a health outcome (Paasche-Orlow and Wolf, 2007). However, the evidence basis is still small, so, taking a closer look, it seems that it may be worthwhile to question this assumption and broaden the perspective.

The aim of this chapter is to describe the possible relationship between patient participation and health literacy and the resulting challenges for further development in the context of healthcare. Initially, both concepts are briefly introduced, and possible commonalities and differences highlighted. This is followed by an in-depth examination of the challenges for participation in the care process. The focus is on direct interaction between adult patients, especially those with low health literacy, and health professionals in healthcare. Building on that, a model is proposed to describe the conceptual relationship between health literacy and participation as enhancing approaches. Finally, opportunities for further development are considered.

Patient participation in interaction with health professionals: a conceptual approach

Participation at the micro level of healthcare means the involvement of patients and citizens in decision-making in interaction situations (Collins et al, 2007). This also means the transfer of power and control to the individual. Furthermore, participation addresses taking into account the beliefs, values, preferences and priorities of patients and also addressing the emotional state of the patient (Collins et al, 2007). A key factor in patient participation is the relationship between the health professional and the patient, which is based on partnership. The aim is to establish a cooperative professional relationship in which patients are actively involved in the care process from the beginning (Sahlsten, 2007).

The legitimation of participation is primarily based on normative theory, referring to the implementation of statutory patient rights such as self-determination (WHO, 1994; Thompson, 2007), which are part of national and international charters and legislation. In 1986, the Ottawa Charter, established by the World Health Organization (WHO), called for the promotion of participation and self-determination by patients and citizens in health-related decisions (WHO, 1986). In this context, self-determination rights aim at patients making their own decisions (for example, concerning their own body or the carrying out of examinations and treatments). These decisions may contradict expert opinions or even the views of a social majority. While approaches to self-determination, usually located as a prerequisite for participation, refer to the individual, patient participation is focused on interaction with health professionals (Davies et al, 1997). Furthermore, in utilitarian approaches to the legitimation of patient participation, the positive effects on aspects of health and quality of life are highlighted, which include positive effects on patients' knowledge and understanding of disease, greater involvement of patients in decision-making and treatment processes, and the reduction of exclusion and discrimination against certain patient and population groups (Joosten et al, 2008; Coulter et al, 2015).

Participation can manifest in various ways, such as physically active participation in care, communicative participation or through social participation (Messer, 2018). Most importantly, participation is about patients being offered the opportunity to decide for themselves, how and to what extent participation should take place, rather than forcing them to achieve a predefined degree of involvement (Ashworth et al, 1992). While various participatory interventions are available, among the most prominent is the shared decision-making concept (Messer, 2018).

Health literacy: from basic literacy to a complex concept

As with participation concepts, health literacy also addresses aspects that can be important for the interaction between patients and health professionals. However, health literacy has undergone a rapid development process, from a basic literacy approach, mostly focusing on reading, comprehension and numeracy, to a complex and multidimensional skill-based concept, focusing on the ability to search, find, understand, evaluate and apply health information, including knowledge and motivation (see Chapters 1 and 14, this volume).

Furthermore, depending on the research traditions, health literacy can either be seen as a risk or an asset, respectively (Nutbeam, 2008). From the perspective of risk-based approaches, low health literacy is a risk factor because a lack of patient skills has a negative impact on the participatory interaction as well as on health outcomes (Nutbeam, 2008). To reduce the risk, health literacy has to be addressed in the clinical process. On the other hand, health literacy as an asset is understood as a resource enabling people to exert greater control over their health and health-related decisions. The focus is on empowering people through specific, needs-based information, training and support (Nutbeam, 2008; Edwards et al, 2009).

The commonalities in these approaches include an emphasis on health literacy as a requirement to maintain access to healthcare, the ability to interact with health professionals and participation in health-related decisions (Batterham et al, 2016). These aspects are mostly relevant at the beginning and during the care process. Thus, the conceptualisation of health literacy as a prerequisite for participation in the interaction with health professionals appears to be obvious (Paasche-Orlow and Wolf, 2007; Ishikawa and Yano, 2008).

Furthermore, it seems that the focus on decision-making processes is one of the central elements of health literacy, which are also central to participation concepts. However, in some prominent health literacy concepts it is not intended to make 'any' decision, but rather, an appropriate decision (Nielsen-Bohlman et al, 2004) that has also a beneficial effect on one's own health (Nutbeam, 1999; Kickbusch and Maag, 2005; Squiers et al, 2012), meaning that the expected decision is already normatively laden. This seems to create its own challenges, so that low health literacy is often associated with reduced patient participation, as described above (Collins et al, 2004; DeWalt et al, 2007; Kripalani et al, 2010; Barton et al, 2014; Seo et al, 2016). Regarding this context, it might be worth taking a closer look on the challenges for those with low health literacy.

Challenges for people with low health literacy to participate in the care process

Robust empirical studies investigating the relationship between health literacy and participation are rare and focus primarily on decisions in the patient–provider relationship. In the following this is examined more closely. It should be noted that most of the included studies mainly used functional literacy measures to identify people with low health literacy, focusing on reading, comprehension and numeracy (Baker et al, 1996; Parikh et al, 1996; Katz et al, 2007; Wolf et al, 2007; Smith et al, 2009; Aboumatar et al, 2013; Easton et al, 2013; Protheroe et al, 2013; Menendez et al, 2017). However, in this context, one used multidimensional self-assessment health literacy measures (Wigfall and Tanner, 2018), while another one mixed them with functional measures (Ishikawa et al, 2009). Nevertheless, it should be noted that most measurement approaches are criticised due to a lack of validation of the measurement instruments (Pleasant, 2014; Gerich and Moosbrugger, 2016; see Chapter 5, this volume).

Prior to the doctor's visit, three-quarters of patients with low health literacy in a survey conducted by Aboumatar et al (2013) preferred an active role in decisions about their care (that is, they wanted to make decisions together with their doctor, or alone). There was no statistically significant difference from patients whose health literacy was assessed as adequate (Aboumatar et al, 2013). However, during the doctor's visit, people with low health literacy seem to experience participatory care less often.

In their scoping review, Malloy-Weir et al (2015) examined the relationship between health literacy and the stages of the individual treatment decision. The included studies are characterised by variable and partly contradictory findings that stimulate questioning of the apparently negatively charged association between low health literacy and participation (Malloy-Weir et al, 2015). The authors concluded that there is no comparability of the available studies. The reasons for this include the heterogeneity of study populations and, importantly, the theoretical problems of the survey measurement instruments for health literacy.

A patient survey in the US also showed no statistically significant difference in the shared decision-making between people who understood health information and those who reported difficulties in understanding (Wigfall and Tanner, 2018). However, the interest in the physician as a source and mediator of information is of particular importance for people with low health literacy (Smith et al, 2009). Further studies have shown that there is also no difference in communication between patients with high and low health literacy during their visits, except that patients with low health literacy ask fewer questions about medical aspects than patients with adequate health literacy, and they less look for additional information (Katz et al, 2007; Ishikawa et al, 2009; Aboumatar et al, 2013; Menendez et al, 2017).

In this context, one has to ask for the underlying reasons for people with low health literacy abstaining from asking questions, and if this puts a strain on patients. Several studies indicate that some patients are afraid of being judged for their questions by health professionals or have already had those experiences (Baker et al, 1996; Parikh et al, 1996; Easton et al, 2013; Protheroe et al, 2013). For example, patients with low health literacy may already have had stigmatising and discriminatory experiences, both within and outside of healthcare (Easton et al, 2013). Patients with low health literacy often do not even inform their own family about existing problems (Parikh et al, 1996). Out of shame or because they don't feel able to do so (Protheroe et al, 2013), they refrain from asking in-depth questions or pointing out their problems directly (for example, to mask difficulties in reading or understanding the medical information; see Baker et al, 1996; Parikh et al, 1996; Wolf et al, 2007; Easton et al, 2013). In turn, this impairs their wellbeing, relationship with their health professional and ability to manage themselves in the care process (Easton et al, 2013). Although affected patients wish health professionals to take this into account, they feel a deep sense of shame when they are tested for such problems and the information is kept in their health records, accessible and visible to all health professionals involved (Wolf et al, 2007; Easton et al, 2013). In addition, patients reported that they did not feel they had permission to ask questions; they saw a more passive, wait-and-see behaviour as part of their role, or did not have the desire to ask questions or even discuss the issue with the doctor (Smith et al, 2009; Protheroe et al, 2013). Another aspect is indicated by the finding that some patients, who are more likely to consider their health professional as a paternalistic figure, were satisfied with this situation as it met their expectations (Smith et al, 2009; Protheroe et al, 2013). Nevertheless, they attached importance to a trusting relationship with their doctor, in which they are perceived and respected as a person (Smith et al, 2009).

The reasons patients were not looking for information outside of their doctor's visit included that they had difficulty reading or understanding written information, felt well informed by their health professionals or simply had no interest in continuing to deal with it (Protheroe et al, 2013). In some cases, they resorted to their own social network as a source of information (Smith et al, 2009; Protheroe et al, 2013). This suggests that they are less critical towards the assessment of the quality of different sources of information (Smith et al, 2009). Patients with low health literacy also report frustrating experiences in navigating the healthcare system (for example, dealing with complicated appointment systems) (Protheroe et al, 2013).

Overall, it cannot be assumed that patients with low health literacy are not interested in active participation. However, they may have other preferences about the form of collaboration with health professionals instead, and these must be negotiated in the participation process. In order to explore further interaction between health literacy and patient participation, it seems helpful to consider the possible significance of the two concepts in the individual phases of healthcare, since people with low health literacy carry their experiences from everyday life as well as their biography into this interaction. At the same time, it may help to examine the phases and situations before and after the interaction with the health professionals. Therefore, in the following, the conceptual relationship between health literacy and participation is discussed.

The conceptual relationship between health literacy and participation: a model design

The earlier presented findings on participation and health literacy indicate that it is difficult to strictly define separate fields in which health literacy and participation can be significant. Figure 40.1 illustrates the possible interaction between health literacy and participation in the healthcare setting. In the following, each of the phases is described in the context of health literacy and participation: (1) dealing with one's own health; (2) visiting health facilities and contact with health professionals; (3) coping with the disease or the health challenge; and (4) healing or continuation of healthcare. This preliminary model was inspired by the phases of the progression and coping with chronic illness as introduced by Corbin and Strauss (1988) and the models of Ishikawa and Yano (2008) and Kamei et al (2017), aiming at health literacy and participation in healthcare.

Dealing with one's own health

The person in his or her environment

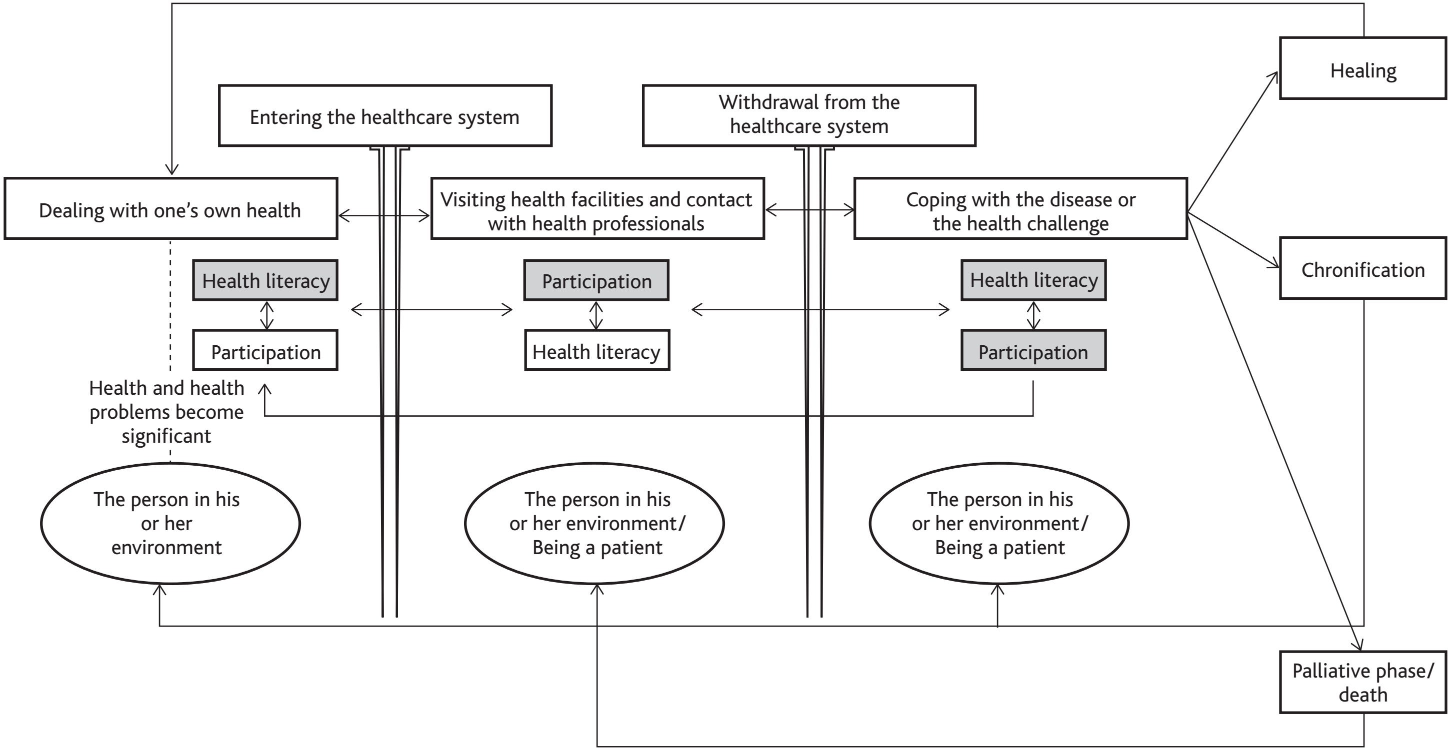
At the beginning of the process, as presented above, one must consider that the person is socially embedded in his or her own environment (see also Chapter 37, this volume). As such, the person is characterised by needs and values such as physical, social, psychological, spiritual, moral and relational needs. Their everyday life is shaped by various aspects such as work, social relationships, education, religion and biographical experiences.

On a practical day-to-day level, one's own life can be marked by beneficial and harmful influences on health, such as the health behaviour (for example, smoking, lack of sleep) or external influences that affect the person's living situation (for example, exposure to fine dust and noise). Nevertheless, at this point, active engagement with one's own health does not have to be at the forefront of daily life or even an active effort to do something in favour (or against) one's own health. This is where health literacy comes in, with the aim of preventing the onset of diseases and creating an active awareness of the maintenance and promotion of one's own health. It is important to note that, prior to entering the healthcare system, the person may have rarely or never had contact with the system before due to health problems.

Health and health problems become significant

An active confrontation with one's own health can now take place in different ways. On the one hand, in the context of prevention and early detection measures, a person can consider contacting the health system (for example, for vaccinations, dental check-ups). On the other hand, a person can also perceive a change in his or her health status (for example, he or she feels symptoms that cause discomfort).

Figure 40.1: Conceptual relationship between health literacy and participation in the healthcare setting



It could be the first time or a re-occurrence of a temporary or chronic disease of varying degrees of severity. Each situation poses different challenges for a person to recognise and interpret their complaints and decide whether they require examination or treatment (for example, persistent fatigue, constant thirst); possible self-treatment (and know how to carry it out); or a visit to a health professional (and know the right professional contact person or how to find a suitable health professional in their own environment and to get access). In other cases, if, for example, an emergency situation arises, these considerations must be taken into account much more quickly or other steps taken. This also includes knowing or recognising that a self-treatment attempt beyond the first aid treatment is not appropriate (for example, in the case of signs of a heart attack or stroke).

It is apparent that, in this phase, a person's health literacy can play a particularly important role in actively entering the healthcare system when dealing with one's own health. This includes, for example, knowledge and finding information about health protection measures, symptoms and how to contact the right health professional.

Participation is reflected most significantly at the level of social participation (for example, in terms of access to information channels and high-quality information, such as free access to evidence-based information, and also in terms of access to the healthcare system itself).

Visiting health facilities and contact with health professionals

If the person enters the healthcare system, this is usually done by visiting a health facility (for example, a doctor's office or a hospital) and/or by contacting a health professional (for example, a doctor or nursing staff). Additionally, the person now assumes the patient's role. Depending on the patient's concerns and state of health, decisions are required related to necessary examinations and treatment, and possibly also regarding nursing and social support. It may be necessary to develop and negotiate lengthy and complex treatment strategies and care packages. Sometimes, however, there is also a reciprocating interplay between the phases (for example, between an examination, self-observation of the patient and a new examination).

The availability and comprehensibility of information, which is a crucial component of health literacy, are also important factors when interacting with health professionals and health facilities. However, the opportunity for participation is particularly important in this phase, including participation in (informed) decision-making and physical participation. In this context, a prerequisite is to focus on the patient's values, preferences and priorities, and to consider the patient's living, health and social situations, which may be affected by the individual's environment as well as experiences of the patient as a person. The health literacy-specific need for independent search, retrieval and evaluation of information by patients should not be necessary (for example, to understand symptoms, a diagnosis or treatment options), as these should now be presented in an understandable way by health professionals.

Coping with the disease or the health challenge

The possible temporary or permanent withdrawal from the healthcare system is linked to coping with the disease or health challenges, but the role of being a patient can be continued. This means that the patient is no longer in direct physical contact with health professionals and/or institutions. However, the healing process or dealing with a chronic illness in everyday life is ongoing, and must now be handled by the patient and his or her relatives in a self-management arrangement (for example, the use of drugs). An interplay with the preceding phase is possible (for example, in complex and protracted treatment processes, such as for oncological or cardiovascular diseases).

In this phase, the importance of available information and the ability to apply these is increasing, and thus the importance of health literacy. Participation plays a major role, especially at the level of social and physical opportunities. It can be assumed that previously experienced participation in decisions on one's own treatment and the shaping of the life situation can increase the motivation and willingness to apply these.

Healing or continuation of healthcare

If a patient can be cured of his or her health problems, he or she will return to his or her original environment. It may be possible that the person will retain an increased awareness for their own health, at least temporarily. On the other hand, patients with chronic diseases may also enter this phase while being in a symptom-free state of their condition (for example, chronic skin diseases or allergic respiratory problems). However, in the case of severe diseases, persistent need for long-term care or even terminal phases of life, direct contact with health professionals can often remain almost permanently. In this enduring state of patient–provider interaction, it will require a constant exchange of information with the health professional, decision-making and shaping of participation, while all of which will need to be adapted to the changing health conditions of patients.

Résumé

Although this model should be empirically tested and refined in future research, first, it can already be used to highlight three key aspects related to the relationship between health literacy and participation:

- It highlights the different phases of healthcare that a person can pass through and possible linkage as well as the dominating forms of health literacy and participation in each of these phases. This leads to overlaps and phase-wise alternating prioritisations. The greatest overlap lies in direct interaction between patients and health professionals, while at the same time, most of the friction can be located here.

- It emphasises that the person is embedded into his or her environment and biography, which is maintained throughout the entire healthcare system, irrespective of whether it is a matter of a health literacy or participation concept. This is intended to create an awareness that the experience and action of patients in dealing with health and care situations is characterised by a complex, comprehensive context that can only be considered in part in most studies. This 'daily life' is characterised by individual priorities (for example, securing livelihoods) and previous experience outside the healthcare sector, such as stigmatising one's own abilities.
- The model provides an opportunity to comprehend participation also as a prerequisite to facilitate health literacy. This is not based on a linear process, but rather on a dynamic cycle in which both concepts stand in a mutually reinforcing and weakening interplay.

It seems that the interaction between health literacy and participation runs through the entire healthcare system and focuses on overlapping processes. However, empirical findings to date are concentrated on a relatively small part of the system. There are still gaps to be filled in the perspectives. The key challenges that arise are addressed in the following section.

Perspectives for further development

While health literacy primarily addresses how people search, find, understand and evaluate health information (Sørensen et al, 2012), participation goes beyond the individual abilities to deal with health information. Participation focuses on access and interaction in healthcare processes in order to facilitate the involvement of patients in decision-making and their self-determination (Collins et al, 2007).

All this argues in favour of retaining the conceptual separation and sharpening the concept boundaries of participation and health literacy in order to make them empirically comprehensible. Indeed, possible incompatibilities with the health literacy concept seem to appear, which are considered in the following section.

Locating health literacy in further development: a ground-breaking decision

Health literacy is about the prerequisites that a person requires in order to make decisions that promote their own health (Sørensen et al, 2012). It seems to be very common that patients are categorised according to their level of health literacy. There are attributions such as 'insufficient', 'problematic', 'sufficient' and 'excellent' health literacy or 'limited health literacy' (HLS-EU Consortium, 2012; see Chapter 8, this volume). Such approaches bear the risk of stigmatising affected people and even entire population groups by strongly associate them per se with bad skills (Batterham, 2016). Low health literacy is viewed as a deficit of the patient, suggesting that they only need to learn to become capable in order to navigate through the healthcare system competently. In addition, a decision that is not the 'healthiest choice' from the health professional's perspective, however, might suit best from the patient's perspective their overall life situation and wellbeing, seems not to be considered in health literacy concepts. Patients should strive for well-informed, independent and healthy decisions while they are denied the competence to do so in case their decision is not matching a pre-defined health standard. This is somehow contradicting the genuine idea of participation, since the promotion of the patient's self-determination and freedom of choice, both core principles of available participation concepts, seems not to be possible as intended. In this context, there seems to be a mismatch between the aims of health literacy and participation. Therefore, the link between health literacy and participation cannot be sustained if patients are not offered the freedom of choice to take whatever decision they understand to be the best for themselves.

This chapter highlights that health literacy and participation can be linked, but depending on the health literacy approach, either risk- or asset-based, it seems more or less meaningful, respectively. The risk-based concept facilitates health literacy as a paternalistic approach, aiming at compliance by getting patients to follow recommendations and decisions that health professionals consider appropriate (Nutbeam, 2008). Whereas this approach is already being used in healthcare research and practice, it is somehow contradicting the fundamental idea of participation. The asset-based concept of health literacy instead is much closer to the meaning of participation, as discussed within the scientific literature. Therefore, if the asset-based concept of health literacy was applied in the healthcare context, health literacy and participation could be used as a resource that recognises the right to self-determination and autonomy of patients, and supports patient-centred healthcare. The potential for further development of this kind of 'health literacy and participation approach' lies in the proportionate support of people with complex health needs and/or in challenging life situations. This approach would also require considering the complex interplay between the living environment, health context, individual health literacy skills and the abilities of health professionals, all of which influencing the whole care and participation process.

Enabling patient participation to promote health literacy

Although participation and health literacy are much debated concepts, to date, their relationship is hardly investigated and not much is known about how or if patient participation may influence health literacy (Malloy-Weir et al, 2015; Kamei et al, 2017). There are some research findings indicating that participation may have beneficial effects on certain health literacy relevant skills, including the improvement of knowledge, an increase in self-perceived control and a better understanding of the disease (Joosten et al, 2008; Coulter et al, 2015; Stacey et al, 2017). However, this assumption has far-reaching consequences on participation processes and the development and delivery of patient information. By letting patients participate, their personal preferences and priorities could be asked for, and could then support both developing user-friendly and patient-shaped health information as well as their successful uptake by patients. Moreover, including and using patients' voices in this process would also ensure that information is patient-centred, reliable and shaped to their needs and demands. At the same time, participatory experiences, such as involvement in decision-making, taking part in discussion and mutually determining action, could encourage patients with low health literacy to ask questions and express their needs, wishes and comprehension problems. By supplementing such an approach, health literacy could take greater account of social processes and the classification of information into the subjective realm of life.

Empowerment of health professionals and health facilities to provide health literacy-based patient information and counselling

All these trends point to another critical aspect that the health literacy concept should address. Currently, health literacy approaches often involve that responsibility for good or bad health is shifted towards patients. However, the other side of the coin that should also be considered is that health professionals with inadequate communication skills, incomprehensible information material and forms, under-resourced structures in health facilities, complicated access routes and long waiting times for healthcare are, in turn, symptoms of weaknesses of health systems. Patients' difficulties in finding and navigating their way around should not be attributed to the alleged lack of their skills. Assuming inadequate health literacy in this case hides problems in the health system and leaves people seeking help alone. Therefore, it is also important to consider the limits of the shift in responsibility and its feasibility.

Future research and action should focus more on improving the health literacy of health professionals and health facilities and their responsiveness to participatory approaches. They must be able to provide and communicate information in a way that is tailored to the needs of patients and geared to their abilities and interests. For this purpose, for example, methods of communication such as plain language, teach-back methods and person-centred communication are already available from related areas. In the best case, a compatible promotion of health literacy and participation would lead to the development of more user-friendly health systems and professionals with both aiming to best serve the needs of their patients.

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A lifespan perspective on health literacy: Ageing and end-of-life issues

Barbara K. Kondilis

Introduction

Developmentalists group late adulthood and older groups in slightly varying age groups as understandably this may change numerically or linguistically, varying by culture or society. This chapter focuses on the normative developmental process of ageing in the context of health literacy, utilising literature and anecdotal examples, and perspectives from those who care for our very valuable older population. Those who are older, in particular, the frail elderly, suffering from poor physical and mental health, or who have other co-morbid chronic diseases, access more services (including A&E), accumulating higher costs (see Chapter 10, this volume). Leaders in the field have promoted broader more ecological models of health literacy, although by and large these mainly apply to adults (Kickbusch, 2001; Kerka, 2003; Zarcadoolas et al, 2005, 2006; Nutbeam, 2008; Freedman et al, 2009; Sørensen et al, 2015). There is little published literature addressing health literacy across the lifespan, particularly towards the end of the life cycle. No matter what culture, subculture or country one is from, it is clear that similar issues ensue. Health literacy affects all, from economically disadvantaged and other marginalised groups, to anyone who accesses healthcare in person or online. Our ageing population is both cherished and at times a somewhat neglected group. Future generations can benefit from interactions with older groups, finding ways to support elders, and better understanding the concepts of death and dying. This in turn builds more positive and healthier communities. It is clear that collaboration, improving communication, highlighting community strengths, being inclusive of varying perspectives, can extend through the end of the life cycle, benefiting all in both the short and long term:

> Growing old can be a matter of growing deep. It doesn't always happen, but the opportunity is there. (Moore, 2004, p 300)

Overview

A lifelong learning perspective can enhance our understanding of the various competencies acquired over the lifespan, how they interact and, most importantly, how they are likely to contribute to improvements in individual and population health, a reduction in health disparities, potential monetary gains in governments that promote health education and health promotion, and intergenerational gains for overall health. Regarding the ageing population, the defined age groups include the young old (60-75), the old (75-85) and the oldest old (85 and older). Aspects of chronic health issues are highlighted in the context of the groups addressed in this chapter (for chronic disease and health literacy, see Chapter 12, this volume). The aim of this chapter is to address perspectives and related health literacy interventions with a particular focus on ageing, death and dying issues. Health literacy is seen beyond an individual-level issue, as a social or community-level issue. How we define 'ageing' or use language to address the concepts of disease, the challenges faced by caretakers and the overall grief and bereavement process at the end of life is emphasised.

Ageing and end of life: related interventions and perspectives

There is little published literature addressing health literacy across the lifespan, particularly towards the end of the life cycle. A systematic review of eight articles, all relating to urban settings in the United States, conducted by Chesser et al (2016), reported significant associations between low health literacy and poorer health outcomes, mixed findings in the associations between medication management and health literacy, whereby the authors emphasise a 'need for a standardised and validated clinical health literacy screening tool for older adults' (2016, p 1). However, this and other related research, leads one to question whether medical models traditionally focusing on 'evidence' in the US (Payer, 1996) can or should apply throughout the globe, or whether sharing perspectives and looking at things from a grey zone can contribute more effectively with less burden on healthcare professionals and systems. Notably, the burdens of economic crises (Kentikelenis et al, 2011), overburdened staff and medical mismanagement, whether public or private settings, have largely negative consequences in health-related outcomes, infrastructures and societies (Dunbar et al, 2011).

The strengthening of social capital, which is building networks (formal or informal) at individual or community level for social gain, is one area that several studies looking at adult populations focused on (Black et al, 2013; Yang et al, 2013; Kim et al, 2015). These studies demonstrate the benefits of building social capital including two large-scale Asian studies of over 1,000 people each in the respective countries of South Korea and Taiwan. Specifically, the South Korean sample demonstrated that social capital could attenuate the effect of low functional health literacy on health information resources, efficacy and behaviours (Kim et al, 2015). The study from Taiwan looked more closely at social capital networks, concluding that females and those with higher education have higher health literacy, as well as those they deemed to have 'higher health communication ability' based on a six-item scale that measured the ability to communicate in a clinical setting, with no differences found by age and income (Yang et al, 2013, p 900).

The human development field and specifically the *lifespan perspective*, from pre-birth on, helps us better understand age-related changes in our behaviour, thinking, emotion and personality development (Boyd and Bee, 2012). Both personal and collective *health literacy* can be viewed as an interactive dance and the importance of our social and work-related environments as key issues in public health (Nutbeam and Kickbusch, 2000; Kickbusch, 2001; see also Chapters 14 and 23, this volume). The oldest old is the fastest growing in advanced economies like in the US, and there are challenges related to health literacy such as the quality of healthcare (Parker et al, 2016). It is clear from existing data that those who are older, particularly the middle aged to the elderly, and those who suffer from poor physical and mental health, access more services including A&E, often have other co-morbid chronic illnesses, and accumulate higher costs in already economically disadvantaged societies, including those in economic crisis (Kentikelenis et al, 2011; Lahana et al, 2011; Kondilis et al, 2012, 2013; Simou and Koutsogeorgou, 2014; Sørensen et al, 2015). Overburdened systems and a lack of resources can lower the quality of care, the spread of hospital pathogens, medical personnel likely burn-out, which in turn leads to medical mistakes and the likelihood of patient death, as best described in *Deadly healthcare* (Dunbar et al, 2011).

Some projects specifically focus on ageing and improving health literacy, such as the European 'Intervention Research on Health Literacy among Ageing Population' (or IROHLA programme), looking at the population aged 50 and above (EuroHealthNet, nd). IROHLA launched in 2012, reviewed ongoing health literacy programmes and projects, and identified and validated a set of 20 interventions or evidence-based guidelines, in what they indicate is part of a comprehensive approach for addressing the health literacy needs of the ageing population, with 22 European partners – a multidisciplinary group including universities, public health agencies, organisations representing older people, healthy cities, companies and businesses. Examples of the IROHLA health literacy focal points include computer literacy or digital literacy (for example, using computer and software for practical tasks), cultural literacy (understanding similarities and differences in customs, values, beliefs of one's own culture and the cultures of others), financial literacy (ability to understand and take adequate actions in budgeting, accounting for income and expenses), information literacy (ability to know the need for information and to be able to identify, locate evaluate and effectively use this information), media literacy (informed, critical understanding of the mass media) and visual literacy (ability to understand and produce visual messages) (see www.irohla.eu/about/health-literacy).

Similarly, the American Association for Retired Persons (AARP), in a blog post by Flowers (2015), indicates that low health literacy costs billions to the medical system, and lists several priority areas for older adults, including making wise insurance coverage decisions, navigating the healthcare system (including filling out complex forms or locating providers and services), sharing personal information such as health history with providers, engaging in self-care including chronic disease management (indicating that four out of five older adults suffer from at least one chronic condition), and finally, taking medications correctly.

These projects can also provide valuable information for countries with ever-changing population landscapes due to globalisation, as indeed 'advancing health literacy' continues to be the global challenge for the 21st century (Nutbeam and Kickbusch, 2000), and notably even more so for immigrant or transient groups.

Psychotherapist Thomas Moore, author of several therapeutic and self-help-oriented books, talks about the concept of age and 'ageing' in his book *Dark nights of the soul*, specifically, the concept of age being what we imagine it to be and that ageing is not imaginary – it is real, although we should not lose touch with our youth (Moore, 2004, p 290). The desire for younger people to be older or older people to be younger sometimes leads to quests for the fountain of youth, some focusing only on death, and with ageing, besides failing physical strength, there is an entire world of feelings, images and thoughts that can lead to greater powers of mind and imagination. In discussing living 'more vigorously with an open heart' (Moore, 2004, p 300), Moore states the experience in many older people of melancholy that 'often characterises aging', but it is only a tone of everything one does and it is not the same as depression (2004, p 295). He refers to the life review, mirroring the Eriksonian theory of psychosocial development for older adults and the stage of 'ego integrity versus despair', where those who achieve ego integrity must come to terms with who they are and have been, how they lived their life and the choices they have made, as well as opportunities gained or lost (Boyd and Bee, 2012, p 460). Moore (2004, p 299) reminds us that one of the greatest things we can do as human beings is to 'raise a child who is happy and wise', and be good neighbours and involved citizens. One could argue that this is reflective of the relationship between the micro and macro levels when we talk about 'building' health-literate societies, although this is not explicit in any of the texts discussed here.

The burden of caring for the sick and ageing, having proper living arrangements in the later years and access to appropriate care cannot be ignored from the ageing and health literacy equation – all these factors are influenced by an individual's ability, their resources (social, financial), societal viewpoints and policy. Cultures strong in filial piety, the belief in the duty to care for elders, may also be influenced by their financial situations and the eventual adoption of more Western-style government programmes for the elderly (Boyd and Bee, 2012). More elders in countries where they are not restricted to work past a certain age are currently choosing to work after retirement (Boyd and Bee, 2012), and according to the Society of Actuaries' (2011) 2007-11 report, out of those interviewed, about 45 per cent indicated they do not expect to retire, and it seems the reasons are to mostly prevent a drastic decline in their living standards. As societies we need to account for phenomena such as economic crises where younger people have to work long hours, emigrate to other countries or regions to work and cannot care for their elders themselves, and restrictive economic policies can lead to a drastic reduction in all government spending, limiting access to care and increased health risks (Kentikelenis et al, 2011; Kondilis et al, 2013).

Challenges and opportunities of contemporary society

To live well in our contemporary and ever more global society requires having competencies in a range of literacies, among them reading literacy, computer-technological literacy, financial literacy, science and civic literacy, to name a few. This is often referred to as the field of 'new literacy studies' (Gee, 1991; Street, 1995, 2003). As contexts and culture may vary, so do the effects of different literacies under differing conditions (Street, 2003; see also Chapters 36 and 39, this volume). Ageing and the seeming 'digital divide' (Sarkar et al, 2011) may prove that those who have higher competencies in the afore-mentioned literacies may have an advantage by being knowledgeable and using technology (from computers to smartphones), although having access does not necessarily assume one will be 'successful' during one's older ageing years, physically or socially. The European Health Literacy Survey (HLS-EU) data collected across eight European nations indicated that those aged 50+ who are less educated, and those who perceive their health as 'bad', have lower overall health literacy (Sørensen et al, 2015; see also Chapter 8, this volume). Contrarily, in smaller 'cultures' (cultures within cultures), those living in small towns or villages, who may have better diets or even better genetics, live longer and happier despite their ailments, such as on the island of Ikaria, Greece (see Buettner, 2012). This example and countless more provide proof that the combination of genetics and the environment play a role in successful ageing, hence the lifelong debate of nature versus nurture (Boyd and Bee, 2012). Perhaps they were thinking of Odysseus' journey and his return as an older man to his island of Ithaca, as the EU has an 'ITHACA' project with nine European Regions on healthy ageing, to share experiences and 'good practices on smart health and care innovation, with the aim to improve active and healthy ageing of the population' (see www.healthyageing.eu/projects, para 1).

If researchers address the possible 'divide' in education on health literacy (Kickbusch, 2001), calling for increasing our education for improved health literacy in schools (Marks, 2009, 2012; McGovern, 2010; see also Chapters 2 and 34, this volume), then why not advocate for better understanding of generational issues and basic developmental tasks of older people as a way to improve relations and mitigate health outcomes? Granted, for many countries, there is no systematised way of doing things, and it seems that younger people are aware they need more general health education for both communicable and non-communicable diseases, including nutrition issues (Vardavas et al, 2009). The field of developmental science currently integrates genetic aspects, neuropsychology, neuroanatomy and clinical psychology in addressing developmental groups; and educational institutions have specialties in 'applied developmental psychology' where besides research and interventions, practitioners, organisations and political decision-makers are provided with fundamental knowledge with an emphasis on 'prevention' for such areas of child development, family and health (Freie Universität Berlin, nd).

Typical health issues resulting from the natural ageing process include loss of biological functions such as sight, hearing, possible dementia or loss of working memory and what are termed 'cognitive challenges', as well as an overall decrease in reflexes which, in turn, can affect behaviours (Baltes et al, 1999; Boyd and Bee, 2012; Chesser et al, 2016). These changes should keep us in tune with our policies, in re-evaluating our procedures for how to handle such issues as having an elder re-take a driver's licence exam after a certain age, particularly if there was any documented careless driving, even for the Queen of England herself (Epstein, 2015). Social and personality development issues in the older years focus more closely at activity, disengagement and overall maintenance of one's health. The importance of trust in the healthcare profession and better communication practices in the delivery of health information for many diseases, including chronic diseases more common in older age, are the topics of several articles and books (Schillinger et al, 2003; Taylor, 2009; Candlin and Crichton, 2013; van Wert, 2017). Issues leading to distrust of the system, where medical personnel are overworked, often making medical mistakes that prove fatal to patients and particularly older population groups, need to be continuously addressed in communities at large (Dunbar et al, 2011).

Positively, on the psycho-social side, multiple studies prove that those who have better coping skills, have strong religious beliefs or spiritual orientation, actively use their support systems and receive support towards maintaining their health or dealing with a chronic health issue like diabetes (for example, via self-management) have better health outcomes (Schillinger et al, 2003; Taylor, 2009; Boyd and Bee, 2012). Rowe and Kahn (1998) indicate that the 'successful ageing paradigm' has three components including good physical health, retention of cognitive abilities, and continuing engagement in social and productive activities, and another aspect of successful ageing is a subjective sense of life satisfaction. Although some have criticised this paradigm as leading to potential ageist stereotypes, the overall view is that for gerontological research the paradigm has broadened how the latter study old age (Boyd and Bee, 2012). Could this not be enhanced if people have higher health education and higher literacy? We can certainly glean that these people, regardless of culture or socioeconomic orientation, likely have a more positive health literacy baseline.

Notably, the constant strive, or some would say 'need for evidence' particularly showcased in US culture (Chesser et al, 2016), may miss aspects of a more holistic approach to dealing with disease-related issues, where there are possible 'grey zones', especially in issues of trust-building between individual healthcare providers and their patients (Candlin and Crichton, 2013). There are clear advantages to improving health literacy both on the communication and decision-making front that include cost savings and improving the satisfaction of patients and providers (Chesser et al, 2016). However, as medical journalist Lynn Payer emphasised in her book *Medicine and culture*, we need to examine our approach, the language we use and perhaps medical aggressiveness in how we diagnose, treat or prevent illness as 'taking something out rather than adding something to increase the resistance' (Payer, 1996, p 127), and how 'scientific' medicine takes over the rather 'unscientific' desires of the patient (1996, p 155).

When thinking about developing materials that are easy-to-read and that can relate to the ageing population, we need to think about pragmatics and text theory, which come from the field of sociolinguists. Zarcadoolas' (2011) article on 'the simplicity complex' calls for simplifying the language of health communication and health promotion materials as the challenge of the 21st century, referring to low literacy as the 'silent killer'. She refers to plain language theory and the history of functional literacy tests as well as readability, which was more popular in the US in the 1950s and 1960s, as gross screening tools. Although language may be simplified, this does not mean that the end user can 'decode' the message correctly to understand what action they need to take for their health; researchers need to integrate knowledge from the fields of health communication, linguistics, social psychology and adult education, among others, in a dialogue about health literacy, in discussing how new media and human factors engineering can contribute, as well as practical application for communicators (Zarcadoolas, 2011). Those with diverse health literacy apparently process text and picture passages about self-care topics differently, as a study on older adults with hypertension revealed (D'Andrea, 2010). Although a small sample of 41 older adults in a community in Illinois, US, this study found that health literacy was related to the total time spent during the first read of text, and at the points of processing the higher knowledge, individuals (with higher health literacy) were better able to differentiate between relevant and irrelevant pictorial information; the researcher indicated that this may be useful in the design of multimedia documents for this target population (D'Andrea, 2010). Past studies have focused on the importance of readability and access of printed material such as health pamphlets distributed to patients in hospitals and health centres (Kondilis et al, 2010). Furthermore, easy-to-read health information for consumers of special groups such as those on Medicaid (Root and Stableford, 1998) confirm that older people have lower health literacy as compared to younger people (Rudd, 2007).

The internet is becoming increasingly popular as a source of health information, and large-scale datasets from sources like Eurobarometer track usage – when comparing several European countries those in Northern Europe use the internet as an important mass media source of health information while this is less common in Southern European countries, although the use of the internet for health information is clearly now on the rise (Kummervold and Wynn, 2012). E-systems can help personalise patient records as a way to help doctors both track and communicate better with their patient's part of the 'patient-centred' movement (Krist and Woolf, 2011). Furthermore, more advanced systems look at organisation-wide changes for improving healthcare settings and systems oriented for more effective interventions or treatment, such as having shared medical appointments/group visits for helping those with chronic diseases like diabetes better manage their conditions (Krish et al, 2008), since we know older people tend to be more 'forgetful' special attention will be particularly helpful to this group.

Osborne (2005) provides strategies and suggestions that evolve around better communication of messages to several categories of patients including special groups like those who are deaf and hard of hearing, promoting Health Literacy Month (in October), which addresses several issues including risk communication, the internet, using short stories and narratives to better communicate with patients. This is validated by van Wert (2017), who discusses the importance of storytelling with elder patients whose families are both trying to find appropriate treatment and alternatives, seeking options for care such as palliative care consultation, and generally navigating the healthcare system during illness and the end-of-life stage. Looking to the family as a way to assess the patient's health literacy abilities as well as decision-making and developing and adapting transition planning tools as part of the Transitional Care Model were presented in Nishita and Browne's (2013) paper, which are useful for those experiencing caregiver burden and/or a high number of hospitalisations. Furthermore, if we were called to teach health literacy in school health promotion starting with the new millennium (Peterson et al, 2001) and beyond (McGovern, 2010), we also have a responsibility to promote health literacy to all levels of caretakers and healthcare providers working with families and their older clients and patients.

A married woman in her early forties, discussing her ageing parents, commented:

> 'Both sets of our parents on both sides have many chronic health problems. They don't "listen" necessarily to what their children tell them, I think they are fighting the idea of getting old … their doctors confuse them with too much information about their medication. How can they remember everything? We can't even do it and we are younger! They often forget since their mind does not work the same as when they were younger … they have complicated treatment issues, they have to think of things like their diet and medication, and if they don't have caretakers like us, they don't do well and everyone suffers. I wish that healthcare professionals would figure this out … my father fell and hurt himself because he doesn't want to wear his glasses. He didn't see where he was going on a sidewalk [pavement] which had many potholes. My mother-in-law fell last week and did not want to tell us to not get us upset, and she doesn't have support and lives far from us in a rural area. It's hard.' (personal communication with M. Gerakoulakou, 17 December 2017)

Death, dying, grief and bereavement

If you bring up the concept of 'death', you may be met with stares and often superstitions, even fear in bringing the issue up, but this is an inevitable part of life. Dealing with loss is not a new phenomenon in research; grief is a normal emotional response to loss and death, and this feeling, along with others, can be intensified with the death of a loved one. Kübler-Ross (1969), in her initial work with cancer patients, suggested that loss and grief counselling is a field in clinical psychology that deals with helping individuals cope with the emotional pain in order to return to their normal development. The therapy techniques mostly focus on helping people understand the normal stages of the grieving process, and provide them with the necessary support while they go through mourning. Kübler-Ross (1969) suggested the 'five stages of the grief cycle', including denial, anger, bargaining, depression and acceptance, although a person may not go through these stages in this order. Other thanatologists (those who study issues related to death) have created similar stages and also bring up the issue of pathological grief, a set of depression-like symptoms following the death of a loved one for more than a period of two months, which some call 'post-trauma' (Gerrish et al, 2009). The recommendation is to diagnose and treat this condition to prevent additional mental and physical health issues, including long-term depression or even suicide, particularly for widows/widowers (Boyd and Bee, 2012). The issue of coping is of particular concern for younger people including adolescents, since researchers indicate that coping may be more difficult for them, and may have a significant lasting disruption if it is not dealt with adequately – the selective memory of events associated with loss and management of memories may prevent one's normal development stage (Jacobs et al, 2000).

One cannot overlook the idea of cultural traditions and rituals as ways to support those individuals and groups better cope through the grief cycle. Cultural traditions involve *rituals*; this is generally defined as repetitive social practices, which differs from typical daily routines. There is a type of ritual schema that often have roots in myth and religion, although some rituals such as birthday parties are not religious in nature but very much part of a cultural norm (Schultz and Lavenda, 2009). Various cultures around the world still practise rituals that involve ancestor worship and may even involve sacrifice (usually of an animal), elaborate burial ceremonies and the preparation of specific food dishes – these hands-on practices are called 'mourning rituals' and some transcend through ancient times (Schultz and Lavenda, 2009).

Furthermore, the physical burial space reflects the religious and cultural traditions of the times, with respective statues, symbols and physical material such as marble or stone used for grave markers or 'tombstones' in cemeteries throughout the world. Cemetery records and headstone inscriptions are sources of birth and death information for future generations, and also for historical records of how death was recorded (see www.ancestry.com/wiki/index.php/Cemetery_Records). The images that follow include traditions from ancient to modern Greece, and colonial times in the US (see Figures 41.1, 41.2, 41.3).

Figure 41.1: Ancient female mourners, Crete, Greece (Archaeological Museum of Chania, Crete)

Source: Photograph taken by B. Kondilis (2016)

Figure 41.2: Ioannis Poulakos family grave, Laconia, Greece

Source: Photograph taken by B. Kondilis (2017)

Figure 41.3: Lexington Cemetery, Lexington, Massachusetts, United States

Source: Photograph taken by B. Kondilis (2017)

Interestingly, some artefacts place more emphasis on the cause of death (colonial Lexington), others on the emotional consequence of death (the mourners of Crete), while others are familial personal images or religious cultural symbols.

Transitional care is gaining more attention in research literature, as it relates to specific cultures and elders and making healthcare decisions (Nishita and Browne, 2013). This may involve getting support both within and outside the home, and for those who have long-term dehabilitating or terminal illness it may be necessary to prepare the family and caretakers for potential loss (Boyd and Bee, 2012). Furthermore, caretakers may suffer from potential burn-out, referred to as ‘caretaker burden’, if these individuals are not doing enough self-care; it is likely, for example, for those elders who lose a spouse to suffer themselves from an illness as their immune system may be compromised – the first two years are critical after a loved one’s passing (Boyd and Bee, 2012). Understanding the stages of death, preparing for death if possible, may allow people to handle end of life in a more ‘health-literate’ way. A counselling psychologist who has been working for over five years with clients on issues related to loss indicated, ‘when there is some knowledge about death and dying the therapy is shorter and is more effective … the goal is to get the client reconnected with life.… The building of trust is a fundamental major part of the counselling process’ (personal communication with A. Sgourou, 15 December, 2017).

Addressing the life cycle and related issues should be part of our formal and informal education. This knowledge and planning for action can better support caretakers, families and communities who are dealing with both cross-generational and intercultural issues, since advancing health literacy at the micro and macro level is a benefit for us all.

Discussion

The need for continued work regarding health literacy is clear, as is the long-term goal for healthier and better functioning societies, particularly for older individuals whose physical and mental functioning are at a natural decline, for those who have chronic health issues, who are marginalised, or who may have socioeconomic disadvantages. The need to emphasise cultural strengths is always a positive, and 'culture' can be defined by context and thinking about the health frames including the language we use. In turn these frames affect how we see ageing as a normative process and our need to evaluate any relevant policies or procedures and reinforce our individual and community education or re-evaluate policy. Caretakers and family members, community members, are natural resources for healthcare providers to tap into, focusing on patient-centred approaches, and looking to transitional care as options for people and their loved ones.

Patients/clients and their family/caretakers can benefit from increasing their own health knowledge base, obtaining the support that is available to them, whether real or virtual from the online world, including any professionally trained people they may access. On the other hand, healthcare providers, educators and other related administrators must keep up with health education efforts (disease prevention and health promotion) for all ages and at all societal levels, not excluding policy. Non-governmental organisations in countries can be of particular help to both economically disadvantaged and other marginalised groups in accessing care, working on chronic health issues, building networks for better collaboration and highlighting community strengths.

Keeping positive short and long-term outcomes in mind is part of our investment in building and assessing health literacy. Notably, both a physical and philosophical long-term 'investment' benefits everyone involved. The strengthening of social capital at individual or group level, regardless of current economic situation or country of origin, can seemingly improve health literacy for better outcomes. This will, in turn, positively affect both caretakers and future generations.

Conclusion

The ageing process as well as intergenerational issues on the inevitable stage of the end of life go hand-in-hand with related sociocultural practices and ramifications, as societies continue work on building and supporting health literacy across the lifespan. The role of the caretaker, whether in private or public settings, individual or collective, online or face-to-face, in helping people access information and care, as they transition to end of life, is key. This chapter has addressed some of the issues involved with older individuals whose physical and mental functioning are at a natural decline, in particular for those with chronic health issues, those who are marginalised or those with socioeconomic disadvantages.

Health literacy is not only a focus on the individual, but also at the social or community level. We cannot deny that the elderly benefit all societies by sharing their knowledge and experience, and in turn they also benefit from a more open, supportive and well-functioning society. Thus, the interplay of the micro- and macro-levels, continued support for health promotion and disease prevention, the constant strive for improving patient–provider relations, building networks in social capital, infrastructure and re-examining policy, these can all work towards enhancing health literacy across the lifespan.

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42

Salutogenesis and health literacy: The health promotion simplex!

Luis Saboga-Nunes, Uwe H. Bittlingmayer and Orkan Okan

Introduction

By introducing the Ottawa Charter for health promotion (WHO, 1986), the World Health Organization (WHO) not only changed the public health discourse, but also emphasised new perspectives on personal skills needed for promoting health and wellbeing over the life course. While the Charter highlighted that health promotion is built on an asset-based approach towards health, aiming at enabling people to exert greater control over their life and health, the stream initiated by this drift has enabled two concepts to become the most important subject matters in contemporary international health research: health literacy and salutogenesis. The first is known to be the indicator of the so-called health-related personal skills introduced in the Ottawa Charter (Kickbusch, 1997); the latter, a health paradigm, a complementary approach to the traditional pathological biomedical vision prevailing in the healthcare context (Antonovsky, 1987).

When examining the scientific discourse around health literacy, we are surprised to see that while scholars have been extensively discussing the 'literacy' component of the composed term 'health literacy', discussion of the 'health' element is hardly to be found. Nevertheless, the rich and ongoing discussion on literacy has intersected health. Today, broad literacy concepts addressing functional, interactive and critical literacy are added to the health literacy discourse, giving way to multiliteracies and social literacies to merge with health literacy (see Chapters 14, 18, 36 and 39, this volume). This was not only the impetus for multiple research strains that broadened the theoretical and conceptual discussion, but also facilitated the uptake of health literacy by various research disciplines, such as healthcare, medicine, public health, education, psychology or sociology. In turn, this was fuel to the very engine driving the development of health literacy. Given the fact that discussing one component of health literacy in this detail has had tremendous benefits for understanding the concept, exploring the other part with similar consideration may extend the concept's frontiers and expand the conceptual discussion surrounding the asset-based characteristic of health literacy that is already being discussed. Whereas the health literacy community provides many different definitions and models – also depending on the underlying scientific discipline (see Chapters 1 and 2, this volume) – basically health literacy is about searching, understanding, evaluating and using information to promote health and making informed health decisions (Nutbeam, 2000; Nielsen-Bohlman et al, 2004; Sørensen et al, 2012; Malloy-Weir et al, 2016). This conceptualisation is supported by almost all available models and definitions. However, more dimensions and components are associated with the concept, and more discussion is needed in its context of health.

The need to rethink, and maybe also construct, the health component of the health literacy concept and its social representation needs to consider that health can be understood and approached in different ways. In this chapter the salutogenesis paradigm is the guiding health framework. In this context, Antonovsky's theory of the Sense of Coherence (SOC), serving as the core of the salutogenesis model, has emerged as a promising approach to deal with the complex topic of health today. The building process of the SOC is closely connected to the Generalised Resistance Resources (GRR), where health literacy can be included as a macro-social GRR. Defining health as the epicentre of the human fight against chaos (entropy) propels the individual to acquire or sort out characteristics that will enable them to make choices (from several options) that will determine either a decrease or a relative increase in their health experience towards the maximum ease. Health literacy can therefore play a leading role in a citizen's consciousness fight against chaos. At the same time, it can contribute to the understanding that there are no continuous and permanent increases in options towards the maximum ease, but that there is a finiteness in humanity, life, the planet and its resources.

The aim of this chapter is, therefore, to explore the health dimension of health literacy while health is approached from an asset-based perspective. As such, we find it most plausible to recognise the salutogenesis paradigm – including the SOC theory – to serve as this asset-based health approach. Health literacy is discussed and placed into the salutogenesis framework as a macro social GRR in the context of the building process of the SOC. This leads to the health promotion simplex – an effort to bring the complexity of health to simple terms.

Public health and the advent of health promotion

In a time when Western societies faced a dramatic shift towards neoliberalism (Dixon, 2000; Bourdieu, 2003; Harvey, 2007; Crouch, 2011; Brown, 2015; Jessop, 2016), the very meaning of health itself needed to be addressed – and is still needed. While the World Health Organization (WHO, 1986) claimed for strengthening individuals' control over their own health and other life dimensions, by re-orienting settings towards health promotion, the control over the life worlds (German: *Lebenswelt*) (Husserl, 1970) has decreased significantly for an increasing number of people. To give just one example, the United Nations (UN) mentioned a decade ago that there was 'a growing sense of unease over the economic course that has been charted in recent years … where increased economic insecurity has been associated with rising inequality and the squeezing of social provisioning…, intractable poverty has fed a vicious circle of economic insecurity and political instability and, on occasion, ferocious communal violence' (UN, 2008, p v). Since the 1980s the significant decline of social security in the fields of unemployment, retirement and even health (Crouch, 2004) led to fragmented biographies, increasing feelings of fear and decreasing trust in many countries (Giddens, 1991; Beck, 1994; Berger, 1996; Berger and Konietzka, 2001; Wilkinson, 2005). This lack of congruence between a convincing normative frame for health, based on health promotion and the Ottawa Charter, and the plea for an increment of personal control over life conditions, on the one hand, and the increasing inequities and insecurities for the majority of the working people, on the other (Wilkinson and Pickett, 2008; Piketty, 2014) produces a tension or contradiction that is not easy to address. What is relatively clear against this backdrop is that the rising insecurity and unforeseeability in economic terms leads to an increasing level of chaos on personal and societal levels.

Following the International Conference on Primary Health Care and the 'Declaration of Alma-Ata' (WHO/UNICEF, 1978), which defined the goal to reach 'Health for All' by the year 2000, up until 2018 the WHO has held nine international conferences on health promotion (see Table 42.1). However, since the Ottawa conference (WHO, 1986), the call for health promotion was echoed six times before Nairobi (WHO, 2009), where the recognition of the *existing health gap* became another reminder that most of the recommendations have yet to be implemented (Saboga-Nunes, 2012) in order to achieve the mirage proposed at the foundation of WHO (in 1948): the attainment of 'not only of the absence of disease and infirmity, but the state of complete physical, mental and social wellbeing' (WHO, 1948). The theme of the Nairobi Conference was 'Call to action for closing the implementation gap in health promotion'. Its aims were focused on '… putting people at the centre of care; … by insisting that health systems provide accessible and comprehensive information and resources for health promotion…' (WHO, 2009, p 6). In order to achieve this, the need to implement innovative approaches was outlined in five conference working documents. In one of them, *Health literacy and health promotion: Definitions, concepts and examples in the Eastern Mediterranean region – Individual empowerment*, health literacy is closely articulated with health promotion (Kanj and Mitic, 2009). In the following two conferences in Helsinki in 2013 (WHO, 2013) and Shanghai in 2016 (WHO, 2017), health literacy assumes a central standing in the overall achievement of the Sustainable Development Goals (SDGs) and to increase empowerment and equity (WHO, 2017).

From New York in 1948 (WHO, 1946) to Shanghai in 2016 (WHO, 2017), 70 years went by, with new epistemological insights that have helped to shape contributions through which health promotion principles and strategies have become clearer in the midst of increasing complexity. These are considered of significant value in improving the promotion of health. Nevertheless, simultaneously, limitations are increasingly being perceived, affecting short-,

Table 42.1: The World Health Organization's Global Conferences on Health Promotion

No	Year	Location	Focus topic	Source
1st	1986	Ottawa, Canada	Charter for health promotion; Health for all by the year 2000 (based on the Declaration of Alma Ata)	WHO (1986)
2nd	1988	Adelaide, Australia	Healthy public policy	WHO (1988)
3rd	1991	Sundsvall, Sweden	Supportive environments for health	WHO (1991)
4th	1997	Jakarta	New players for a new era – Leading health promotion into the 21st century; Capacity building for health promotion	WHO (1997)
5th	2000	Mexico City, Mexico	Bridging the equity gap	WHO (2000)
6th	2005	Bangkok, Thailand	Policy and partnership for action: Addressing the determinants of health	WHO (2005)
7th	2009	Nairobi	Call to action for closing the implementation gap in health promotion	WHO (2009)
8th	2013	Helsinki, Finland	Health in All Policies (HiAP)	WHO (2013)
9th	2016	Shanghai, China	Sustainable Development Goals (SDGs); All for health, health for all	WHO (2017)

medium- and long-term health promotion. The ambition of *healthcare* systems, or more accurately stated, *disease and treatment* systems, the development of an *International Classification of Diseases* (ICD) (WHO, 2016) and of a specific arsenal of technology, along with the growth of the medications and interventions industry, has, in most countries of the world, absorbed all available resources that societies agreed to set apart for this purpose. The cost of *disease and treatment* systems is increasingly competing with other crucial areas (like health promotion) of social need in the search for cohesion and stability (for example, justice, security and education), where social and cultural sustainability are (with environmental sustainability) pushed to enduring treats.

Public health and the pathogenesis complexity

Today, greater expectations are expressed by patients regarding the systems for treatment of disease. This has resulted in increasingly vocal complains regarding depersonalisation and compartmentalisation of care. The citizen-centric approach (another golden rule of modern public health) has been compromised. On the other hand, these systems have become so expensive that it seems an impossible mission (if nothing is changed) to achieve the golden rule of *health for all*. The idea of modernity, of the infinite expansion of the curative dis-ease human experience, so that it will eventually embrace every human being, has been shown to be very finite, and in some ways, a receding horizon (as new dis-eases and menaces are emerging at an alarming rate). The limits are in sight and compromising the current model of human development within the SDGs perspectives. The mirage proposed by the pathogenic paradigm, while demanding ever-expanding complexity and means, has revealed abundant limitations.

At the nine WHO consensus meetings (referred to above), and although they have been acclaimed around the world as noble, it is unquestionable nowadays that more is needed than admirable declarations. At the epicentre of this 'tornado of needs' are the concepts of *health*, *illness*, *sickness* and *disease*. Health promotion (with a few notable exceptions) continues to be mostly a declaration of intentions, and the lack of theoretical developments is jeopardising the deficiency of further developments into the practical consequences of the health promotion ideology.

Salutogenesis and the quest for a theory of health promotion

Health promotion, basically a dynamic 'process that focuses on people's empowerment, in order to facilitate their control over their health' (WHO, 1986), has been declared a missed opportunity for most of the inhabitants of the world (WHO, 1984), mostly because a good theory that would maximise its potential was missing. This caught the attention of Aaron Antonovsky (1985). He started his quest by posing an unusual research question (outside of the pathogenic paradigm). Instead of focusing on traditional approaches, he asked: *Why do certain people suffer less than others*?

From this starting point, he caught worldwide attention while proposing the *salutogenesis* paradigm as the answer. It could be said that this was so successfully done that today salutogenesis has become, in some contexts, a *buzzword* that is ubiquitously used without much concern and sometimes void of its deep meaning. For instance, in some cases the term 'salutogenesis' is aligned closely with the concept of resilience or coping (Antonovsky, 1987; Johnson, 2004; Harrop et al, 2007; Langeland et al, 2007). In social-psychological approaches, the core of Antonovsky's theory, the SOC, is predominantly used to forecast empirically individual general health status, particular health outcomes or health choices. The value of the salutogenesis paradigm and the sense of coherence is often reduced to its explanatory power as an independent variable to a variety of different outcomes. Simultaneously, salutogenesis is accused of not being tested enough empirically (Bengel et al, 2001); it is a shortfall to use the salutogenesis predominantly as an empirical tool. Although there are undoubtedly open questions and a need for advancement and progress in the salutogenesis paradigm, the most valuable aspect of it is the holistic theoretical impact.

The health promotion 3-simplex and the sense of coherence theory

Antonovsky's innovative way of looking at *health* (*ease*) and its *menaces consequence* (*dis-ease*) is not focused on building the perfect health condition (*ease*). It is not a recipe for a perfect world, but rather a *modus vivendi*, a way of living in this one with the potential for health (*ease*) that each person has, while being empowered to improve it. Antonovsky was not looking towards a state of a total or perfect health (besides the absence of *dis-ease*), but pointing a finger towards the natural condition of every human being: fighting the chaos of everyday life, managing stressors in a healthy (*ease*) way. While he dealt with complexity through a simplex approach, he *glued together* simplices to form a simplicial complex (for example, a tetrahedron, a 3-simplex).

Life is a negentropic asset – every breath, action and move catalyses order from the chaotic circumstances of everyday life. The basic question is then: *Why do some people do this better than others?*

Thus, the point of departure is not the search for what is pathological. Instead, it is the direction toward life (*salus*), the teleonomic perspective that every being has inscribed in their most basic behaviour to fight entropy. In this way, strengths are identified – the positive factors that allow individuals to use their resources to move to the next level of *ease* (wellbeing), despite prevailing conditions. For Antonovsky, life is permanent coping ability, dealing with events, people and environment. These elements have to be coherently arranged in order to promote health and wellbeing. What a person is, is not as important as what they believe they are, and thus a person finds sense in their own life. Life events are arranged by everyone according to specific frames and organised according to basic ideas of what life is, what others are and what things represent. Therefore, since life is basically *salus* or *vita*, and the opposite of this is *morbus* or *mors* (death), people in their struggle for survival search for those salutary elements that will enable their *salus*, which is their *ease* or wellbeing. This is the basis of the salutogenesis paradigm in the search for the origins of health. The departure point of the search for salutary factors, in terms of the information theory, is the search for negentropy. Negentropy could be considered as the vertex to all original vertices, where the 3-simplex originate from.

Antonovsky's salutogenesis paradigm (Antonovsky, 1985) is built on the key concept of the SOC as the centre of life control (Antonovsky, 1987). This theory proposes answers to the *salutogenic question* – considered as the motivational basis of any behaviour enacted and attitude held by an individual or a group. The SOC, as a global orientation to the world, perceives it *comprehensible*, *manageable* and *meaningful*. This is a 3-simplex. The SOC is a central dispositional orientation in the lives of all human beings that thrive in the dis-ease–ease continuum.

These are the three components of what the SOC represents, the core of health promotion theoretical conceptualisation in this approach. The SOC, then, can be defined formally as:

> a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that (1) the stimuli [for example, need to control weight] deriving from one's internal and external environments are structured, predictable

> and explicable; (2) the resources [for example, for weight control] are available to one to meet the demands posed by these stimuli; and (3) these demands are challenges, worthy of investment and engagement [for example, it pays to have normal weight]. (Adapted from Antonovsky, 1987, p 40)

The importance of this paradigm is shown by the inclusion of this perspective in the WHO *Health for all* guidelines (WHO, 1999, pp 28-9)*:* 'environments [that are] created that help people to gain a sense of coherence and cope with stressful situations and events.' The recognition by the WHO of Antonovsky's proposal emphasises the relevance of his own words, written 10 years earlier (Antonovsky, 1987, p 19).

From the simplistic duality to the dis-ease/ease health continuum

People throughout their lives confront a variety of tasks shaped by biological, historical and psychosocial forces; the more successful they are in resolving these tasks, the more likely they are to maintain or improve their places on the health dis-ease/ease continuum (Antonovsky, 1987, p 3). The SOC is a significant determinant of such success and plays a major role in health promotion (Antonovsky, 1987, p 19). At one of the extremities of this continuum is *dis-ease* (disfunctionality) and at the other extreme is *ease* (maximum functionality). People move on this continuum experiencing more or less ease in their everyday lives (Saboga-Nunes, 1998).

The assumption is that everybody is in a permanent state of heterostasis – in other words, of imbalance, disorder or instability (Antonovsky and Bernstein, 1986; Antonovsky, 1987, p 130). Everyone is submitted to pressure toward increasing entropy as the 'prototypical characteristic of the living organism' (Antonovsky and Bernstein, 1986, p 2). Instead of considering homeostasis, of the biomedical model (Cannon, 1939) or self-regulated processes (the prevalent perspective during the time Antonovsky started to reflect about his theory), every effort in life is concentrated on moving toward less entropy in heterostasis (Noack, 1997, p 95). A metaphor often used by Antonovsky compared life to a river, which he called the river of life:

> my fundamental philosophical assumption is that the river is the stream of life. None walks the shore safely.… Wherever one is in the stream … what shapes one's ability to swim well? (Antonovsky, 1987, p 90)

From the salutogenic perspective, what is also important is to understand that people can be in the water and yet survive with their particular skills. It is therefore important to understand how the personality disposition that Antonovsky called the SOC allows people to fare in the water, some managing better than others, since life is an imbalanced state. The normal condition is not balance and health (in the sense of the WHO definition of health) but imbalance (heterostasis), which leads to suffering and sometimes to dis-ease.

This is the context in which Antonovsky utilises the concept of entropy; the question is then how to contribute to counteracting this natural law of degradation, which can be considered as the vertex of life. This is called negentropy, or negative entropy, where a system can reorganise itself again, a characteristic that Antonovsky attributes to humans, as complex systems in the midst of other systems: 'The human organism is a system and, like all systems, it is at the mercy of the power of entropy' (Antonovsky, 1993, p 7). Consequently ease (or health) is a permanent building process, as it can be jeopardised by a process of loss and degradation (dis-ease) (1993, p 10).

Uniting the dots for the health continuum: the role of the General Resistance Resources

Following this approach, Antonovsky researched for factors that were connected to the ease pole of the continuum (dise-ease/ease), looking for what was contributing to the health condition of individuals. He called these factors *Generalised Resistance Resources* (GRR) (Antonovsky, 1985, 1987, pp 18, 19, 28): 'phenomena that provide one with sets of life experiences characterized by consistency, participation in shaping outcomes and an underload-overload balance.'

The GRR are generally present at the disposal of humans, in different types of conditions. They contribute to reinforcing a person's resistance to facing the stream of life, which promotes negentropy, and so they are called *resistance*. These GRR help to make *sense* out of the countless stressors that a person is submitted to. This is what originates the personal SOC. In 1987, Antonovsky characterised stressors as *Generalised Resistance Deficits* (GRD) (Antonovsky, 1987). This meant that the move to the ease pole was geared with life experiences that strengthened the SOC, while negative experiences would lead to the other, dis-ease pole, which weakens the SOC. In this way GRR contributed to increasing the amount of entropy and GRD worked to increase the amount of negentropy, that is, to increase the SOC that 'orchestrates this battle-ground of forces promoting order or disorder' (Antonovsky, 1987, p 164). A move from pathogenesis can be experimented with GRR, using, for instance, immunology and microbiologic models, where pathogens are fought by internal defences or by external immunology (such as vaccines). From a pathogenic behaviour model, in which lifestyles are considered as direct causes of disease and death (Antonovsky, 1984), a change can be considered in the context of the salutogenic model.

In order to cope well, people's 'readiness and willingness to exploit the resources that they have at their potential disposal' (Antonovsky, 1984, p 121) is critical. This is where the dots are united towards ease. It is essential to believe that the input from one's environment and the feedback is information and not *noise* or, in simple words, that life makes sense. This is called *comprehensibility*, the first dimension of the SOC (Antonovsky, 1987, p 16) (or the first simplex). The belief that stimuli make sense, are ordered, structured and predictable is essential but not sufficient for the individual to cope well. People not only have to know the rules, have the information for living healthy but must also have confidence in the resources at their disposal. They have to reject the idea that the cards of life are stacked against them, and that consequently they can never stop. The stimuli, or the stressors, are always there, making demands. But if people are persuaded that a variety of appropriate resources to meet these demands are available, then a person can cope well and move towards the ease end. This second component/dimension of the SOC is defined as *manageability* (Antonovsky, 1987, p 17) (or the second simplex). To believe that people understand what it means is a life-promoting strategy and that they can manage its process is not enough. The motivational element is crucial. People must wish to cope with life events and build positive life experiences. They must see the demands posed by the stimuli as making sense emotionally. The stimuli may be painful and sad. They can fall into despair or be determined to continue the struggle. This third component of the SOC is called *meaningfulness* (see Figure 42.1) (Antonovsky, 1987, p 18) (or the third simplex).

Everyday life experiences determine the SOC (Arrow A, see Figure 42.1). Comprehensibility, manageability and meaningfulness are precursors of an individual's actions (the 3-simplex). If these life experiences are comprehensible, manageable and meaningful, this will generate (Arrow B) GRR, which will, in turn, shape new life experiences (Arrow C) that contribute to wellbeing (at the ease pole of the continuum). These experiences are based on sources of GRR (Arrow D) that are events or perceptions without a pre-established pattern: they can be used and mobilised depending on the building up of SOC that everybody experiences (Figure 42.1).

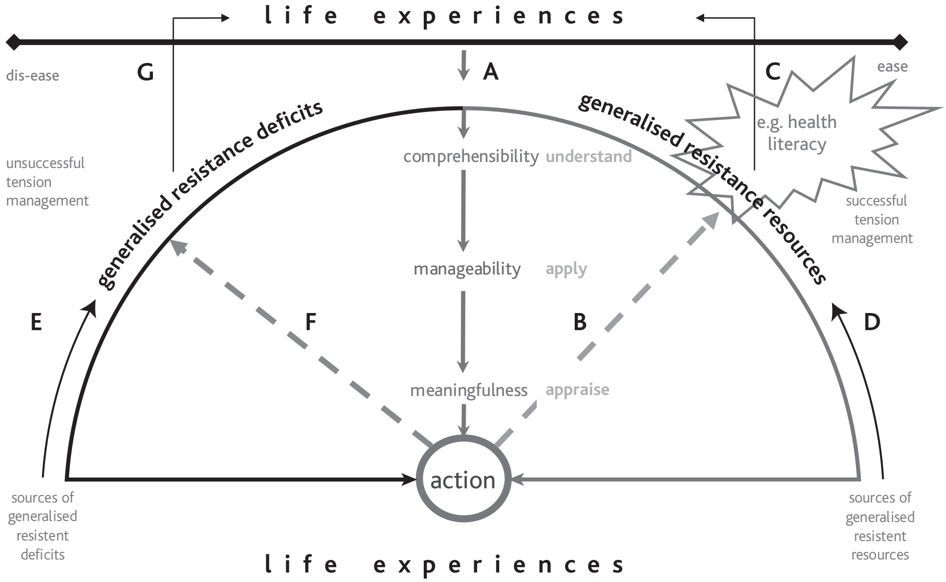
There is another pathway that can be triggered by (Arrow E) sources of GRD that are implicated in the development of GRD (Arrow F) that shape negative life experiences, leading the affected person to the pole of dis-ease, when tension management has been unsuccessful (Arrow G). This leads to increased entropy.

The SOC theory is one of the contributions that the salutogenic paradigm has sustained while responding to the public health goal of fostering healthier citizens and communities. For some researchers, salutogenesis is in itself equal to health promotion (Freidl et al, 1995, p 16).

From the cycle of knowledge to the core of the health literacy concept as General Resistance Resource

As referred to earlier, health literacy was brought to the health promotion field, more emphatically, in Nairobi. Bengt Lindstrom and Monica Eriksson (2011, p 90) 'introduce[d] the salutogenic framework in educational science by starting a discussion about the content of health education and health literacy expanding towards healthy learning, with the emphasis on healthy, giving a direction similar to the salutogenesis.'

Figure 42.1: The salutogenic perspective of health literacy and the sense of coherence theory in the dis-ease/ease continuum



Source: Adapted from Saboga-Nunes (2012)

During the last 20 years, many proposals have emerged to clarify this concept (that is, health literacy) and its operationalisation. Among the many definitions to date, we consider the one that states that 'health literacy is linked to literacy and entails people's knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course' (Sørensen et al, 2012, p 3).

This definition has a core node where sits all the argument of what is meant by health literacy and that could be made explicit with the cycle of knowledge (Sørensen et al, 2012). This cycle that aims at the pursuit of health information starts with (1) *access* that 'refers to the ability to seek, find and obtain health information'. Next, it focuses on the (2) *understanding* of health information 'that is accessed'. On a third step this health information needs to be (3) *appraised*, which means the 'ability to interpret, filter, judge and evaluate the health information that has been accessed'. Finally, health information needs to be (4) *applied*, that 'refers to the ability to communicate and use the information to make a decision to maintain and improve health' (Sørensen et al, 2012, p 9).

These are seen as actions that are based on *competencies, skills or abilities* and they represent dimensions of health literacy (Sørensen et al, 2012). When a closer analysis of these dimension is considered it can be emphasised that they are in parallel with the 3-simplex dimensions of the SOC theoretical model: indeed, after obtaining and accessing health information, its *understanding* represents a parallel with the first dimension of the SOC, that is, *comprehensibility* (see Figure 42.2). Understanding something will deploy meaning, and will counteract a person's entropy, in a world of multiple levels of information that may be inaccessible or contradictory. This way the stimuli will apprehend meaning and will be considered as components of an ordered environment, which is defined as *comprehensibility*. Appraising information as introduced earlier is in parallel with the *meaningfulness* dimension of the SOC (to interpret, filter, judge and evaluate the health information – to create meaning and sense based on information). Appling information is closely linked to *manageability* of the SOC (to communicate and use information and make decisions based on the information).

Moreover, this parallel of health literacy with the theoretical approach of the SOC that sees in the GRR the foundation to its building (or the dots connecting the road map to the ease pole of the continuum) extends the list of the GRR. As referred to before, GRR covers the characteristics of a person (or a community) that enable the individual's skills to handle successfully life events and stressors, and ultimately are the basic foundation of any person's SOC development. For Antonovsky, the GRR can be systematised in eight groups, such as physical; biochemical; artefactual-material; cognitive; emotional; valuative-attitudinal; interpersonal-relational; and macro-sociocultural (Antonovsky, 1985, pp 102-19).

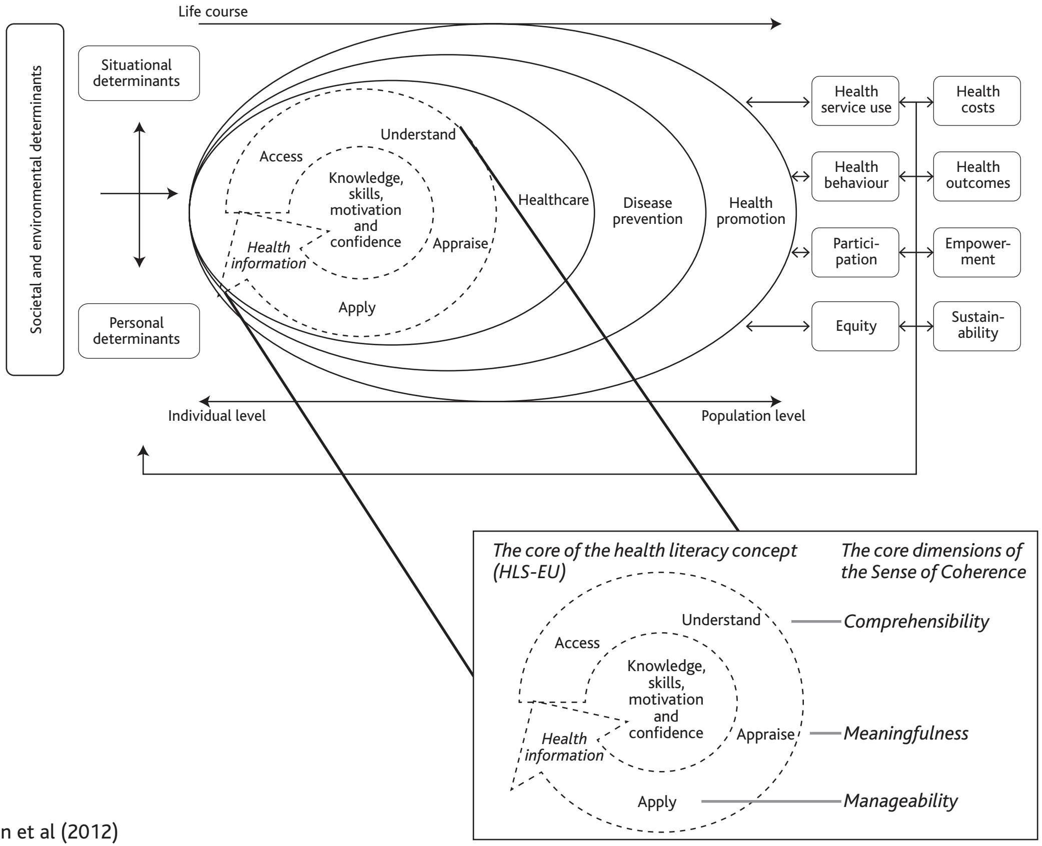
Health literacy is therefore a macro-sociocultural GRR. It is one component to be added to the list of the GRR, that embraces the all set of characteristics that will enable a person to activate skills, that will contribute to handle life events successfully, and move toward the ease end of the continuum.

To have a strong health literacy will contribute to having a person higher positioned on the continuum dis-ease–ease. In addition, it will contribute to a higher level of SOC, since it will add to having consistent, balanced life experiences with high participation in decision-making. On the opposite side, a person who is lower in health literacy levels will face misunderstanding, inconsistences with low balanced life experiences and low participation in decision-making – the core of the health promotion goal.

Conclusion

Today *scepticism*, *finitude*, *plurality*, *textuality* and *difference* have embraced the health field. Consciousness about limits has given place to the certitude that there is no permanent, endless expansion, even for ending dis-ease. Therefore, the need to reconstruct the health field and its social representation needed the salutogenesis new paradigm. Inside this paradigm several theories made emphatically how health can be created; in this context Antonovsky's theory of the SOC has emerged as a promising approach, in the last 20 years, to deal with the complex topic of health today. The building process of the SOC is closely connected to the GRR, where health literacy can be included as a macro social GRR. The current comprehensive discourse about health literacy is maybe (and hopefully)

Figure 42.2: The salutogenic perspective placed into the health literacy framework



Source: Adapted Sorensen et al (2012)

a trigger to bring the salutogenesis paradigm to the forefront in the need to reconstruct the health field and its social representation (Mittelmark et al, 2016; Saboga-Nunes, 2016).

To keep a greater picture in mind, humanity is finite either because life is limited, or because humans rely on external resources that are limited and thus might threaten human life when they run out. Such resources are the bedrock of human life and also their health, and without wise management of these finite resources, human sustainability can be severely damaged, leading to chaos or quasi chaotic states. The choices people make will determine the future path of humanity (for example, by continuing to use fossil energy we will see an increase in the negative consequences on human health and planet degradation; without an urgent change in consumption patterns and industrialisation, we will be destroying rain forests, the oceans, or heavily polluting the soils and water supplies). This is where health literacy can make an impact to protect human flourishing and development by making appropriate micro-, meso- and macro-level health decision, especially at the policy-making, decision-making and power levels.

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Health literacy in a social context: A meta-narrative review

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Introduction

Health literacy is often defined as how individuals 'obtain, process, and understand basic health information and health services in order to make appropriate health decisions' (Ratzan and Parker, 2000, p vi). Much health literacy research has focused on the functional skills of individuals (Lee et al, 2004; Guzys et al, 2015) and/or on the capacity of healthcare providers and health systems to support individuals with low health literacy (Baur, 2010). However, a growing body of empirical health literacy research looks beyond the individual level to the social structures in which people live (for example, dyads, families and social networks), acknowledging the role of support and resources from the social environment (Sentell et al, 2017). This literature spans diverse disciplines, topic areas and methods.

Synthesising such research is important, but challenging. The conceptualisation and operationalisation of health literacy has varied across time, disciplines, methods and research communities (Altin et al, 2014; Guzys et al, 2015). The field of health literacy continues to expand, despite lack of consensus on its central construct (Mackert et al, 2015). Likewise, the effect of social relationships on wellbeing is a broad area of research with a long history, ranging from studies of how an individual's social connections affect access to resources, to fields that focus on social structure (rather than the individual) as the unit of study (Lomas, 1998). Terms such as social networks, social support, social ties, social integration and social practice are distinct in theoretical literature, but are sometimes used 'loosely and interchangeably' in the empirical literature (Berkman et al, 2000, p 843). As with health literacy, such concepts have evolved over time and remain contested; for example, the discussion about whether social capital should be measured at the community level (a collective attribute of the group) or at the individual level (an outcome of an individual's social relationships) (Poortinga, 2006). There is, however, broad consensus that such contextual factors are critical to health outcomes (Kickbusch et al, 2013).

Given this complexity, we conducted a meta-narrative review to explore the diversity of research approaches to the social context of health literacy across the life course. Meta-narrative review is a relatively new method for evidence synthesis, with publication standards (Realist and Meta-narrative Evidence Syntheses: Evolving Standards [or RAMESES]) first published in 2013 (Wong et al, 2013). A constructivist approach to literature reviews, meta-narrative reviews compare and contrast research traditions, defined as 'a series of linked studies, each building on what has gone before and taking place within … a particular set of assumptions and preferred methodological approaches…' (Wong et al, 2013 p 2). Meta-narrative reviews are appropriate for complex areas of research where different research methods, designs and questions have been used to explore a common problem (Greenhalgh et al, 2005).

We previously examined the intersection of health literacy and social context in a systematic literature review of quantitative empirical research (Sentell et al, 2017). Other reviews on health literacy within a social context have had a similarly narrow scope. A review by Lee et al (2004) set a research agenda for improved understanding of the relationships between health literacy, social support and health outcomes. A 2015 review considered health literacy measurement at the population level, finding little measurement of social context (Guzys et al, 2015). Two reviews considered caregiver/family literacy in cancer-focused communication, noting that an individual's caregiver or family is relevant to health outcomes (Bevan and Pecchioni, 2008; Sparks and Nussbaum, 2008). These reviews concluded that social context is important to health literacy, but understudied.

Research questions

We compare research traditions (defined here as a body of research with a shared conceptualisation of health literacy and social context, drawing on a shared theoretical and empirical background) with the aim of understanding the different ways the intersection of health literacy and social context has been empirically researched. Our research questions are based on the meta-narrative review questions outlined by Greenhalgh and Wong (2013): (1) What are the different ways that empirical research has conceptualised health literacy beyond the individual level? (2) What theoretical and methodological approaches have been used? (3) What insights can be drawn by comparing different approaches and their findings? And (4) What social science theories, perspectives and/or methods are missing?

Iterative searching and scoping

We initially searched seven major health-related databases (PubMed, CINAHL, Sociological Abstracts, Social Science Citation Index, ERIC, Academic Search Complete and PsychINFO), restricted to English language (due to lack of resources for translation). Search terms were 'health literacy' plus the following terms: dyad OR triad OR caregiver OR social network OR social capital OR social support OR social network analysis/es. After browsing relevant papers and drawing on our knowledge of the field, we then searched the same databases for the following exact phrases: social health literacy; group health literacy; community health literacy; family health literacy; neighbourhood health literacy; caregiver health literacy; and distributed health literacy. These searches were lasted updated in February 2017. We also hand-searched the bibliographies of relevant articles.

Studies were excluded if they were dissertations, focused on the individual level only and/or lacked measurement or exploration of the interaction between or intersection of health literacy and social context. Our focus was on the interpersonal and community levels of interaction (that is, the micro- and meso-levels) but did not extend to the institutional or systems level. We therefore excluded studies that examined only relationships within the health system (for example, relationships between patients and providers). We also excluded studies that examined only the relationship between the individual health literacy of caregivers and the health outcomes of those they were caring for (for example, parents caring for children), but included studies that examined the health literacy of both members of a carer/patient dyad. Drawing on the meta-narrative review principle of pragmatism (Greenhalgh and Wong, 2013), we excluded the rapidly growing research area of people accessing health advice from others online (including via social media) due to the volume of material, and the blurry boundary this field creates between social networks and mass communication. This would be a productive area for future review. Finally, we excluded from analysis studies of interventions to improve health literacy through social connections (such as establishing patient support groups or training lay health educators), but such studies are discussed in 'implications for practice'.

We first analysed only the relevant quantitative empirical studies that used the specific term 'health literacy' (Sentell et al, 2017). The analysis covered 34 studies, mostly published in the last five years, and found significant overlap in the conceptualisation and measurement of 'health literacy', 'social capital' and 'social support'. The review highlighted disparate conceptualisations of the intersection of health literacy and social context, confirming the value of further exploration using a broader, interdisciplinary meta-narrative review approach.

We then re-examined both qualitative and quantitative empirical work, also informed by theoretical articles (including commentaries and editorials). Following best practice in meta-narrative review, we integrated the advice of researchers from a number of interdisciplinary fields on relevant articles and research traditions. These included: the history of health literacy research and current topics (TD, CA); health literacy in technology (PM, JM); health literacy in children and adolescents (PM, JM, OO); quantitative methods in social network analyses (JD); family context, parenting and support systems (EM); literacy and education theory (OO); social network analyses in vulnerable communities (OVB); health disparities (TS) and international health literacy (OO).

Data extraction

We classified relevant articles into empirical (qualitative or quantitative), theoretical or other (for example, scale development). For empirical papers, we developed a data extraction form based on the study research questions and meta-narrative review quality standards (Wong et al, 2013), which included methodological approach, research field, country of research, health issue, target population, key theoretical/conceptual basis and key findings.

Meta-narrative review

As can be seen in Figure 43.1, which describes our analysis process, a total of 1,048 studies were included in the initial phase of the meta-narrative review. After full text review, 34 quantitative and 19 qualitative papers met inclusion criteria. We compared and contrasted these articles in an iterative process to classify research traditions, then received guidance from experts and conducted a third round of literature searching. A total of 10 additional empirical studies met inclusion criteria. The total number of studies included was 63. All empirical articles meeting study criteria are listed in Table 43.1.

Categorising articles by research tradition proved challenging as many studies did not state an explicit theoretical basis or did not clearly articulate their approach to health literacy. Our previous review of quantitative papers (Sentell et al, 2017) divided papers into one of three categories of perspectives on the intersection of health literacy and social context; when we considered qualitative work, along with broader inclusion criteria, more categories emerged and existing categories were refined. We compared and contrasted articles in an iterative process, developing thematic categories that mostly distinguished research traditions across two domains highly relevant to research and theory: (1) whether they viewed health literacy as an individual skill or a social practice, and (2) whether they focused on the collective or individual level of analysis.

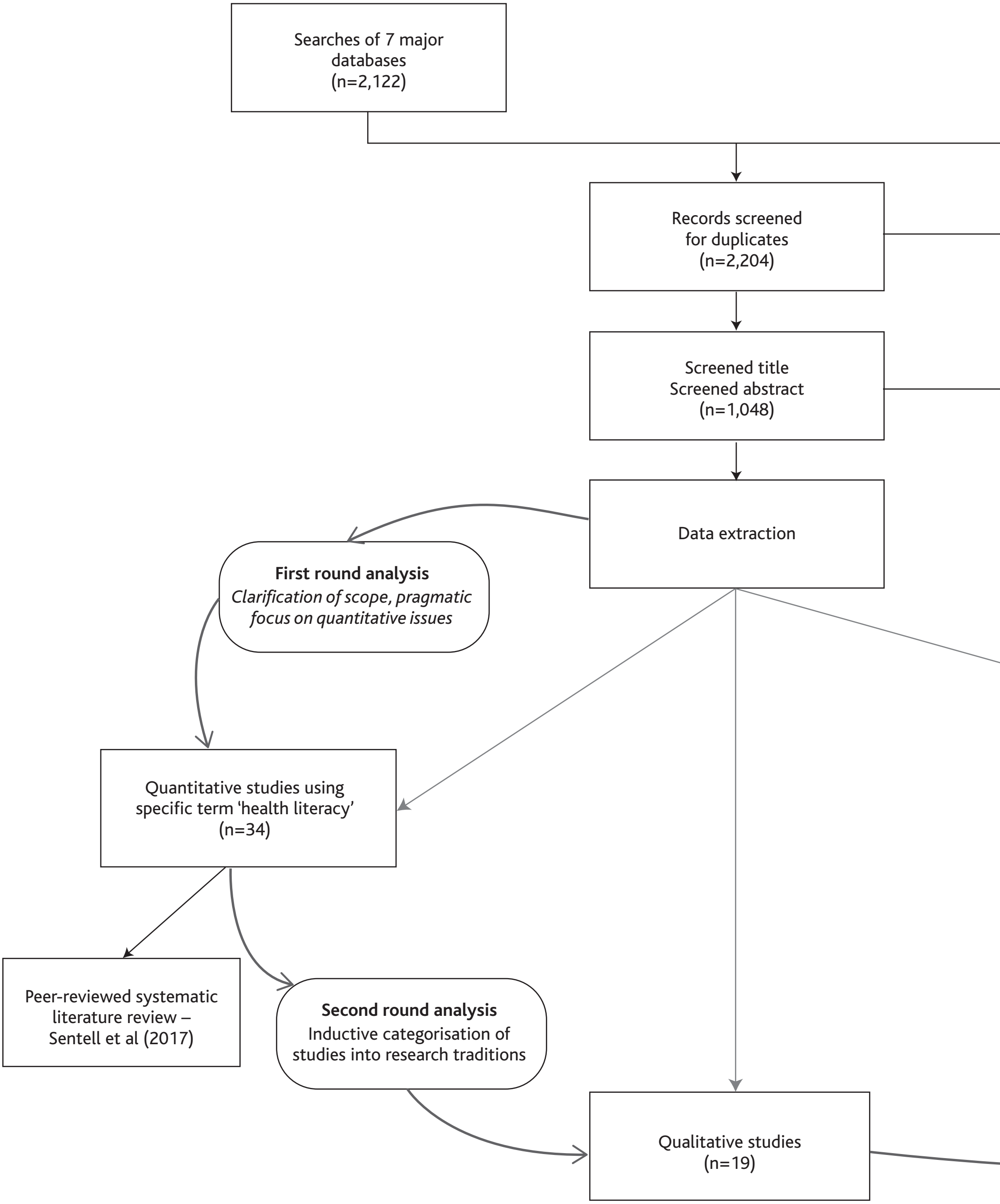
Six research traditions were identified. At this point, we recognised that our thinking about research traditions had been greatly informed by theoretical and empirical literature that did not use the specific term 'health literacy', but relevant to understanding the ability to 'obtain, process, and understand basic health information and health services in order to make appropriate health decisions' (Ratzan and Parker, 2000, p vi). For example, Choi (2008) described the role of social networks in the health care of Marshallese migrants. We included such papers in our analysis; however, an exhaustive search for all relevant studies not using the term 'health literacy' was impractical.

The research traditions are shown in Figure 43.2. Although research traditions are presented as separate boxes in the diagram, the overlap in the literature and the emergent nature of health literacy research mean that these research traditions should not be seen as separate streams of research, but as different channels of a braided river, splitting off and rejoining. The grey lines indicate particularly strong connections.

Table 43.1: Empirical studies identified under each research tradition

Research tradition	Description	Methodology	Approach to health literacy	Studies
Association	Studies measuring the association between individual-level functional health literacy and individual-level social capital, social support or social engagement	All quantitative	Functional individual skill	Kalichman et al, 1999; Arozullah et al, 2006; Lee et al, 2006; Lee et al, 2009; Johnson et al, 2010; Osborn et al, 2010; Rosland et al, 2010; Ussher et al, 2010; Rosland et al, 2011; Inoue et al, 2013; Yang et al, 2013; Fry-Bowers et al, 2014; Mayberry et al, 2014; Stewart et al, 2014; Waldrop-Valverde et al, 2014; Aikens et al, 2015; Hahn et al, 2015; Kim et al, 2015; Kobayashi et al, 2015; Maneze et al, 2016; Dong 2016; Zou et al, 2016; Waverijn et al, 2016; Geboers et al, 2016; Matsumoto et al, 2017
Resource	Studies that explore how social networks serve as a resource that individuals can draw on to support their health decisions	Qualitative or mixed-method	Social practice or quantitative measurement of functional	Macario et al, 1998; Zanchetta et al, 2007; Adkins and Corus, 2009; Bakeera et al, 2009; Smith et al, 2009; Wharf Higgins et al, 2009; Mayberry et al, 2011; Ellis et al, 2012; Mårtensson and Hensing, 2012; Edwards et al, 2012; Donelle and Hall, 2014; Rowlands et al, 2015; Black et al, 2017
Distributed	Studies that view health literacy as a shared capacity that should be understood (and measured) at the collective level	Qualitative and quantitative	Mostly social practice, quantitative papers use functional	Papen, 2009; Hunter and Franken, 2012; Hogden et al, 2013; Treloar et al, 2013; Edwards et al, 2015; Sentell et al, 2014; McGrath et al, 2015; Fairbrother et al, 2016
Definition	Studies where health literacy includes, by definition, having or leveraging social connections	Quantitative and qualitative	Functional individual skill	Jordan et al, 2010; Schmidt et al, 2010; Rubin et al, 2011; Santos et al, 2014; Beauchamp et al 2015; Chung et al, 2015; Lambert et al, 2015; Dodson et al, 2016; Jessup et al, 2017
Aggregate	Studies that view health literacy as a functional skill of the individual, where findings are aggregated or compared at the population level or within dyads	All quantitative	Functional individual skill	Cimasi et al, 2013; Garcia et al, 2013; Levin et al, 2014; Driessnack et al, 2014; Chisolm et al, 2015
Knowledges	Studies that view health literacy as the ability to negotiate multiple knowledges, including social knowledge	All qualitative	Social practice	Hinder and Greenhalgh, 2012; Lloyd et al, 2014; Schölmerich et al, 2016

Figure 43.1: Search strategies



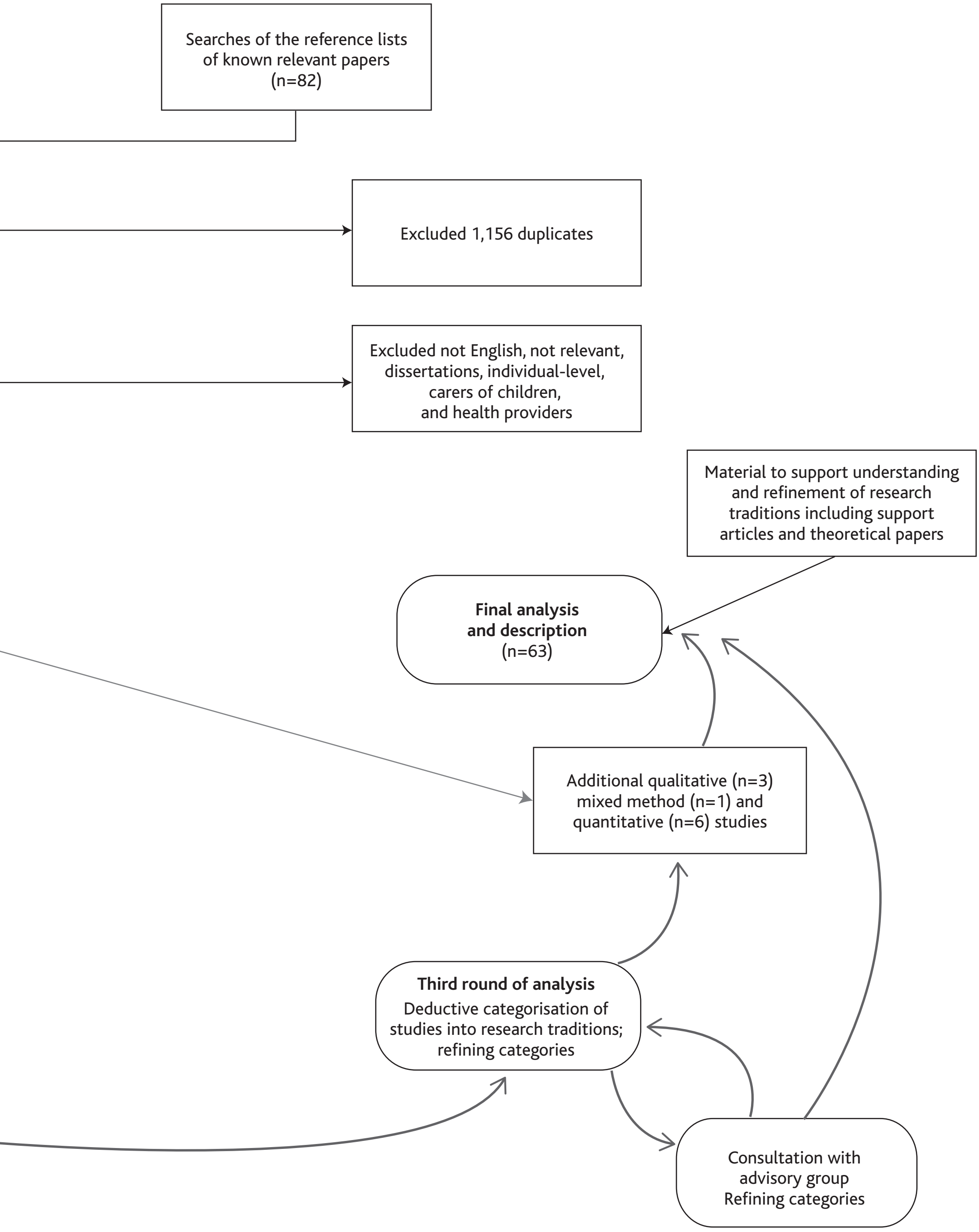
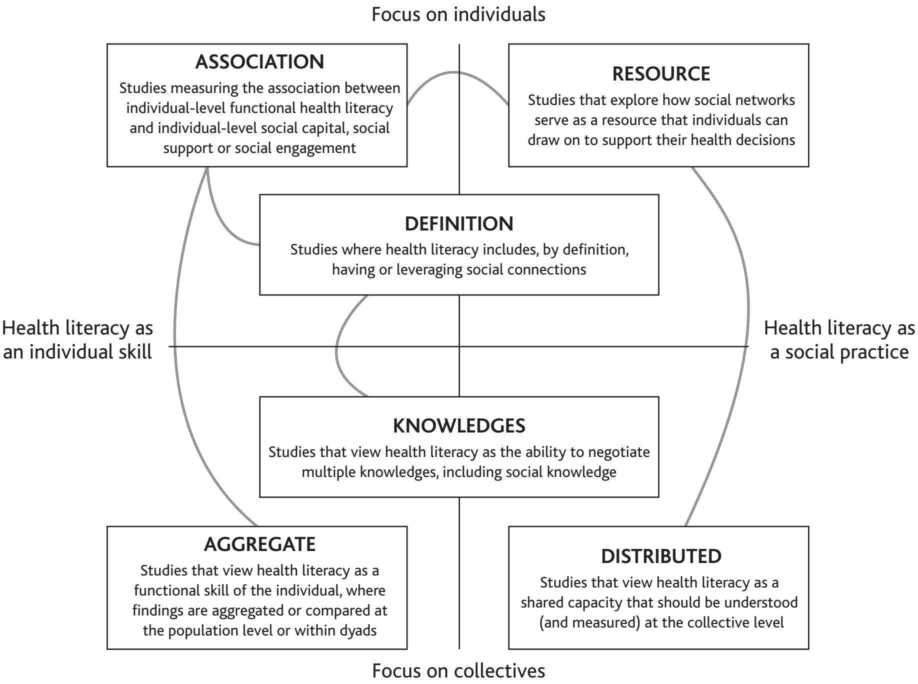

Searches of the reference lists of known relevant papers (n=82)
Excluded 1,156 duplicates
Excluded not English, not relevant, dissertations, individual-level, carers of children, and health providers
Material to support understanding and refinement of research traditions including support articles and theoretical papers
Final analysis and description (n=63)
Additional qualitative (n=3) mixed method (n=1) and quantitative (n=6) studies
Third round of analysis
Deductive categorisation of studies into research traditions; refining categories
Consultation with advisory group
Refining categories

Figure 43.2: Research traditions



ASSOCIATION
Studies measuring the association between individual-level functional health literacy and individual-level social capital, social support or social engagement

RESOURCE
Studies that explore how social networks serve as a resource that individuals can draw on to support their health decisions

DEFINITION
Studies where health literacy includes, by definition, having or leveraging social connections

KNOWLEDGES
Studies that view health literacy as the ability to negotiate multiple knowledges, including social knowledge

AGGREGATE
Studies that view health literacy as a functional skill of the individual, where findings are aggregated or compared at the population level or within dyads

DISTRIBUTED
Studies that view health literacy as a shared capacity that should be understood (and measured) at the collective level

The six research traditions (which we named for ease of reference) were: *association*: studies measuring the association between individual-level functional health literacy and individual-level social capital, social support or social engagement; *resource*: studies describing friends, family and social networks as a resource the individual draws on to support health decisions; *distributed*: studies describing health literacy as a distributed capacity, understood at the collective, rather than individual, level; *definition*: studies that include the skill of having or leveraging social connections in the definition of health literacy; *aggregate*: studies measuring individual-level functional health literacy, but aggregating such measures at the dyad or population level; and *knowledges*: studies viewing health literacy as the ability to negotiate multiple types of knowledge, including social knowledge.

Association

Association studies take a functional view of health literacy and examine the association between health literacy and a type of social connectedness (such as social capital, social support or social engagement), both measured quantitatively at the individual level. Of the 25 studies in the *association* research tradition, 16 were published between 2013 and 2017, so researchers have had little opportunity to build on each other's work: despite shared analysis methods and conceptual approaches, *association* studies showed little cross-citation. A key paper shaping this research tradition is Lee et al's (2004) agenda-setting review of social support, health literacy and health, cited by 12 studies (nine on social support and three on social capital). The questions underpinning *association* studies are whether people with low health literacy have more or less social support/social capital than those with higher health literacy, and whether this influences health outcomes, with mixed findings. More detail on these studies can be found in our previous review (Sentell et al, 2017).

Resource

The *resource* research tradition uses qualitative or mixed-methods to explore how friends, family and social networks are a resource for individual health decisions. Examples include Ellis et al (2012) who found that arthritis patients in Australia with low or intermediate health literacy obtained health information from people in their informal social networks who could better understand health issues, and Bakeera et al (2009) who found that the social resources of people in Eastern Uganda affected their ability to obtain health services. In many *resource* studies (such as Mårtensson and Hensing, 2012; Mayberry et al, 2014; Rowlands et al, 2015) the role of friends and family as a resource for health literacy was a finding rather than an a priori topic of investigation. *Resource* studies draw on a range of health communication theories, but Adkins and Corus (2009) also drew on the field of consumer studies, and outline how the perspective of literacy as a social practice (rather than a functional skill) has developed in the fields of literacy, consumer studies and now health literacy.

Collectively, the *resource* studies suggest further qualitative research may help to explain why *association* studies show such mixed results (see Sentell et al, 2017). For example, Mayberry et al (2011) conducted quantitative assessment suggesting participants had very low literacy, numeracy and computer skills, but also frequently accessed electronic health records. This apparent paradox was resolved when focus groups revealed that they often had more literate family members act as 'online delegates' and access records on their behalf. *Resource* studies also indicate a nuanced view is needed on how social support and health literacy interact. Those who have low literacy may draw on their social network for support, but they may also feel shame and attempt to conceal their low literacy from their social network (Adkins and Corus, 2009; Ussher et al, 2010). Specific health conditions may affect the balance between support and shame (for example, Zanchetta et al, 2007, found that men were unwilling to talk about prostate cancer). Support may also look different for different patient populations (for example, Donelle and Hall, 2014, found that female prisoners relied on networks of outreach workers and support groups, but lacked support from family and friends).

Distributed

The *distributed* research tradition views health literacy as a shared capacity that resides in the social network. In contrast to *resource* studies, where members of the social network support individual health literacy, *distributed* studies see health literacy as being understood (and even measured) at the collective level. These studies were primarily qualitative.

A key paper shaping this research tradition is Papen's (2009) exploration of how patients drew on social connections to overcome challenges with health information and health decisions. Nearly all participants in the study had someone who could undertake literacy tasks on their behalf. Papen regards these 'literacy mediators' as evidence for health literacy actually being located within the social network, whereby health literacy is something that groups (such as families) achieve collectively. Papen notes that 'an individual's health literacy could thus be seen as the sum of what she knows and is able to do herself and what she is able to achieve with the support from friends, family and other significant people in her environment' (Papen, 2009, p 27).

Papen's research connects health literacy to the field of 'new literacy studies', an interdisciplinary body of research that regards literacy as a social practice rather than a cognitive process (Street, 2003; Papen, 2012; see also Chapter 36, this volume). Such research uses qualitative and ethnographic methodologies (Black et al, 2016), focusing on the context in which literacy is situated. Therefore, studies in the *distributed* research tradition explore how people use information in their everyday lives. For example, McGrath et al (2015) highlight the implications of such theories for older adults who may be socially isolated; Edwards et al (2015) demonstrate the implications for including families in health decision-making; and Fairbrother et al (2016) explore how children's health literacy practices are embedded within their families. Edwards et al (2015) connect the concept of distributed literacy to the concept of distributed decision-making, which explores how 'our decisions are routinely distributed "over" people, they emerge, transform and solidify in and through multiple interactions with multiple others, significant or otherwise, over a period of time' (Rapley, 2008, p 436).

Another qualitative study in the distributed research tradition (Hogden et al, 2013) explores the extent of caregiver participation in decision-making for patients with amyotrophic lateral sclerosis. Despite a similar research approach and similar findings on the distributed nature of health literacy, this study does not cite others in the *distributed* research tradition, highlighting the challenge of connecting inductive findings to emerging trends in the diffuse literature.

Only one quantitative paper was categorised as being part of the *distributed* research tradition: Sentell et al (2014) show that each percentage increase of average health literacy within a community is associated with a 2 per cent increase in self-reported health for individuals in that community, concluding that both individual- and community-level health literacy are significant, distinct correlates of individual health status. We also found papers on community literacy that did not use the specific term 'health literacy' but show the promise of a quantitative approach to the 'distributed' conceptualisation of health literacy. Parashar (2005) found that a child's immunisation status was associated with the proportion of literate women in the district (independent of the education status of the child's mother), while Andrzejewski et al (2009) found that the proportion of literate adults in a community was a predictor of individual health knowledge.

Definition

Definition studies include the skill of having or leveraging social connection in the definition of health literacy, often operationalising Nutbeam's expanded definition of health literacy as including 'personal, cognitive and social skills' (2000, p 263). Many studies classified into this research tradition are related to the development and use of the Health Literacy Questionnaire (HLQ) and its predecessor, the Health Literacy Management Scale (HeLMS). These are multidimensional measures developed in response to broadening conceptual definitions of health literacy. HLQ includes a five-item scale of social support for health, with questions such as 'I have at least one person who can come to medical appointments with me' (Osborne et al, 2013; Beauchamp et al, 2015). Importantly, both the HeLMS and the HLQ were grounded in qualitative research with patient and healthcare providers about the skills important for health literacy, and this research highlighted the importance of including a social support construct (Jordan et al, 2010). Therefore, the HLQ includes some elements of a social practices perspective (common to other research traditions that were grounded in qualitative research), while also retaining questions from a functional literacy approach assessing individual ability to understand health information (Osborne et al, 2013). Other *definition* studies focused on different aspects of communication than the HeLMS and HLQ (for example, such as Rubin et al's 2011 Measure of Interactive Health Literacy, which focuses on individuals' propensity to actively seek information in interpersonal interactions) but had a similar approach of a social practices perspective supplementing, rather than supplanting, a functional health literacy perspective.

Aggregate

In the *aggregate* research tradition, health literacy is a functional skill of the individual, measured using objective tests or subjective screening, which can be aggregated at the population level (Cimasi et al, 2013) or compared within dyads (Garcia et al, 2013; Driessnack et al, 2014; Levin et al, 2014; Chisolm et al, 2015). These studies are all quantitative. Other studies that aggregate individual findings at the population level were likely excluded at the abstract stage (such as studies that merely described the prevalence or population distribution of low health literacy) but such studies could also be viewed as part of the *aggregate* research tradition. The five included studies incorporate an additional level of analysis beyond the individual level that led them to be included in this meta-narrative review.

Cimasi et al (2013) examined aggregate health literacy at the population level, and the association of population level. They found that low community-level health literacy rates are associated with increased community-level rates of preventable hospitalisations (considered a proxy for access to care), demonstrating how health literacy affects primary care and public health. Although they use data from the National Assessment of Adult Literacy, which has an individual, skill-based approach to measuring health literacy, Cimasi et al (2013) argue that future research should take an ecological approach to health literacy. Other critiques of population assessments (see, for example, Guzys et al, 2015) suggest that the direction for this research tradition may shift away from aggregation of individual-level assessments to measures specifically designed to assess the health literacy of communities, perhaps connecting to the concepts seen in the *distributed* research tradition.

Four studies compared the health literacy of patients and their carers. Garcia et al (2013) compared older adults with their caregivers and found that in a small proportion of dyads the caregiver had lower health literacy than the patient, while another study with older adults (Levin et al, 2014) found that caregivers consistently had higher health literacy than the patient, but that caregiver health literacy was still sometimes 'inadequate'. Chisolm et al (2015) also identified discordant dyads between adolescents and their parent, including caregivers with lower health literacy than the patient. Driessnack et al (2014) looked at child–parent dyads and did not find significant differences between their Newest Vital Signs (NVS) scores. Overall, these studies suggest that patient health outcomes are the result of both patient and caregiver health literacy, and that both independent and dyadic communication needs should be considered in health literacy interventions. Despite the similarities in design and research question, these four dyadic studies do not cite each other. This could be due to the close dates of publication or the fragmentation of health literacy research across different health issues and patient populations.

Knowledges

Knowledges studies are qualitative explorations of how health literacy involves the ability to negotiate multiple knowledges, including social knowledge. The key paper that led to the creation of this category was Lloyd et al's (2014) exploration of the health literacy practices of people with chronic health conditions (either HIV or chronic kidney disease), which explicitly links health literacy to emerging research traditions in the field of information literacy. This paper was published in the *Journal of Librarianship and Information Science*, unlikely to be identified in a cursory search by a health researcher, demonstrating the importance of the meta-narrative review process within the multidisciplinary field of health literacy. They explain a 'discursive shift' in information literacy from perspectives based on functional skills to a relatively recent perspective that sees information literacy as a sociocultural practice, where becoming information literate is mediated through interactions in a social setting. Positioning health literacy as information literacy in a specific context, they show the need for a similar shift in understandings of health literacy.

As with the *distributed* research tradition, the *knowledges* research tradition regards health literacy as a practice, rather than a skill or ability, and is concerned with the type of knowledge seen as legitimate in a given context. In this conception, health literacy practices enable people to draw on a range of information sources to make health-related decisions, including epistemic sources (rule-driven, objective and expressed in text), corporeal sources (experiential, embodied knowledge resulting from everyday living) and social sources (information derived through interaction with others, with may be implicit and difficult to express in writing). Lloyd et al (2014) describe how ongoing interactions, often through social groups or patient support groups, were the main social source of information, and were particularly important for sharing living experiences. Other social health literacy practices included orienting others to information, such as helping significant others to understand their health condition; sharing information with peers, particularly experiential information about issues such as self-care; and creating knowledge, such as compiling scrapbooks of recipes to share with others. They highlight that patients were not just consumers of information, but also active creators of information for family and friends. They outline a series of questions arising from their research, which could be considered a research agenda for the *knowledges* research tradition:

> how are the health information landscapes of people with chronic health conditions shaped; how does living with a chronic health condition ground the information experience of people; what are the sources of information that compose the health landscape; and how do people develop information practices that will inform their decision making. (Lloyd et al, 2014, p 214)

The other two papers included in the *knowledges* research tradition do not explicitly redefine health literacy in the way that Lloyd et al (2014) do – indeed, Hinder and Greenhalgh (2012) focus on self-management and refer to health literacy as a resource, while Schölmerich et al (2016) refer to health literacy in a way that is almost synonymous with health knowledge. However, both papers highlight the importance, and the challenge, of negotiating competing knowledges. Both studies draw on Giddens' structuration theory, which acknowledges both the constraining influence of people's environments, but also their autonomy and ability to act against constraints. Schölmerich et al (2016) examine how pregnant women from different cultures negotiate the misalignment of advice between health professionals and social networks. The study also illustrates the social practices perspective that different types of knowledge may be seen as more or less legitimate; in this case, personal experience of pregnancy was sometimes deemed to be more legitimate than medical knowledge. Unsolicited advice from the social network had a negative side, sometimes being 'stressful' or 'bossy'. Schölmerich et al (2016) conclude that health literacy interventions relating to pregnancy should include social networks (particularly mothers and sisters) to ensure consistency of advice.

Hinder and Greenhalgh (2012) use an ethnographic approach to look at the physical, intellectual, social and emotional demands of diabetes self-management. This work included managing the input of family, friends and colleagues, which was not always supportive; input could also be nagging or poorly aligned with medical advice. Hinder and Greenhalgh (2012) call for studies of self-management to better acknowledge the meso- and macro-level conditions that affect management, including roles, relationships and material conditions within the family. Together, the papers classified as *knowledges* illustrate how research traditions are evolving in fields related to health literary, such as literacy, information literacy and self-management, and how such developments influence the conceptualisation of health literacy.

Discussion

The rapid proliferation of health literacy research has led to a broad and diffuse literature, with multiple perspectives on the social aspects of health literacy. While all research traditions presented may prove useful directions for future research, greater conceptual clarity is needed in order to progress the field. The empirical studies described in this review frequently lacked a connection to the theoretical literature, failed to clearly articulate their theoretical basis or drew on multiple, sometimes conflicting, conceptualisations of health literacy and/or social capital within a single paper. Linking empirical health literacy research more strongly to social theory will provide a firmer basis for research beyond the individual level.

The six suggested thematic groupings we present are based on shared assumptions and methodological approaches, but there is little cross-citation and building on previous work – in part due to studies being published within a similar time period. As health literacy is a relatively new field of research, the research traditions are still 'emerging', and may separate further or consolidate in future. This review highlights the need for greater attention to integration. In particular, the field lacks integration of qualitative and quantitative research, and has underused qualitative methods. Qualitative research offers explanatory power to the mixed findings seen in quantitative studies. Such issues may include how stigma and shame surrounding low health literacy may affect social support, and explorations of the 'dark side' of social capital where strong ties and community obligations may bring costs without benefits (Andriani, 2013). The potential benefits of greater integration may also come from qualitative findings suggesting new conceptual approaches for quantitative research.

Implications for research

Health literacy research has produced useful findings that have shaped practices and interventions, and has led to a greater understanding of how the health system can be more responsive to highly vulnerable populations. However, by focusing largely on a functional definition of literacy, public health and medicine risk neglecting the richer and more nuanced viewpoints on this topic currently available in communication, literacy theory and decision analysis. This is supported by a recent review from bibliometric analysis on health literacy literature by Massey et al (2017), which highlighted opportunities to better integrate research across disciplines.

Methodologically, this review found that health literacy research has rarely used social network analysis. This is surprising given social network research highly relevant to health literacy, such as investigating how social network composition influences health knowledge (Fonseca-Becker and Valente, 2006), or comparing the health-seeking behaviours of those with larger and smaller social networks (Askelson et al, 2011). Social network analysis may be useful to quantify the perspectives seen in the *resource* research tradition by using network analyses to predict ties and changes in ties, or in the *distributed* research tradition by examining the structures (components, cliques, neighbourhoods) and network properties (density, centrality, degree) that allow a network to effectively share distributed health literacy. Future work might also integrate theories of behavioural economics and the interface with health decision-making and literacy (Hostetter and Klein, 2013).

A challenge for future research will be exploring not only how health literacy is developed, used and sustained in a social context, but also connecting such practices with measurable health outcomes at both the individual and population level. For example, the studies presented in the *knowledges* and *distributed* research traditions provide an interesting and useful perspective on how health literacy is developed and used, but rarely test empirical connections with health outcomes or behaviour. Also, social connectedness can lead directly to health outcomes (Lee et al, 2004). It will be important to differentiate such direct outcomes from the distinct pathway of social connections supporting health literacy, and health literacy supporting health outcomes.

Finally, this review suggests the benefits of greater international collaboration and connection in the health literacy field. Most quantitative studies, especially those in the *association* research tradition, came from the US, while the qualitative studies came from many countries, particularly Australia and the UK.

Implications for practice

Each of the research traditions provides a line of evidence to support or suggest interventions to improve health literacy. For example, *distributed* supports community-based interventions to improve health literacy (as seen in Galiatsatos and Hale, 2016, where lay health educators were trained to improve health literacy in faith-based communities) while *knowledges* indicates the need for support to negotiate different sources of health knowledge (as seen in Zanchetta et al, 2012, where community health agents helped clients to harmonise scientific and popular health knowledge).

Overall, the perspectives on health literacy presented highlight the importance of interventions that both support and supplement the patient's social resources, including leveraging existing social networks, developing new social networks and providing health navigators and health coaches (Heaney and Israel, 2008). In particular, the view of health literacy as being collectively achieved challenges individualised notions of responsibility that underline many current health policies (Papen, 2009), and provides a theoretical basis for peer-support and community-based interventions. For those working at the individual level, such as healthcare providers, the studies in this review highlight the importance of considering patients' social context when discussing treatment options, and considering including family and friends in shared decision-making. However, the literature also shows that such interventions should not be implemented without a nuanced perspective on the potential positive and negative aspects of social networks. Further research may also highlight the implications for different health issues and different stages of the life course.

Strengths and limitations

The strength of this review is the meta-narrative approach to understanding the multiple research traditions emerging in health literacy research in social context. This broad perspective of health literacy captures a range of views, particularly those in literacy and information science, which might be missed in alternative review approaches that are more constrained in terms of inclusion criteria, or focus more tightly on a specific topic. Indeed, this review demonstrates the need for investment in synthesis: while primary research is usually the priority for funding bodies and career advancement, proliferation without consolidation will limit the field.

Our broad perspective is also in some ways a limitation, resulting in 'blurry boundaries' around which studies should (or should not) be included, and undoubtedly other relevant articles exist. For example, health literacy is closely connected to many related fields (including self-management, patient decision-making, patient activation and health communication), and such fields are encountering similar questions in how to explore social context, and whether processes should be understood at the individual or collective level (Batterham et al, 2016; Black et al, 2016). Also, the meta-narrative process requires time for analysis, consultation and synthesis, but health literacy is a rapidly developing field, so relevant articles will have been published since the iterative search process concluded. We are aware that the restriction to studies in English also eliminated some highly relevant work (such as Okan et al, 2015). Thus, we present a broad overview of relevant bodies of work, emerging trends and contrasting approaches, rather than a comprehensive accounting of all relevant articles.

Conclusion

As Moore et al (2005, p 1337) write: 'there is a complexity and depth to the concept of social capital and social networks that has yet to be fully explored and exhausted in public health research.' This comment is particularly apt in the case of health literacy. Our review adds support to previous calls for a social perspective on health literacy (such as Lurie and Parker, 2007; Nutbeam, 2008; Sørensen et al, 2012), and reveals current research gaps. In particular, we highlight the challenge – and promise – of negotiating the diverse, even contradictory, conceptual perspectives on the topic. Like the parable of the six blind men who each described part of an elephant, the six research traditions presented in this review provide useful perspectives on a complex topic, but greater communication between them will build a stronger evidence base.

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44

Health literacy for all? Inclusion as a serious challenge for health literacy: The case of disability

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Introduction

The concept of health literacy started its triumphal march from the healthcare sector. In this context, health literacy meant 'simply' to be able to read and understand the patient information leaflet of a prescribed drug. Despite ongoing theoretical and conceptual improvement and the growing number of publications (for example, Nutbeam, 2000; Sørensen et al, 2012; WHO, 2013), the link between the personal level of health literacy on the one hand, and the personal literacy and educational performance on the other, continued to be more or less unquestioned. In most of the health literacy concepts and models, to be health-literate means, at least to some extent, to be educated (Nutbeam, 2009). Thus, it is not surprising that statistically there is a high correlation between the formal educational status of a person and the individual rating regarding different health literacy scales. It seems as if education has replaced the economic resources of action regarding the significance of health inequalities.

In the last few years there has been a visible differentiation of the health literacy discourse, regarding first, the theoretical models and concepts (Sørensen et al, 2012; Bröder et al, 2017; Okan et al, 2018; see Chapter 1, this volume), second, some sub-concepts of health literacy such as eHealth literacy or mobile health literacy, and third, specific target groups that should be addressed by health literacy empowerment interventions in order to strengthen their personal health literacy level. In most cases, target groups are senior citizens, children and adolescents or immigrants. Surprisingly, people with disabilities are rarely mentioned in the context of health literacy in particular and health inequalities in general. They are rarely addressed, for instance, as a special target group for health literacy interventions. Even in the recent World Health Organization (WHO) publication *Health literacy: The solid facts* (2013) there is neither a link to people with disabilities nor to inclusion nor to the International Classification of Functioning, Disability and Health (CF), which was developed by WHO itself in 2001.

In parallel, people with disabilities are the focus of a broad international discourse on inclusion, following the *Convention on the Rights of Persons with*

Disabilities (CRPD), entered into force in 2008 by the United Nations (UN) and ratified by 174 nation states (UN, 2017). Although the right to health is an important feature of the Convention (Article 25), in the context of inclusion, most of all the right to inclusive education is highlighted in scientific, political and public discourses. The topic of health and health inequalities in general and health literacy in particular is rarely mentioned in the context of inclusion and CRPD (cf Hollenweger, 2006). In this respect, there is a mutual non-perception of the two discourses.

In this chapter we argue that it would be fruitful and insightful if the concept of health literacy would face challenges posed by the concept of inclusion. In its very core, the concept of inclusion means societal participation in each field of agency for all people, independently of the individual resources of action. Applying this principle to the concept of health literacy would mean that health literacy is not centred on individuals' capacities and skills, but would lead to a health literacy perspective that is closer to the WHO slogan: making the healthier way the easier choice (cf NHS Scotland, 2017). To bring together these two broad discourses, we start to present very briefly some basic understandings of health literacy, focusing on the measurement tools and conceptualisations of health literacy in order to prepare it for an *inclusive addition*. Next, we also sketch very briefly some basic ideas of the concept of inclusion. We also want to identify some major challenges for the health literacy concepts. We then sketch some consequences for an inclusion-oriented health literacy concept and practice.

Concept and measurements of health literacy and the significance of education

According to the current state of empirical research, there is no doubt that individual health literacy is linked to social determinants. In sum, the WHO stated that:

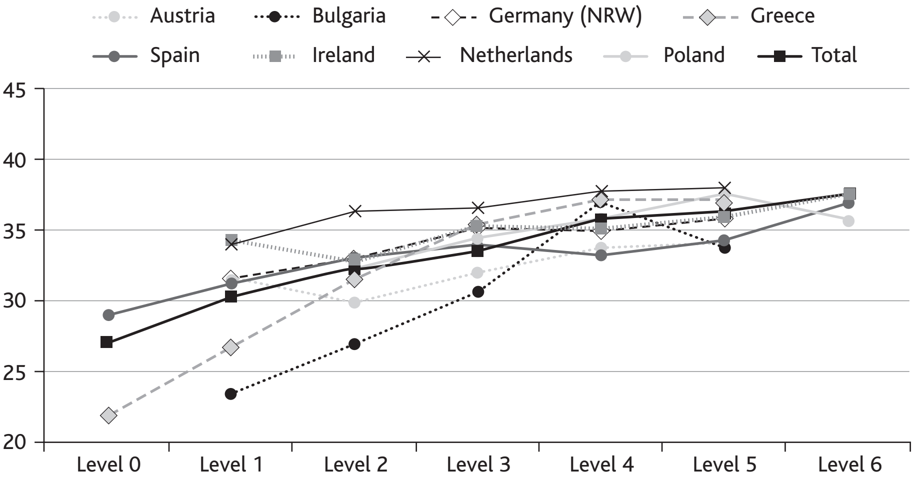
> specific vulnerable groups have much higher proportions of limited health literacy than the general population in Europe, including lower social status (low self-assessed social status, low level of education, low income and problems in paying bills), with worse health status (measured by self-perceived health, long-term illness and limitations in activities because of health problems) or relative old age. (WHO, 2013, p 14)

Nevertheless, in the health literacy research there is a strong tendency to focus on individual education status or educational performance as the most important factor of health literacy. This is particularly true for the measurement practices of health literacy.

As Pleasant et al (2011, p 11) point out: 'Building a comprehensive approach to measurement of the social construct called health literacy may well be the most significant and necessary task facing health literacy research and practice.' Health literacy research is still a work in progress, or in Levin-Zamir et al' terms (2017, p 133) 'a dynamic construct', up to now 'no gold standard measure for HL [health literacy] has emerged' (Nguyen et al, 2017, p 190). Thus, at present, more than 150 health literacy measures exist (2017, p 189; see also Chapters 5 and 6, this volume). Depending on the measurement tools, the relation between health literacy and education is measured as a direct (on the basis of objective tests and performances) or indirect (on the basis of self-reported skills) relation (Ormshaw et al, 2013; Kiechle et al, 2015).

The indirect measurement strategy refers to scales on self-reporting attitudes and/or behaviour, for example, the European Health Literacy scale (HLS-EU 47) (cf Sørensen et al, 2012; Pelikan et al, 2013; see also Chapter 8, this volume), the Health Literacy Measure for Adolescents (HELMA) (Ghanbari et al, 2016) or the US-based Health Activity Literacy Scale (HALS) (Rudd, 2007). One of the fundamentals of this strategy is that an overwhelming number of studies prove a stable positive correlation between individuals' (formal) educational level and the corresponding level of health literacy (for an exception, see Wångdahl et al, 2015). Generally speaking, the higher the education level, the higher the self-reported comprehensive health literacy level. To give just a few examples: the HLS-EU has shown for six of the eight participating countries weak or moderate correlations (even in multivariate analysis, where gender, age, social status and financial deprivation are controlled) between educational status and general health literacy level (with the exceptions of Austria and Ireland) (see Figure 44.1). In a representative Japanese survey from 2006 a research group found that 'individuals with a low level of educational attainment were also likely to have limited communicative/critical HL' (Furuya et al, 2013, p 508). In a recent representative

Figure 44.1: Mean scores of general health literacy by education for countries and total



Source: HLS-EU Consortium (2012)

Swiss survey, it was shown that people with low education possess less health literacy (Schweizerische Akademie der Medizinischen Wissenschaften, 2015). In a representative German survey from 2013 conducted by the Robert Koch-Institute, which is responsible for official health monitoring in Germany, the low educational status group has nearly a double share of people with inadequate health literacy compared to the high educational status group (Jordan and Hoebel, 2015, p 945).

All these empirical correlations refer to theoretical models that conceptualise the formal educational status as an individual resource of action, which is linked with self-reported health literacy. But theoretically at least, it is possible and sometimes plausible that people with a low educational status and/or those with little competencies in writing and reading have a high level of health literacy, for instance, regarding healthy daily routines or even patient autonomy. In a recently conducted survey in Afghanistan, we found out that even those who are illiterate reported – to a smaller share, of course – adequate health literacy (measured by HLS-EU Q16) (cf Harsch et al, forthcoming). This means that individual educational level correlates very much with the self-reported health literacy level, but it does not determine it. So it is possible that people with low educational status are principally able to live a healthy lifestyle, albeit having limited educational resources.

In the direct measurement strategy, the mostly often used instruments measure skills and performances directly:

> The large majority of empirical HL research has used the Rapid Estimate of Adult Literacy in Medicine (REALM) and the Test of Functional Health Literacy in Adults (TOFHLA), or some variant of these tools.… The REALM is a word pronunciation test that uses medical words, an extremely narrow lens through.… Alternatively, the full TOFHLA includes reading, numeracy, and document literacy, and the modified cloze procedure to ensure that the TOFHLA tests a person's understanding. (Nguyen et al, 2017, p 190)

The individual test scores on these instruments differ significantly according to educational background and completed years of school (cf Carthery-Goulart et al, 2009).

Although there is some critique that tests like REALM or TOFHLA are too narrow to catch a more comprehensive understanding of health literacy outside clinical settings (see, for example, Nutbeam, 2009, p 304; O'Neill et al, 2014, p 2), particularly in healthcare and curative settings the use of these tests are still the standard procedure. And there are some good reasons for it, for example, because of relations between literacy level and specific medical knowledge: 'Low literacy is associated with less diabetes-related knowledge and may be related to other important health outcomes' (Bailey et al, 2014, p 582). But there are two strong limitations to a direct link between health literacy and education: first, if a high educational level is reached, almost no differences in health outcomes are found between high educated people with little and high health literacy, measured by a short version of the TOFHLA (Hansen et al, 2015). Second, a measurement strategy that links directly the individual literacy level and health literacy level leads to the result that an illiterate person has, *by definition*, almost no health literacy, although this is not very convincing. Such a direct test strategy is furthermore challenged by the fact that there are large groups of immigrants and minority ethnic groups in each country of the world who are not able to speak the language of the majority as good as the native speakers. This means that the validity and test fairness of REALM, TOFHLA etc are basically limited. This is true even for the US or Canada, where a lot of empathy regarding minorities could be supposed. For the case of Canada, Omariba and Ng stated (2015, p 390) that, 'from a health literacy perspective, poor knowledge of English and French means that individuals are not able to communicate, access, and use health information to maintain their health.' And for the US case, Nguyen et al (2015, p 1503) mentioned that, 'most existing HL measures were developed and validated in English. Among them, there is a strong bias towards the validation of measures in White and Black populations. Using tools that are not well-validated for a given population can lead to substantive measurement error.'

These insights bring to the fore the very fundamental challenge of diversity of individuals and social groups for the concepts, models and measurements of health literacy. Research on diversity and social determinants in public health discourses normally refers to the three basic structural components of societies: class, gender and race/ethnicity. Another important dimension that is regularly taken into account is age. While the research results are not always clear for the gender dimension, we know that there are (partly strong) correlations between educational status, social (and employment) status, belonging to a minority ethnic group and to an older age group on the one hand, and the average level of health literacy on the other (cf Canadian Council on Learning, 2008; Pelikan et al, 2013; WHO, 2013; Zok, 2014; Omariba and Ng, 2015; Hearian et al, 2017; Levin-Zamir et al, 2017). But little is known about the relationship of health literacy and other important dimensions of diversity. For instance, it is still an open question as to whether sexual orientation is associated with functional, adequate or critical health literacy.

The state of research regarding disability and health literacy is hardly better. The measurement of disability is sometimes reduced to self-reported activity limitations. Omariba and Ng (2015, p 391) describe their (very vague) operationalisation-strategy:

> Disability was ascertained from five questions on current disability and activity limitation related to vision, hearing problems, speech, learning, or any other disability or health problem lasting six months or more. Respondents who replied affirmatively to any of the listed conditions were considered as having a disability; all others were defined as disability free.

According to this operationalisation 27 per cent of Canadians older than 16 belong to the group of people with disabilities. The advantage of such a measurement strategy is surely to make clear that people with any kind of disability make up a very large group in every society. However, the group of people with disabilities also includes those with severe and multiple disabilities, or intellectual disabilities, who are not able to fill out a questionnaire.

All of the presented measurements in this chapter are not feasible to measure the health literacy level of a considerable group of people with disabilities. This is a challenge, because the recognised diversity within health literacy will be limited from the beginning if only human beings are taken into consideration who are able to fill out a questionnaire. Furthermore, this has implications for policy strategies to increase the health literacy level particularly of vulnerable groups (WHO, 2013). It is important to note that the standard strategy and policy of increasing the health literacy level as a tool to improve the population's health in general is challenged very much in case of people with severe and multiple impairments (or of functional illiterates, but this is another discussion). As Don Nutbeam (2009, p 304), one of the pioneers of the health literacy concept, noted, 'health literacy can be developed by education. Health literacy can be regarded as a measurable outcome to health education in the same way that measures of literacy are used as one way of assessing the success of school education.' This widely accepted perspective is not only limited to highly industrialised countries, but also to countries of the Global South. A similar statement comes from an Iranian research group: 'Health Literacy capacity may be affected by individual and social factors that are modifiable using education' (Haghdoost et al, 2015, p 2).

What might happen if increasing education is hardly possible or impossible to manage? From a traditional health literacy approach, people with disabilities, who are hardly or not able to read and write, have, by definition, no health literacy. If somebody is not able to find, understand, appraise and apply health information, for instance, because of brain damage or traumatic learning blockades, then the health literacy level is near to zero. Consequently, those people belonging to these groups are more objects than subjects in the healthcare sectors and settings, and barely part of any health promotion perspective. This is sensitive because health literacy is called one important strategy of (patient) empowerment and participation (for good practice, for example, see NHS Scotland, 2017; see also Chapter 40, this volume), and such a perspective finally puts people with severe disabilities in a passive status, reduces their autonomy theoretically and neglects their subjectivity to a certain degree. This is hardly compatible with a WHO perspective that claims the best health for all people (WHO, 1986).

But what is an alternative to this perspective? First of all, it could be assumed that every person in the world has some abilities and competencies, independently from educational or cognitive performance. Thus, we are able to assume that even people with severe and multiple impairments have health literacy and are able to cope with their everyday life as well as possible (Feuser, 1996). So, the perspective should be that if measurement instruments are not able to measure the competencies of specific groups, it should not mean automatically that these groups have no competencies, and in our case, health literacy. Rather, scientific research should find ways to develop concepts and measurement instruments that are able to show the competencies of the groups concerned. If we want to find out what health literacy means as part of the agency in everyday life of, for example, people with disabilities, we need to change the methodological approach. It is necessary to watch people with disabilities closely to explore their potentials, their spectrum of autonomy, and to value them as human beings and people independently from the grade and severity of their impairments. For this change in perspectives the United Nations' (UN) *Convention on the Rights of Persons with Disabilities* (CRPD) and the subsequent discourse of inclusion, as well as the International Classification of Functioning, Disability and Health (ICF) from the WHO, are promising starting points.

CRPD, ICF, inclusion, health and health literacy

In the development of human rights and in the formulation of human rights declarations and human rights conventions by the UN there is a comparable and analogous process as in the WHO. The latter comes from the broad non-medical definition on health in 1948, progressed to the Declarations of Alma-Ata and Ottawa Charter focusing on health promotion, and continues to the Nairobi Declaration and to the last two WHO Conferences in Helsinki and Shanghai, where health literacy played a crucial role (see Chapter 42, this volume). While the programmatic development by the WHO continues to widen the normative frames regarding health equity, and to concretise the methods and policies to increase health equity, the logic of the progress in human rights – at least according to one common understanding of human rights education (cf Sahrai et al, 2015a, b; Gerdes et al, 2015) – is to emphasise the rights of discriminated groups as the subjects and recipients of human rights. Therefore, it is no coincidence that in the preamble of the CRPD the overarching general significance of human rights are emphasised as well as the 'universality, indivisibility, interdependence and interrelatedness of all human rights and fundamental freedoms' for people with disabilities. The main aim of the CRPD is to also ensure the full possible amount of human rights for people with disabilities. The preamble of the CRPD (UN, 2017) emphasises in paragraph v the 'importance of accessibility to the physical, social, economic and cultural environment, to *health and education*, and to information and communication, in enabling persons with disabilities to fully enjoy all human rights and fundamental freedoms.' Even widely unknown in the public health field, this Declaration is, by its very nature, relevant for a comprehensive health perspective because people with disabilities are, from another angle, to a very large degree simply people with chronic diseases. Furthermore, Article 25 of the CRPD addresses health issues directly (see Box 44.1).

Box 44.1: UN Convention on the Rights of Persons with Disabilities, Article 25 – Health

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:

a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;

b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;

c) Provide these health services as close as possible to people's own communities, including in rural areas;

d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;

e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;

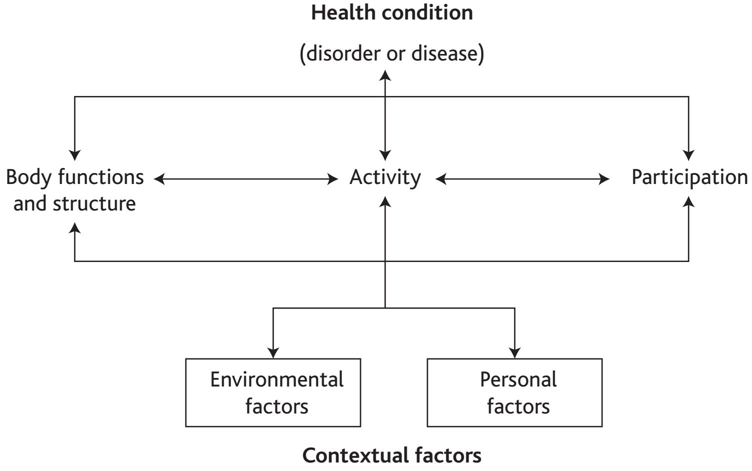
f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

Particularly relevant for the health literacy context is the demand for providing people with disabilities the same range, quality and standard of health programmes in the area of population-based public health programmes (see above CRPD, Article 25[a]). It is urgent to note that this demand is not an *add-on* for health literacy policies but a human right for each person, including those with any disability!

To bring health literacy models, concepts and policies closer to people with disabilities, the *distinction between functionings and disabilities*, which was supported by the WHO itself 15 years ago, is of particular value. This differentiation comes from the ICF (WHO, 2002; cf also Hollenweger, 2003). 'ICF is WHO's framework for health and disability. It is the conceptual basis for the definition, measurement and policy formulations for health and disability. It is a universal classification of disability *and* health for use in health and health-related sectors' (WHO, 2002, p 2; original emphasis). Although meant as a complementary tool to the ICD-10 classification, this classification is rarely known in health literacy discourses: 'ICD-10 is mainly used to classify causes of death, but ICF classifies health' (WHO, 2002, p 3). The basic idea of ICF is to distinguish impairments of a person's body (regarding physiological/psychological body functions and body structures understood as anatomical parts of the body) from social and environmental factors that hinder people with impairments from activity and participation. In this perspective, disability is always an interaction of individual characteristics and contextual factors. This is illustrated in Figure 44.2.

While a biomedical perspective on disability focuses on a single person and its disease and disability, the social model of disability refers to the social construction of disability. The strength of the ICF is to value each perspective and combine the medical and social approaches to a biopsychosocial model of disability. In this integrated model, education is also addressed as an individual factor (next to gender, age, coping styles etc), but from this perspective low educational status or performance would not have an *automatic impact* on health literacy, at least at the theoretical and conceptual level. If disability is conceptualised as the ineluctable interplay between personal characteristics and environmental and social conditions, then the health literacy of people with disabilities could not be reduced to a personal resource or skill either, particularly for those individuals with severe impairments. In Table 44.1 some examples are listed for the interplay between personal characteristics and social and environmental influences on different outcomes.

Figure 44.2: ICF model of functioning, disability and health



Source: WHO (2002)

Table 44.1: Examples for the interplay between individual and social/environmental factors

Health condition	Impairment	Activity limitation	Participation restriction
Leprosy	Loss of sensation of extremities	Difficulties in grasping objects	Stigma of leprosy leads to unemployment
Panic disorder	Anxiety	Not capable of going out alone	People's reactions lead to no social relationships
Spinal injury	Paralysis	Incapable of using public transportation	Lack of accommodations in public transportation leads to non-participation in religious activities
Juvenile diabetes	Pancreatic dysfunction	None (impairment controlled by medication)	Does not got to school because of stereotypes about disease
Vitiligo	Facial disfigurement	None	No participation in social relations owing to fears of contagion

Source: WHO (2002)

This means that an increase in individuals' health literacy could also be triggered by environmental and social factors: 'Reductions in the incidence and severity of disability in a population can be brought about by enhancing the functional capacity of the person and by improving performance by modifying features of the social and physical environment' (WHO, 2002, p 5). According to this approach, individuals' health literacy is socially embedded, it is part of flexible situations and opportunity structures that enable, support or hinder individuals' resources of action (see Chapter 37, this volume). At this point of the argument the CRPD comes in again, since it refers primarily to the duties of states to ensure the maximum of opportunities for people with disabilities, and to abolish social structures that hold some extra limitations of activity and participation for people with disabilities.

Following the entering into force of the CRPD in 2008, a worldwide discourse on inclusion started emphasising the right to full inclusion for people with disabilities into communities and society. States that have signed the Convention commit themselves to make visible efforts in including people with disabilities and to stop discrimination and social exclusion. The most visible field, especially in Europe, is the field of education, which is also particularly significant for health literacy. In Germany and Switzerland, for instance, for 10 years the hierarchically differentiated school systems has faced more and more problems of legitimisation. In accordance with the critical sociology and pedagogy of education, under the discourse of inclusion, the call to establish an inclusive school system and to liquidate the traditional separated school system for children and adolescents with disabilities (special needs education) has gained new power (cf Pfahl and Powell, 2011; Biermann and Powell, 2016). Although there are different understandings of inclusion, it is widely accepted that inclusion is a 'new paradigm for the analysis of current societal structures and the fundament for comprehensive reform programmes' (Hollenweger, 2006, p 45). In line with ICF and CRPD, the concept of inclusion refers to a shift in perceiving disabilities. The (still very present) focus on the specific demand of one single subject in terms of special needs education is questioned by an inclusive perspective, and should be replaced by a more participatory-oriented practice. This idea reflects the basic assumption in the concept of inclusion: people with disabilities are conceptualised as just another dimension of the big variety of human beings – analogously to dimensions like (()), race/ethnicity, gender, sexual orientation or age. To close the loop: if health literacy concepts, measurements and policies are meant to reflect the heterogeneity of a population in order to measure adequately, develop tailored policies and to empower people, then people with disabilities have to be taken into consideration. Thus, until now an almost unquestioned link between education and health literacy presented above should be questioned against the background of inclusion. However, this has some consequences for the concept of health literacy itself. In the following we present two different opportunities for health literacy concepts, models and measurements to deal with the topic of inclusion and disabilities.

Health literacy: inclusive or exclusive

The motto and general goal of the WHO is to achieve *Health for all* (WHO, 1998). If health literacy is really a significant factor for health outcomes, as shown by many international research studies, then it is not compatible with the WHO main goals to exclude a group of people, for example, with disabilities, arguing that they have too little educational performance to understand, appraise and apply health information. That means that policy programmes that are implemented to increase the health literacy level of the population – for example, community-based programmes – must include programmatically and practically people with disabilities, no matter how severe the degree of disability of a person (Feuser, 1996). From the perspective of the general goal *Health for all* by the WHO, two different strategies are possible in reaching the demands of people with disabilities. The first strategy could be to widen the concept of health literacy substantially; the second one, to keep the concept of health literacy narrow and to widen the WHO programmatic issues since the Nairobi Declaration (WHO, 2009).

Widening the health literacy concept addresses at least two different issues. First, it should have become clear that neither the indirect nor the direct measurement of health literacy is suitable for different minority groups, including minority ethnic groups, due to language differences, senior citizens or people with disabilities. The predominantly cognitivistic concept of health literacy needs a turn to look for health literacy in everyday life. This could be realised by ethnographic studies that accompany people, peer groups or families following methodological approaches such as action research or participatory health research. Regarding the health literacy in the everyday lives of people with disabilities it is paramount to conceptualise health literacy as the interplay between subjects and the social and physical environment. Then the health literacy of people with disabilities comes to the fore, and they are more than a group of underscorers who are always at risk of becoming stigmatised because of their poor test results (Kronzer, 2016). In this case, according to the biopsychosocial model of disabilities, health literacy needs an intersubjective turn (cf Habermas, 1981). From here it is necessary and, in our view, possible to transport the idea and concept of health literacy to organisations, institutions and even societies. For the healthcare sector this demand is clearly formulated by the WHO: 'Action must take place in many sectors: health professionals urge the education sector to improve the literacy skills of populations, but the health sector itself must take action to remove literacy-related barriers to information, services and care' (2013, p 26). But there are hardly any concepts or operationalisations for a health-literate society (cf Nielsen-Bohlman et al, 2004).

Another strategy to include people with disabilities in health discourses and programmes comes from a perspective on human rights and the theory of justice. If people with certain severe impairments will never be able to be high scorers on the traditional cognitivistic and education-oriented measurements, the absence of (such an understanding of) health literacy, however, must not have any negative effect on the best possible health status for these people. They should be enabled and empowered to reach the maximum of health under difficult circumstances without having functional, adequate or even critical health literacy skills. To us, it is an open question which of both strategies is more challenging and more promising, but we are sure that people with disabilities should gain greater attention both in health literacy and health research.

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Capacity building for health literacy

Stephan Van den Broucke

Introduction

Health literacy is gaining critical importance in healthcare, public health and health promotion. While the concept was originally only used in a medical context to refer to a patient's ability to understand doctors or nurses' instructions and recommendations, contemporary views consider health literacy as a key factor for public health and health promotion as well. At the same time, the meaning and scope of the concept have expanded to also include more complex and interconnected abilities, such as health information seeking, acting on written health information, communicating needs to health professionals, problem-solving, critical thinking and communication, along with a multitude of social, personal and cognitive skills that are imperative to function in the health system (Nutbeam, 2000; Peerson and Saunders, 2009; Van den Broucke, 2014; see also Chapters 1 and 2, this volume). The enhanced scope of health literacy is well captured in Sørensen et al's (2012, p 3) definition, according to which health literacy 'entails people's knowledge, motivation and competencies to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course.' This definition incorporates both the medical and public health perspectives on health literacy, and accounts for the knowledge and competencies that are required to meet the complex demands of modern society with regard to being ill, being at risk for illness and staying healthy.

The crossover of health literacy from the medical to the public health field did not come about by chance. An impressive body of research has been produced in the last decade that links low health literacy to less healthy lifestyles (Kaufman et al, 2001), low participation in screening programmes (Lindau et al, 2002; Dolan et al, 2004) and less optimal use of preventive services (Scott et al, 2002), in addition to decreased medication adherence, poor knowledge of disease, poor adherence to self-care management and suboptimal use of health services poor (Davis and Wolf, 2004; Vandenbosch et al, 2016). On the other hand, the available evidence suggests that nearly half of the adult population in the US, Europe and Asia have limited or insufficient levels of health literacy (Institute of Medicine, 2004; Sørensen et al, 2015; Duong et al, 2017; see Chapter 8, this volume). So, while the importance of health literacy for public health and health promotion is increasingly acknowledged, it is becoming clear that low health literacy is not just a problem of a small minority, but of a significant part of the population (Kickbusch et al, 2013; Van den Broucke, 2014).

To address this 'health literacy epidemic', different types of strategies can be considered. First, limited access to and understanding of health messages due to low health literacy can be compensated by ensuring better health communication through applying health literacy tools and guidelines in the healthcare, disease prevention and health promotion settings. Second, the level of health literacy in the population can be enhanced through health education. And third, the need for health literacy can be reduced by creating and strengthening health literacy-friendly settings (Kickbusch et al, 2013; see also Chapters 8 and 31, this volume). These actions require integrated policies at local, national and international level to empower people to make sound health decisions in different settings: at home, in the community, in the educational system, at the workplace, in the healthcare system and in the media. While the health sector can lead by example through the creation of healthcare settings that promote and support health literacy, civil society, politicians and the private sector can all contribute to addressing the health literacy challenges (see also Part 2 of this volume regarding health literacy-related policies). International organisations such as the World Health Organization (WHO) can provide moral and political support and guidance. As a case in point, the *Shanghai Declaration on promoting health in the 2030 Agenda for Sustainable Development* (WHO, 2017), which was the outcome of the 9th Global Conference on Health Promotion in November 2016, recognises health literacy as a critical determinant of health, and commits to developing, implementing and monitoring intersectoral national and local strategies for strengthening health literacy in all populations and in all educational settings.

To successfully address the challenges of limited health literacy, it is necessary that the public health system and other actors involved have sufficient capacity to do so. Indeed, strengthening the capacities of different actors to respond to limited health literacy will affect people across the whole lifespan. The core dimensions of public health capacity have been described in a number of conceptual frameworks. Using these dimensions as a conceptual basis, this chapter considers the capacities that are required to address health literacy challenges, and offers suggestions to strengthen these capacities with a view to addressing health literacy.

Public health capacity

The term *capacity* refers to a system's ability to produce desired outcomes – in the case of public health, to improve and protect the health of the citizens. This ability depends on the performance of the organisations that operate within the system, and on the relationships between them. In turn, the performance of these organisations depends on organisational factors like leadership, the effectiveness of the structures and processes through which they operate, the deployment of resources and the knowledge, skills and commitment of the individuals that make up the organisations (Zonta and Wilson, 2000).

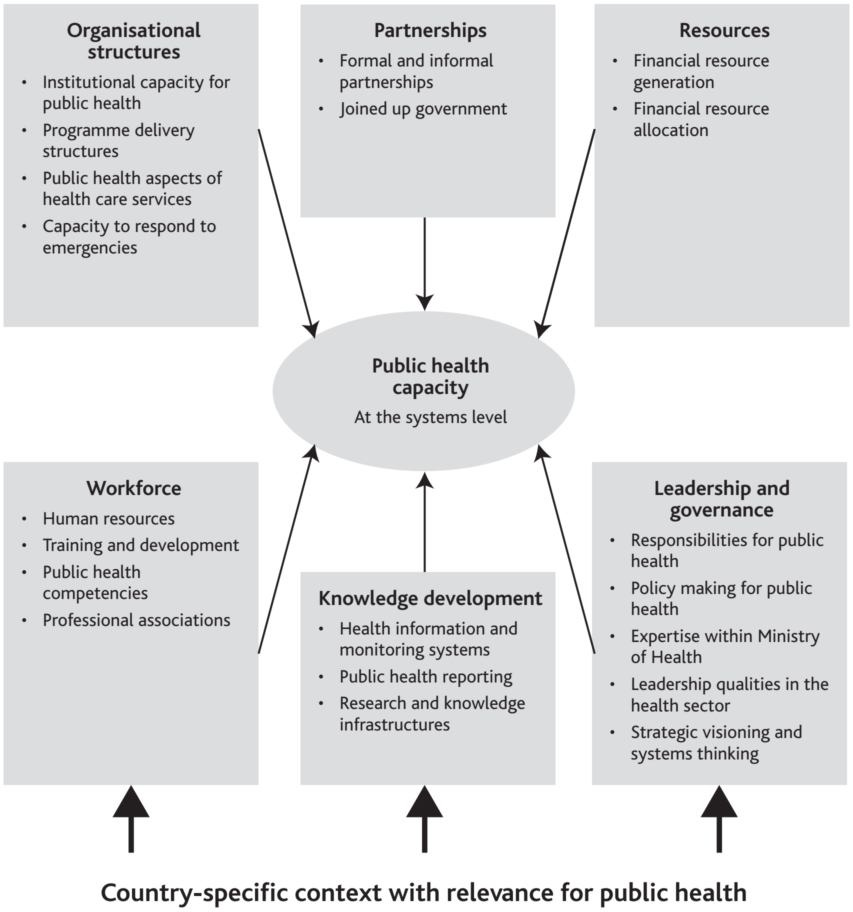
The concept of capacity was introduced to the field of public health and health promotion in the late 1990s, to highlight the requirements for successful and sustainable implementation of health promotion programmes and interventions. It is closely linked to *capacity building*, or the process by which individuals and organisations obtain, improve and retain the skills and knowledge that are needed to do their jobs competently. The introduction of capacity building in public health coincided with a shift of focus from directly trying to influence the health of the population towards enabling systems and networks to conducting public health actions in a self-determined and sustainable manner (Aluttis et al, 2014). As such, public health capacity building is not aimed at directly improving the population's health status, but at ensuring that the conditions are in place to achieve health improvement and to multiply and sustain this improvement over time, independently of external events. The underlying idea is that enhancing the capacity of the public health system to sustain health effects provides an added value to the health outcomes that can be achieved by direct interventions (Hawe et al, 1997). This was recently underscored by the World Health Assembly Resolution WHA69.1 (WHO, 2016), which considers effective and comprehensive public health services a means to support the achievement of universal health coverage in the context of the Agenda for Sustainable Development.

A key principle of capacity building is that it builds on the existing capacities of the system. Attempts to enhance public health capacities must therefore be based on an analysis of which capacities already exist, how well they are developed, and how well they link together as a system. This analysis is referred to as *capacity mapping*, and ideally involves a systematic assessment of existing capacities based on a predefined conceptual framework. Capacity mapping does not assess the performance of the public health system, but focuses on the system's *ability* to fulfil its functions within a set of given resource constraints. Whether the objectives of the public health system are achieved is the subject of conventional health system performance assessments (Aluttis et al, 2014).

The value of a capacity-building approach for public health and health promotion was highlighted in a seminal paper by Penny Hawe and colleagues (1997), and gave rise to several attempts to conceptualise and assess public health and health promotion capacities (for example, Alwan et al, 2001; La Fond et al, 2002; Catford, 2005). A review of these frameworks by Aluttis et al (2014) resulted in the identification of six core domains for public health capacity, which must be adapted to the country-specific context (see Figure 45.1): knowledge development; a competent workforce; organisational and institutional capacity; partnerships; leadership and governance; and financial resources.. Each of these domains can be further broken down into a number of subdomains, providing more in-depth insights into the dimensions of public health capacity.

By virtue of its systemic and holistic nature, this framework looks at public health capacity from a health promotion perspective: It focuses on health systems

Figure 45.1: Conceptual framework for public health capacities



Source: Reproduced from Aluttis et al (2014)

and services as *enablers* that promote health in a self-determined and sustainable manner, and considers health improvement as a task of all governance activities within a whole-of-society approach. As such, it can serve as a conceptual framework to consider the capacities of public health systems to address the health literacy challenge at regional, national and international level, and as a guideline for efforts to strengthen these capacities.

Capacities to address the health literacy challenge

Drawing on the conceptual framework presented above, the capacities that are required to address low health literacy in the population can be identified in reference to each domain.

Knowledge development

A first capacity domain is the development of a strong knowledge base with regard to health literacy. Over the past decades, research related to health literacy has proliferated and continues to expand exponentially. Whereas before 2000 a mere 34 referenced articles were published on the topic, at the beginning of 2018, more than 7,000 publications mentioning health literacy are listed in PubMed, 75 per cent of which have been published in the last five years. As a result, a rapidly growing body of evidence attests to the relationship between health literacy and health-related behaviour, health service use, treatment and medication adherence, self-care management, health outcomes and healthcare expenditure (Berkman et al, 2011; Kickbusch et al, 2013; Van den Broucke, 2014). Perhaps even more importantly there is a growing convergence of definitions and conceptualisations of health literacy, notwithstanding the fact that it remains an evolving concept. Major steps in the process towards this convergence were the publication of the reports *Health literacy: A prescription to end confusion* by the Institute of Medicine (2004), and *Health literacy: The solid facts* by the Regional Office for Europe of the WHO (Kickbusch et al, 2013). The latter drew on the results of the European Health Literacy Survey (HLS-EU) (Sørensen et al, 2015), which produced an integrated definition and conceptual model capturing the most comprehensive evidence-based dimensions of health literacy (Sørensen et al, 2012), as well as a questionnaire measuring these dimensions at population level (see Chapter 8, this volume). Several countries in Europe and Asia have used this questionnaire or similar tools (Osborne et al, 2013) to document the level of health literacy among their citizens, enabling comparisons between countries (Sørensen et al, 2015; Duong et al, 2017). A range of other health literacy measures have also been developed, some of which are specific to certain health problems or situations (see https://healthliteracy.bu.edu; see also Chapter 5, this volume).

These definitions and operationalisations provide a solid basis to strengthen the capacity to further expand and use the knowledge base on health literacy. Yet this requires a research infrastructure at national and international level that allows for the systematic collection of relevant high-quality data regarding the health literacy of the population, the determinants and consequences of low health literacy, and the effects of interventions aimed at tackling low health literacy, with a view to inform evidence-based policies. Particularly relevant would be to set up monitoring systems to measure the evolution of population health literacy over time, and to evaluate the effects of interventions within and outside the healthcare setting to enhance health literacy or help low health-literate people access and navigate health services. In addition, existing knowledge gaps should be addressed, such as the role of health literacy in explaining health inequalities or the relationship of health literacy to other 'literacies' (for example, mental, media and digital literacy; see Chapters 4, 17, 18, 19, 25, 36 and 39, this volume).

Workforce development

Next to knowledge development, a well-trained public health workforce is another key capacity domain for public health. This entails the availability of a sufficient number of qualified public health professionals, as well as an adequate management of these human resources and the availability of training options. The need for a competent health workforce as a key condition for the delivery of effective health services has been recognised for decades. However, while most health systems still strongly focus on treatment, cure and care, the growing burden of non-communicable diseases, widening health inequalities and the higher value placed on shared decision-making in care and prevention put increasing and shifting demands on health services, which require different skills and competencies of professionals (see Chapter 40, this volume).

Attention for health literacy is part of these competencies. While public health and healthcare professionals do not control the mechanisms to improve the health literacy of their patients or community members, they can adapt the procedures for communicating and interacting with people, make the forms and materials they use more health literacy-friendly, and improve their own communication skills. This can be achieved through incidental or informal learning as well as through formal learning strategies. Health professionals can make use of best practice guidelines and tools to identify and support people with low health literacy, as is recommended by the Institute of Medicine's expert committee on health literacy (IOM, 2004; see Chapter 21, this volume). More significant change, however, can be expected from including health literacy awareness and skills training in their basic training curriculum. In addition, professionals can take specific health literacy development courses for continued education, which exist in multiple formats (Naccarella and Murphy, 2018). An example of such a programme is 'Building capacity among primary healthcare providers to address literacy and health', developed by the Department of Primary Health Care in Nova Scotia, Canada (Carpenter et al, 2005), which helps service providers to identify health literacy issues in patients, and supports them to address literacy as a determinant of health and wellbeing. Another example is 'Health literacy: Help your patients understand', developed by the American Medical Association Foundation (2005). Research has shown that health professionals who are alerted to the limited health literacy of the people they work with are more likely to use helpful strategies for communication and education, such as involving family members or friends, using pictures or diagrams or reviewing the understanding of medication leaflets (Seligman et al, 2005).

However, while communication techniques are generally taught in clinical skills courses as part of the required health professional curricula, there is no consistent curriculum across institutions or disciplines, and specific skills for addressing low health literacy are seldom included. To encourage the more systematic consideration of skills training related to health literacy in the curricula for health professionals, these skills would ideally be included in certification and accreditation systems. In this regard, it is worth noting that the Core Competencies Framework for Health Promotion (CompHP) developed by the International Union for Health Promotion and Education (IUHPE) explicitly lists health literacy as a required core knowledge and skill for the professional health promotion specialist (Barry et al, 2012).

Organisational and institutional capacity

A competent public health workforce can only operate effectively when it is embedded in a supportive organisational structure. Organisational capacity refers to the degree to which structures, systems, procedures and practices of organisations within a community are in place to attain their mission and objectives, and that change is managed effectively. As such, building the organisational capacity to address health literacy can involve interventions in various areas of organisational functioning. These include strategic planning (for example, introduce health literacy as a core element in the business plans of organisations in the health sector), management change (for example, involve senior managers in steering committees for projects dealing with health literacy), improving policies and procedures (for example, ensure the allocation of a budget to initiatives to enhance health literacy), introducing quality systems (for example, use quality guidelines and tools for actions to address low health literacy), reviewing recognition and reward systems (for example, incorporate attention for health literacy in job descriptions and reward employees who achieve well in this area), or changing the organisational culture (for example, encourage attitudes in support of health literacy).

The inclusion of strategies to address health literacy in organisational functioning is at the core of the *health literate organisation* concept. An organisation can be considered as health-literate when it 'makes it easier for people to navigate, understand, and use information and services to take care of their health' (Brach et al, 2012, p 1). As such, the concept acknowledges that in addition to an individual's abilities, the demands and complexities of health and social care systems are also vitally important. Brach et al (2012) list 10 attributes of a health-literate organisation: (1) it has leadership that makes health literacy integral to its mission, structure and operations; (2) it integrates health literacy into planning, evaluation measures, service users' safety and quality improvement; (3) it prepares the workforce to be health literate and monitors progress; (4) it includes populations served in the design, implementation and evaluation of health and related information and services; (5) it meets the needs of populations with a range of health literacy skills while avoiding stigmatisation; (6) it uses health literacy strategies in interpersonal communications, and confirms understanding at all points of contact; (7) it provides easy access to health and related information and services and navigation assistance; (8) it designs and distributes print, audio-visual and social media content that is easy to understand and act on; (9) it addresses health literacy in high-risk situations, including care transitions, communications about medicines, etc; and (10) it communicates clearly what health plans cover and what services individuals will have to pay for (see also Chapter 32, this volume). Checklists to measure the presence of these attributes in a health or social care organisation have been developed (Thomacos and Zazryn, 2013), while other authors (for example, Dietscher et al, 2015) have developed more complex models of health literate organisations (see Chapters 8 and 31, this volume). While this suggests that the idea of a health-literate organisation is still an evolving concept, in terms of capacity building these models and tools offer guidance for the quality improvement process that will help organisations enhance their capacity to address health literacy in a systematic way.

Partnerships

Since health literacy is not only a concern for the healthcare sector but also requires integrated action by civil society, politicians and the private sector, collaboration between organisations at local, national and international level creates possibilities to join forces in addressing the health literacy challenges. Examples of partnerships for health literacy at national level are becoming increasingly common. For instance, the National Alliance for Health Literacy in the Netherlands, which was established in 2010, unites more than 60 organisations including patients' associations, associations of healthcare providers, health institutions, health insurance providers, academic institutions, industry and businesses to work on a common agenda of sharing knowledge and experiences, advocating for the incorporation of health literacy into the operations of health institutions and planning joint actions. In a similar vein, the Multi-stakeholder Collaboration in Ireland groups the National Adult Literacy Agency, the Department of Health and the Health Service Executive, as well as university departments and the pharmaceutical company MSD. In Belgium, the Well Done Health Literacy consortium unites health insurance funds, associations of healthcare providers, the heart and cancer foundations, academics and a pharmaceutical company to advocate for health literacy and hand out an annual Health Literacy Award. At international level, Health Literacy Europe and the Global Working Group on Health Literacy of the IUHPE bring together researchers and practitioners from different countries and disciplines to further the knowledge on health literacy and the ways to address the health literacy challenge.

Other partnerships operate at community level, where community members can collaborate to improve policies, programmes and practices related to health literacy. An example of such a partnership at community level is given by Gillis (2004), who describe how participatory research, undertaken through a university–community partnership, resulted in the identification and prioritisation of actions to improve practices and policies addressing the health literacy needs of a rural community in Atlantic Canada. The participatory research process not only enabled the building of the case and the commitment, but also revealed the complex interactions between literacy and health, including direct and indirect impacts of literacy on health. It also provided members with opportunities to identify commonalities and differences in their approach to the subject, their respective institutional structures and practices, and opportunities for learning across disciplines, communities and sectors.

Developing partnerships seems a promising component to strengthen the public health system's capacity to address the health literacy challenge. However, the effectiveness of a partnership depends on the extent to which the organisations that participate in the network share common goals, mutual perspectives and resources, and are able to communicate effectively. These elements are contained in the concept of *partnership synergy*, which can be defined as the extent to which the perspectives, resources and skills of the organisations in a network contribute to and strengthen the work of the group (Lasker et al, 2001). The synergy that is achieved within a partnership is reflected in the way partners think about the partnership's goals and plans, the types of actions they carry out and the relationship the partnership develops with the broader community. Thus far, very little research has been conducted into the strength and effectiveness of the partnerships between organisations in the health sector (Edwards et al, 2015), and evidence regarding the synergy between partners within health literacy networks is non-existent.

Resources

When considering the capacity of a health system, the issue of resources is always a sensitive one. Simply put, the possibility to develop all other capacity domains often depends on the availability and allocation of resources. Resource allocation involves the decision-making processes that ensure that an appropriate mix of goods and (financial and non-financial) resources is made available to organisations in the sector or community, to maximise the chances of reaching the goals. Besides financial resources, human resources, information, administrative and physical resources must also be considered.

Leadership and governance

The allocation of resources is intricately related to governance. Governance can be defined as the attempts of governments or other actors to steer communities, countries or groups of countries in the pursuit of their goals. In the context of health policy, this goal is health as integral to wellbeing, which is pursued through whole-of-government and whole-of-society approaches (Kickbusch and Gleicher, 2012). Governance for health promotes joint action of health and non-health sectors, of public and private actors and of citizens, and requires a synergistic set of policies, many of which reside in other sectors than the health sector or even outside the government. Leadership refers to the characteristics of people within an organisation or community to search opportunities for growth, to set examples, to inspire, mobilise and enable others to act, and to encourage them by recognising their contributions to success.

In the current context, health literacy enjoys a great deal of attention from policy-makers at local, national and international levels. A growing number of countries is recognising low health literacy as a health problem, and are developing policies and measures to address this problem. Internationally, the mandate for taking action on health literacy is powered by the fact that the United Nations (UN) considers health literacy as important for the achievement of targets related to the Sustainable Development Goals (SDGs), the recognition of health literacy as a critical determinant of health in the *Shanghai Declaration* (WHO, 2017), and by the mentioning of health literacy in the European Union (EU) Health Programme 'Health for Growth' (2014-20) (European Commission, 2014). These actions clearly show a momentum for governance on health literacy, but in order to act on it there is a need for leadership. Building leadership for health literacy requires the identification of champions who are able to mobilise actors and communities, encouraging their visioning and strategic thinking, and strengthening their personal, interpersonal, organisational and technical skills.

Building capacities for health literacy

Capacity building does not originate from one particular theoretical model, but represents an integration of views from different theoretical backgrounds, including organisational development, community development, networking theory, empowerment theory, adult learning theories, diffusion of innovations theory and social ecological approaches in health promotion. This heterogeneous background is also reflected in the strategies that have been proposed for public health capacity building. In this regard, four strategies can be distinguished to strengthen the capacities to address health literacy (Hawe et al, 1997):

- a *top-down* organisational approach, which aims at improving the possibilities for responding to the challenge of health literacy through organisational restructuring, reviewing policies and practices and ensuring or mobilising staff, logistics and financial resources;
- a *bottom-up* organisational approach, which encourages health professionals to become 'reflective practitioners' through continuous learning and improvement programmes;
- a *partnership development* approach, which encourages partnerships and collaborations between organisations that strive to enhance health literacy, in the expectation that collaboration will pool the available means and free resources for programmes to address the health literacy challenge; and
- a *community organisation* approach, which aims to encourage individuals and organisations in the community to actively participate in community actions to solve the problems of low health literacy.

Whichever of these strategies is preferred, efforts to strengthen the capacity to address health literacy will need to respect the principles of capacity building. These include:

- *Respect and value of pre-existing capacities:* Capacity building always takes place in existing structures. Within these structures, some level of capacity is always present. Effective capacity-building practice should acknowledge this capacity and build on it. This requires the identification of pre-existing skills, competencies, structures, partnerships and resources, and linking these with content, context, technical and capacity-building expertise, using processes that enable exchange of expertise and facilitate contributions from all partners.
- *Responding to context:* Capacity building takes place in an existing environmental, economical, organisational and cultural context. One needs to be aware of this context, observe it and be ready to respond to it. Therefore, capacity-building efforts should ideally be preceded by an assessment of these contextual aspects, and contextual changes should be monitored as part of the ongoing evaluation.
- *Well-planned and integrated strategies:* Effective capacity building uses a combination of strategies to achieve change at the individual, group, organisational and community levels. To coordinate these different components and to make sure they reinforce each other, capacity building should be carefully planned. Health promotion workers are familiar with the use of planning models stating the objectives, target group, methods and organisational aspects of interventions aimed at behaviour change. Similar models could be developed and used in interventions aimed at building or strengthening capacities.

Conclusion

Addressing problems-related to low health literacy is a shared responsibility. Different actors and stakeholders need to combine and integrate actions to enhance health literacy in the population, ensure better communication about health and its determinants, develop health literacy-friendly settings and empower people to make sound health decisions in the context of their everyday life: at home, in the community, at the workplace, in the healthcare system, in the educational system and in the traditional and social media.

While the health sector can lead by example through encouraging and assisting healthcare providers to detect low levels of health literacy in patients and to adapt their communication, an important role is also to be taken up by civil society. Patient associations and organisations working with older people or with disadvantaged groups and communities can all contribute to educate people on health issues, to support them in understanding and critically evaluating health information and to make informed decisions. This process can be supported by way of integrating health literacy as a key issue in public health policies, as well as in educational, social welfare policies at the local, national and international level.

None of this can be achieved without sufficient capacity. In this chapter, we drew on the notion of public health capacity building to discuss the ways in which the capacity of health systems and other stakeholders can be strengthened to respond to the challenges of low health literacy. Specifically, we considered six core domains of capacity building: knowledge development, workforce development, organisational and institutional capacity, partnerships, financial and non-financial resources, and leadership and governance. In each of these domains, we specified the conditions that need to be put in place in order to respond to the problems of low health literacy. Thus, knowledge development for health literacy involves a continued investment in health literacy research and in the dissemination of its findings. Workforce development for health literacy involves training health providers to identify and address low health literacy, and ensuring that such training becomes part of the curriculum and accreditation of health professionals. Strengthening the organisational capacity for health literacy involves building health literacy-friendly organisations and settings. In terms of resources, an investment of human and financial resources is essential, and with regard to partnership, there is a need to combine efforts to empower individuals and communities through improved sectoral and intersectoral collaborations on the topic of health literacy. Finally, governance for health literacy means that policies for health literacy must be developed at the local, national and international level, while there is a need to identify and encourage champions who are able to mobilise actors and communities to address health literacy.

Strengthening these capacities can be done through different strategies. What is the 'best' strategy depends on the specific context. However, whichever strategy is followed, it is important to remain true to the principles of capacity building, which include respect and value of pre-existing capacities, responding to the existing environmental, economical, organisational and cultural context, careful planning, and using a combination of strategies to achieve change at individual, group, organisational and community levels.

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"As a field of study and practice we benefit from international thinking about health literacy as a public health priority. This book is a much-needed resource for improving health literacy locally, regionally and globally."
Sabrina Kurtz-Rossi, International Health Literacy Association

Health literacy addresses a range of social dimensions of health, including knowledge, navigation and communication, as well as individual and organisational skills for accessing, understanding, evaluating and using information. Particularly over the past decade, health literacy has become a major public health concern globally, as an asset for promoting health, wellbeing and sustainable development.

This comprehensive handbook provides an invaluable overview of current international thinking about health literacy, highlighting cutting-edge research, policy and practice in the field. With a diverse team of contributors, the book addresses health literacy across the lifespan and offers insights from different populations and settings. Providing a wide range of major findings, the book outlines current discourse in the field and examines necessary future dialogues and new perspectives.

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ISBN: 978-1-4473-4451-3
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