



Improving Health
Literacy for
People with
Low Literacy:

An analysis of a
South African
HIV health
education
programme

Njabulo Mbanda





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Chapter 1

Who the book is intended for

The South African (SA) National Department of Health (NDoH) has combined best practices and other lessons learnt over the years into comprehensive policies and guidelines for the management of chronic diseases. This is especially for human immunodeficiency virus (HIV), tuberculosis (TB) and various other non-communicable diseases (National Department of Health, 2016). These policies are significant, as these chronic diseases have contributed significantly to the burden of disease in the country. The SA context also has high numbers of users of the public healthcare system. These citizens who speak 11 different official languages present with various health information needs (because of the differences in culture, ethnic groups, health conditions and education levels). These dynamics make it important for the healthcare providers (HCPs) to accommodate the health information needs of the different users. Moreover, some users of the public healthcare system are not on chronic treatment and thus a huge component of the work of the NDoH ought to be directed in prevention programmes whose aim is to ensure that people adopt a healthier lifestyle; and to promote overall wellness.

Such a prevention approach renders huge opportunities for accurate, relevant and timely health information. In this instance health information does not refer to the type of summative, epidemiological health information that the health ministry might use in planning of their programmes. That which is usually in the form of health indicators which are aggregates for populations, age groups, programmes and diseases. Instead, in this book I am referring to health information that is designed to educate people and communities about their health, mostly known as health promotion. However, with the enhanced attention on the prevention of lifestyle illnesses, and the promotion of self-

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care and management, health promotion comes across too broad and ineffective as an intervention strategy.

This health promotion is usually delivered in the form of health education either individually or to groups. The World Health Organization (WHO) defines health education as a form of messaging that aims to increase individuals' and communities' knowledge and influence their attitudes. Health education is provided in order to help people to promote, improve and control their health (World Health Organization Western Pacific Region, 2017). However researchers are now interested in understanding why and how individuals seek, obtain and use health information that is obtained during health education. This has translated to a much-needed focus on health information whose aim is to enable individuals to make informed decisions about their health. In this way, low literacy and health literacy have received increased attention due to their association with poor understanding of health information, and consequently negative health outcomes. Although a substantial amount of research discusses health literacy and its role; there are gaps in explaining the relationship between health literacy, low literacy; as well as various determinants of health (social, cultural, political, educational and economic implications). This relationship is particularly significant for lower- and middle-income countries (LMICs) where most clients might not speak English as a first language; nor the same language as that of the healthcare providers. Healthcare providers (or practitioners) are the central target audience for this book, as they provide a variety of health services to people in the private or public health facilities; of which in most cases, this service ought to include an element of health information; provided either as counselling, general health education or prescription instructions. The term 'healthcare professional' (HCP) in this book refers to medical practitioners (doctors, nurses), allied health professionals, pharmacists, and counsellors who provide different forms of health services.

This book aims to share research findings and views from the recipients of health education programmes. The

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objective is to present the importance of the understanding of health information provided with the purpose of enabling the receiver to use the information at a later stage. The book offers an appraisal of a different angle of health information which has rarely been made available in discussions about the phenomenon within the healthcare settings, since these sources are usually biased to the views of persons with adequate literacy or the healthcare providers. The book draws insight from the fields of public health (through focusing mainly on health information), augmentative and alternative communication - AAC (introducing the importance of the use of visual aids and the dual processing of multimedia messaging) and psychology (using theories of information processing to explain recall of messages and understanding). This is done in order to enhance the work of members of the public health community; a list is inclusive of public health researchers, scholars and specialists; as well as HCPs at different levels, i.e., both clinical and non-clinical.

The view shared in this book is distinctive from other books on health communication literacy and promotion within the healthcare settings, because most of these have predominantly focused on online resources and case studies from high-income countries such as the United States (US). These books have targeted literacy, infants, or school-going youth and not health information needs per se. This book focuses on health information on adults with low literacy and the effective dissemination and understanding of health information on people living with chronic illness (such as HIV/AIDS). Finally, the contents are also suitable for the different directorates and health ministries; and their partners who inform, influence or take part in the development of policies and guidelines. Sharing results from fieldwork conducted in South Africa gives the book potential to be used as an additional source in short courses, certificates or diplomas in community health and nursing, medical humanities, and the sociology of health. Moreover, the fact that the research was conducted in SA does not limit the applicability of the findings. Instead it is my view is that the findings can be applied to

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countries with a similar context to SA, as well as high-income countries where seekers of healthcare might have medical aid or health insurance and have low levels of education.

Chapter 2

Defining Health Information

Introduction

In order to distinguish between the various forms of health information that are available, it is crucial to define the different forms as they are understood and used in different healthcare settings. A broad view of strategies of health information is presented in order to help to understand the type of health information that is the main focus of this book. As a result, this chapter provides definitions and a background of health promotion, education and information and their various uses. This is done in order to demonstrate the move from the broad strategy known as health promotion, to a focus on health information, which is targeted at the individual, thereby offering a rationale for focusing on the health information needs of people with low literacy.

Health promotion

Table 1 depicts the various types of health information; and outlines the aim, strategy or format; as well as the targeted audiences. The term 'health promotion' has undergone various definitions and interpretations, most of which depend on the use and intention (Nutbeam, 1998). These terms have often been used to underpin efforts of health education, which are generally assumed to educate groups of people through mass media, as an attempt to help people change their lifestyles, and move towards a state of optimal health (Viner & Macfarlane, 2005). Despite its focus on broader societal health education and mass messaging, health promotion is associated with helping efforts to help individuals reduce unhealthy behaviours and promote healthier behaviours. This is also why the term is closely linked to efforts of disease prevention (Tannahill, 1985).

Table 1: Different types of health information

Type of Health Information	Aim	Strategy/format	Target
Health Promotion	Messaging, education	Mass media, social media	Community, groups
Information, Education and Communication (IEC)	Messaging, awareness	Printed/(social) media, reading materials	Community
Routine Health Information	Planning, budgeting, monitoring and evaluation	Data elements, indicators, numbers, reports	Health departments, ministries, programmers, policymakers, funders
Health Education	Education, empowerment, counselling	Health education, individual or group counselling	Groups, individuals, patients, clients

Chapter 2

Health promotion has received criticism from many critics who point out its narrow nature because it overlooks the community and individual level. The WHO defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”. Therefore, the WHO views health promotion as the process of enabling people to increase control over, and to improve, their health. This means that health interventions should be able to address curative, palliative, preventative, treatment and care aspects of health. Such interventions are deemed to have the potential to cover health-promoting activities that can address elements of individual behaviour change.

Following on from health promotion’s focus on group and behaviour change, one might find that health promotion efforts tailored at different age groups might tackle different lifestyle changes. These efforts are likely facilitated through a combination of strategies to increase awareness, change behaviour, and create environments that support good health practices. For instance, health promotion for little children would be tailored in such a way that is dependent on adults or parents. This is because most health behaviours of young children are predominantly governed by parents’ rules and instructions. On the other hand, health promotion messaging for adolescents may be addressing socio-behavioural factors that may cause risk and harm to this age group. For example, adolescents are prone to peer pressure and resultant incidences of early sexual debut, contracting HIV, excessive use or abuse of alcohol and drugs and a variety of mental health issues. Consequently, evidence also shows that health in adolescence can have a considerable impact on the development of adult conditions such as chronic illness, obesity and certain mental health conditions (Viner & Macfarlane, 2005).

In other words, health promotion messaging also has to align with the times and prominent health-related matters that a particular group may be experiencing. Currently, adolescent depression is a highly prevalent disorder amongst adolescents across the world, and where untreated, it is associated with substantial morbidity, school dropout, teenage

pregnancy, suicide, substance abuse, as well as considerable health expenditure (Mufson et al., 2004). In a country like SA, some of the depression cases are closely linked to suicidal thoughts or attempts, negative feelings about the family background or situation, as well as having experienced forced sexual intercourse (rape, early sexual debut, molestation) (Shilubane et al., 2014). Moreover, adolescents and young adults (ages of 15 to 24 years) account for 63,3 per cent of the total number of unemployed persons in the country. This number consists of both educated young people and those with low literacy. However, Statistics South Africa shows that even amongst graduates (those who have completed high school and have a tertiary qualification), the unemployment rate can be as high as 33,1 per cent (Statistics South Africa, 2017), thereby rendering them prone to various unhealthy behaviours. This is why most school-based prevention programmes in the country have taken direction towards preventing substance misuse or abuse, teenage pregnancy; and addressing a variety of other harmful or risky behaviours such as bullying. These programmes also target mental health-related challenges (Nutbeam, 2000). These health promotion activities remain as group-administered interventions due to the nature of the schooling environment being more suitable for such interventions, instead of one-on-one sessions. School-based health promotion activities can thus only be suitable for the youth and adolescents of school-going age, since they don't address the needs of adults who are living with chronic illness. In this way a programme like the NDoH chronic health education programme is an important tool for HCPs who interact with adults of this population since the programme serves as a tool for the provision of health information in a standardised and comprehensible format for adults to understand.

Information, education and communication (IEC) Materials

Another strategy of providing health information that has been widely used in the public health arena is information,

education and communication (IEC) materials. IEC refers to health education materials that are used to convey public health messaging as a means to support, promote certain health behaviour or create awareness (Thorseth, 2020). IEC materials typically come as flyers, posters, leaflets, brochures and can also be posted on social media, appear as television and radio adverts. Although cost effective and the most widely used health promotion strategy for disseminating health information and modifying health attitude and behaviours (Halliday, 2020), some researchers still believe that the use of IEC materials is not a strategy powerful enough on its own, to influence and change behaviour. This suggests that IEC materials should always be complemented by another strategy such as one-on-one health education counselling, which targets the individual more directly.

An example of an IEC strategy that became popular during the Coronavirus disease 2019 (COVID-19) era was the health messages that were shared through various social media platforms. These IEC messages were a resultant combination of joint efforts by the WHO, government agencies, and various health organisations to compile, share and enforce prevention, infection control measures, and the relevant COVID-19-related health information (Nguyen & Catalan-Matamoros, 2020). Amongst these were mass campaigns to share awareness, preventative health messages and on various platforms, mostly using the media. These efforts were being implored to ensure the availability of updated information on variants, vaccines and physical distancing measures. Unfortunately, these health messages were competing with different sources of misleading information leading to a phenomenon called misinformation. Misinformation is false information that is spread without necessarily intending to mislead the receiver, though in most instances it does. For example, misinformation around the COVID-19 virus was a result of the myths and theories being spread about the virus, its aetiology and trust or around the vaccination process. The main challenge with misinformation is the fact that the

interpretation of the health information and its authenticity is left to the discretion of the receiver.

Health information

A programme like the NDoH health education programme is therefore important, since individual health information with the intention to educate has not always been the focus of health information within the public health field. This is because, for the most part, the term “health information” has usually referred to indicators from routine health information systems (RHIS) through which governments plan, budget and monitor health programmes and health outcomes (AbouZahr & Boerma, 2005) and assess the utility and effectiveness of programmes in order to improve performance (Aqil et al., 2009). United Nations’ Sustainable Development Goals (SDGs), especially SDG 3 for health and well-being (Nolen et al., 2005). Health indicators also serve the needs of health departments, planners, programme managers, ministers for planning and programming. However, they are not suitable for individual health information.

Health education

One of the ways in which to mitigate for the lack of individual health messaging in health promotion, IEC materials, and routine health information, is to invest in health information that is especially designed to educate individuals. In order to do this, health departments should engage in effective strategies, tools and interventions that are suited to provide adequate, accurate and effective health information at the individual level. Individual health information is important especially in the case where behaviour change is the desired end goal, since this form of education, when delivered appropriately, can empower the receiver to carry out the desired health behaviour. By definition, this health information enables individuals to understand, engage and manage their health or health conditions (Ishikawa & Yano, 2008; Zukoski et al., 2011). Such information has been mostly obtained through written

health education materials (Mwingira & Dowse, 2014; van Beusekom et al., 2018) but research indicates that it is better when the information is provided by healthcare providers (Kalichman et al., 2005a; Kim & Lee, 2016). This is the type of health information that is the focus of this book and will be explained in the upcoming chapters; against related terms such as health literacy, and low literacy.

A model for health-enhancing activities

Tannahill (1985) suggests that any health-enhancing activities should comprise three overlapping spheres, which are health education, prevention, and health protection. Health education is described as any communication activity aimed at enhancing well-being and preventing ill-health in individuals and groups. In this model, health education is provided to help people to promote, improve and control their health; through favourably influencing their knowledge, beliefs, attitudes and behaviour (Tannahill, 1985; World Health Organization Western Pacific Region, 2017). Prevention is related to activities aimed at reducing the risk of occurrence of a disease, illness, injury, disability, handicap or some other unwanted event or state (such as pregnancy, HIV or preventable chronic illnesses) (Tannahill, 1985). This is probably one of the reasons why global campaigns to promote maternal and child health, to prevent communicable diseases, and to promote immunisation have been undertaken by the WHO; attending to illnesses that were seen as global threats to human security. In developing countries, health education directed towards these goals remains a fundamental tool in the promotion of health and the prevention of disease (Nutbeam, 2000). As a result, an analysis of the use of the African Union's "Africa Health Strategy 2016 – 2030" shows that most African health ministries have now incorporated child and maternal health as a focus in their national health frameworks (African Union, 2015; Toure et al., 2012).

Over time, if campaigns continue to focus only on the transmission of information they may fail to address the glaring effects of the social and economic determinants of

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health that affect various individuals in lower- and middle-income countries (LMICs). These are mainly poverty, malnutrition, violence, vulnerability of groups, unemployment and education level (Marmot et al., 2008; Marmot & Bell, 2018). A shift towards individual behaviours requires a concerted and consistent effort in addressing these determinants.

An example of successful health promotion or campaign that yielded positive results in an LMIC context is the HIV programme in South Africa. Due to the high HIV prevalence rate and its relationship with determinants of health within the country (Ameh et al., 2017; Mabaso et al., 2019), this programme has derived a lot of support and funding from various partners (Mills et al., 2008; Pillay et al., 2020). The attention to the programme has led to massive awareness campaigns which can be linked to the success of the voluntary counselling and testing (known as 'VCT') programmes, whose main aim was to promote people testing for HIV. VCT is seen as the first step towards the prevention of future illness if one is infected; and spreading the disease from the lack of knowledge of one's status whilst not taking medication. Moreover, adolescent girls and young women make up at least 40 per cent of new infections in the country (Bekker et al., 2015; Pettifor et al., 2013). Following a deep analysis of this data, researchers suggest that health information addressing adolescent risk behaviours should also address social, structural and economic determinants of health and well-being amongst this group. The SA NDoH, together with their partners and other NGOs, has committed to continuously ensure that VCT services are widely and broadly available; in order to match the amount of health information that has been sent out to the masses (Ameh et al., 2017; Gold & Ejughemre, 2013; Johnson, 2012). Moreover, the country aligns itself with guidance from organisations such as the WHO and funders like the U.S. President's Emergency Plan for AIDS Relief (PEPFAR), the United Nations International Children's Emergency Fund – now the United Nations Children's Fund (UNICEF) and the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global

Fund), who provide a broader view of the pandemic globally (Errol et al., 2012; National Department of Health, 2020b).

Health protection refers to the legal controls, regulations or policies of practice that are aimed at the prevention of ill health amongst people in the community. Such measures shape the public health system, also known as primary healthcare. Many African citizens rely on public healthcare systems (Mbanda, 2020). Following from this, universal health coverage has been seen as key to health protection, because universal health coverage refers to a situation where all citizens obtain quality health services without risking financial hardship or out-of-pocket payments (Elebesunu et al., 2021; Evans et al., 2013). Tannahill (1985) therefore puts forth that the relationship between health education, prevention, and health protection can be used to model holistic health education interventions, as demonstrated in Figure 1.

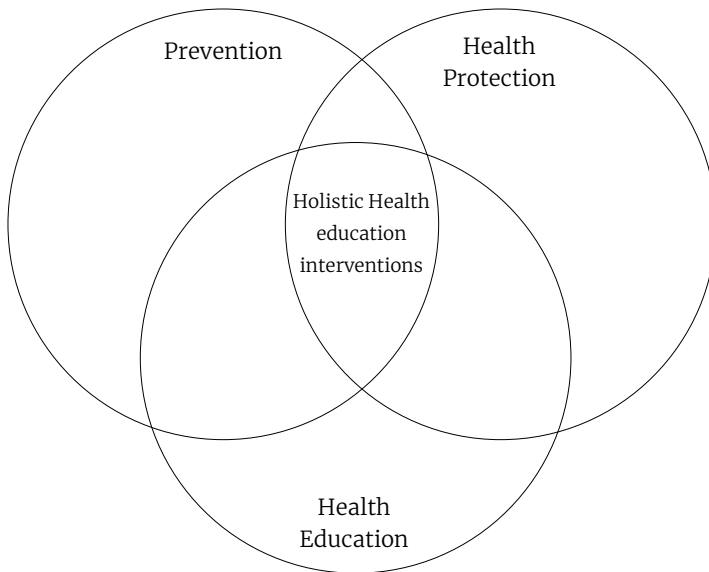


Figure 1: A model of health promotion (Tannahill, 1985)

The model depicted in Figure 1 is promoted as a framework for holistic health education interventions due its ability to

incorporate both positive and negative aspects of health. Moreover, Nutbeam (2000) warns that despite insights from the likes of Tannahill and his earlier work on health promotion (Nutbeam, 1998), interventions which relied primarily on mass communication have failed to achieve substantial and sustainable results in terms of influencing behaviour change. Interventions of this nature are not advisable in the LMICs context, since their potential to close the gap in health status between different social and economic groups in society has been found to be limited (Nutbeam, 2000). This is because in these contexts, the role of social, economic and environmental factors in determining risk of disease and adverse outcomes from disease is crucial in the epidemiological analysis of health and disease burden (Nutbeam, 2000). Moreover, when it comes to adults, a lot of HCPs are likely to not be aware of how much understanding their clients have of some of the less frequently discussed concepts, like mental health (Ameh et al., 2017; Dube & Uys, 2016), gender-based violence or overall wellness. This suggests the need for a tailor made approach to adult health education, especially if those adults have low literacy.

Conclusion

An overview of health information in all its various forms shows the diversity of the concept and how it has evolved over the years. Of note are the differences in strategies and aims when the different types of health information target different audiences. This illustrates the relevance of health education; and its suitability for empowering individuals with health information to manage their own lives. The inclusion of the health promotion model by Tannahill (1985) serves to show that health education may be more effective when complemented by elements of health prevention and protection, since these elements contribute towards holistic health education interventions.

Chapter 3

The Prevalence of Low Literacy

Introduction

Conversations on low health literacy have increased in the past few years. Health practitioners have been concerned about patients' understanding of the medical instructions they receive and their ability to carry these through, when back at home without the "doctor who gave the orders". This has usually been referred to as health literacy. However, health literacy is not enough of a concept to explain some of the complexities in giving, receiving, understanding and acting on health information that people with low literacy face. This is because low literacy adds a significant challenge in understanding instructions needed for everyday life. The following chapter provides an overview of low literacy globally and in South Africa. The chapter also outlines the importance of understanding the effects of low literacy for healthcare settings; this is especially for groups who rely on public health systems as their only source of healthcare.

Defining low literacy

Low literacy is common around the world (Ryan et al., 2014). However, a clear majority of people with low literacy live in lower- and middle-income (LMIC) countries (UNESCO Institute of Statistics, 2014). Research shows that although the global literacy rate has increased by 4 per cent every five years over the past 65 years, some of the poorest countries in the world still experience significant levels of illiteracy (Roser & Ortiz-Ospina, 2016)). Although now classified as an upper middle-income country, an approximated 13.7 per cent of the South African population either have no formal schooling nor have completed a level of education that is beyond Grade 7 (Khuluvhe, 2022; Statistic South Africa 2021). Moreover,

despite an increase in the number of children aged five years or more who are enrolled in basic education schools (Grades 1 to 12) (Statistics South Africa, 2017), the number of people between the ages of seven and fifteen, who remain enrolled and are able to complete primary school tends to drop rapidly (Statistics South Africa, 2017). Lower levels of education may lead to low literacy, which is understood as the inability to read, write, or use numbers with sufficient proficiency to achieve one's goals (Easton et al., 2010; Sheridan et al., 2011). Throughout this book, I define low literacy as the instance where a person has not completed more than seven years of formal schooling or basic education, i.e. lower than or equal to Grade 7 (Aitchison & Harley, 2006; Carstens et al., 2006). This is synonymous with the term functional literacy, which refers to an instance of the inability to read, write or use information that one is presented with.

Literacy in healthcare settings

Literacy is an important skill in healthcare settings, as it is argued that together with education, it is a key determinant of health (Kickbusch, 2001; Neille & Penn, 2015). Therefore, it is crucial for healthcare professionals to be aware of the impact of low literacy amongst the clients they serve, as low literacy often leads to poor health literacy (Negarandeh et al., 2012; Williams et al., 2016) which is the inability to understand and take action from health information received (Lambert & Keogh, 2014; Nouri & Rudd, 2015). Health literacy is formally described as a set of cognitive and social skills that determine one's ability and motivation to seek, understand and use the information to promote one's health and well-being (Berkman et al., 2011). Thus, poor health literacy inevitably results in a variety of poor health outcomes (Ryan et al., 2014), such as lower use of healthcare preventative services (Berkman et al., 2011; Peterson et al., 2011) increased costs for hospitalisation (Boyle et al., 2017) lower treatment adherence (Keller et al., 2008), poor understanding of health information (Malloy-Weir & Cooper, 2017; Nouri & Rudd, 2015), or poor self-management of chronic conditions.

Since the majority of users of the public health system might have low literacy, Coovadia et al. (2009) assert that this might mean that the system caters for people with low health literacy. Since health literacy is a strong predictor of health outcomes, this indicates the need for health education programmes that are specialised for people with low literacy within the health care settings (Grebler et al., 2014; Mwingira & Dowse, 2014).

A review by DeWalt et al. (2004) found that 16 studies reported a positive and significant relationship between reading ability and the use of healthcare knowledge whilst review by Berkman et al. (2011) reported that low health literacy was associated with poor ability to understand or follow medical advice, and poor health outcomes, which is the focus of this book. Interestingly, the same reviews showed that most interventions for people with low literacy that had primarily focused on medicine-taking instructions or labels did not have an effect (Dowse & Ehlers, 2005), since they were passive in nature and did not require any action from the patient (Wali et al., 2016). In this way, research suggests that interventions targeting health literacy outcomes related to chronic illnesses such as diabetes and HIV need a more interactive strategy (Al Sayah et al., 2012; Dyrehave et al., 2016) Such interventions, which foster understanding, are critical for a context like SA where diseases like HIV and TB require education on health-promoting and risk-reducing behaviours (Audet et al., 2017).

The challenge with current health education interventions for people with low literacy

When it comes to current health education interventions for people with low literacy, a couple of challenges can be listed. Firstly, most healthcare systems are designed in favour of patients with adequate literacy levels (Mophosho, 2018; van den Berg, 2016) and who speak the languages spoken by the health professionals (HCPs) (Lambert & Keogh, 2014, (Schmidt von Wühlisch & Pascoe, 2011; Schubbe et al., 2018). However, when patients have low literacy and do not speak

the language of the health professionals (Mophosho, 2018; van den Berg, 2016), they run the risk of being unable to adequately participate in the healthcare system. This leads to healthcare professionals assuming that patients have understood the health education received and will be able to carry out the health instructions and cultivate the necessary health behaviour at home (Hunter-Adams & Rother, 2017).

Secondly, there is a definition conundrum whereby researchers have tended to use measures for health literacy in defining and as a proxy for literacy levels (DeWalt et al., 2004). Moreover, these measures for literacy are either based on word recognition e.g. the Rapid Estimate of Adult Literacy in Medicine (REALM), or reading comprehension and numeracy skills related to health information like the test of Functional Health Literacy in Adults (TOFHLA) (Keller et al., 2008). Challenges with other tests like the Wide Achievement Test (WRAT) and Newest Vital Sign (NVS) which also focus on numeracy (Keller et al., 2008), are that these are only available in English and are a little outdated. Furthermore, studies making reference to literacy levels also tend to rely on individual self-reports of literacy rather than using standardised literacy assessments (McCormack et al., 2010; Nguyen et al., 2017). However, self-reporting is not a reliable measure of literacy since people with low literacy in particular, may over-report their actual literacy levels due to feeling ashamed. Other concerns about references to health literacy pertain to the suitability of health education and materials for people with lower literacy levels (Zellmer et al., 2015). This is because many of these current health education materials such as pamphlets, take-home leaflets, medicine instructions or labels are designed by health professionals and researchers with adequate literacy levels (Park & Zuniga, 2016).

Furthermore, health education programmes are provided in written or spoken formats (Schubbe et al., 2018; Webb et al., 2008) whereas research shows that the manner in which health education is delivered is key to improving its understanding. Guidelines proposed for the readability of health education materials for people with low literacy

(Friedman et al., 2010) suggest having a readability level that suits readers with limited years of schooling (Badarudeen & Sabharwal, 2010; Brown et al., 2016). If health-enhancing activities are meant to incorporate elements of prevention, an unbalanced dependence on materials that require reading ability may translate to a limited chances that people with low literacy will receive adequate health information. In light of the model of health-enhancing activities suggested by Tannahill (1985). Such a case might compromise any efforts to improve health and promote self-management in people with low literacy. Reviews which have determined the effectiveness of intervention strategies on health outcomes for people with low literacy (Sutherland & Isherwood, 2016), share a general consensus that health education materials for people with low literacy should read at sixth grade level (Schubbe et al., 2018; Williams et al., 2016). This is especially seeing that lowering of the readability level from the tenth to the sixth grade was found to increase the suitability of the materials for people with low literacy (Williams et al., 2016).

Other systematic reviews on improving knowledge about medication adherence (Wali et al., 2016; Kim & Lee, 2016) have concluded that the three most effective interventions for people with low literacy in terms of their targeted health outcomes are: easy-to-read patient education materials; “written communication” which is best for improving cognitive and psychological outcomes such as health knowledge. The second set of effective interventions are conversations between patients and the healthcare professional, also known as “spoken communication”. These are most suitable for discussing patients’ experiences with illness. The third set of interventions which are delivered verbally by a trained healthcare professional, are “empowerment”. These are effective for improved self-care and self-management behaviour (Kim & Lee, 2016). Moreover, empowerment interventions have important objective for health education due to the ability to helping “those without real power to acquire it” for their health (Tannahill, 1985:167). The effectiveness of empowerment interventions is notable

in the context of SA where most people with low literacy depend on healthcare providers who are often perceived as the “experts”. Similarly, when Lee et al. (2012) identified effective intervention strategies to improve health outcomes in patients with cardiovascular disease they discovered that tailored counselling, which involved individuals discussing their health matters with a healthcare practitioner, was an effective strategy for desired behaviour change in patients with low literacy. The success of this intervention strategy was attributed to its ability to give both the healthcare professionals and the patient the opportunity to engage, and enhance the latter’s understanding of health information. This aligned with the definition of health education, as seen by Tannahill (1985), who asserts that the activity should be an opportunity for enhancing well-being and assisted individuals and communities with skills to prevent or diminish ill-health.

The importance of visual aids in health interventions for people with low literacy

Reducing the readability of materials alone may not have a significant effect on health knowledge (Brown et al., 2016). Hence, it has been suggested that in addition interventions for people with low literacy should additionally consider adding visual aids (Houts et al., 2006; Pignone et al., 2005). ‘Visual aids’ in this book refers to a range of simple black-and-white (or colour) pictograms, pictures, drawings, videos, photonovelas or photographs (Park & Zuniga, 2016; van Beusekom et al., 2018). For instance, mixed interventions utilising simplified written materials, pamphlets, comparison charts, video tutorials, oral overviews, and a combination simplified consent forms have been found to have a positive effect on self-management, health knowledge, and self-efficacy (Sheridan et al., 2011). In fact, the effectiveness of visual aids in health interventions for people with low literacy is best summarised by Park and Zuniga’s (2016) review, which found that ten out of the eleven studies using picture based interventions reported a positive effect for health outcomes. Following from the above-mentioned review

one of the outstanding concerns is the desire to include a broader definition of picture-based health interventions; also consider the papers from LMICs, which are known to have higher proportions of people with low literacy. Thus a scoping review by Mbanda et al. (2020), aimed at examining the extent, nature, and range of interventions that used a broad range of visual aids in health education programmes for people with low literacy. For the purposes of this book only the summarised findings of the review will be outlined. These will be in terms of the development of the visual aids, the effects of visual aids on health outcomes and lastly the comparison of visual aids interventions against, text and verbally instructed interventions.

The development of visual aids

In this review most studies described visual aids primarily as pictograms which are black-and-white illustrations or line drawings usually used in pharmaceutical or prescription labels (Kheir et al., 2013). Other visual aids mentioned animated videos, computerised or art images, fotonovela (a story book) and various forms of multimedia such as presentations. The involvement of stakeholders in the development of visual aids was said to be key in enhancing the effectiveness of health education programmes for people with low literacy (Roberts et al., 2010), although more than half of the studies in the review did not unpack the details of how stakeholders were involved in the development of visual aids. Of those studies that did involve the stakeholders, engagement was conducted primarily through interviews (Berthenet et al., 2016; Yong et al., 2018) and focus groups (Dowse et al., 2010; Kandula et al., 2009).

Attributes of the visual aids

On the role of certain attributes of the visual aids one study by Hwang et al. (2005) found that even commonly used medical illustrations could be ambiguous and misleading, whereas Carstens et al. (2006) asserted that both people with high or low literacy may struggle to recognise abstract images such

as non-human and abstract objects. Interestingly, people with low literacy recognised visual aids representing HIV/AIDS information within a human body much more easily than people with high literacy (Carstens et al., 2006). On the other hand, van Beusekom et al. (2015) found that pictographs not related to HIV of isolated organs (such as intestines, lungs and kidneys) were considered clearer by some people with low literacy.

In general, people with low literacy to prefer red visual aids depicting objects with which they were familiar (Bacardi-Gascon, Jimenez-Cruz, & Jones, 2002; Dowse et al., 2010), and those depicting simple actions (Chuang et al., 2010; Webb et al., 2008), since complex illustrations could draw attention to irrelevant details (Delp & Jones, 1996; Houts et al., 2006).

Acceptability of visual aids

When exploring the acceptability of visual aids, African-based researchers found that local isiXhosa people with low literacy preferred medical instructions using a locally developed pictogram set than that from the US (Dowse & Ehlers, 2001). Similarly, Poureslami et al. (2012) found that culturally appropriate visual aids had the ability to increase the knowledge and understanding of health information in people with low literacy. Studies such as these reiterate the importance of cultural acceptability of visual aids to the target audience, as a measure to increase their potential to improve the ability to facilitate recall and understanding of information, ensuring acceptability and reducing ambiguity of visual health messages (Katz et al., 2006).

The effects of the type of visual aids on health outcomes

Studies in the review further outlined the different effects of visual on targetted outcomes. When Choi (2013; 2015) investigated the acceptability and comprehension of discharge instructions they discovered that pictograms were effective for the comprehension and recall of health information. Similarly, when Kalichman et al. (2013), examined a pictogram-guided

adherence skills-building counselling intervention for limited literacy adults living with HIV, they found that pictogram adherence counselling mitigated for the presence of lower literacy levels. In contrast, lower literacy participants (≤ 85 per cent comprehension) demonstrated greater adherence to the general health improvement counselling offered than those who received pictograph-guided and standard adherence counselling. The success of pictograms was attributed to their ability to depict complex information in a form that was easily understood by people with low literacy (Choi, 2012). Consequently pictograms were deemed to be the best type of visual aid for the comprehension of health information for people with low literacy (Park & Zuniga, 2016). As a result, Dowse et al. (2011) and Kalichman et al. (2013) concluded that patients with low literacy benefited from interventions that used visual aids and were also implemented by trained healthcare providers. This was in line with earlier research that suggested that tailored counselling and empowerment as the most appropriate strategies for behaviour change outcomes in people with low literacy (Lee et al., 2009).

Comparison of visual aids, text and verbal instructions

To take it a step further, some researchers opted to not only assess the effects of visual aids but to compare interventions that have text only against those that have text and visual aids. With some of these interventions the text also referred to spoken inputs that were augmented by the set of visual aids. Participants who received discharge instructions comprising both text and visual aids were more satisfied with the intervention than those who received standard discharge (text-only) instructions (Kheir et al., 2013; Meppelink & Bol, 2015). In another study, Dowse et al. (2011) found that participants who received pictogram-enhanced verbal instructions recalled and understood more HIV/AIDS health information better than those who received text-only instructions. Kheir et al. (2013) found that medicine labels consisting of pictograms accompanied by verbal instructions

fostered superior comprehension when compared to text-only labels (Carstens, 2007).

Iconicity of visual aids

Visual aids need to be comprehensible to the target audience. One notable attribute of visual aids is iconicity. Comprehensibility can be explained in iconicity, is a concept which is mostly used in the field of Augmentative and Alternative Communication (AAC) (Fuller & Lloyd, 1997; Evans et al., 2006) and refers to an association formed by a viewer (i.e. the people with low literacy) with a particular symbol (visual aid) and its referent (the intended idea) (Dada et al., 2013). This association exists on a continuum, with *transparency* at one end and *opaqueness* at the other (Dada et al., 2013; Haupt & Alant, 2002). Transparency is known as the 'guessability' of a visual aid and is when the 'symbol' is highly suggestive of its referent (Bornman et al., 2009; Dada et al., 2013), while translucency implies that the meaning can be understood by the majority of viewers once the referent has been revealed. Opaqueness is when there is no apparent relationship between the symbol and its referent (Berthenet et al., 2016; Huguet, 2012; Kheir et al., 2013). When Roberts et al. (2010) used a pictorial asthma action plan, they found that the majority of participants could guess the meaning (*guessability*) of the pictograms and that most pictograms were deemed to represent their intended image well, once the meaning was revealed (*translucency*). This was gathered from the participants' ability to adequately recount the appropriate actions using the pictorial plan.

In another study, Berthenet et al. (2016) even found significant differences in translucency scores amongst lower- and higher-educated participants. These differences in preference for visual aids between people of different literacy levels are important since it points to the fact that the needs of people with low literacy have largely been overlooked or concealed by the views of people with higher literacy; when it comes to the development of health education materials. Henceforth, Mbuagbaw and Ndongmanji (2012), assert

that the involvement of people with low literacy is strongly suggested as a remedial action to this previous oversight. In this book iconicity is referred to as comprehensibility. Hence the standards established by the International Organization for Standardization (ISO) are used to evaluate and discuss the comprehensibility of NDoH visual aids in the National Department of Health health education programme.. These standards refer to a criterion of ≥ 67 per cent for comprehension, i.e. visual aids that are transparent (guessed correctly) by at least 67 per cent of participants; or a translucency score where least 67 per cent of participants recognise the meaning of the visual aid after it has been revealed (Berthenet et al., 2016). Since studies that follow the ISO standards might be able to minimise the use of 'opaque' visual aids and increase the iconicity of visual aids. The ISO standards were used during the iconicity phase in this study.

Theories of information processing that support the effects of visual aids

Theories of information processing can be used to explain the cognitive skills and phases required for problem solving (Simon, 1978) and have often been used to explain adult learning using multi-media messages (Mayer, 2001). Mayer's cognitive theory of multimedia learning (Mayer, 2001) and Paivio's (1969) dual coding theory are two such theories associated with the dual mechanism of processing of text messages that are augmented by visual aids and auditory input. Mayer's cognitive theory of multimedia learning opposes the unimodal assumption, namely that humans process information from one form of input. Rather puts forth that people learn better from processing a combination of verbal and non-verbal inputs (Mayer, 2001).

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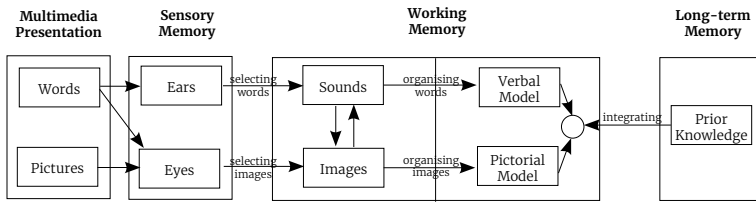


Figure 2: Mayer’s Cognitive Theory of Multimedia Learning (Mayer, 2001, p. 37)

In Mayer’s cognitive theory of multimedia learning (CTML) (depicted in Figure 2) the dual channels of human information processing, are verbal and non-verbal inputs. These are two modalities processing words and pictures respectively. According to Mayer (2001), active learning involves a co-ordinated set of cognitive processes that take place in working memory. Further integration of processed information from *working memory*, together with one’s prior knowledge (cultural, traditional, local, contextual), leads to the formation of *long-term memory*. It is this long-term memory that is used to infer that understanding of health information that has been received and has been processed by the recipient; since the person can recall and recite the information. Although it is acknowledged that remembering information may not mean that someone understands the message; what is being implied through CTML is that visual aids help the message to be retained long enough to be integrated with one’s own knowledge and this increases the chances of understanding the message received. The dual and simultaneous processing of verbal and non-verbal inputs may enable people with low literacy to map out (Wood et al., 2009) and associate (Clark & Paivio, 1991) spoken health information with the visual aids that are being pointed to. This strategy of simultaneously pointing to and speaking (auditory) input is referred to as augmented input and is widely used in the field of AAC (Allen et al., 2017; O’Neill et al., 2018).

Researchers have attributed the effectiveness of visual aids to the ‘pictorial superiority complex’ (Arndt et al., 2015), which argues that combined auditory (verbal) and visual

channels of learning enable people with low literacy to hold both words and visual aids in their working memory, thereby enhancing recall of information (Campbell et al., 2017). This is because the 'pictorial superiority' allows visual aids to augment the written or verbal health message by attributing greater activation in certain parts of the brain which in turn, facilitates learning through recall of the image (Arndt et al., 2015; Katz et al., 2006) by brain activation in the working memory (Houts et al., 2006; Mayer, 2001). Working memory represents a network of functional processes that enable the understanding through the cognitive performance of tasks such as reading, problem-solving or learning (Baddeley, 1983). Working memory comprises of two subsystems which are responsible for the processing of visual and verbal inputs. The 'visuospatial scratchpad' being responsible for non-verbal representations whilst the 'articulatory loop' is responsible for verbal representations (Baddeley, 1983). The 'pictorial superiority complex' exists because pictorial inputs may hold a more symbolic meaning than their associated labels (verbal inputs) thereby easier to recall (Nelson et al., 1976).

Moreover, for people from different cultures, different types of images varying levels of symbolic meaning attached to the images. The variability of symbolic meaning is important in a diverse context such as South Africa.

However some researchers caution that, people with low literacy may have limited processing capacity due to the limited number of years spent at school (Matsuyama et al., 2011; Park & Zuniga, 2016). Processing ability comes with practice, and the less years spent at school, the less years spent at school the less practice a person has. In this regard, Mayer warns against 'cognitive overload' (Mayer & Moreno, 2003) which occurs when the amount of inputs exceeds the processing capacity of the individual (Mayer, 2001). This may cause the person to lose all information or remember much less than the desired amount of information at the time for recall (Mayer & Monero, 2003). Hence, Mayer advises that people with low literacy should not be presented with too much information at a given time.

The author aimed to elucidate the iconicity of visual aids in this study to evaluate their potential to provide symbolic meaning to the target audience.

Conclusion

The literature presented in this chapter points to a close relationship between health literacy and low literacy within the healthcare settings, however it is also evident that the interchangeable usage of these terms may be the cause for neglecting the special needs of people with low literacy within lower- and middle-income countries. Thus the reviews shared in this chapter were important in outlining the scope and nature of interventions for people with low literacy, highlighting the emerging positive effects of visual aids and useful intervention strategies. These discussions are crucial in a discussion proposed suitable health education programmes for people with low literacy, since they provide a good basis for the development of interventions and complementary assessment tools that will be effective to this group of people.

Chapter 4

A tool for assessing the understanding of HIV health information in people with low literacy

Introduction

One of the objectives of this book is to share the results, and recommendations from an experiment that took place in KwaZulu-Natal, which aimed to assess the understanding of health information in people with low literacy. The focus on people with low literacy was invoked by literature which has demonstrated that adults in this group have been left out, in the development and design of health education materials that are presumably for them. I am of the view that this apparent exclusion from the important processes of design, development and assessment, is the very reason that most current health education materials, possibly even the NDoH health education programme, might not be adequately addressing, nor deriving the positive effects in understanding of health information, amongst people with low literacy. This is over and above the fact that healthcare providers do not have the time nor the tools to assess the understanding of health information amongst their clients. Thus, the following chapter outlines a process that was followed in designing a tool for the assessment of understanding of HIV health information. The tool was designed in order to complement the research design for an experiment and allow for the assessment of health information during the intervention. The chapter is thus a combination of literature, guidance and summary of processes for developing culturally appropriate health education materials. These processes include identification,

translating, testing and finalising the materials for aptness, and demonstrating the importance of including the target audience, i.e. people with low literacy in the processes.

The National Department of Health (NDoH) Education Programme

South Africa's antiretroviral (ARV) programme is one of the biggest in Southern Africa (Naidoo et al., 2017; Vermund et al., 2015). The Integrated Access to Care and Treatment (I-ACT) programme and the NDoH's health education programme of 2016 are two of the programmes rolled out with the aim of improving clinical outcomes and adherence for people living with HIV (National Department of Health, 2016; 2019). With updates and changes in HIV policies, the use of the IACT has been phased out and the NDOH introduced the AGL. This programme was designed by the Department of Health in order to enable delivery of effective differentiated care to patients within the healthcare system; as a minimum package of interventions to support linkage to care, adherence and retention in care of people living with HIV, TB and non-communicable diseases (NCDs) (National Department of Health, 2020a). The NDoH programme is open for use by HCPs, community health workers or HIV counsellors to provide health education in spoken format; and the contents include images (visual aids) to illustrate the health information (National Department of Health, 2016).

At the time of writing this book no known studies had considered the effectiveness of the NDoH's health education programme on the understanding of health information in people with low literacy. This was to be expected as measuring the understanding of health information might have been a challenging task due to no consensus on the basic psychometric aspects nor availability of a health information measurement (Huan et al., 2014). In the next section I share a process informed by literature that we followed in designing and testing a questionnaire to assess the understanding of HIV health information. The assessment was designed as a pre-test-post-test questionnaire which would assess for

understanding of health information in people with low literacy before and after they received HIV health information through the NDoH health education tool. This chapter also describes the appropriate translation procedures that give way to culturally and linguistically appropriate assessments.

Why was the development of the questionnaire conducted in KwaZulu-Natal?

The development of the HIV health information questionnaire took place in KwaZulu-Natal (KZN), a province in which isiZulu is the home language of most of the residents (Kharsany & Karim, 2016; Statistics South Africa, 2019). KZN contributes the highest numbers to the national HIV prevalence rate (Kharsany & Karim, 2016; Vermund et al., 2015). Due to its vast rural settings, there are higher levels of people with low literacy who reside amongst the more traditional, non-urban settings (Statistics South Africa, 2016). Research shows that high percentages of persons 20 years and older who have reportedly never received any formal schooling (Statistics South Africa, 2019) and that this is a group of adults that is potentially overlooked due to most research on literacy focusing on younger or school-going children, and not on the understanding of verbal and written health information.

The development of the HIV health information assessment questionnaire

According to research, health information interventions would be more effective if designed with an accurate estimation of the literacy of the target audience in mind. However, as stated in Chapter 3, most existing measures of literacy in the health settings are unsuitable for people with low literacy in terms of their format and mainly the dependence on reading comprehension and numeracy skills. In addition, these instruments tend to measure health literacy and not the understanding of health information (Osborn et al., 2007; Paasche-Orlow et al., 2006). In view of this, two pre-existing health education programmes were identified for the purpose of developing a health information questionnaire

that would be suitable for people with low literacy in the South African context. The first tool, Brief Estimate of Health Knowledge and Action (BEHKA-HIV) (Osborn et al., 2010) was an assessment previously used for HIV treatment adherence. The main aim of the BEHKA-HIV was to measure treatment adherence and not to assess the understanding of living with HIV. Furthermore, the questions of this tool that were related to HIV treatment were based on outdated HIV/AIDS treatment guidelines since HIV guidelines are frequently updated. That said, the NDoH frequently updates their guidelines for various chronic diseases. Accordingly, at the time of the development of this tool BEHKA-HIV was not aligned with the most current guidelines (National Department of Health, 2016; 2019). The second tool was the NDoH's health education programme (see Figure 1).

Since my interest was in assessing the overall understanding of health information, two questions from the BEHKA-HIV, were transformed into five new questions which were based on the latest NDoH guidelines (National Department of Health, 2019). The questions were designed to cover information on living with HIV (National Department of Health, 2016) and dealt with information that was deemed useful even for people recently diagnosed with HIV (James et al., 2018). The rest of the items that were included in the HIV health information assessment questionnaire were derived from the "Education on HIV and ART" section of the NDoH health education programme. Careful consideration was taken to write all items in clear and simple language, and ensure each question addressed only one idea per item (Artino et al., 2014). The aim of developing this questionnaire was so that the questions would align directly with the content of the HIV health information (the "Education on HIV and ART" section of the NDoH health education programme). In this way we could determine and infer the understanding of health information in an experiment involving people with low literacy

Use of multiple-choice responses for the assessment











The decision to use a multiple-choice format for the responses in the questionnaire was an attempt to lessen the anxiety of the participants. This is since they would not have to write or which might have lead to struggling to articulate themselves (Cremers et al., 2017). A 24-question assessment was finalised with five multiple-choice options for each question, which was later revised to four options seeing that 5 options may have too many responses for participants to recall. Each multiple-choice question was represented by a visual aid in order to elicit meaningful responses from the participants through visual memory (Mantri-Langeveldt, 2019). These visual aids were Bildstöd™ symbols from a Swedish website of graphic symbols that were selected used specifically for communication in healthcare settings (see Table 2).

Validity of the HIV health information assessment questionnaire



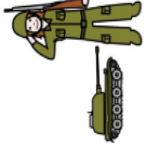







Three experts were consulted for the purpose of establishing face and content validity of the assessment. Face validity was sought in order to ascertain that the items in the questionnaire were reasonable, unambiguous and clear enough to elicit the intended responses from the participants (Oluwatayo, 2012). For content validity, the panel validated the relevance of the items in measuring the understanding of HIV health information (Taherdoost, 2018). The expert panel achieved this by commenting on i) the appropriateness of the items in measuring the understanding of HIV health information; ii) the use of multiple-choice to elicit responses; and iii) the ability of the Bildstöd™ symbols to help people with low literacy respond better to the multiple-choice questions. These three experts were selected based on their experiences with health services, community services and HIV. The experts also had to be competent in spoken and written isiZulu and English and their. Details are shown in Table 3.

The experts consolidated feedback and endorsed the items of the questionnaire, stating that they adequately covered



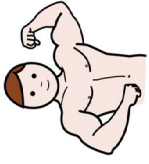





Table 2: HIV health information assessment questionnaire with visual aids (Bildstöd™ symbols)

Question	Choices					Answer
	1	2	3	4	5	
Q1	<p>HIV is a virus that enters the body</p> 	<p>HIV is found in the lungs</p> 	<p>HIV makes you think of dying</p> 	<p>HIV makes you feel weak</p> 	<p>I am not sure of the answer</p> 	
Q2	<p>Visual aids (Bildstöd™ symbol)</p>	<p>They are found in one's bones</p> 	<p>They are cells that carry illness in the body</p> 	<p>Cells that cause to get a very bad cough</p> 	<p>I am not sure of the answer</p> 	
	<p>What are CD4 cells?</p>	<p>They are like soldiers of the body</p> 				
	<p>Visual aids (Bildstöd™ symbol)</p>					

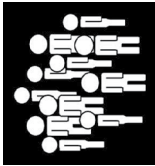
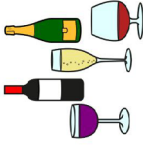
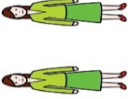
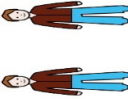



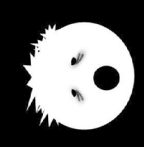


Chapter 4

Question	Choices					Answer
	1	2	3	4	5	
Q3	<p>An HIV negative person will appear thin</p> 	<p>An HIV negative person is fat</p> 	<p>An HIV negative person has many strong soldiers</p> 	<p>An HIV negative person doesn't get sick</p> 	<p>I am not sure of the answer</p> 	
Q4	<p>Visual aids (Bildstöd™ symbol)</p> 	<p>Visual aids (Bildstöd™ symbol)</p> 	<p>Visual aids (Bildstöd™ symbol)</p> 	<p>Visual aids (Bildstöd™ symbol)</p> 	<p>Visual aids (Bildstöd™ symbol)</p> 	
	<p>Why do we take viral load blood?</p>	<p>Viral load blood shows how much HIV is in the blood</p>	<p>Viral load blood shows if someone is hurt</p>	<p>Viral load blood shows if someone has a fever</p>	<p>I am not sure of the answer</p>	
	<p>How do you see an HIV negative person?</p>					


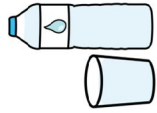








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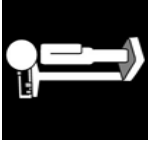




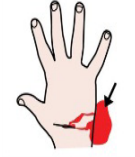


Question	Choices					Answer
	1	2	3	4	5	
Q5	What does HIV do?	HIV kills the CD4 cells	HIV causes a person to faint	HIV makes the body stronger	I am not sure of the answer	
	Visual aids (Bildstöd™ symbol)					
Q6	When do you take ARVs?	ARVs are started anytime	ARVs are started when you eat	ARVs are started when you are told by the nurse	I am not sure of the answer	
	Visual aids (Bildstöd™ symbol)					

Chapter 4



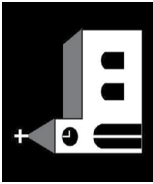
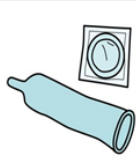



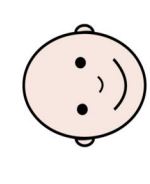


Question		Choices					Answer
		1	2	3	4	5	
Q7	Who is at risk of contracting HIV?	Everyone is at risk of contracting HIV	Only people who drink alcohol are at risk of contracting HIV	Only women are at risk of contracting HIV	Only men are at risk of contracting HIV	I am not sure of the answer	
	Visual aids (Bildstöd™ symbol)						
Q8	How do you know you have HIV?	When one has contracted HIV, they feel happy	When one has contracted HIV, they may feel sad	When one has contracted HIV, they may feel sleepy	When one has contracted HIV they may have itchy skin	I am not sure of the answer	
	Visual aids (Bildstöd™ symbol)						

Improving Health Literacy for People with Low Literacy


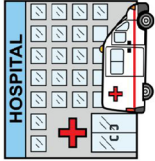
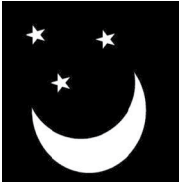


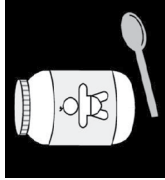
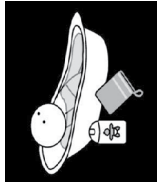


Question		Choices					Answer
		1	2	3	4	5	
Q9	What do you do when ARVs make you sick?	When ARVs make you feel sick you should go to the doctor	When ARVs make you feel sick you should drink a lot of water	When ARVs make you feel sick you consult a traditional healer	When ARVs make you feel sick you should stop taking them	I am not sure of the answer	
	Visual aids (Bildstöd™ symbol)						
Q10	How can you know that you have HIV?	You can tell you might have contracted HIV when you fall	You can tell that you might have contracted HIV if you feel sad	You can tell that you might have contracted HIV if you like jumping	You can tell you have contracted HIV if you feel too tired	I am not sure of the answer	
	Visual aids (Bildstöd™ symbol)						

Question	Choices					Answer
	1	2	3	4	5	
Q11	<p>A person can know their HIV status through consulting a traditional healer</p> 	<p>A male who looks healthy can know their HIV status through asking their partner</p> 	<p>A person can know their HIV status through an HIV test</p> 	<p>A person can know their HIV status through monitoring their weight</p> 	<p>I am not sure of the answer</p> 	
Q12	<p>How is HIV transmitted?</p> 	<p>HIV is transmitted through breathing the same air as an HIV positive person</p> 	<p>HIV is transmitted through sharing eating utensils with an HIV positive person</p> 	<p>HIV is most commonly transmitted through contact with HIV positive blood</p> 	<p>I am not sure of the answer</p> 	
	<p>Visual aids (Bildstöð™ symbol)</p> 					


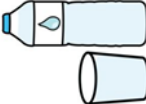



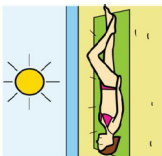




Improving Health Literacy for People with Low Literacy

Question	Choices					Answer
	1	2	3	4	5	
Q13	How can you prevent infection your partner with HIV?	You can prevent infecting your partner by sleeping on the same bed	You can prevent infecting your partner by giving them traditional muthi	You can prevent infecting your partner by taking them to church	You can prevent infecting your partner by practicing safe sex	I am not sure of the answer
	Visual aids (Bildstöd™ symbol)					
Q14	When should ARV treatment be taken?	ARV treatment is taken only when you have a headache	ARV treatment is only taken by those who are sick	ARV treatment is taken only if you want to feel happy	ARV treatment is taken every day of your life	I am not sure of the answer
	Visual aids (Bildstöd™ symbol)					



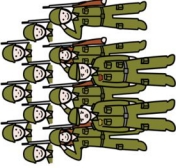




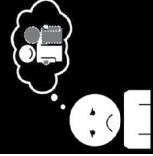



Chapter 4

Question	Choices					Answer
	1	2	3	4	5	
Q15	<p>ARVs should be taken at the same time</p> 	<p>ARVs should be taken at the hospital</p> 	<p>ARVs should be taken at night</p> 	<p>ARVs should be taken in the morning</p> 	<p>I am not sure of the answer</p> 	
Q16	<p>How can a mom infect her baby with HIV?</p>	<p>An HIV positive mother could infect her new-born baby through feeding them</p> 	<p>A HIV positive mother could infect her new-born baby through giving them a bath</p> 	<p>An HIV positive mother could infect her new-born baby through breastfeeding</p> 	<p>I am not sure of the answer</p> 	
<p>Visual aids (Bildstöð™ symbol)</p>	<p>Visual aids (Bildstöð™ symbol)</p>	<p>Visual aids (Bildstöð™ symbol)</p>	<p>Visual aids (Bildstöð™ symbol)</p>	<p>Visual aids (Bildstöð™ symbol)</p>	<p>Visual aids (Bildstöð™ symbol)</p>	











Improving Health Literacy for People with Low Literacy

Question		Choices					Answer
		1	2	3	4	5	
Q17	How is HIV treated?	HIV is treated through traditional medicine 	HIV is treated through drinking lots of water 	HIV is treated with medication called antiretrovirals 	HIV is treated with an injection 	I am not sure of the answer 	
Q18	How long should one take ARVs for?	ARVs are to be taken only when you are at the beach 	ARVs are to be taken only when you have a headache 	ARVs are to be taken when you exercise 	ARVs are to be taken even if you feel strong and healthy 	I am not sure of the answer 	

Chapter 4

Question	Choices					Answer
	1	2	3	4	5	
Q19	<p>Pills that prevent illness</p> 	<p>Pills that give you energy</p> 	<p>Pills that assist the body's soldiers</p> 	<p>Pills that strengthen the bones</p> 	<p>I am not sure of the answer</p> 	
Q20	<p>How does family help a person who is HIV positive?</p> 	<p>It is helpful to have family to support you through your ARV journey</p> 	<p>It is helpful to do the ARV journey alone</p> 	<p>It is helpful to tell the whole community about your HIV status</p> 	<p>I am not sure of the answer</p> 	
	<p>Visual aids (Bildstöd™ symbol)</p> 					

Improving Health Literacy for People with Low Literacy

Question		Choices					Answer
		1	2	3	4	5	
Q21	What is the immune system?	A virus found in the body	An illness that causes your face to be itchy	The blood	A system that makes up the army of the body	I am not sure of the answer	
	Visual aids (Bildstöd™ symbol)						
Q22	What do you do when you vomit in the 1st hour after taking ARVs	You ignore that, it is normal	You take another dose immediately after	You stop taking them	You go see a doctor	I am not sure of the answer	
	Visual aids (Bildstöd™ symbol)						

Chapter 4


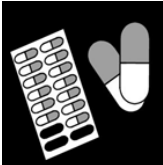



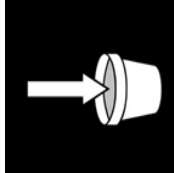

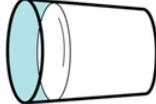
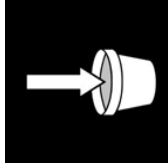

Question	Choices					Answer
	1	2	3	4	5	
Q23	<p>Healthy food is the very cure for HIV</p> 	<p>ARVs are the cure for HIV</p> 	<p>There is no cure for HIV</p> 	<p>There is no cure that beats exercise for HIV</p> 	<p>I am not sure of the answer</p> 	
Q24	<p>When you take ARVs the virus should decrease in your blood</p> 	<p>When you take ARVs your CD4 cells should die in your blood</p> 	<p>When you take ARVs Your soldiers should decrease in your blood</p> 	<p>When you take ARVs the virus should increase in your blood</p> 	<p>I am not sure of the answer</p> 	

Table 3: Expert Panel Descriptions

Expert	Profession	Training	Age (yrs.)	Number of years working in HIV education	Gender
Expert 1	HIV Programme Co-ordinator	BA Social Work	28	3	Male
Expert 2	Professional Nurse	National Diploma in Nursing	38	10	Female
Expert 3	Professional Nurse	National Diploma in Nursing	55	32	Female

Table 4: Details of translators

Category	Translator 1	Translator 2	Translator 3	Translator 4
Professional Training	BSc Engineering, Sports	Master's in Early Childhood Intervention (MECI) Hon. Psychology BA Sociology and Psychology	National Diploma in Nursing	Higher Diploma in Teaching
Occupation	Translator and transcriber	Health Systems Strengthening Programme coordinator	Professional Nurse	Teacher
First language	IsiZulu	IsiZulu	IsiZulu	IsiZulu
2nd Languages	English	English	English	English
Other languages	Not specified	Afrikaans, IsiXhosa, Sesotho	Afrikaans	Afrikaans
Translation experience/ working with multilingual documents	11 years	11 years	32 years	40 years

information about living with HIV. According to the experts this was because the content covered by the questionnaire was information that is not readily available to clients in primary healthcare (PHC) settings. They suggested the addition of a question relating to opportunistic infections addressing the knowledge on co-morbidity of TB and HIV. The multiple-choice format was deemed as a good strategy to assess HIV health information in people with low literacy (Shisana et al., 2014) and the use of visual aids also found favour with the panellists as they felt that these would assist participants not to have to think too hard about the right words to respond with. The picture (visual aid) would assist them (Tsang et al., 2019).

Translation of the HIV health information assessment questionnaire

Translating the tool into a local language (isiZulu) was deemed necessary, since the questionnaire was going to be conducted within KZN. Although the experiment was not peer reviewed for its psychometric qualities, a multistep, rigorous translation process which was informed by recommendations for cross-cultural research (Brislin, 1986; Peña, 2007) was undertaken. Through a combination of methods, this process ensured reliable translation, that was in favour of the target audience (Brislin, 1986) and prevent the potential loss of meaning of the constructs (Peña, 2007). The details of the four translators are outlined in Table 4.

The translators were selected based on their experience working bilingual documents with the healthcare settings as well as experience in working within people in different communities. The main criteria for selection was that the translators had to be proficient in English and isiZulu, (Acquadro et al., 2008) the translation process summarised in Figure 3.

Chapter 4

Translator 1 Forward-Translation	Forward-translated from English (source language) into isiZulu (target language)
Translator 2 Back-Translation	The isiZulu questionnaire back-translated into English (Brislin, 1986), Not <i>blind</i> back-translation
Translator 3 Cultural equivalence	Reviewed the translated documents matched against the original (English) document
Translator 4 Linguistic equivalence	Complex isiZulu health/medical terms kept in English Accommodation of the language used by the local people

Figure 3: Translation process followed for culturally appropriate health information tools

Firstly, the questionnaire was forward-translated from English (source language) into isiZulu (target language) by Translator 1, who jointly confirmed her translations with other translators (Acquadro et al., 2008). Next, the questionnaire was immediately back-translated into English (Brislin, 1986). This was not blind back-translation as this step was done by the researcher Translator 2 and was not blind to the original contents of the tool (Acquadro et al., 2008). Upon completion of the back-translation, Translator 3 reviewed the translated documents (in isiZulu) and matched these against the original (English) documents in order to ensure consistency and accuracy of the translated terms (Acquadro et al., 2008; Peña, 2007). This reviewer (translator 3) aimed to establish *cultural equivalence* and confirm that accurate and appropriate language was used to convey the health information in a manner that would be acceptable to the target audience (Squires, 2009). This step also attended to the level of difficulty of the items to ensure that it does not pose a threat to the questionnaire's validity and reliability (Peña, 2007). Translator 3 discovered that some of the terms in the isiZulu version were too complex and suggested that these medical terms be kept in English. This was because the isiZulu terms used in the translated version were not in the dialect used by the local people when referring to some health content

(Peña, 2007; Squires, 2009). Therefore, terms such as “ARV”, “HIV” and “CD4 cell” were retained in English in the isiZulu version. Through following this guidance, *linguistic equivalence* was obtained (Brislin, 1986; Peña, 2007). In the final stage, Translator 4 rewrote all the items of the questionnaire in isiZulu incorporating all the metrics and linguistically equivalent inputs.

Testing the HIV health information questionnaire on the target audience

As a final step prior to implementation of the completed questionnaire was tested on a small group of people with low literacy for its suitability (Zhang et al., 2015). This phase also included the provision of a health education intervention (using the NDoH health education programme) as a means to enable the assessment of HIV health information before (pre-test) and after (post-test receiving HIV health information). The participants for this testing phase were selected using the same criteria as the participants that would take part in the actual experiment. These criteria were as follows: Participants had to be between the ages of 18 and 65 years. Since this book is based on a study of adults with low literacy, and not young children, adolescents or youth of school-going age. The participants also spoke isiZulu as their first language and they had less than seven years of formal schooling (Hoogwegt et al., 2009). This was so that they could fit the definition of a person with low literacy was outlined in this book i.e a person with less than seven years of formal schooling (Carstens et al., 2006; Dowse & Ehlers, 2001; Hoogwegt, 2007).

The testing period ran over four phases during the four testing phases, participants provided feedback on the design, user-friendliness, content and practicality of the questionnaire. In terms of the procedures followed; At pre-test, the questions were read out to the participants whilst the researcher simultaneously pointed to the corresponding visual aids and the multiple-choice options on the questionnaire. Reading and pointing at the same time was informed by theories of dual information processing which suggest that

the processing of written messages augmented by visual aids and auditory input, aids retention and comprehension of information (Clark & Paivio, 1991; Mayer, 2001; Paivio, 1969). This method, assisted the participants with recollection of response options through the use of visual aid representations (Wood et al., 2009). The participants were then provided health information through the NDoH's health education programme, after which they took a 30-minute-break and then a repeat of the very same questions as a post-test. This was for the first three phases, because the last phase the questionnaire had changed (from multiple choice to open-ended questions). Thus there was no pointing during the reading of the questions.

The recommended number of participants for testing a tool is 35 or more, a total of 20 participants took part in this testing phase, after many were lost due to being a "no-show" or being unreachable on the day set for the exercise. The demographics of this group of participants were not disaggregated, sub-classified or analysed since the aim of the phase was simply to obtain their opinion about the tool. Nine participants took part in the first phase. All of their post-test scores did not show the anticipated improvement. In fact, the participants' pre-test knowledge seemed quite satisfactory, whilst in 11 of the questions, they performed worse in the post-test than at the pre-test. It was concluded that re-wording some of the items might mitigate for the confusion though none would be eliminated for the next testing phase. Table 5 presents the consolidated proceedings from testing phases one to four.

The revised questionnaire was tested on six new participants (four others did not show up). Further inconclusive results amongst the participants lead to some questions being removed since all participants knew these at pre-test a total of 14 questions. Two questions were rephrased: 'Q8, How do you know that you have HIV?' was rephrased to 'What is the only way to be sure that you have HIV?' and Q24, 'What happens in your body when you take ARVs?' was rephrased to 'What do ARVs do to HIV in the body? A further

Table 5: Summarised findings from testing of the HIV health information assessment questionnaire

Description of version of questionnaire	Objectives	Findings/Results	Recommendations	Changes implemented for the next phase
Phase 1, No. (n) 9				
Pre-test post-test questionnaire with Bildstöd™ symbols Individual health education participant booklets	To determine the sensitivity of the pre-test post-test questionnaire in determining understanding of HIV health information. To establish the appropriateness of the multiple-choice format. To determine the appropriateness of the multiple-choice format Bildstöd™ symbols in aiding people with low literacy in responding to multiple-choice questions (Cremers et al., 2017). To determine the appropriateness of using the NDoH health education flip chart together with individual participant booklets	No notable improvements from pre-test to post-test. For some questions the performance was worse at post-test than at pre-test. (Questions 3, 8, 20, 22 and 23), indicating that the multiple-choice format was not appropriate for this group. Multiple-choice confused some participants whilst others felt that visual aids helped them to remember the responses but only if they if they immediately knew the answer. Participants also asked questions on content that was not covered in the HIV education programme provided Most participants followed with the researcher on the flipchart (Wood et al., 2009)	Questions 7, 9, 12, 13 and 17 were considered for revision or exclusion, since all nine participants knew the answers at pre-test and post-test. Easy questions mentioned above should be considered for revision after the next testing phase. Health information pertaining to questions raised to be emphasised during the health education sessions. The participants' individual health information booklets can be left out since they don't make much of a difference.	Questions 3, 8, 20, 22 and 23 were excluded as they were not understood by participants.

Description of version of questionnaire	Objectives	Findings/Results	Recommendations	Changes implemented for the next phase
<p>Phase 2, No. (n) 6</p> <p>The revised pre-test - post-test questionnaire with Bildstöd™ symbols</p>	<p>To determine the sensitivity of the rephrased questions</p> <p>To determine the appropriateness of using the NDoH health education flip chart together without individual participant booklets</p>	<p>Participants still scored high on 12 pre-test questions (2, 6, 7, 9, 11, 12, 13, 14, 15, 16, 17 & 18)</p> <p>This confirmed that the multiple-choice was not the best method to be used to assess the understanding of HIV health information in people with low literacy.</p> <p>Participants were able to follow the session by watching as the researcher pointed, and listening to the health information given (Wood et al., 2009), without the distortion of individual health education participant booklets</p>	<p>Suggestions to remove, rephrase, add and convert some questions</p> <p>Seven questions were converted to an open-ended format (Mansoor & Dowse, 2003) and some new ones were added (as outlined in Table 3.9).</p> <p>The strategy of providing the health education session verbally while pointing to the visual aids (Kandula et al., 2009; Negarandeh et al., 2012) was suitable for participants during the health education session.</p>	<p>Questions being removed (n=14), Questions rephrased (n=2)</p> <p>Questions added (n=5); and</p> <p>Questions converted from multiple choice to open-ended format (n=7).</p> <p>Visual aids left out.</p>

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Description of version of questionnaire	Objectives	Findings/Results	Recommendations	Changes implemented for the next phase
<p>Phase 3, No. (n) 3</p> <p>Revised pre-test post-test questionnaire with multiple-choice and open-ended questions</p>	<p>To test the combined pretest-post-test questionnaire with both multiple choice and open-ended questions</p> <p>To assess participants' preferred method of assessment.</p>	<p>All three participants scored very high on both the pre-test and post-test multiple-choice questions.</p> <p>2/3 participants scored better in the post-test when using open-ended questions (from 3 to 8; from 4 to 8 correct responses)</p> <p>All three participants preferred the open-ended question format.</p>	<p>Change the whole questionnaire to open-ended questions (Beckstead, 2014).</p>	<p>Questionnaire changed to open-ended</p>
<p>Phase 4, No. (n) 2</p> <p>The open-ended pre-test post-test questionnaire with no visual aids</p>	<p>To determine the appropriateness of the open-ended pre-test post-test questionnaire in covering the understanding of HIV health information.</p>	<p>participants scored better in the post-test than in the pre-test.</p>	<p>The open-ended version to be used for the main data collection.</p>	

five questions were added. These were, ‘What does HIV do when it enters the blood?’, ‘What will happen if you do not take your ARVs?’, ‘What is a common illness in HIV-positive people?’ ‘Why is the CD4 blood test done?’ and ‘What does HIV do to your immune system?’ A major change, though contrary to literature, was changing some multiple-choice questions to open-ended format (n=7) (Cremers et al., 2017; Mantri-Langeveldt, 2019). This was since the result suggested that the multiple-choice format was failing to demonstrate the desired understanding of the questions, and thus, unable to help assess for the understating of HIV health information (Kheir et al., 2013; Volandes et al., 2010; Yong et al., 2018).

The above mentioned changes necessitated for two more phases. Thus the third phase aimed to test the appropriateness of the rephrased multiple-choice (n=15) and newly added open-ended (n=7) questions (Artino et al., 2014). All three participants who took part in this phase positively expressed their preference for the open-ended questions since they found it easier to respond in their own words. Following from this first positive outcome, all questions were changed to open-ended format and tested for the last time. The final phase focused on appropriateness of a full set of open-ended questions in adequately covering the construct (HIV health information) (Artino et al., 2014). Notable improvements were seen at post-test for all participants; hence this version of the questionnaire was taken as the final one (please see full set of open-ended questions in Table 6).

Conclusion

This chapter unpacks that the process followed for the development of a culturally appropriate health information assessment tool includes a variety steps and the inclusion of stakeholders. The developers of materials must be mindful of the literacy levels and needs of the target audience at all times. As can be seen even when the relevant steps are followed some unforeseen challenges may arise, as was observed in the first three rounds of the testing phase where the participants struggled with the picture-based version of the tool, leading

Table 6: Final HIV health information assessment questionnaire: open-ended format

Questions (English)	Questions (IsiZulu)	(Please Write the Responses Here)	Response Code (0; 1)
1. What happens to you when the “HIV” (virus) kills the soldiers of the body?	1. Kwenzekani kuwena uma igciwane i- “HIV” libulala amasosha omzimba		
2. Why do we test for the CD4 count (in the blood)?	2. Kungani kuhlolwa ubungako beCD4 egazini (i-CD4 count)?		
3. Apart from TB, what is another common illness an HIV positive person can get?	3. Ngaphandle kwe-TB, yisiphi isifo esijwayelekile esingatholwa umuntu one-HIV?		
4. What is one of the symptoms that could indicate that someone has contracted HIV?	4. Iyiphi enye yezimpawu ezingakhomba ukuthi umuntu angahle abe ne-HIV?		
5. What are CD4 cells?	5. Yini ama CD4?		
6. Why is a viral load test done?	6. Kungani kuhlolwa ubungako begciwane elisemzimbeni (i-viral load test)?		
7. Why is the HIV virus clever?	7. Kungani igciwane i-HIV lihlananiiphile?		
8. How can an HIV positive pregnant mother reduce the chances of infecting her unborn baby with HIV?	8. Owesiname okhulelwe one-HIV angawehlisa kanjani amathuba okuthelala umntwana wakhe ongakazalwa nge-HIV?		
9. What would happen if you don't take ARV medicines as you should?	9. Kungenzakalani egciwaneni i-HIV uma ungase ungayidli imishanguzo yakho ngendlela?		

Questions (English)	Questions (IsiZulu)	(Please Write the Responses Here)	Response Code (0; 1)
10. After how many months on ARVs should one have their 1st viral load test done?	10. Kumele uhlolelwe emva kwezinyanga ezingaki izinga legciwane (viral load) emva kokuthi uqale imshanguzo amaARV?		
11. Why is it helpful for a breastfeeding mother to be on ARV medicines?	11. Kusiza ngani ukuthi umama oncelisa ibele adle imshanguzo ama -ARV?		
12. What should you do if you vomit within the 1st hour after taking your ARV medicines	12. Kumele wenze njani uma uphalaza lingakapheli ihora uphuze imshanguzo ama -ARV?		
13. How do ARV medicines suppress the HIV virus?	13. Imishanguzo ama -ARVs iicindezela kanjani igciwane elisemzimbeni?		
14. How much of the virus must be in the body if your ARV medicines are working?	14. Kumele libe ngakanani igciwane elisemzimbeni uma imishanguzo yakho ama -ARV esebenza?		
15. What is one of the ways in which family can assist an HIV positive person?	15. Iyiphi eyodwa yezindlela umndeni ongamsiza ngayo umuntu oneHIV?		
16. How are symptoms of a person infected with HIV different to symptoms of any other illness?	16. Kungabe izinkomba zomuntu otheleleke nge-HIV zihluke ngani kunezokunye ukugula okujwayelekile?		
17. When should you have another viral load test after you have had your very 1st one?	17. Kumele uphinde nini ukuhlolelwe izinga legciwane (viral load) emva kokuthi usuhlolele okukuqala?		
18. What happens when the HIV virus encounters few ARVs in the blood?	18. Kwenzakalani uma igciwane- HIV lihlangabezana nemishanguzo emincane egazini?		

to the eventual omission of the visual aids and the use open-ended questions only. Moreover, the chapter suggests that the usual 'pure' back-translation does not always equate to the best version of translated tools for people with low literacy. This is a huge implication for researchers who conduct research in areas where participants do not speak the official or local language, or that of the health care providers. A well-designed tool has potential to assist healthcare providers in assessing clients' ability to understand, retain and recall health information thereby giving way to the designing of interventions that have an increased chance of addressing the health information needs of people with low literacy.

Chapter 5

The understanding of HIV health information in people with low literacy

Introduction

In order to conduct the experiment at the selected research sites, ethical clearance was sought and obtained from the University of Pretoria. Further ethical clearance was sought from the National Department of Health for official permission to use the NDoH health education programme for research purposes. This permission was sought even though the then Minister of Health, Dr A .P. Motsoaledi, had stated in the preface that the guidelines were for the use by all healthcare providers, medical practitioners, development partners and civil society organisations, as well as the private sector and community health workers. Ethics clearance was also sought from the KZN Department of Health (DoH). This was necessary in order to be able to conduct the system in the KZN DoH clinics.

Where the experiment took place

The experiment took place at two clinics within the district of eThekweni. eThekweni is a metro district with 114 PHC facilities, within three districts, six regional and one tertiary hospital/s (KwaZulu-Natal Department of Health, 2016). These clinics are situated in 110 wards that cover an area of 2 297km². Despite being highly urbanised, the district has pockets of rural communities that exist on the outskirts of the west, south and north sub-districts, where access to services falls short (see Figure 4). ; Hence the selection of two clinics from the south sub-district, which is furthest from the central

business district (CBD) and more rural than other sub-districts (KwaZulu-Natal Department of Health, 2016).

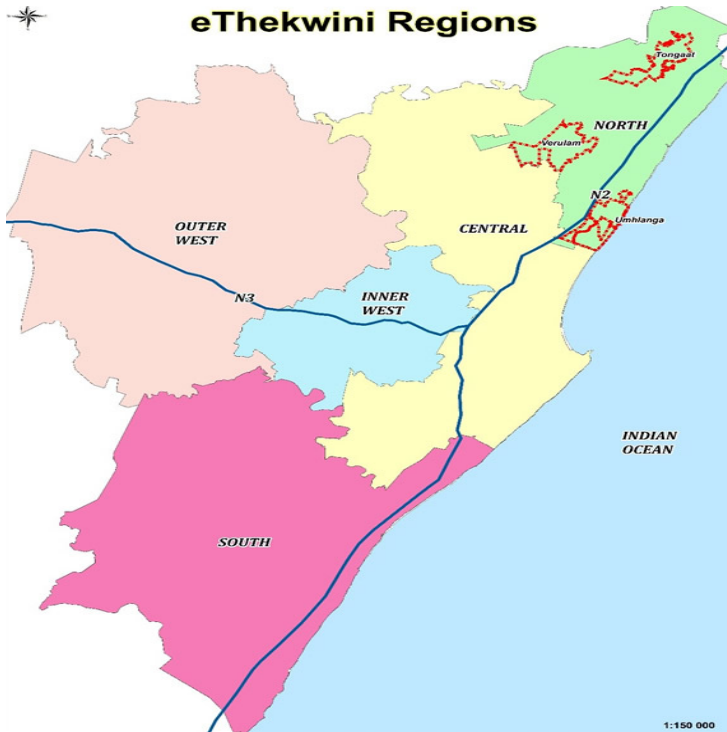


Figure 4: Map of eThekweni sub-districts (regions) (KwaZulu-Natal Department of Health, 2016).

Recruitment at the KwaZulu-Natal DoH facilities

At the clinics, the aim was to integrate with the daily flow and impose as little disturbance as possible. As someone who had been providing technical support to NDoH programmes for a little over 14 years, I was aware that the clinics would be providing services according to the NDoH guidance that clinics separate their services into three streams: minor ailments, chronic illness, and maternal and child health services (National Department of Health, 2018). This design comes from the Integrated Clinical Services Management (ICSM)

model whose aim is to help respond to and manage the growing burden of chronic diseases in South Africa. A model whose objective is to ease the overcrowding, reduce waiting time and promote the provision of comprehensive quality services to the users of the public health clinics (National Department of Health, 2018).

We recruited people from all three streams' waiting areas but targeted days when the clinic was serving clients who collect chronic medication. This was in anticipation that some of the clients would be interested in getting the "additional information" This was how the research intervention was introduced to patients who showed an interest in the study. Moreover, as patients arrived in the morning. Information was provided in the form of a health education session. This was conducted in conjunction with the daily information sessions that the clinics should conduct every morning. The research team even assisted the clinic, by forming part of the facility team thereby allowing some of the staff to begin setting up their consultation rooms while our research team provided health information. For some clients, participating in the study helped as they could engage the researcher whilst waiting for their turn. Moreover, in order to maximise recruitment activities within a shorter period, recruitment took place at two clinics (alternating days) as outlined in Table 6.

Table 7 shows that there was a large drop in numbers from the participants originally approached to the actual number who remained to complete all the activities of the experiment (pretest, intervention and post-test). The table shows that a total of 215 participants met the selection criteria and whilst a total of 100 agreed to participate in the study. When a sample of 90 participants was reached and had completed either one of the three interventions, this was deemed an appropriate (Kheir et al., 2013). Most of the recruitment took place in clinic A since clinic B not only had a lower catchment population, was less busy and the structure did not allow for adequate visibility of the research team. At times, the research team had to use a gazebo as additional

Table 7: Recruitment at the DoH clinics

Research site	Catchment population	Participants informed	Participants who met the study criteria	Participants who signed consent form	Participants who completed the experimental task
Clinic A	38 965	625	190	86	78
Clinic B	27 626	50	25	14	12
Total		675	215	100	90

Table 8: All Participant Demographics

Demographic	Category	Experimental Task (N=90)	Comprehensibility Task (N=39)
Age	18-30 yrs.	13 (15%)	7 (18%)
	31-40 yrs.	12 (13%)	11 (28%)
	41-50 yrs.	19 (21%)	14 (36%)
	51-60 yrs.	46 (51%)	7 (18%)
Gender	Female	74 (82%)	33 (85%)
	Male	16 (18%)	6 (15%)
Level of education	No schooling	11 (13%)	32 (82%)
	1-4 yrs. of education	25 (27%)	
	5-7 yrs. of education	54 (60%)	7 (18%)
Employment Status	Unemployed	71 (79%)	36 (92%)
	Self- employed	3 (3%)	2 (5%)
	Full time employed	3 (3%)	0%
	Part-time or other	11 (13%)	1 (3%)

space and this could have added to the hesitation from some potential participants. Further attrition was attributed to time and transport constraints, since participants were dependent on the availability of public transport such as taxis, or lifts. Another reason why some participants could not stay for the whole duration of the experimental task was that some had taken time off work, most of which were piece or temporal jobs where non attendance meant “no work, no pay”.

Experimental Task Participant demographics

Most participants reported a government grant or pension as their source of income (Hall, 2011; Inoue et al., 2013). The mean age (N=90) was 47.5 years (SD = 12 years), with an average level of education of 3.4 years (SD = 0.9 years).

Table 8 shows that most of the participants (82 per cent, or 74 in total) were female, while only 18 per cent (16 were male). Approximately 13 per cent (11 of the participants had no schooling, 27 per cent (25 had one to four years of education and the majority (60 per cent or 54 in total) had completed five to seven years of education. A further analysis into the demographics of the experimental groups (depicted in Table 9) revealed that an estimated 45 per cent of participants in groups 1 and 2 were between the ages of 51 and 65 years, whilst only 63 per cent of participants in the control group fell within this age group. Level of education was separated into three categories: no schooling, one to four years of education, and five to seven years of education. Across all three groups there were very low numbers of people who had never been to school (less than 14 per cent). In both groups 1 and 2, 30 per cent of the participants had between one and four years of education. Group 2 had the highest number of persons with five to seven years of education (63 per cent), which was 19 out of the 30 participants.

Table 9: Group Demographics: Experimental task

Demographics characteristic	Group 1 (with visual aids) (n=30)	Group 2 (without visual aids) (n=30)	Group 3 control group (n=30)
Age -n (%)			
18-30 years	7 (23.3%)	5 (16.7%)	1 (3.3%)
31-40 years	5 (16.7%)	5 (16.7%)	2 (6.67%)
41-50 years	4 (13.3%)	7 (23.3%)	8 (26.7%)
51-65 years	14 (46.7%)	13 (43.3%)	19 (63.3%)
Level of education n (%)			
No schooling	3 (10%)	4 (13.3%)	4 (13.3%)
1-4 years of education	9 (30%)	7 (23.3%)	9 (30%)
5-7 years of education	18 (60%)	19 (63.3%)	17 (56.7%)

Determining the understanding of HIV health information using augmented input

In order to determine the understanding of HIV health information, participants were interviewed individually, using the open-ended HIV health information assessment tool described in the previous chapter. In a closed room (to maintain confidentiality) We read the pre-test questions to each participant and wrote down their responses in the response column of the questionnaire (Kripalani et al., 2008; Mantri-Langeveldt, 2019). Thereafter, the NDoH’s health education flipchart tool was placed on the table. With the side showing the health information demonstrated by a small visual aid in the top right-hand corner facing researcher (see Figure 5), whilst the side facing the participants showed the idea and only the visual aids pertaining to the health information that was being provided (see Figure6). Thereafter, Group 1 received the NDoH’s HIV health education programme verbally with the NDoH visual aids showing to the participants. The researcher read the health information out loud and pointed to the corresponding NDoH visual aids simultaneously

(Clark & Paivio, 1991; Kim & Lee, 2016). Group 2 received the same NDoH's HIV health education programme verbally, but without the NDoH visual aids being shown. In this instance, the researcher did not show or point to any of the NDoH visual aids. A third group of participants (Group 3) was used as the control group and received the same intervention as group 1; the only difference is that they received the intervention after they had completed both their pretest and post-test (McMillan & Schumacher, 2010; Schlosser, 2003).

Assessing the comprehensibility of the NDoH health education programme visual aids

The second exercise aimed to determine describe the comprehensibility of the visual aids used in the NDoH's health education programme since no literature for this existed at the time. For this comprehensibility task participants were recruited from two community-based organisations (CBOs) in KZN. One CBO was in Durban whilst the other was in Pietermaritzburg. A separate group of participants (N=39) not involved in the experimental task were recruited for These participants were recruited using the same criteria as participants for the experimental task. A larger portion of the participants were mostly between 41 and 50 years old (36 per cent), followed by those who were between 31 and 40 years at 28 per cent (n=11). As was the case in the experimental task most were female (85 per cent) and had no schooling (85 per cent) (see Table 7).

In the same manner as similar studies (Kheir et al., 2013; Roberts et al., 2010), the semi-structured interviews for the comprehensibility task were administered to participants individually. A response booklet was used in order to assist with administering the exercise. The booklet included 19 visual aids from the NDoH health education programme. Under each visual aid (*for transparency*) was a three-point visual aids Likert scale (see Figure 7) on which participants could select responses (*for translucency*) (Batorowicz et al., 2017).

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Figure 5: NDoH's health education flipchart facing the researcher



Figure 6: NDoH's health education flipchart facing the participant

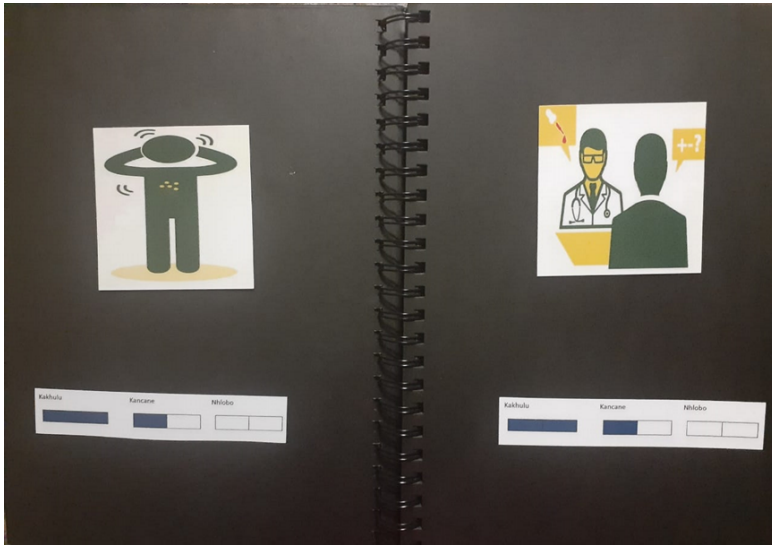





Figure 7: Participant response booklet: stakeholders' perspectives

Transparency and translucency of the visual aids

To determine transparency, participants were asked: *What do you think this picture means?* or *What do you see when you look at this picture?* For translucency, the researcher first revealed the meaning of the visual aid by asking the participant, *If I told you this is...* (e.g., *a virus / being sick / blood*), *how much would you say this picture looks like* (e.g., *a virus / being sick / blood*)? A three-point visual aids Likert scale (Berthenet et al., 2016) with pictographic differentials indicating “a lot”, “a little”, and “not at all” was utilised to assist participants to select their responses (see Table 10). (Bernal et al., 1997; Mantri-Langeveldt, 2019). Participants’ responses were recorded on a participant scoring form, which contained the same information as the participant response booklet with additional columns to record responses (open ended for transparency, and the choice on likert scale for translucency).

Table 10: Scoring form for the comprehensibility exercise

	Idea	Visual aid	Participant's transparency response	Transparency Response code (0/1)	Translucency		
1	Virus				A lot	A little	Not at all
2	CD4 cell/ soldier of the body				A lot	A little	Not at all
3	HIV -negative person				A lot	A little	Not at all

Conclusion

The processes followed in determining the understanding of HIV health information in people with low literacy were separated into two exercises for the purposes of unpacking aspects of understanding of health information. The experimental task gave way to a process for the determination of effectiveness of NDOH health education programme in providing HIV health information to people with low literacy, whilst the comprehensibility exercise was an engagement with the stakeholders to investigate whether or not the visual aids held sufficient iconicity for this group. Together these exercises which were conducted with the stakeholders in the communities, had the advantages of engaging different samples on different aspects of the health education programme. Consequently, the next chapter discusses the results from these two exercises both separately and fusing some of the findings. This is done to create a comprehensive view of the understating of health information in people with low literacy, drawing from comparisons of performance on the pretest-post-test questionnaire between the groups as well as aspects of the health education programme content and format.

Chapter 6

Results of the experimental and comprehensibility tasks

Introduction

Chapter 6 is one of the most important chapters in the book since the discussion is centred around observations and interpretations from the experimental and the comprehensibility exercises. This is in line with the main aim of the book which is to demonstrate the improvement of health literacy for people with low literacy with a critical analysis of the NDoH HIV health education programme. The deliberations also serve to emphasise the importance of health education for individuals, as detailed in Chapter 2.

Understanding of HIV Health Information

After consulting a statistician, an analysis of the differences in the understanding of HIV health information, amongst the three experimental groups (1, 2 and 3) was established by comparing overall pre-test and post-test scores per group. If the post-test scores were higher, it would mean that there was improvement in understanding and vice versa. An overall improvement was seen in the post-test scores of 'groups 1 and 2, as shown by the higher mean ranks of the post-test scores ($M = 61.2\%$; $M = 51.8\%$ respectively), compared to lower mean ranks of their pre-test scores ($M = 50.3\%$; $M = 48.9\%$ respectively). Group 3 (the control group), on the other hand, showed a decline of 13.8 per cent in performance, with a lower post-test mean rank ($M = 23.5\%$), than the pre-test mean rank ($M = 37.3\%$). The statistically significant improvements in groups 1 and 2 can be interpreted as an indication of an improved understanding of HIV health information amongst

these participants due to receiving HIV health information in the form of a verbal health education session.

Certain questions in the questionnaire were seen to produce greater increases in the understanding of HIV health information than other questions. For example, group 1 exhibited an improvement in knowledge about mother-to-child transmission (Question 8) - and about when to seek medical attention (Question 12), whereas group 2 showed notable improvements in knowing about important blood tests for a person living with HIV (Questions 10 and 17). The above findings are supported by research on interventions delivered verbally by a healthcare provider (i.e., spoken inputs) which improved the understanding of health information in people with low literacy (Lee et al., 2012; Negarandeh et al., 2012). This improvement was even greater when the information was about living with a chronic disease (Gerber et al., 2005; Lee et al., 2009; Sheridan et al., 2011). This was especially when interventions addressed complex health information, such as the interpretation of blood results like CD4 counts and viral load (Kalichman et al., 2005), or knowledge of how and when to seek medical attention (Sutherland & Hayter, 2009).

Understanding of HIV Health Information within Groups

Within-group analyses (presented in Table 11) revealed that there were significant improvements (as in, differences between) the pre-test to post-test scores in groups 1 and 2. The lack of significant changes from pre-test to post-test in group 3 was expected as this was the control group that did not receive the intervention between the pre- and post-test.

Understanding of HIV Health Information between Groups

The between-group analyses indicated that there were only significant differences between post-test scores of groups 1 and 3 ($U=73.5$, $p<0.05$) with a large effect size ($d=0.91$); and between groups 2 and 3 ($U=167$, $p<0.005$); ($d=1.02$). However,

Table 11: Understanding of HIV health information: Within - group comparisons

	Group 1 (with visual aids) (n=30)		Group 2 (without visual aids) (n=30)		Group 3 (control group) (n=30)	
	Pre-test	Post-test	Pre-test	Post-test	Pre-test	Post-test
Mean rank	50.3%	61.7%	48.9%	51.8%	37.3%	23.5%
p value	<0.05*		<0.05*		0,15	
Effect size	0.87		0.82		N/A	
Interpretation of effect size	Large		Large		N/A	

the hypothesised difference that would have been due to the pictorial superiority complex from the NDoH visual aids between group 1 (with visual aids) and group 2 (without visual aids) was not observed (Nelson & Reed, 1976). This means that the NDoH visual aids were not effective in facilitating an elevated level of understanding of HIV health information in the group which received the health education programme with visual aids.





Transparency of the Visual Aids Used in the NDoH Programme

Moreover, Table 12 illustrates that none of the NDoH visual aids assessed for comprehensibility met the recommended ISO score of 67 per cent for transparency. Seven of these visual aids had a transparency score of zero per cent, meaning that none of the participants could correctly name or identify these visual aids were those representing “virus” [🦠]; “soldiers of the body” [🦠]; “HIV-negative person” [👤]; “tired” [🤔]; “fever” [🤒]; “blood” [🩸]; and “taking medication at the same time” [👤]. These transparency results of the comprehensibility exercise are important for understanding the outcomes in the experimental task since they allude to something about the iconicity of the visual aids that were shown to participants (of group 1).






Translucency of the Visual Aids Used in the NDoH’s Health Education Programme






When it comes to translucency thirteen of the 19 NDoH visual aids obtained the recommended score of at least 67 per cent of the participants identifying the visual aid correctly once the meaning was revealed (Berthenet et al., 2016). The visual aids that looked look “a lot” like the intended visual aid were for medicine-taking instructions (Berthenet et al., 2016; Kalichman et al., 2013) such as [👤] “a person taking medication”, and “time to take medicines” – [👤] or [🕒] – which all had a 97.3 per cent score for translucency. Visual aids for chronic illness health-related information such as “virus”

Table 12: Transparency scores of the visual aids used in the NDoH's health education programme (%)

Idea	Visual aid	Number of the visual aid	n (%)
A person taking medication		14	64.1%
Testing for HIV		8	61.5%
Time to take medicines		18	41.0%
Go to see the doctor		17	33.3%

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Idea	Visual aid	Number of the visual aid	n (%)
An HIV-positive person		4	30.8%
Flu		5	30.8%
Mother breastfeeding a baby		11	28.2%
Time to take medication		13	28.2%
A sick person		16	15.4%

Idea	Visual aid	Number of the visual aid	n (%)
Unprotected sex		10	17.9%
Family		19	5.1%
High and low		12	5.1%
Virus		1	0%
Soldier of the body		2	0%

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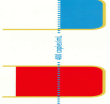


Idea	Visual aid	Number of the visual aid	n (%)
An HIV-negative person		3	0%
Tired		6	0%
Fever		7	0%
Blood		9	0%
Taking medication at the same time		15	0%

Table 13: Translucency scores of the visual aids used in the NDoH's health education programme (%)






Idea	Visual aid	Number of the visual aid	Not at all	A little	A lot
Virus		1	41%	18.4%	39.5%
Soldier of the body		2	18.4%	18.4%	63.2%
An HIV-negative person		3	18.4%	34.2%	47.4%
An HIV-positive person		4	7.9%	26.3%	65.8%



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Idea	Visual aid	Number of the visual aid	Not at all	A little	A lot
Flu		5	21.1%	21.1%	57.9%
Tired		6	18.4%	28.9%	52.6%
Fever		7	7.9%	23.7%	68.4%*
Testing for HIV		8	2.7%	10.8%	86.5%*
Blood		9	2.6%	15.8%	81.6%*

Idea	Visual aid	Number of the visual aid	Not at all	A little	A lot
Unprotected sex		10	8.3%	8.3%	83.3%*
Mother breastfeeding a baby		11	10.5%	12.2%	76.3%*
High and low		12	8.1%	5.4%	86.5%*
Time to take medication		13	0%	2.7%	97.3%*
A person taking medication		14	0%	2.7%	97.3%*

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Idea	Visual aid	Number of the visual aid	Not at all	A little	A lot
Taking medication at the same time		15	0%	5.4%	94.6%*
A sick person		16	2.7%	16.2%	81.1%*
Go to see the doctor		17	10.8%	2.7%	86.5%*
Time to take medicines		18	0%	2.7%	97.3%*
Family		19	5.4%	8.1%	86.5%*

[] and “flu” [] scored the highest percentages (41 per cent and 21 per cent respectively) for *not* looking like their intended idea i.e. “*not at all*”. See Table 13.

The fact that 86 per cent of the NDoH visual aids met the 67 per cent criterion score for looking “*a lot*” like their health idea reiterates research that says that translucency can be improved through prior exposure to visual aids (Mansoor & Dowse, 2003; Roberts et al., 2010) In this regard some researchers would have suggested that it might have been better to train the experiential task participants first on the NDoH visual aids prior to the implementation of the HIV health education assessment and intervention (Wood et al., 2009). Prior training is said to assist visual aids to become familiar and culturally appropriate; as well as enhance their ability to increase knowledge and understanding of health information (Bacardi-Gascon et al., 2002; Davis et al., 2003; Poureslami et al., 2012). Other studies have shown that people with low literacy even prefer locally developed pictograms (Dowse & Ehlers, 2001), since these are deemed to be more transparent and translucent (Dowse et al., 2011, 2014).

The results of the comprehensibility task are notable as they demonstrated that none of the NDoH visual aids met the ISO standards for transparency (Berthenet et al., 2016), and that this could be because the visual aids were unfamiliar to the participants, who were probably seeing them for the first time. This finding illustrates that unless practitioners and patients are familiar with the visual aids, health education materials could be developed in vain, and not derive the desired effects. Overall, the results from both the experimental and comprehensibility tasks also emphasise the benefits that carefully designed health education interventions are best when delivered by a healthcare provider (Kim & Lee, 2016; Nouri & Rudd, 2015), preferably in the same language as the recipients. The lack of the effectiveness of the visual aids in this instance could be correlated with the lack of, or unknown, involvement of the target audience in their development and selection of the NDoH visual aids (Berthenet et al., 2016; Mbuagbaw & Ndongmanji, 2012).

Conclusion

The findings discussed in this chapter clearly support literature that states the importance of health information that is provided for the purposes of health education. The findings also show that this is especially on new or complex health knowledge that is not usually found in standard consultations or counselling. On the importance of using the NDoH health education programme for the provision of health education, the NDoH might welcome such findings because there is a perception that staff do not have enough time to provide health education to their clients, and that when they do, they might not have time to use a tool such as the already existing health education programme. The results further reiterate that health information be given verbally to people with low literacy, since this is the most appropriate because their reading ability is limited. The fact that both groups 1 and 2 of the experimental task showed improvement in the understanding of HIV health information attests to the fact that the verbal input by the researcher was beneficial to those participants. However, the lack of significant improvement in group these two very same groups together with the results of the comprehensibly task, shows that the effects of the visual aids were not derived because the NDoH visual aids did not score high on transparency and have relatively acceptable translucency.

Chapter 7

Recommendations for developers of health information

Introduction

To conclude, I would like to offer a set of recommendations from the literature, processes and findings that have been shared throughout the preceding chapters. These recommendations can serve as a set of guidelines or comprehensive toolkit for the target audience already outlined in Chapter one, i.e. providers of health education programmes for people with low literacy. This is especially within African countries, and where the majority of the people rely on receiving verbal health communication at public healthcare facilities. My main argument is an emphasis on the development of appropriate health information assessment tools, acknowledging HCPs as key information sources for people with low literacy; and the inclusion of people with low literacy in the design, development and evaluation of these health education materials.

Understanding the importance of comprehensive health education

The literature shared in this book highlights not only the distinct definition but also the importance of health education provided for the purpose of enabling individuals to understand, engage and manage their own health. The research also justifies the relationship between low literacy and poor health outcomes, and how this is related to poor health education, which makes the issue of low literacy an important one in the health settings. Moreover, drawing from the logic from theories of information processing helps in understanding the most suitable method of delivery of health

information to people with low literacy; one which includes the use of dual methods (inputs) and takes advantage of the pictorial superiority complex.

Through distinguishing between the different types of health information, the suggestions from Tannahill's (1985) model through which a holistic view of health-enhancing activities are brought to life. This holistic approach has the potential to not only improve individual or community health, but it also gives way to health protection. The relationship between health education and health protection is key because it demonstrates that discussions of health enhancement must neither be bottom-up nor top-down. Instead, these discussions should adopt a balanced view, taking into cognisance the fact that policies influence implementation and practice, as much as practice and data from the grassroots level should be able to inform policy.

The Inclusion of literature from African countries

The literature rendered in this book offers a broader perspective, which includes a view from LMICs, which are hugely underrepresented in current literature on health information, that is dominated by the Western view (Houts et al., 2006; Park & Zuniga, 2016; Pignone et al., 2005). Over and above the abundant literature on visual health education materials, this book adds context to the discussion on the different intervention strategies that healthcare providers can use to target understanding of chronic disease health information amongst people with low literacy. Such insights benefit society because the views and experiences of people with low literacy which are quite prominent in the findings help to shape the recommendations for public health settings. The perspective from the indigenous people (e.g., Zulu community in KwaZulu-Natal), is a view that can be applied to other indigenous groups in other countries with similar socioeconomic profiles as South Africa and low literacy rates. The views from indigenous groups usher a deeper understanding into the way in which different ethnic groups describe (or understand) visual aids that portray health-

related ideas. These experiences, will help people with low literacy to validate their own experiences and gain the courage to engage more confidently with healthcare providers.

The development of an appropriate health information assessment

The development of the HIV health information assessment was conducted in line with recommendations for the development of materials for people with low literacy. This important phase of our research shed light on various useful strategies that must be considered for the target audience. Developers of health information assessments should always consider engagement of subject and field experts to ascertain validity of newly developed tools and be mindful of the importance of testing the tool on the target audience, prior to its implementation. This is so that the best format of questions, sessions, duration etc., can be determined. Drawing from theories from psychology, the processes followed during the experiment demonstrate the reason for the potential benefits of health education interventions which are grounded in theories of information processing (Park & Zuniga, 2016), such as the dual coding theory (Paivio, 1969) and Mayer's cognitive theory of multimedia learning (Mayer, 2001). Integrating knowledge from these theories will ensure that interventions are comprehensive, since they will be planned with the aim of maximising the cognitive skills and phases that adults utilise when learning or solving a problem (Simon, 1978). The implication of cognitive overload during the experiment indicates that the content of health education should be presented in shorter sessions or portions so as to accommodate the processing capacity of people with low literacy; and reduce the possibility of forgetting information at a later stage (Mayer & Moreno, 2003). In addition, the rigour that was used in the translation process allowed for the attainment of metric and cultural equivalence and ensured that the content of the materials was simple and understandable to participants (Peña, 2007).

Healthcare professionals as key health informants

Researchers have highlighted the benefits of dissemination and understanding of health information within healthcare settings. The most notable benefit being the potential to contribute to self-management or self-care of chronic illnesses, especially to people who cannot read or write. The outcome of the experiment that was done at the two clinics point to the benefits health professionals who deliver health education interventions with an understanding of their clients' literacy levels. Moreover, the experiment was administered through a communication technique called augmented input, and adopted from the field of augmentative and alternative communication (AAC) and typically used with people who experience difficulties with communication. The introduction of this technique offers a way in which healthcare providers can deliver health interventions through verbal inputs, (typically presented as written text) and add the use of visual aids.

Inclusion of people with low literacy in the development of health information materials

Subsequently, the book draws on literature about the iconicity of visual aids, and highlights two attributes of the iconicity of the NDoH visual aids; transparency and translucency. Understanding iconicity facilitates the production of programmes that resonate with potential users' social, cultural, linguistic experiences, thereby increasing their acceptability and impact. People with low literacy must be included in the development or selection of acceptable and appropriate visual aids. This is way to increase the transparency and translucency of the visual aids and the likelihood of the visual aids complying with the recommendations for suitability which are suggested in literature (Mansoor & Dowse, 2003; Organisation of International Standards, 2014). Once developed, an important step is to train (Kheir et al., 2013; Kripalani et al., 2007) both health care providers and the target audience on visual aids prior to the implementation of the intervention. Training

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allows for maximum analogical ability (Lonke et al., 1999). For policymakers, these findings contribute to a more distinctive concept of low literacy which is not synonymous with health literacy, thereby advocating for accurate assessments of the construct within the healthcare settings. This understanding of the definition of low literacy will add value to the interpretation of the relationship between health literacy with low literacy and the understanding of health information.

The South African NDoH is fortunate that their HIV guidelines are regularly updated since the programme has received a lot of attention from external funders and the NDoH itself. To this extent, the health education programme that was used in this book, has been updated since the experiment was last conducted in KwaZulu-Natal. These recommendations that are founded in literature and can guide stakeholders who are currently updating guidelines and programmes for people with low literacy.

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Glossary

Augmentative and Alternative Communication

Augmentative and alternative communication (AAC) is a field of clinical practice that aims to enhance communicative competence for persons with little or no functional speech (LNFS) (by replacing or augmenting natural speech or handwriting. AAC includes aided approaches (such as the use of alphabet or picture communication boards, speech-generating devices), as well as unaided approaches (such as the use of gestures and signs from sign language). A broad range of unaided and aided methods are used in AAC, and graphic symbols form a very important component of aided AAC systems (Fuller & Lloyd, 1997). Selecting graphic symbols (also referred to as visual aids in this book) is one of the most important considerations when implementing AAC.

Augmented Input

Augmented input refers to the use of spoken and written words to enhance the comprehension of spoken communication messages. Although these are typically used for individuals who are unable to speak (Wood et al., 2009), in this book, augmented input was used during the experimental task to enhance participants' comprehension of the NDoH's health education programme.

Bildstöd™ symbols

The visual aids or Bildstöd™ symbols were selected from a library of Bildstöd™ symbols that is freely available from their website. Bildstöd™ symbols are developed and shared by Swedish researchers and comprise a variety of graphic symbols (visual aids) used for communication, specifically in healthcare settings

Community-Based Organisation

A nonprofit organisation whose main existence is usually based on fulfilling or representing the needs of a community or certain groups of people. The CBO is usually invested in provision of social, human or health service and relies on funding as they do not generate profit.

Graphic symbol

A visual symbol that represents something else (its referent) to convey an idea (Fuller & Lloyd, 1997). In this book a graphic symbol refers to a picture, photograph, pictogram or logo used instead of words with the purpose of enhancing health information or an instruction.

Healthcare provider

According to the National Health Act no. 61 of 2003 (hereafter referred to as the National Health Act), the term healthcare provider (HCP will be used in this book to refer to any healthcare practitioner, personnel, providers or worker who provides a variety of health services (South Africa, 2004) to persons within the private or public health sectors (Coovadia et al., 2009; Hall et al., 2005). These services include those rendered by doctors, nurses, allied health professionals, pharmacists, health scientists and counsellors who provide different forms of therapy (Mophosho, 2018; van den Berg, 2016; South Africa, 2004).

Health education

The World Health Organization (WHO) defines health education as a form of messaging for learning that aims to increase individuals' and communities' knowledge and influence their attitudes (WHO, n.d.). Health education is provided to help people to promote, improve and control their health, hence it is also known as health promotion (World Health Organization Western Pacific Region, 2017).

Health information

Information that enables one to understand, engage and manage their health condition (Ishikawa & Yano, 2008; Zukoski et al., 2011). This information can either be obtained through written health education materials (Mwingira & Dowse, 2014; van Beusekom et al., 2018) or from a healthcare providers (Kalichman, et al., 2005b; Kim & Lee, 2016).

Health literacy

Health literacy refers to a set of cognitive and social skills that determine one's ability and motivation to seek, understand and use information to promote one's own health and well-being (Ishikawa & Yano, 2008). Low health literacy refers to an inability to follow medical guidance or make the necessary changes to improve one's health (Lambert & Keogh, 2014).

Health promotion

Health promotion is the process of enabling people to increase control over, and to improve, their health. Health promotion generally denotes a comprehensive social and political processes that not only targets individual behaviour and actions but is also directed towards changing social, environmental and economic determinants of individual and public health (Nutbeam, 1998).

Iconicity

Iconicity is one of the considerations mainly used to describe graphic symbols in the field of AAC (Fuller & Lloyd, 1997; Evans et al., 2006). The term refers to any type of association formed by a viewer to link a symbol (visual aid) and its referent (the intended idea) (Dada et al., 2013; Evans et al., 2006). This association is not only a visual one (Schlosser et al., 2007) but it exists on a continuum, with transparency at one end and opaqueness at the other (Dada et al., 2013; Haupt & Alant, 2002).

Opaqueness

Opaqueness is when there is no apparent relationship between the symbol and its referent, the symbol is considered to be opaque (Dada et al., 2013; Huguet, 2012).

Transparency

A visual aid is considered transparent when there is a strong association between it and its referent, and when the visual aid is highly suggestive of its referent – thus, the meaning can be easily understood without additional cues. In some studies, the transparency of a symbol (visual aid) is also known as its guessability. According to the International Organization for Standardization (ISO), a visual aid is transparent if it is guessed correctly by at least 67 per cent of participants (Organisation of International Standards, 2014).

Translucency

A symbol (visual aid) is said to be translucent when the perceived relationship between the symbol and its referent is not readily guessable but can be recognised once its meaning is revealed (Bornman et al., 2009; Dada et al., 2013). In line with the ISO standards, Bethernet et al. (2016) suggest that visual aids (symbols) that receive translucency scores of 67 per cent or above should be deemed as translucent.

Understanding of health information

The understanding of health information entails processing health information and the ability to recall (Houts et al., 2006) the information at a later stage (Carstens & Snyman, 2001).

The NDoH's health education programme

A programme of the NDoH which was developed with the aim of enhancing access to healthcare services, supporting adherence to chronic treatment, and improving clinical outcomes (National Department of Health, 2016). The

programme also comes in the form of a flipchart that can be out on a table with two different sides showing to the session provider and the health information receiver.

Literacy

Literacy is traditionally understood as the ability to read and write (Gee, 1998). Literacy allows a person the ability to acquire certain knowledge or understanding (Gee, 1998) and it is shaped by factors such as culture, identity, power, and the prevailing sociocultural contexts (Perry, 2012).

Low literacy

Low literacy is defined as the inability to write or use numbers effectively (Pignone et al., 2005) and with insufficient proficiency to achieve one's goals (DeWalt et al., 2004; Easton et al., 2010). In this book, a person with low literacy is someone who has less than seven years of formal schooling, in other words who had not passed Grade 7 (Chuang et al., 2010).

Person living with HIV

A person who has been tested positive for human immunodeficiency virus (HIV). They may or may not be on anti-retroviral (ARV) treatment.

Visual aids

Visual aids refer to any pictorial, photographic, standardised graphic symbols (Katz et al., 2006) and line drawings that can facilitate the establishment of joint attention or understanding of a particular shared concept (Nunes, 2008; Staunton, 2015). In this book visual aids refers to the images used in the NDoH HIV health education materials.

