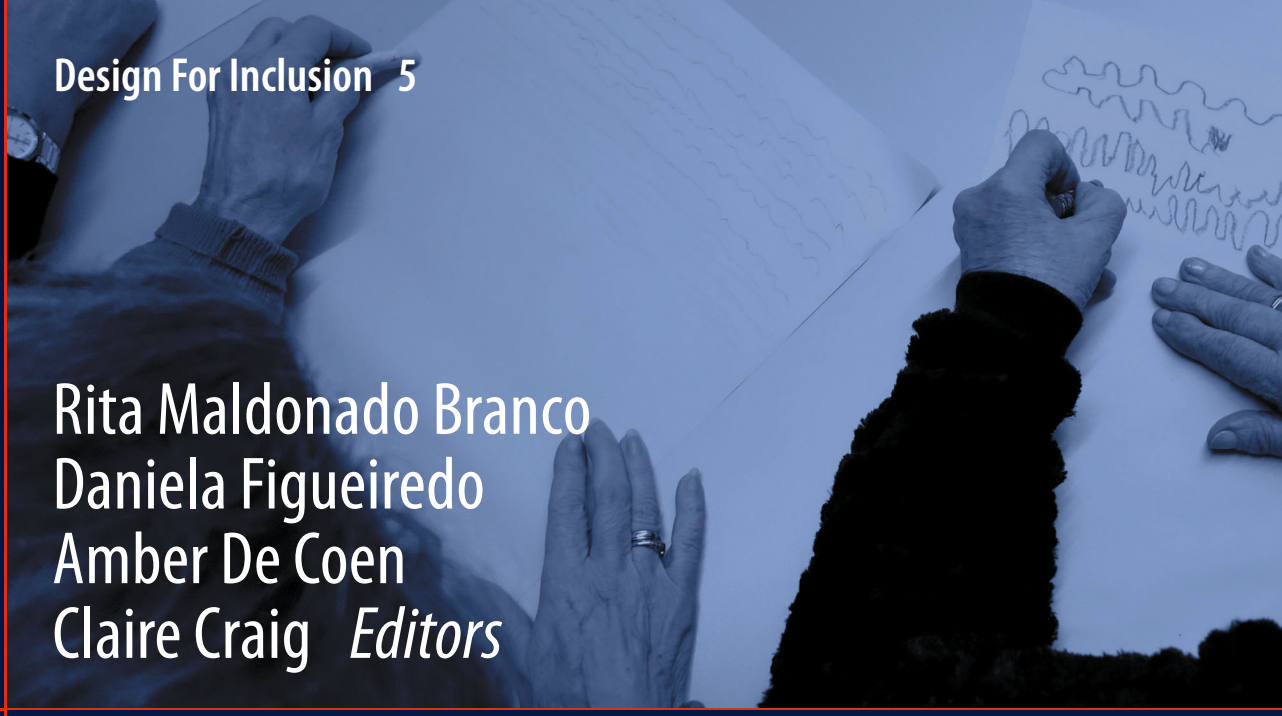
Design For Inclusion 5



Rita Maldonado Branco
Daniela Figueiredo
Amber De Coen
Claire Craig *Editors*

Dementia Lab 2025: Ethics + Aesthetics in Design

Proceedings of the 7th Dementia Lab Conference, D-Lab 2025, March 13–14, 2025, Aveiro, Portugal

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DEMENTIA LAB ethics + aesthetics in design 2025

Springer

Editors
Rita Maldonado Branco
Department of Communication
and Art, Research Institute
for Design, Media and Culture (ID+)
University of Aveiro
Aveiro, Portugal

Daniela Figueiredo
RISE-Health, School of Health Sciences
(ESSUA)
University of Aveiro
Aveiro, Portugal

Amber De Coen
LUCA School of Arts
KU Leuven
Genk, Belgium

Claire Craig
Sheffield Hallam University
Sheffield, UK

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Preface

Welcome to the proceedings of the 7th Dementia Lab Conference, hosted in Aveiro, Portugal by the University of Aveiro, and jointly organized by the Research Institute for Design, Media and Culture (ID+), and the Center for Health Technology and Services Research at the Associate Laboratory RISE—Health Research Network (CINTESIS@RISE).

The Dementia Lab Conference brings together designers, researchers, academics, artists, care practitioners, industry specialists, caregivers, and people living with dementia to create an open forum for the sharing of research on the role of design in supporting the needs of people living with dementia. Since its inception in 2016, the Dementia Lab Conference has provided a supportive space for the sharing of insights emerging from research and for promoting debate and discussion with the purpose of advancing the role of design in enabling individuals with dementia to live well. To do this, we highlight the value of design in addressing the personal and societal challenges that a diagnosis of dementia brings, offering a complementary view to existing clinical or biomedical approaches. At the heart of this design perspective is a focus on identity, personhood, and a recognition of the unique lived experiences of dementia. The Dementia Lab community values inclusive, person-centered approaches to be celebrated and shared among like-minded designers, researchers, health professionals, caregivers, and other professionals working in this context.

Given this focus, it is highly appropriate that the theme of Dementia Lab 2025 is *ethics and aesthetics*. As researchers and designers working in the context of dementia care, we are tuned into the importance of navigating and developing practices to promote autonomy, and ways of ensuring the voices of people with dementia are heard and responded to. Central to ethics are notions of justice and the need to challenge factors that limit opportunities available to individuals because of stigma. As designers, we need to be aware of the subtle messages that many of the products and environments we create communicate about who people living with dementia are. Aesthetics in this context become more important. By aesthetic we not only refer to beauty but to an embodied engagement with the world, through the senses, that becomes even more crucial to acknowledge and incentivize as the dementia journey progresses.

We invited original research contributions that spoke to this broader theme and added to the state of the art of dementia-related design research

or design-related dementia care research. Full papers spoke to one of three subthemes and these proceedings are structured in a way as to reflect these. The first focused on **designing with people with dementia**. Papers within this subtheme include methodological approaches to maximize participation including the design of materials for engagement, as well as more methodological and theoretical contributions expanding the concept of personhood and considering how different frames of reference can shape design research and practice. **Including design in dementia care** is a second sub-theme. Interestingly, several papers here also relate to the design and introduction of technologies into care settings. These are wide-ranging—from social robots to enhance social interaction to co-design activities to support technology acceptance. The final subtheme links closely to **design within cultures of care**, which draws together themes of ethics, aesthetics, and design in long-term care environments including the importance of food and culture in care and participatory approaches to creating a sense of home.

This year, we received 20 eligible submissions for the full paper track, of which ten were accepted after a rigorous double-blind peer-review process. The submissions were coordinated by the program committee members who managed the review process and recruited external reviewers based on matching expertise or relevance to the paper's topic. Each submission received at least three expert reviews (two reviews and one meta-review). This year we added a further, important dimension to the process by inviting a small group of people with lived experience of dementia to act as reviewers. To facilitate this process individuals submitting to the conference were asked to include a plain-language abstract. During an initial group meeting, individuals with lived experience of dementia identified how best to approach the process to maximize their involvement. Following this discussion, we made short video recordings of the abstracts. A total of five meetings were held with individuals who gave feedback on the work's clarity, interest, relevance, and main message. The insights and perspectives offered through this process were invaluable and the feedback was also fed into the review process. Each paper was extensively discussed during program committee meetings, and after careful consideration, ten full papers were accepted for publication in the conference proceedings and oral presentation at the conference. This year's full paper track showcased the variety and breadth of applications through which design can contribute to the lives of people with dementia and their personal contexts, as well as the many perspectives that different design disciplines can bring.

You will see examples of how design practices and methods can empower individuals through participatory aproaches that place people living with dementia at the heart of the design process. The papers further advance the field of design in dementia by raising awareness of broader ethical questions and challenges. This is not only concerning how and where design research is undertaken but also some of the wider ethical questions about more systemic societal injustices facing individuals living with dementia that limit opportunities for participation. The work contained in

these proceedings shows the key role that design can play in the conception of products and environments that recognize the importance of the aesthetic and, in doing so, can help to stop the perpetuation of stigma and some of the unrealistic assumptions around who people living with dementia are.

The decision to make this edition of Dementia Lab proceedings Open Access wishes to support this aim to change societal perceptions about people living with dementia.

The editors would like to thank everyone who contributed to making the Dementia Lab 2025 Conference and Proceedings a reality. These include the dedicated Scientific Committee members, the Organization committee, its collaborators and advisors, Springer, and our sponsors: the Research Institute for Design, Media and Culture (ID+), the Center for Health Technology and Services Research at the Associate Laboratory RISE—Health Research Network (CINTESIS@RISE), the University of Aveiro, the Alzheimer Nederlands, the Expertise Center Dementia and Technology within the Technical University of Eindhoven, the Stichting Alzheimer Onderzoek and the Expertisecentrum Dementie Vlaanderen. A very special thanks to Jane Buckels, Lorraine Brown, and Howard Gordon, who gave their time to review the plain language abstracts and to Marney Walker who supported this process. Finally, we are also grateful to all the authors who submitted their work to the Dementia Lab 2025 and to the people with dementia and those supporting them who participated in the research showcased at this conference.

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Contents

Designing with People with Dementia

From Handover to Participation: How Do Handover Approaches Support Participatory Design Together with People with Dementia?

Lieke Lenaerts, Niels Hendriks, and Andrea Wilkinson

Abstract

Participatory design is widely advised as a means for designers to have direct contact with people living with dementia, establish a designer-participant connection and design products that meet participants' needs. However, involving people with dementia in the design process often poses challenges, showing the need to explore alternative methods to design for people who have dementia. This research investigates the use of handover approaches in design education. A handover approach is a coherent set of organising principles, methods and tools to carry out the process of transferring information about people living with dementia. This study provides a descriptive qualitative analysis of the development and evaluation of a handover workshop through case studies in five educational design contexts. Each case started with the handover workshop, followed by a design process involving participants with dementia. Upon analysing the outcomes, intriguing findings occurred regarding the perceived resonance and positive impact of the handover workshop on the participatory design process. This paper moves away from the use of handover approaches as an alternative design approach and instead moves towards the use of handover approaches to create a more general understanding and awareness for people who have dementia in the initial phases of the design process. The paper discusses (1) how handover approaches can prepare designers for participatory design together with people living with dementia, and, (2) the contribution of handover approaches to the participatory design process. These insights contribute to a growing understanding of the potential of handover approaches in supporting participatory design together with people with dementia, adding to existing methodologies.

Keywords

Dementia design · Handover approaches · Design education

L. Lenaerts (✉) · N. Hendriks · A. Wilkinson
LUCA School of Arts, Paleizenstraat 70, 1030 Brussel, Belgium
e-mail: lieke.lenaerts@luca-arts.be

N. Hendriks
KU Leuven, Oude Markt 13, 3000 Leuven, Belgium

A. Wilkinson
Thomas More University of Applied Sciences, Zandpoortvest 60, 2800 Mechelen, Belgium

1 Introduction

More than 55 million people live with dementia worldwide and this number will only rise due to the ageing population and the absence of a

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cure [44]. Designers must respond to this growing demand by offering products that meet their needs and enhance their quality of life [35]. By involving people with dementia in the design process (i.e. participatory design) designers have direct contact, establish a designer-participant connection and gain an understanding of their product needs [17, 23]. However, involving participants in design processes is complex. The nature of dementia can hinder the design process, with people who have dementia forgetting their role or the purpose of the project or needing ongoing assistance [43]. Designers must adapt the design process to the participants' abilities, yet some designers lack adaptivity with the risk of placing excessive demands on people with dementia regarding the workload and tasks in the design process [15, 19]. Furthermore, the designer-participant connection can become emotionally overwhelming and negatively influence the design project (e.g. participants in distress, designers taking on tasks outside of the design scope) [22, 37]. Additionally, the many organisational tasks of participatory design can hinder the involvement of people living with dementia (e.g. recruitment, ethical approvals, selection and adaptation of design methods to the participant's abilities) [15, 22].

The challenges of participatory design show the need to explore alternative methods to design for the needs of people living with dementia. This research looks at handover approaches when designers are unable to obtain direct interaction with people who have dementia [25, 34]. A handover approach transfers dementia experiences and -insights for designers to gain an empathic understanding and generate design concepts. Examples are movies depicting the progression of dementia or virtual reality to experience daily life situations of a person who has dementia [27]. Handover approaches focus on transferring an understanding for people with dementia as unique individuals, through anecdotal and relational insights based on emotional connections with participants, contrary to other tools that generalise, objectify or quantify participant insights (e.g. persona, marketing data).

Since the use of handover approaches in the dementia design context has been generally under-evaluated, this paper describes the development of a handover workshop and the evaluation of this workshop in a series of five comparative case studies in the educational design context.

2 Methodology

This study aims to evaluate the use of handover approaches in design practice by developing and implementing a handover workshop. This section details the process of creating and evaluating the workshop within an educational design context.

2.1 A Scoping Review on Handover Approaches

A scoping review identified handover approaches transferring dementia-related insights to designers. Using Google Scholar and snowball sampling (i.e. forward and backwards citations) multiple papers were found discussing 'tools', 'approaches', and 'methods' for transferring 'user insights', 'experiences', 'empathy' and 'information'. Several studies explored handover methods, most focused on end-users other than people with dementia. Given the specific sensitivity required when designing for people living with dementia, these studies were set aside for future research. In total 13 papers addressing tools for transferring dementia insights were included for developing the handover workshop.

2.2 Development of a Handover Workshop

The fundament for the handover workshop is based on the Empathic Handover Approach [34]. In this approach, one member of the design team first establishes a connection with participants to

gather first-person experiences (i.e. the 'harvest' phase). These experiences and insights are then transferred to other designers who did not have direct contact with people with dementia (i.e. the 'handover' phase). Lastly, the team generates initial product concepts (i.e. the 'ideation' phase). Since the Empathic Handover Approach has been evaluated in both the professional [34] and educational design context [35], the three sequential phases (i.e. Harvest, Handover, Ideation) served as the structure for the handover workshop developed for this study.

Harvest. In the Empathic Handover approach, a designated member of the design team 'harvests' dementia-related insights through personal interactions with people living with dementia to afterwards 'hand over' these insights to the other members of the design team [34]. In this research, the first author assumed this role due to her commitment to the research. As the 'handover facilitator', the first author engaged directly with people who have dementia and their network of (in)formal caregivers for two years. Through weekly visits, she gained rich dementia-related insights and developed an empathic understanding. To gather diverse perspectives, she interacted with individuals with dementia from various backgrounds (e.g. nationality, culture, religion), at different stages (e.g. early, moderate, advanced) and forms of the disease (e.g. frontotemporal, Alzheimer's, young onset) in various settings (e.g. at home, daycare centre, care home). She observed interactions between caregivers and people with a diagnosis of dementia, noting how behaviours occurred during interactions [6]. The richness of these interactions was captured through fieldnotes, sketches, video, photo and audio recordings [9]. Additional participatory approaches were used to collect personal objects and create hand-made artefacts [42]. Trust was built in the facilitator-participant relationship, enabling people living with dementia to share their daily challenges and problems. This narrative of struggles offers designers opportunities to develop meaningful products. However, it was balanced with people's acceptance of their diagnosis, positive outlook on life, and willingness to try diverse products to enhance their quality of life. This positive framing is included to encourage them to approach the design process with optimism and motivation.

However, dementia is an especially subjective domain of experience. Every individual who has dementia is unique and views expressed by people other than the person with dementia cannot be considered as a proxy for the individual's perspectives [4]. The facilitator has to remain mindful of this during the harvest phase [6, 11]. Furthermore, everyone carries unconscious biases from exposure to cultural attitudes about dementia. There is a need for the handover facilitator to recognize biases and how subconscious feelings can influence the harvest phase [32]. Literature shows that education on dementia and increased awareness provide a method to minimise unconscious bias [14].

Handover. In the handover phase, the facilitator represents the participants, transferring the harvested insights to designers who did not meet people living with dementia in person [34]. Participants were asked to indicate important dementia-related insights. Additionally, guided by the principles of ethical mindfulness, the facilitators' emotions were used to select insights focusing on the individual's history, subjective experiences, and objective behaviour, considered either inspiring to generate design concepts or significant in the everyday lives of people living with dementia [6, 13].

Drawing from the 'harvest' and scoping review, a handover workshop was developed featuring two sequential activities and corresponding tools: empathic questions and handover boxes. (1) Empathic questions aim for designers to retain dementia insights by connecting them to their own experiences, eliciting empathy for participants through autobiographical memory [34]. (2) Inspired by the Life Story Boxes [8] handover boxes were developed. The Life Story Boxes are used in the care context to encourage reminiscence therapy between individuals with the diagnosis of dementia and formal caregivers [8]. Similarly, handover boxes aim to encourage

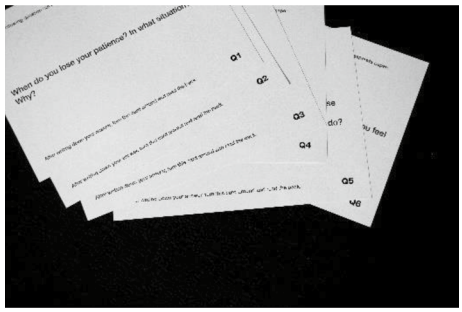

Fig. 1 Empathic questions

Fig. 2 Handover box

designers to engage with the stories of people living with dementia with whom the facilitator had interacted. The boxes include rich descriptions, visual material and physical objects collected during the harvest phase. These objects serve as tangible prompts to inspire ideation [25]. The handover facilitator relied on these two tools to facilitate the active transfer of dementia-related insights and promote knowledge retention during the case studies in the educational design context [18]. Furthermore, the handover facilitator provided support when designers encountered difficulties using the tools, offering clarification and in-depth insights to enrich their understanding (Figs. 1 and 2).

Ideation. In the third phase, the designers generate concepts for individuals with dementia based on the insights gained during the handover phase. Group ideation fosters discussion about the routines, abilities, needs and preferences of people who live with dementia, encouraging a level of co-ownership in the ideation phase.

Evaluation. An evaluation is incorporated after the handover workshop, during which the concepts generated in the ideation phase are collectively presented and discussed. The evaluation phase, an addition to the Empathic Handover Approach (i.e. harvest, handover & ideation), provides an opportunity for the facilitator and designers to debrief and address any unresolved issues related to the design process. It ensures clarity and alignment as the team moves forward with the project.

2.3 Five Case Studies in the Educational Context

Five case studies were conducted to validate the use of the handover workshop in design practice. The choice was made to situate the studies in the educational context since prior research showed the challenges of involving participants in this context (e.g. lengthy ethical approvals, time-bound courses, inexperienced young designers) [21]. Each handover workshop was held at the start of a new course when designers have to gain participant insights and an empathic understanding. All workshops were scheduled in advance of a new course focused on designing leisure products for people with dementia and were followed by a participatory design process involving participants who have dementia. This allowed for a comparison between the insights gained during the handover workshop and those gathered during the following participatory process. The workshops were flexible with consistent breaks comfortably pacing each phase (i.e. handover, ideation, evaluation) and tailored to the number of designers, scale of engagement and dynamics of each group. The handover sessions were framed using an asset-based approach [38] to enable participation by focusing on designers' capacities and using the tailored handover approach to nurture creativity and engagement (Figs. 3 and 4).

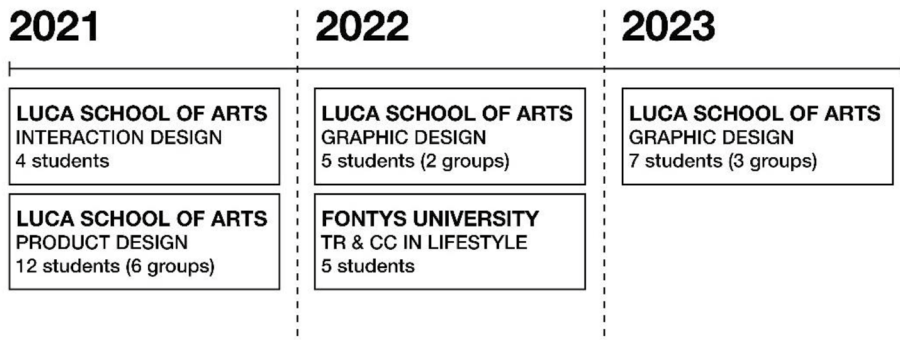

Fig. 3 Schematical overview of the five case studies

Fig. 4 Designer during the handover workshop in the educational design context

2.4 Clustering Findings

In this study, data was gathered from multiple sources to evaluate the impact of the handover workshop. Designers were observed during the design process, capturing immediate reactions and generating knowledge during practice and through reflection on practice [33]. These observations were analysed to identify changes in attitudes and empathic understanding towards people who have dementia, offering insights into the effectiveness of the handover approach. Immediately after the handover workshop, designers completed individual questionnaires or participated in semi-structured interviews to assess their understanding of dementia and perceptions of the workshop. After the presentation of the final products, further semi-structured interviews were conducted to explore the workshops' impact on the participatory design process. All interviews were recorded and transcribed, with the permission of each designer. Additionally, the facilitator and course lecturers assessed the designers' processes and outcomes through grading.

To make sense of interactions between data sets, the first author organised the data from each design team into chronological timelines using the Double Diamond [7], facilitating a detailed view of the design process from the initial handover workshop through to the presentation of final products. Additionally, the first author reviewed questionnaires and interview transcripts, identifying quotes and statements related to the effectiveness and perceived impact of the handover workshop. To assess the value of the handover workshop, a thematic analysis [5] was conducted. This analysis revealed patterns and insights on how the handover workshop influenced designers' understanding of dementia and their design process. The findings, detailed in the following section, illustrate how the handover workshop shaped designers' ability to design for individuals with dementia (Fig. 5).

3 Findings

The case studies demonstrate the potential of the handover workshop to make dementia-related information more accessible by fostering active learning which has been found to promote better knowledge retention compared to more passive approaches (e.g. watching, listening) [18]. One design team stated, "We have learned

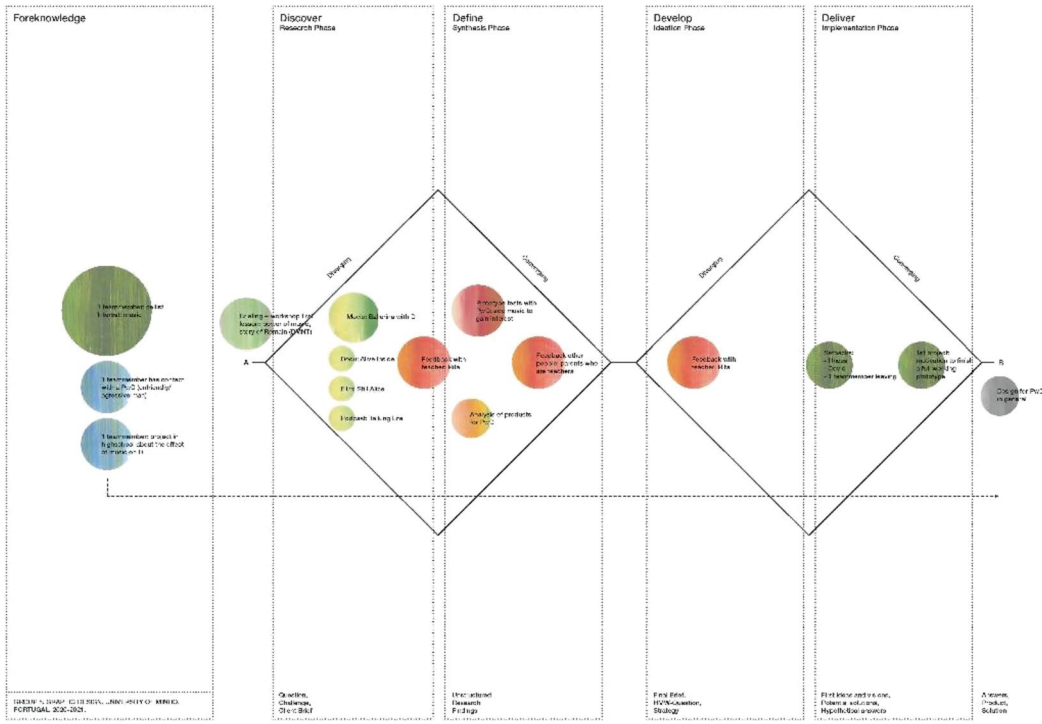

Fig. 5 Chronological timeline from one design team

things in the handover workshop that we would never have found online.“ Additionally, designers reported that the workshop changed their outlook on dementia and helped challenge misconceptions and stereotypes about the condition [22, 40]. One designer described the workshop as “necessary to create a positive picture [of dementia]”. Moreover, some designers could not overcome their fears or anxieties about direct contact with people who have dementia. The handover workshop offered them a way to engage with the design process, avoiding social discomfort. The workshop also provided a vital alternative during the COVID-19 pandemic, when direct contact with vulnerable populations was restricted, allowing designers to continue their work without in-person interactions.

However, some designers expressed mistrust towards the ‘second-hand data’ (i.e. an interpretation of the facilitator) and authenticity of the handover tools. To mitigate this, at the start of the workshop the facilitator clearly mentioned her experience with dementia and the fact that the handover tools were based on her interactions with people who have dementia. Still, who participants really are, is often very different from the way they are described or depicted by others and since designers prefer to gather their own data, they voiced a need for direct contact with people living with dementia [25, 29, 40]. One designer stated: “The things I learned while talking to people with dementia and observing them isn’t something you can correctly grasp with only the workshop.” Physical presence and contextual understanding are crucial and designers risk losing tacit knowledge about people with dementia when only making use of a handover approach, making it also harder for designers to reach a certain level of empathy for people who live with dementia [45]. While empathic understanding has been linked to more successful products [41], the case studies showed that it was difficult to directly correlate high-scoring design outcomes with whether designers had direct contact with participants. However, direct contact is seen as “a prime and irreplaceable

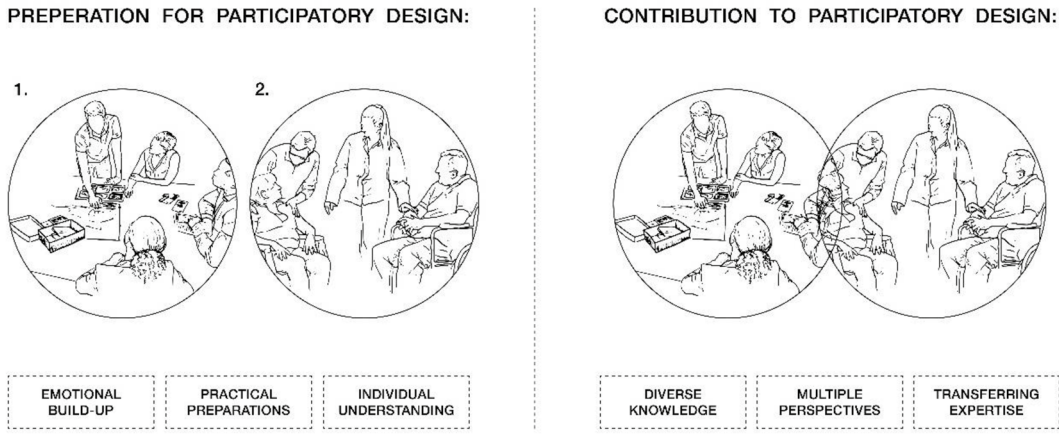

Fig. 6 Overview of the two key categories and subcategories

source for obtaining empathy with users." [41]. One designer stated; "You may have empathy for dementia, but if you haven't actually met a person with dementia, it is not fully developed yet."

4 Combining Handover- and Participatory Approaches

Issues concerning the authenticity of the tools and lack of interaction with people living with dementia indicate the challenge of considering the handover workshop as a stand-alone alternative for participatory design. Despite these challenges, the analysis of the outcomes revealed intriguing findings regarding the workshop's perceived resonance and positive impact on the participatory design process. Two key categories of positive impact were identified: (1) the role of handover approaches in preparing designers for the involvement of people with dementia in the participatory design process, and, (2) the contribution of handover approaches to the participatory design process (Fig. 6).

4.1 Preparation for Participatory Design

An understanding of the reality of living with dementia is fundamental when designing products for this population, not only for design ideation but, equally or even more, for successfully including people with dementia throughout the design process. Designers require time to learn about the symptoms and behaviour associated with dementia to familiarise themselves with the sensitivity necessary for working with individuals with dementia [39]. While literature often focuses on preparing participants, there is a lack of research on preparing designers. A handover approach can transfer particular knowledge and skills for designers to understand the complexity and sensitivity of dementia [26] and prepare designers for the participatory design process together with people living with dementia. One designer stated that the handover workshop "gave her time to prepare herself for what was to come" and another described it as "the first step that leads to the second step" (i.e. the participatory design process). This research addressed three ways in which handover approaches could prepare designers for participatory design together with people with dementia:

Individual understanding

One designer stated; "I didn't know anything about dementia, so this first part was important to grow", highlighting how handover approaches can introduce designers to the dementia context, enabling them to foster an individual understanding of dementia. The workshop also provided support before designers interacted with

participants. One designer stated it was “necessary to create a picture before you talk to someone who has dementia.“ For designers hesitant or uncomfortable to interact with people with dementia, handover approaches can support this interaction [13]. One designer appreciated the workshop because it “guided [her] in the first contact with people with dementia.“ Furthermore, Liddle et al. [22] address the importance of educating designers to gain an understanding of dementia and overcome misconceptions and stereotypes [40]. One designer stated: “I had a negative view of it [dementia], which has changed now [after the handover workshop].” Designers expressed gaining a more positive outlook towards dementia and the role they can play in a persons’ life, resulting in an increased willingness to design for and participate with people who have dementia. One designer said, “I want to design for people with dementia because I know my design will be useful.” Some designers were even motivated to put in the extra work to include participants in the design process.

Empathic understanding

The information transferred during the handover workshop allowed designers to move beyond understanding dementia, fostering an initial empathic connection with individuals with dementia. One participant stated that the workshop was “where the initial empathy started." The handover questions and boxes were seen as ‘empathy-enhancing footage’ [25], as one designer expressed, "The more I hear about his story, the more it touches me." Although designers have a natural tendency toward empathy [1], they may get overwhelmed during the process with individuals with dementia [2, 16]. Handover approaches at the start of the design process could emotionally prepare designers for the interactions with people living with dementia [2]. However, some designers still felt emotionally unprepared during the participatory design process. One designer stated; "You can do all your research, but you are still not prepared for that [interactions with people with dementia]." Literature confirms that students are more likely to become emotionally overwhelmed [2, 13], however, the workshop supported designers in recognising and communicating their emotions about dementia, allowing them to determine whether they were ready for a participatory design process.

Practical preparations

Involving people living with dementia in participatory design requires a prior understanding of dementia to manage logistical aspects such as recruitment, ethical approvals and selecting appropriate methods [10, 22, 43, 46]. The practical knowledge gained via handover approaches can facilitate these organisational aspects and enable the participation of people who have dementia. As one designer stated, “You don’t have to start from scratch." Additionally, the handover workshop prepared designers to collaborate on the topic of dementia. Designers first gain individual understanding, which is then shared in group discussions, fostering respectful communication, common terminology and mutual understanding. One designer expressed that the workshop provided "a way to communicate better about that subject [dementia]". The workshop also served as “a sort of ice-breaker” that facilitated self-perception, collaboration and role allocation within the teams.

4.2 Contribution to Participatory Design

In this research, designers integrated insights from both the handover workshop and participatory design sessions with people living with dementia when developing their concepts. Designers valued the combination of both approaches, since “they show you different aspects of dementia.” Beyond serving as a preparation for participatory design, this study identified three key ways in which handover approaches contribute to the participatory design process:

Diverse knowledge

Combining handover- and participatory design approaches enriches designers’ understanding

of dementia by offering diverse knowledge. One designer noted, "You experience the condition differently in both situations and get different looks. With the workshop more objective and when interacting with people who have dementia more subjective." The handover workshop, based on insights from a larger group of people living with dementia, provides more generalisable knowledge, while participatory design offers deeper, more personal insight into the experience of living with dementia through direct interaction with a smaller group [17, 45]. Furthermore, in participatory sessions often only a small number of participants can be involved and designers are only present during certain times. One designer stated; "I couldn't see everything that happened. I was there for 3 to 4 h. I couldn't observe her outside the time we were together." Here handovers can contribute to participatory design by reporting on longitudinal studies on the progression of dementia and sharing rich stories of multiple individuals with dementia, however, avoiding the "stereotypical" or "average" person with dementia [28]. In the conceptual phase, where designers often seek varied input to fuel creativity, combining both approaches contributes to designers' preference to be as knowledgeable as possible about those they are designing for [9, 25].

Multiple perspectives

The experience of dementia is complex [4]. Encountering multiple perspectives on dementia enriches a designer's insight. During participatory design sessions, designers attempt to understand the individuals' emotional states and anticipate future situations and needs for product development. However, gaining a full understanding can be challenging due to the nature of dementia, for example, participants not being able to communicate, especially in the more advanced stages of dementia. In such cases, designers could rely on handover approaches and facilitators to offer additional insights and perspectives on dementia. Furthermore, both handover and participatory approaches carry the risk of participants projecting individual assumptions about people with dementia. Everyone carries hidden biases due to cultural attitudes about dementia [32]. Bias can be problematic when creating inclusive and wide-reaching design solutions [25]. The case studies showed that on the one hand, facilitators can help frame negative or stereotyped expressions, creating greater awareness of designers' unconscious biases [26]. On the other hand, through direct interaction with participants, as one design team stated; "Our idea was that they [people with dementia] wouldn't be able to answer the questions anymore, but it was that one woman who talked a lot that had dementia. We were surprised by that." Combining handover- and participatory approaches means involving multiple facilitators with complementary perspectives and diverse backgrounds, dementia-experiences and training, which can overcome designers' unconscious bias [14, 24, 25].

Transferring expertise

During the five case studies, the handover facilitator was appreciated for making her knowledge and experiences accessible. Designers found it "more practical to engage with someone who is actively involved and has already done research on it [dementia] and to learn things from them" rather than navigating the complexities of expert literature. In practice, dementia expertise is often transferred by outsiders to enrich the design team's 'insider knowledge' [36]. For example, design research involving people with dementia is often conducted by psychologists, sociologists and anthropologists. Although they often focus more on the effects and influences of design than its forms, their 'expert' insights can provide additional insights and inspiration, particularly in the early exploratory stages of the design process [9, 25]. However, this information is frequently tailored for medical or scientific audiences, making it less accessible and actionable for designers. In design practice, designers often lack the time, training or inclination to pursue this data [21]. Handover approaches could bridge this research-practice gap by translating expert knowledge into formats that are practical and relevant for designers [3, 12, 20, 25].

5 Conclusion

This research looked into handover approaches as a method when direct involvement of people living with dementia in the design process is challenging. A handover workshop consisting of four sequential phases was developed and evaluated through five case studies in the educational design context. This paper shares insights into the potential of handover approaches to transfer dementia-related insights to designers lacking experience with people with dementia. The discussion emphasises the beneficial relationship between handover- and participatory design approaches. Findings indicate that using the handover workshop in the early stages of the design process motivates designers to involve participants and prepares them for this involvement. Additionally, handover- and participatory approaches facilitated by multiple contributors, allows designers to gain varied perspectives on the lived experiences of people with dementia, thereby overcoming unconscious biases.

However, these findings are based on five case studies conducted in Belgium and The Netherlands and a more comprehensive evaluation would benefit from a long-term perspective. This would allow to assess not only the influence of the handover workshop on design outcomes but also the extent to which these outcomes resonate with people living with dementia. Moreover, this paper examines one handover workshop, while the complexity of dementia and diverse design contexts indicate the need for various handover tools since there is no one-size-fits-all solution. Furthermore, the developed workshop is not a recipe to be followed precisely to achieve successful outcomes. Given the complexity of dementia, a gap will always exist between the collected data and the reality of living with dementia [4, 11]. Insights provided by facilitators cannot substitute for the experiences of people who have dementia and participants must be made explicitly aware of this limitation. Additionally, research indicates that cultural attitudes toward dementia contribute to unconscious biases, which affect how information is communicated and interpreted [32]. This introduces the risk of facilitators' perspectives shaping or conditioning the transfer and participants interpreting information differently according to abilities, experiences, motivation and attitudes towards dementia. Designers must remain aware of their positionality and biases when employing handover approaches. Strategies such as involving multiple facilitators with complementary perspectives can help mitigate these risks [31]. Nonetheless, further research into additional bias-reduction strategies is essential, particularly when handover approaches involve data collected and communicated by other facilitators.

This research wants to raise awareness for the limited involvement of people with dementia in design practice. While dementia presents significant challenges to participation, these challenges can be mitigated through education and awareness. Rather than positioning handover approaches as an alternative to participatory design, this research addresses the value of handover approaches to participatory design. Handover approaches can provide an effective means of educating designers, challenging assumptions about the feasibility of people with dementia's participation, and promoting more informed, context-sensitive practices. Instead of handover approaches reinforcing the perception of people who have dementia as incapable, handover approaches, when used thoughtfully, can foster inclusive design processes thus supporting the core principle of participatory design: empowerment.

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Expanding the Concept of Personhood: Towards a Posthumanist Approach to Designing for Dementia

Ralf Vetter, Christopher Frauenberger, Anna Dobrosovestnova, Katharina Brunnmayr, and Helena Anna Frijns

Abstract

Kitwood's concept of personhood in dementia, as a morally charged and intersubjective state, profoundly influences dementia care. We review selected papers from the archived Dementia Lab Conferences of 2019, 2021, and 2022 to examine how researchers apply Kitwood's concept in designing for dementia. We conclude that current approaches drawing on Kitwood's framework overlook the role of the material world in shaping personhood and lack a solid theoretical basis for designing configurations of human and non-human actors in dementia care. To address this gap, we diffractively read Kitwood's concept of personhood through posthumanist theories and demonstrate how personhood and dementia are constituted in relational processes involving people living with dementia and their human and non-human networks. We emphasize the responsibilities of designers in (re-)configuring these relational networks through technological and design interventions and advocate for participatory and speculative methods to co-create socio-material systems that configure"good care.

Keywords

Personhood · Posthumanism · Design

1 Introduction

Designing for people living with dementia is increasingly important, given the rising number of people in our society living with this diagnosis, and the associated requirements to provide quality care [9, 57, 58]. Design can be one effective pathway to address the social, emotional, cognitive, and physical changes accompanying forms of dementia [56] and a growing body of literature explores how design interventions can support the everyday life and care of people living with dementia (e.g. [29, 44, 55]).

In design, theories play a crucial role, as they influence how we understand the phenomena we design for, and challenge our assumptions [41]. Therefore, the choice of theories of dementia (care) shape what we can imagine designing, directly impacting the quality of life for people

R. Vetter (✉) · C. Frauenberger
Interdisciplinary Transformation University, Linz, Austria
e-mail: ralf.vetter@it-u.at

A. Dobrosovestnova · K. Brunnmayr
TU Wien, Institute of Visual Computing and Human-Centered Technology, Vienna, Austria

H. A. Frijns
TU Wien, Institute of Management Science, Vienna, Austria

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living with dementia and their care partners. The Dementia Lab Conference (D-Lab), which first took place in 2016, is a venue dedicated to research designing with and for people living with dementia. Over the past eight years, it has showcased numerous successful.

design efforts contributing to the life and care of people living with dementia. As a relatively young but growing community, it is important to explore and contribute to the theoretical underpinnings of the D-Lab.

Social psychologist Tom Kitwood advocated for person-centered dementia care as an alternative paradigm to neurobiological models, shifting the theoretical and practical foci from disorder and symptom management to the person, their relations, and their quality of life [23, 24]. In the D-Lab community his concept of personhood as "*a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being [that] implies recognition, respect and trust*" [23, p. 8] is a common grounding for design. Having reviewed the archived D-Lab proceedings from 2019, 2021, and 2022, we identified a lack of a solid theoretical basis for design that conceptualises the impact of socio-material configurations on personhood and dementia.

Sociomateriality is a theoretical concept that challenges the separation between social and material, proposing instead a mutual entanglement of human (inter)actions and relations with the physical and technological environment [36]. Along other posthumanist theories, it has been introduced in the HCI (Human–Computer Interaction) community, which focuses on research and design of interactions between people and technologies, to inform a new wave of research [10].

To develop a robust theoretical position for the D-Lab that extend Kitwood's framework to include sociomaterial perspectives, we apply *Diffractive Reading* [1, 14] as a methodology commonly used in posthumanist HCI research for theory engagement, and read selected literature on person-centred care [22–24] and posthumanist thinking [1, 10, 37] through each other.

Thus, this paper contributes a new theoretical framework for designing for dementia that acknowledges the agency of artefacts[1] in constituting personhood and advances the theoretical and methodological foundations of the D-Lab. Responding to this year's theme on ethics and aesthetics, we discuss how artefacts, as sociomaterial actors,[2] actively configure dementia (care) and what ethical challenges this implies. We further highlight how participatory and speculative design approaches can be meaningful in addressing these challenges.

The paper is organised as follows. In Sect. 2, we detail the process and insights from a selective review of the D-Lab literature. In Sect. 3, we proceed to outline our approach to diffractive reading and present the two theoretical strands of personhood and posthumanism. In Sect. 4, we present our diffractive reading, and conclude in Sect. 5 with a discussion on practical applications and future work.

2 Related Work

To explore the application of Kitwood's concept and the impact of design outcomes in dementia care at the D-Lab, we conducted a selective review of the D-Lab proceedings from 2019, 2021, and 2022. We selected only the archived proceedings, as they provided assured accessibility and clear insight into the peer-review process. From the 32 full papers reviewed, we selected 15 that either reference Kitwood's concept or incorporate theoretical or methodological elements of a posthumanist approach, even if lacking an explicit theoretical foundation.

A number of studies at the D-Lab highlight the importance and challenges of Participatory Design (PD) methods in working with people living with dementia, and how these approaches positively impact the design process and outcomes. Hendriks et al. [17] argue that including people living with dementia not only addresses

[1] A term we use to denote all human-made objects.

[2] In contrast, here we denote the active role of artefacts in shaping socio-material interactions.

their unmet needs, but also improves societal perceptions of people living with dementia through reshaping relational dynamics of individuals, care partners, and family members. Similarly, Van Hees et al. [52] and Boulton et al. [2] illustrate how direct participation leads to better design outcomes. Van Hees et al. used an elicitation card game to capture the everyday needs of people living with dementia [52], while Boulton et al. involved them in developing a tool for care workers to envision alternative care models [2].

Further projects like the Emily Carr University Zeitgeist Program [38] and the work by Den Haan et al. [7] emphasise the importance of relational design practices. By creating personalised publications [38] and audio tracks [7], the projects show how meaningful and individualised design processes can create positive social engagement and outcomes that preserve the personhood of people living with dementia. Novy and Thomas explored multi-modal modes of participation through drama play, broadening the design methods and reflecting on the mutual contributions of researchers and participants in creating the final outcomes, embracing an interdependent mode of knowledge production [35]. Suijkerbuijk et al. [45] advocate for adaptivity, flexibility, sensitivity and responsiveness as qualities of meaningful participation, which require designers to take a dual role of researchers and relational facilitators.

Other studies highlight the importance of viewing design outcomes as part of a larger socio-material environment, understanding their role in shaping relations and interactions. McCracken et al. [31] built upon Jordaan's phenomenological placial triad [21] and Wong and Leland's interpretation of the personenvironment-occupation model in dementia (Wong and Leland, 2019 as cited in [31]) to explore the interplay between individuals, their built environment and roles in caregiving. In the Smile project, a simple camera system bridged the divide between people living with dementia and their families in everyday life by showcasing photos from everyday lives of people living with dementia [20]. Kolasinska et al. [25] used canvases as tools to support and sustain the personhood of people living with dementia. Similarly, Gramega et al. [13] placed posters of cultural objects in a day care center and observed shifts in engagement and mood of care recipients. Treadaway et al. [49] successfully developed a therapeutic doll based on principles of personhood and social interactivity in their own Compassionate Design methodology [48] but without an explicit theoretical perspective to it.

Another group of studies highlights how designed artefacts can change the relations between people living with dementia and their care partners. Brophy et al. [3] started from Kitwood's concept and developed a system that encouraged family members to document the life stories of people living with dementia, which were made available in form of magazines to care workers. The outcomes enhanced person-centered care by providing care workers deeper and novel insights into the stories of people they care for. Similarly, de Groot [6] supported care workers with multimedia albums, which became a useful tool for some to engage in more personalised interactions with people living with dementia. Ruitenberg et al.'s study showed how a recipe tool for collaborative cooking shifted the relational dynamics between people living with dementia and care partners, creating increased trust and engagement between them [42].

In summary, we identify several elements of a posthumanist approach at the Dementia Lab conference. Many studies examined PD methods, and Kitwood's concept of personhood [23, 24] served as a common framework for understanding design's role and potentials in dementia (care), however, without in-depth theoretical engagement with Kitwood. Moreover, only a few studies explicitly addressed how materiality actively shapes care configurations and put this on a solid theoretical basis. To offer such a theoretical base that considers human practices of dementia care and the non-human[3] contributions

[3]A term that includes all entities that are not human, e.g. material, technical, regu- latory, natural.

to these sociomaterial systems, we propose integrating Kitwood's concept of personhood with posthumanist theories.

3 Theoretical Perspectives on Designing for Dementia

3.1 Methodology: Diffractive Reading

Diffractive reading is a method particularly suited to engage with multiple theories. It was originally developed by Haraway [14], and adopted by Karen Barad for their theory of Agential Realism [1]. According to Barad, diffractive reading involves reading "*(…) insights from (…) different areas of study through one another (…) [t]o provide a transdisciplinary approach that remains rigorously attentive to important details of specialized arguments within a given field, in an effort to foster constructive engagements across (and a reworking of) disciplinary boundaries*" [1, p. 25]. Rooted in feminist science theories [1, 14], diffractive reading does not follow a fixed methodology, though propositions point to key steps in merging theoretical and practical literature analysis, carefully deconstructing texts without prioritizing one over the other, and drawing insights from nuanced differences [33].

It has recently been adopted in HCI research on studies of human-AI cocreativity [39], woodworking practices [34], human-AI memory enhancements [40], technologies for older adults [28], music interaction [32], and multispecies design with bees [54].

Therefore, diffractive reading is well-suited to our approach of reading Kitwood's concept and posthumanist theories through each other and relating their arguments. In our practice, all authors first read Kitwood's work on personhood [22–24] and convened to discuss their interpretations. Subsequently, in two meetings, we engaged with posthumanist literature [1, 10, 37] and re-read Kitwood's notion of personhood through posthumanist lenses. The first author synthesised and extended the diffractions into a manuscript, which was then iterated by all authors.

As an interdisciplinary team in HCI, Human–Robot Interaction, and Science and Technology Studies, we collaborate on a research project[4] focused on technology development for care, with emphasis on PD and socio-material interventions. While we do not personally experience dementia or provide direct dementia care, we have close connections to individuals diagnosed with it. Our perspective is shaped by our position as researchers in a Central European country with a robust healthcare system that provides formal dementia care but also depends on informal caregiving.

3.2 Person-Centered Care: Relational and Ethical Dementia Care and Being

Person-centered care (PCC) is the leading paradigm in care of people living with dementia [8, 18, 19, 43, 46, 47]. PCC is grounded in Tom Kitwood's theory of personhood in dementia [23, 24] and referenced in design research for dementia, including contributions to the D-Lab (see Sect. 2). The concept of personhood is issue of long-standing philosophical debates on what it means to be a person [18, 47]. Kitwood defines personhood as "*a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust*" [23, p. 8]. We identify three components in his definition: (1) Personhood as a metaphysical state of being, (2) which is produced through intersubjectivity and relationality, and (3) implies an ethical treatment of people living with dementia. We critically situate these components within related literature to lay the groundwork for subsequent diffractive readings with posthumanist theories.

Component 1: "A standing or status" First, Kitwood posits a metaphysical stance on

[4] https://www.caringrobots.eu/?lang=en.

personhood, viewing it as an ontological state or status that distinguishes persons from non-persons. Personhood as a status carries a normative dimension inherently tied to moral implications [43, 47]. Particularly in western philosophy, personhood is defined by a set of criteria, often emphasizing cognitive attributes like agency, communication, or reasoning [8, 18, 23, 43, 47]. Approaches that rely on cognitive criteria are viewed critically because the possible decline of cognitive capacities can render individuals vulnerable to exclusion from moral consideration [18, 43]. Thus, Kitwood re-conceptualised personhood in dementia care by shifting its ontological basis from cognitive criteria to intersubjective and relational ones [8, 23].

Component 2: "that is bestowed upon one human being by others, in the context of relationship and social being" The core aspect of Kitwood's definition articulates personhood as a relational and social process. As he stated, "*our existence is essentially social*" [23, p. 135]. While acknowledging neurocognitive factors in holistic dementia care, Kitwood frames his definition more as a discursive tool–a "generative grammar"–that shifts the focus of dementia care to relations, rather than providing an exhaustive definition of what it means to be a person with dementia [8, 23].

Kitwood draws from various philosophical and theoretical sources [22], but primarily relies on Martin Buber's dialogical philosophy to understand relationships in dementia care [5]. According to Buber, ontological existence is inherently relational and defined by the quality of these relations. He distinguishes two modes of relating: I-Thou and I-It. In I-Thou relating, beings engage holistically, non-instrumentally and mutually [5], reciprocally affirming each other's being and personhood [5, 18]. Conversely, detached and instrumentalised I-It relating leads to the objectification of beings [5]. For Kitwood, I-Thou relating bestows personhood on people with dementia, and such relating remains possible in all dementia stages, independent of cognitive abilities.

Component 3: "It implies recognition, respect and trust". In the final component of Kitwood's definition, the ethical and moral implications an intersubjective personhood concept become evident, which some argue were his primary aim [8, 18, 43]. Kitwood's view of personhood, as a status created through intersubjective, holistic, and positive social relations, inherently positions individuals with dementia as recipients of ethical interactions, or, as Kitwood stated, it "*reveal(s) our moral obligations*" [23, p. 55].

Thus, Kitwood's definition suggests that ethical dementia care is not about performing tasks, but rather about fostering a relational environment and approach where recognition, respect, and trust are nurtured. This offers a normative guideline for care environments and care personnel, emphasising that their role is not merely to manage symptoms but to affirm and sustain the personhood of those they care for.

3.3 Posthumanist Theories in Human–Computer Interaction

Kitwood himself reflected on the role of computers in relations: *"In computers, we have machines that mimic certain aspects of human mental function. We can (and often do) describe and explain the 'behavior' of computers as if they were.*

"*intentional beings (…) However, there is no necessity to do this; it is simply an anthropomorphism–a convenient short cut*" [22, p. 9]. We are ambivalent about Kitwood's position. While computers and all other artefacts are not fully intentional beings, they are neither a mere passive backdrop for human existence. They possess inscribed programs of actions [26], and through our relations to them they have concrete impact on our actions and ways of being. The real shortcut would be to ignore the agency technologies produce in configuring us. Similar ideas have gained prominence in HCI. Particularly the rise of more complex technologies such as social robots or artificial intelligence challenge traditional assumptions of technology design as development of passive tools [10]. Posthumanist theories are one

attempt to move our thinking and approaches on par with the actual relations with technologies. Given the range of posthumanist theories, we are purposefully selective here. Specifically, we draw on Karen Barad's Agential Realism [1] and Maria Puig de la Bellacasa's Matters of Care [37]. Barad provides the ethico-onto-epistemological foundation for our thinking, while Puig de la Bellacasa bridges posthumanism and care. Moreover, we work with the interpretation of posthumanist thinking for HCI, namely, Entanglement HCI [10], as it translates these theories into a new wave of technology design addressing ontology, epistemology, ethics, and design practice.

Ontology As Frauenberger argues, emerging technologies increasingly blur the lines between humans and technology, raising ontological questions [10]. Posthumanist theories posit that humans and non-humans are ontologically inseparable, with their status defined by mutual relations–known as relational or performative ontology [1, 10]. Being is thus enacted through continuous, dynamic intra-actions within socio-material configurations [1].

Puig de la Bellacasa positions care as the foundational ontological activity that binds relational networks of actors. Care, seen as "a species activity" of interdependent human and non-human actors, is inherently performative and essential for sustaining life [37]. As Puig de la Bellacasa notes, "*there has to be some form of care going on somewhere in the substrate of their world for living to be possible*" [37, p. 5]. Thus, when we design technology, we introduce new actors to these configurations and produce new (un)caring phenomena and relations of being.

Epistemology Ontological intersubjectivity influences knowledge production, as human and non-human actors collaboratively enact reality, producing knowledge through their specific configurations [10]. For Barad, these practices merge into an onto-epistemology that emphasises the performativity of being and knowing. Based on it, Frauenberger advocates for a diffractive methodology in HCI, which highlights differences between multiple socio-material configurations, and tracing the evolving relations between humans and non-humans to understand how they generate phenomena.

Similarly, Puig de la Bellacasa views care as an intertwining of ontological and epistemological practices. Drawing on Haraway's notion of situated knowledges [14], she argues that knowledge creation is an active, relational process, where "*beings do not preexist their relatings*" [15, p. 6]. Our interactions in knowledge production continuously generate both knowledge and new modes of being.

Given that our research has "world-making" effects, working in a mode of care requires us to be affectively involved with what we study. Drawing on feminist standpoint theory [16], Puig de la Bellacasa emphasises that knowledge production is neither detached nor neutral, it is shaped by our own experiences and emotions. Researchers that recognize this, care for the ethical and political consequences of their work.

Ethics As we have presented, our knowledge production processes have concrete consequences for our being in the world. With Barad, our being and knowing are matters of performative intra-action within socio-material conditions, making the process of configuration an ethical issue. Consequently, ontology, epistemology, and ethics merge into a singular ethico-onto-epistemological stance [1]. Thus, it is the designers' responsibility to trace accountabilities within these configurations and understand how specific phenomena come into being [10, 12]. Puig de la Bellacasa emphasises a political dimension, stating that to care is "…*to maintain, continue, and repair our 'world' so that we can live in it as well as possible*" [37, p. 3]. While striving to create the best possible world is a moral endeavor, what constitutes the 'best possible world' remains a contested and political issue. Hence, a practice of care embraces complexities, contradictions, and conflicts inherent in our world-making efforts. We cannot "think-for" the actors in a configuration, we need to directly involve them [37].

Design Building on Barad's ethico-onto-epistemology, Frauenberger advocates for a shift in design practice: moving from user-centric

interaction design to designing intra-actions and relationships between actors. In this context, meaningful design seeks to configure relationships that enable individuals to become who they want to be [10].

To achieve this, Frauenberger and Puig de la Bellacasa advocate for participatory design practices that embrace the speculative and inherently ambivalent nature of human-technology relations [10, 37]. Care, as a speculative and generative intervention, strives to "*…add something to the world (…) in order to make a difference. This involves not only detecting what is there, (…) but also to think what is not and what* could be" [37, p. 59].

4 Discussion: Caring Matters// Matters Care

A diffractive reading of Kitwood's theory on personhood, Frauenberger's Entanglement HCI, Barad's Agential Realism and Puig de la Bellacasa's Matters of Care leads us to re-conceptualise good dementia care as a socio-materially entangled, ethico-onto-epistemological practice between humans and non-humans. Thereby, we address three critiques of Kitwood's theory. First, Kitwood's notion of personhood as a status or standing, resembles criteria-based approaches rather than procedural ones [8]. Second, his concept is overly socially contingent, placing the power, responsibility and burden of bestowing personhood solely on care partners of people living with dementia [18, 22, 43], while neglecting the intersubjectivity of care. This often leads to an overemphasis on individuality, autonomy and self-reliance of care recipients [18, 43, 46, 47]. Third, Kitwood's definition remains ambiguous which "others" bestow personhood, with his writings suggesting an anthropocentric view that positions humans as the sole agents in the process [47].

In response, we propose an iterated definition of the phenomenon of dementia (care) through a posthumanist perspective as *a performative, relational process of being that configures dementia (care) through the intra-action of both human and non-human actors. This process of configuration generates ethico-political and affective entanglements of care.*

Based on this definition, we articulate an ethico-onto-epistemological stance and outline methodological implications for designing technologies as actors in dementia care configurations. Given the scope of this contribution, we focus on research-ethical and design-methodological aspects.

4.1 Ontology: Humans and Non-Humans Perform Dementia (Care)

What is it that we design for, what are the phenomena under study? Our ontological stance extends Kitwood's notion of personhood in dementia beyond human relationality. We understand dementia as an intersubjective, performative, and relational phenomenon that involves humans as well as non-humans. In parallel to Kitwood's words: our existence is essentially socio-material. Therefore, as we create artefacts as actors in dementia configurations, we need to become explicit about designing the relations between humans and non-humans and the fundamental impact these will have on human existence.

More than configuring the moral status of people living with dementia, in caring networks of humans and non-humans, we configure the existence of people living with dementia and those that provide care for them. As a performative process, dementia care is dynamic and subject to change based on shifts in actors and their caring intra-actions. Every time we introduce a novel actor, such as a technological artefact, we inevitably shift the configurations of dementia care. The challenge becomes to continuously reconfigure these relations in a meaningful way.

4.2 Ethics: Responsibilities in Designing and Enacting Caring Configurations

Kitwood's primary goal was to advocate for more ethical and relational dementia care. Our diffractive reading extends what constitutes good socio-material dementia care and who is responsible for its becoming.

Both Puig de la Bellacasa and Kitwood offer insights to the defining qualities of caring relations. Kitwood emphasizes relations that are holistic, noninstrumental, and mutual [5, 23] and imply "*respect, recognition and trust*" [23, p. 8]. Puig de la Bellacasa with Fisher and Tronto [50, p. 161] highlights that caring relations are those which "*maintain, continue, and repair our 'world' so that we can live in it as well as possible*". Kitwood expressed the responsibilities of caregivers to provide good, relational care to people living with dementia. As we introduce new actors to these configurations, human and non-human actors share responsibility for creating care configurations that align with good dementia care.

As a direct consequence, we as designers and researchers have to acknowledge our active roles in configuring good dementia care through our research processes and outcomes [1, 37]. Following Puig de la Bellacasa, they should equally come from a position of care [37]. It is not only care that we aim to produce through configuring new intra-actions, we need to embrace it as a methodological stance. Caring researchers engage affectively with their participants and outcomes, think with their own positionalities, and strive to create the best conditions for dementia care.

However, designers are not accountable for all consequences of a re-configuration, as these will evolve beyond the design phase. Instead, responsibility lies in understanding and tracing the ethico-political consequences of technologies [10, 12].

Moreover, the definition of good dementia care will vary depending on individual actors and their relations, requiring methods that address these situated, individual, and potentially conflicting views of care.

4.3 Design: Speculative and Participatory

To align design practices with our evolving understanding of dementia care, we need to adopt new approaches. Frauenberger advocates for moving beyond user- centered design and designing interaction experiences to focus on designing intra- actions and configurations of actors. Meaningful design aims to foster meaningful relations with technology that enable humans to self-realisation.

Both Entanglement HCI and Matters of Care suggest participatory practices that address the ethico-political dimensions of design and embrace the speculative and evolving nature of human-technology interactions. For Puig de la Bellacasa, care, as an ethico-onto-epistemological practice, entails a speculative, generative doing. Working with and from situated standpoints, in care, we seek to contribute something meaningful to the communities we work with [37]. Viewing care as design and design as care transforms it into an intervention, recognising care's performative role in altering configurations. So rather than providing solutions to concrete problems, designs become an opportunity to explore and evaluate alternatives.

In summary, designing socio-material configurations for dementia care necessitates engaging directly with participants through speculative activities that result in design outcomes as interventions to their current care situations.

5 Conclusion and Future Work

Motivated by a gap in the theoretical basis of the D-Lab, in this paper, we propose a new theoretical framework for designing for dementia care. By reinterpreting Kitwood's concept of personhood through posthumanist lenses, we introduce an ethico-onto-epistemological perspective of

dementia as *a performative, relational process of being that configures dementia (care) through the intra-action of both human and non-human actors. This process of configuration generates ethico-political and affective entanglements of care.* Despite our focus on technologies, we propose the framework as a general perspective applicable to any socio-material intervention in dementia (care).

We identify three next steps to advance our theoretical position. First, while our focus has been on the D-Lab community, we have overlooked theoretical and empirical work in the larger HCI community that addresses designing for and with people living with dementia (e.g., [27]). To provide a more comprehensive view, we will conduct a systematic literature review based on our position that includes additional conference venues and publications.

Second, our current discussion of Kitwood's personhood theory, rooted in Buber's dialogical philosophy, and the posthumanist theories of Barad and Puig de la Bellacasa is limited. A more detailed exploration of these theoretical under- pinnings will better ground our ethico-onto-epistemological stance and enhance its application to dementia design practices.

Third, it is crucial to translate our theoretical thinking into practical design and research activities and evaluate whether this results in distinct design out- comes. To do so, we advocate for expanding existing approaches at the D-Lab on participatory and speculative design [e.g. 2, 17, 52, 38], and putting explicit emphasis on the responsibility and affective involvement of researchers and designers [e.g. 35, 45]. Further, Lindley et al.'s method of productive oscillation [30] could inform how to couple theory and design processes. Oscillation in this sense can mean "*considering a theory, building a prototype, reflecting on the prototype, and returning to the theory*" [30, p. 21]. Moreover, Vallgarda's interpretation of design as attunement offers inspiration to possible methods [51]. In our own project work,[5] we have observed how theory has significantly shaped our design approach, leading us to engage in extensive participatory and speculative design [e.g., 4, 11, 53].

Last, we want to point to a potential pitfall. We do not intend to shift the responsibility of caring for people living with dementia onto the material environment. Addressing anthropocentrism in dementia care should not lead to anthropomorphizing our non-human collaborators as substitutes for essential human qualities in caregiving. Instead, we should explore socio-material conditions and how we can configure relations between people living with dementia, their care partners, and artefacts to create the best possible care.

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Does the Mind's Eye Remain Intact? Using Colour to Support the Expression of Everyday Aesthetic Preferences in Dementia

Marney Walker

Abstract

This paper presents insights from a practice-led doctoral study that explored the expression of everyday aesthetic preferences in dementia through design. As an assets-based approach it aimed to utilize capabilities including emotional memory, visuo-sensory sensibilities and an embodied sense of self understood to be relatively unaffected in dementia. A framework of engagement to scaffold conversations about everyday aesthetic preferences was devised using three consecutive video conferencing meetings. The first asked participants to share a favorite mug, the second their colour preferences and the third a favorite space in the home. Personalized booklets using images and quotes from the recordings were sent to the participants following each meeting. This method was first tested with participants without dementia and then with participants with early to moderate stage dementia. This paper focuses on the rationale and criteria for using a set of colour cards as a design probe. A key insight from an analysis of the findings suggested that colour elicited visual memories of objects and environments that held personal significance. The potential for further research into how this method could be used as a tool to enable people with dementia to contribute to how their environment is personalized is considered.

Keywords

Everyday aesthetics · Colour · Preference

1 Introduction

Exponents of the concept of everyday aesthetics see its value in enhancing quality of life [1, 2]. There is a complex interrelationship between utility and appearance in how everyday aesthetics is experienced [3]. In design, words can be insufficient to convey how aesthetic judgements are informed by sensory and haptic interaction, in terms of the way objects are held, manipulated and visually perceived, as well as tactile feedback [4]. In dementia, cognitive impairments can affect orientation, memory and verbal communication [5]. A growing body of research in design for dementia has explored ways to address these issues [6, 7]. In environmental design for dementia visual access has been found to support function and orientation [8]. However, although a person-centred approach

M. Walker (✉)
Sheffield Hallam University, Sheffield, UK
e-mail: marney.j.walker@student.shu.ac.uk

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that prioritizes the maintenance of personhood is advocated in dementia [9], there is little evidence of how this applies to personalizing the environment. Visual stimuli have also been found to be effective to support communication [10]. Building on this knowledge of the efficacy of visual stimuli, this study explored how to create accessible ways to share and think about everyday aesthetic preferences. As an alternative to conventional interview techniques, it employed participatory design research methods to scaffold conversations, a process that utilizes a framework of prompts to guide and support engagement [11].

As a practice led design research study my approach has been informed by a combination of training and expertise in design and healthcare. As an occupational therapist specialising in advising on the design of accessible and inclusive housing [12], central to this is an interest in the impact of the environment on behaviour. My learning from working with disabled and older people is that attention to the negative impact of environments that appear clinical and institutional is often overlooked [13].

This paper reflects on the findings from using colour as a tool to scaffold conversations about everyday aesthetic preferences in dementia. This was one element of a doctoral study that used a framework of engagement entitled 'Shared Looking'. This involved three consecutive meetings that asked participants to share their preferences for everyday objects, colour and favourite spaces. The aim was to build an understanding of their likes and dislikes in the context of home. The context and rationale for inviting participants to share their colour preferences is presented. The design criteria for a set of colour cards are outlined. Tentative findings suggest that asking participants to share their colour preferences is an effective tool to evoke memories and associations with objects, environments and experiences that hold personal significance. The potential for future research to explore how these methods might be used to support agency in how the environment is personalised is suggested.

2 Context

2.1 Environmental Design for Dementia

The efficacy of visual access and familiarity in environmental design for dementia to support orientation and continued engagement in everyday activities has been established [14, 15]. Attention to layouts that incorporate sightlines, lighting, visual contrast and improved coherence through removal of clutter is advocated [16, 17]. The importance of creating a homelike environment that provides a sense of familiarity and human scale by incorporating domestic characteristics are central and recurring themes in design for dementia principles [18, 19]. However, what is familiar to one may be alien to another.

2.2 Personalisation of the Environment

Relevance and specificity of environmental stimulation has been found to have positive impacts on motivation [20]. The importance of object attachment in transitions from home to care settings has been recognized [21, 22]. Although experts in environmental design for dementia recommend, "*involvement of the person living with dementia in personalizing the environment with familiar objects*" [23], it is less evident how this is done in practice. If communication becomes more difficult as dementia progresses, decisions about everyday needs and preferences are increasingly made by others. Transitions into care settings often occur at times of crisis and the prospective resident may not be involved in choosing what to take with them [24]. It is how, when and by whom choices about personal possessions and décor are made that was of interest in this study. By working with participants at earlier stages of dementia, this study explored ways to support expression of everyday aesthetic preferences that could contribute to planning for

future transitions when it becomes more difficult to articulate these wishes.

2.3 Aesthetic Appreciation in Dementia

The origin of the term aesthetics originates from the Greek word 'aisthanomai', "*I perceive, feel, sense*" [25]. If the parts of the brain that are stimulated by creative activity are relatively unaffected until later stages of dementia [26], this may relate to an understanding that sensory sensibilities, and an experiential self is retained [27]. It is the possibility that capabilities related to the visuo-sensory, "*pertaining to or involving visual perception of sensory signals*" [28] might survive, that was the focus of this study. If pleasure associated with beauty is elicited through visuo-sensory, visceral responses this could resonate with notion that whilst factual memory is impaired, emotional memory in dementia endures [29]. In visual arts, the positive impact that arts viewing and participation has on engagement, mood and care relationships in dementia is recognized [30–32]. Some studies suggest that people with dementia retain their aesthetic preferences. People with dementia who chose from a selection of art works, made the same choices two weeks later, although they could not recall being asked before [33, 34]. This implies an ability to respond intuitively to visual images. In art therapy, observations of people at advanced stages being preoccupied with arranging colours and materials, suggests they are, "*searching for something aesthetically satisfying*" [35]. However, there are only a few studies that explore how everyday aesthetic preferences contribute to relationships with objects and environments. Fleetwood Smith et al. [36] have explored aesthetic relationships with textiles and clothing in care settings. A study that experimented with ways to involve people with dementia in how their personal space is organized, offers ways that this could be explored [37].

2.4 Exploring Everyday Aesthetic Experience in Dementia Through Design

Design for dementia advocates a, "*Focus on the strengths and abilities of people living with dementia while compensating for functional changes.*" [19]. This study explored whether utilizing these capabilities offers opportunities to create accessible ways to scaffold conversations about how everyday aesthetics are experienced and expressed. As Hannan et al. point out "*We all know what we like and what we dislike, but finding the words to articulate our preferences can often be more difficult.*" [38]. This implicit, intuitive, non-verbal response to the visuo-sensory qualities of everyday objects and environments resonates with the experience of dementia where word finding becomes an increasing challenge [39].

There is some evidence that visuo-sensory sensibilities in dementia are relatively unaffected by cognitive impairment [29]. Although dementia affects explicit aspects of memory reliant on cognitive processing, aspects of implicit memory concerned with emotion and the senses, understood to be relatively unaffected in dementia has been utilized in design research [40, 41]. It is suggested that an embodied sense of self, formed from lifelong habitual embodied interaction with spaces and everyday objects, survives [42]. If sensory awareness, emotional memory and an embodied sense of self, contribute to everyday aesthetic experience (Fig. 1), this suggests that personal preferences for the way things look could contribute to a sense of familiarity that is recommended in dementia care [43].

2.5 Understanding Everyday Aesthetics Through Design

Hove [4] highlights the challenge for designers in articulating how aesthetic judgements are made where, "*words alone do not suffice in examining form expression,*" but draw on

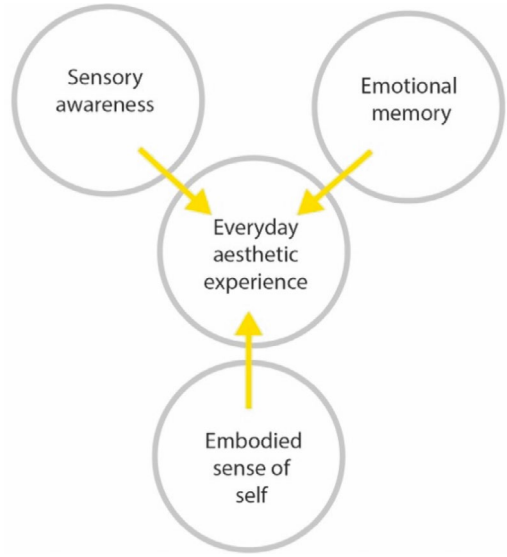

Fig. 1 Factors impacting on everyday aesthetic experience

sensory and haptic relationships with objects and environments. Whitfield [44] critiques an intellectual view of design that overlooks sensory-perceptual, '*pre-linguistic'* knowledge and locates an understanding of aesthetics, not as culturally produced but within a hierarchy: "*from the sensory-perceptual to the linguistic, and from this to cultural*", to account for the emotional and motivational factors associated with aesthetic experience. Based on this, Fig. 2 presents a way to consider where everyday aesthetic experience is situated within these interrelated hierarchies of knowledge. Within a hierarchy from fine arts to the everyday, exposure to fine arts is contingent on access to a particular education and environments. An aesthetic sensibility, which may be different, but can be experienced in everyday life is overlooked. If this is so, then if aesthetics experienced through what Whitfield terms a, "*kind of pre-cognitive cognition*" without the need for higher mental capacity [44] and accessible at a pre-linguistic level, this has relevance to dementia where it has been observed that, "in *the later stages of dementia, the evolution of self is clearly toward a postmemory postlanguage self.*" [27].

3 Method

This practice-led design research study took a constructivist stance, that enables knowledge to be co-constructed through shared engagement between the participants and the researcher. This aligns with methods that aimed to uncover participants' preferences by acknowledging the role of context and subjectivity in shaping knowledge [45]. A mixed methodology was used to devise a framework of engagement to explore how everyday aesthetic preferences are experienced and expressed. Whilst not pure ethnography, as a reflexive and iterative creative thinking process, this approach draws on elements of design ethnography [46], and sensory ethnography [47] to explore preferences for everyday

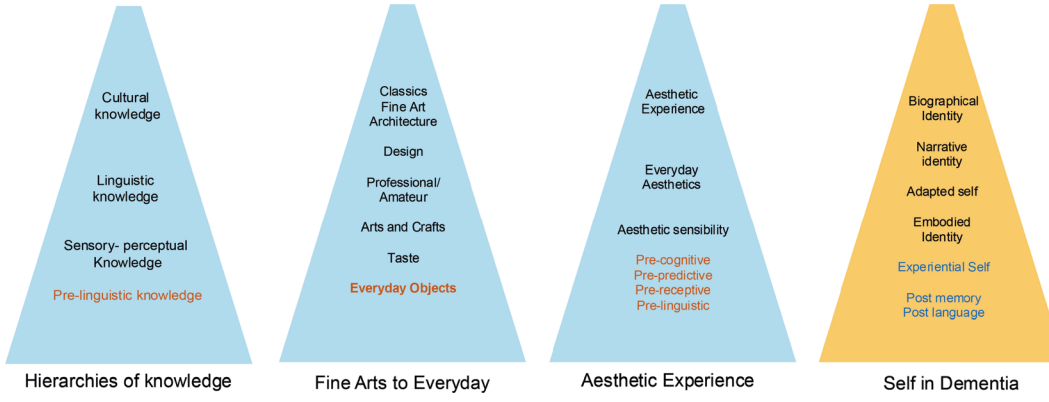

Fig. 2 Relevance of everyday aesthetics to a sense of self in dementia

Fig. 3 Shared looking process

objects, colour and favourite spaces in the home to understand the situated relationships the participants have with their home environment.

Entitled 'Shared Looking' the process involved three consecutive meetings that used different stimuli to scaffold conversations about participants' preferences (Fig. 3). The first meeting asked participants to share their favourite mug and least favourite mug, drawing on object elicitation methods [48]. Drawing on a cultural probe methodology [49] where a variety of tools and tasks can be used to elicit participants' responses, the second used a set of colour cards as a design probe to elicit colour preferences. The final meeting invited participants to share images of favourite spaces in their home. As an iterative process of exchange, following each meeting personalized booklets of images and quotes generated from the meetings were sent to participants. Adapting to the constraints of the social distancing restrictions imposed by the COVID 19 pandemic in the UK, on people living with dementia who were deemed to be vulnerable [50], the study design adopted a form of remote sensory ethnography [51] conducted via videoconferencing.

Informed by an ongoing review of research and practice, alongside learning from people with lived experience, the study was conducted in four phases (Fig. 4). Phase 1 involved exploring ways to support expression of everyday aesthetic preferences with people with and without dementia through email surveys, and workshops. These experiments informed the development of the Shared Looking process tested firstly with participants without dementia in Phase 2. Informed by advice from specialists in design for dementia and dementia care it was then adapted and tested in Phase 3 with people living with dementia. This paper presents insights from observations of how participants in Phase 3 shared their colour preferences.

3.1 Using Colour as a Visual Stimulus to Explore Preference

In the context of design, as Ivanovic claims, colour can act as a "*powerful conductor of memory enhancement processes due to its ability to elicit different emotional responses in each person.*" [52]. Methods used by designers to explore the psychological impact of colour were considered in developing the design probe. Tebbe explored how colours reveal associations with memories and feelings using verbal prompts to trigger subjective colour preferences to create an "*archive of visual experiences*" [53]. Lee [54] uses a set of tools and exercises to support thinking about how personal aesthetic preferences can evoke feelings of pleasure. Both use a framework of verbal phrases and terms to elicit responses. Rather than using verbal prompts, a colour palette was devised as non-verbal stimulus to test whether this could elicit an understanding of subjective relationships with colour.

3.2 Designing a Set of Colour Cards as a Tool for Engagement

A set of 30 colour cards as a design probe was created to initiate and scaffold conversations about everyday aesthetic preferences (Fig. 5). Compared to simply asking people about their aesthetic preferences, initial experiments in

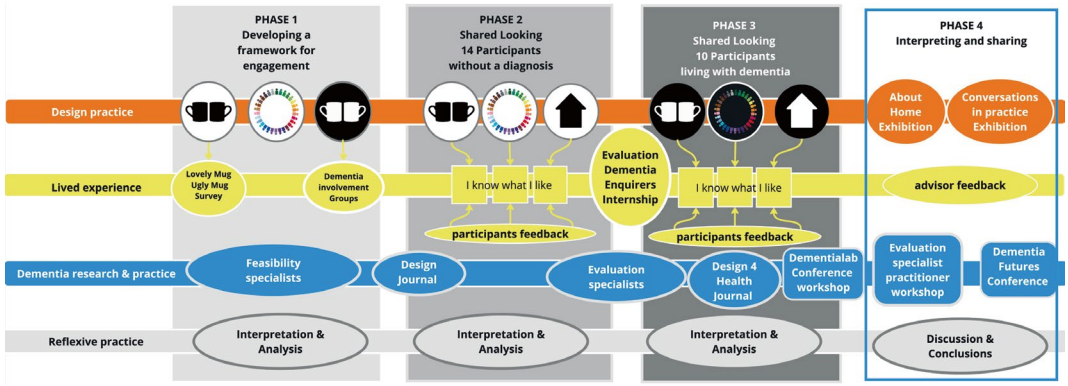

Fig. 4 Phased approach

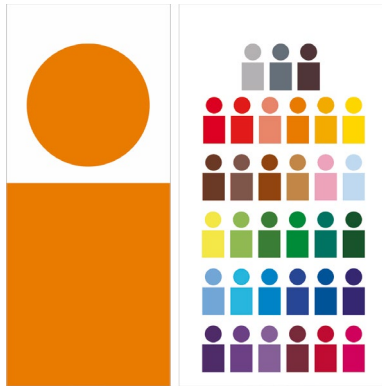

Fig. 5 Colour card design

Phase 1 with a set of Pantone colour postcards[1] provoked immediate and decisive responses. Personal meanings and associations emerged from the process of sorting colours into 'likes' and 'dislikes'. A set of colour cards, that could be easily sent by post for videoconferencing meetings in Phase 2 and Phase 3 was created. The number and range of colours was deliberately limited, intended as an approximation from which preferences could be selected and compared.

The colour cards (Fig. 5) combine a colour spot surrounded by white, and colour bleeding to the edge so that colours could be viewed separately or placed together to explore combinations. The strength of hue and saturation was considered to account for age related visual impairments [55].

To account for limited dexterity and grip, the card holder was designed to make it easier to select the cards (Fig. 6). The size and display were devised to make it easy to send in the post, and to share preferences via video conferencing (Fig. 7).

The number of cards displayed can be reduced to suit individual needs if the display is overwhelming. A topic guide explained the subject of each meeting (Fig. 8).

3.3 Generating and Interpreting the Data

Personalized booklets of images and quotes from the recordings were sent to the participant following each meeting (Fig. 9), compiled from a combination of screen shots, found images, or images provided by the participants. A process of exchanging images between the researcher and the participant that represented their preferences evolved.

A reflexive approach to analysis of the multimodal data [56] generated from the meetings involved close observation and listening, during and after the meetings [57]. This enabled an iterative process that could be adaptable to

[1] Pantone postcards https://www.pantone.com/uk/en/products/lifestyle/pantone-postcards?srsltid=AfmBOooWQ2PxTIJj9ZKDF3qC8ypdB9-ai0RYG8fztXin6__5qsA0ZYrU (accessed 30–11-24).

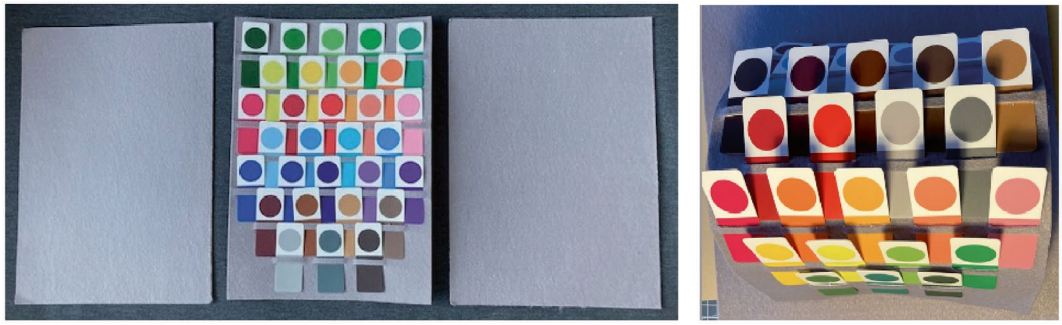

Fig. 6 Card holder

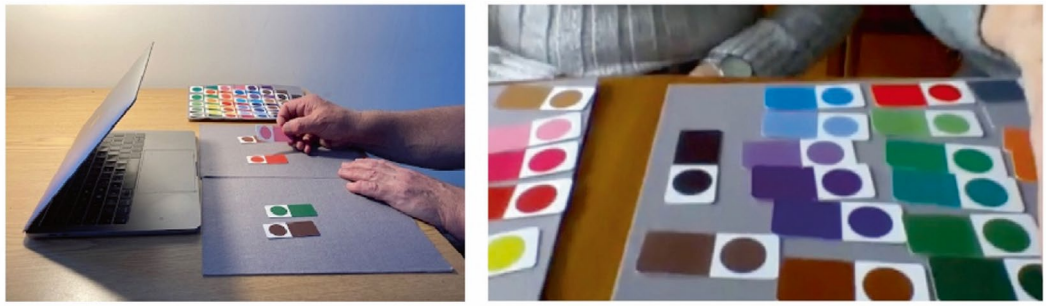

Fig. 7 Sharing via video conferencing

individual participants. Following completion of the active research, the data was revisited to analyse firstly what happened in each of the three meetings, and then how this contributed to building knowledge about the person and what was important to them. This paper reflects on a key insight that emerged from the second meeting about the colour preferences, with participants living with dementia.

3.4 Ethics

Several ethical issues of concern related to capacity, dignity, autonomy, confidentiality needed to be addressed to obtain permission to recruit people with dementia to this study. As Fletcher [58] observes, the complexities of establishing and demonstrating capacity can be seen as too onerous and difficult to overcome. This can lead to excluding people with dementia from the opportunity to participate in research. The ethics application was informed by the Dementia Empowerment and Engagement Project (DEEP) guidelines [59] that state that participants' capacity to make informed decisions and consent should be assumed unless it can be proved that they do not. Capacity should be checked in relation to ability to make decisions and express choices related to specific situations. Ethical approval was obtained from Sheffield Hallam University ethics committee. The protocol incorporated flexibility for each session to be tailored sensitively to respond to individuals wishes and ability to participate. In line with a process consent approach [60], frequent checks with the participant for consent to continue or withdraw, take a break, shorten or terminate the meetings were offered.

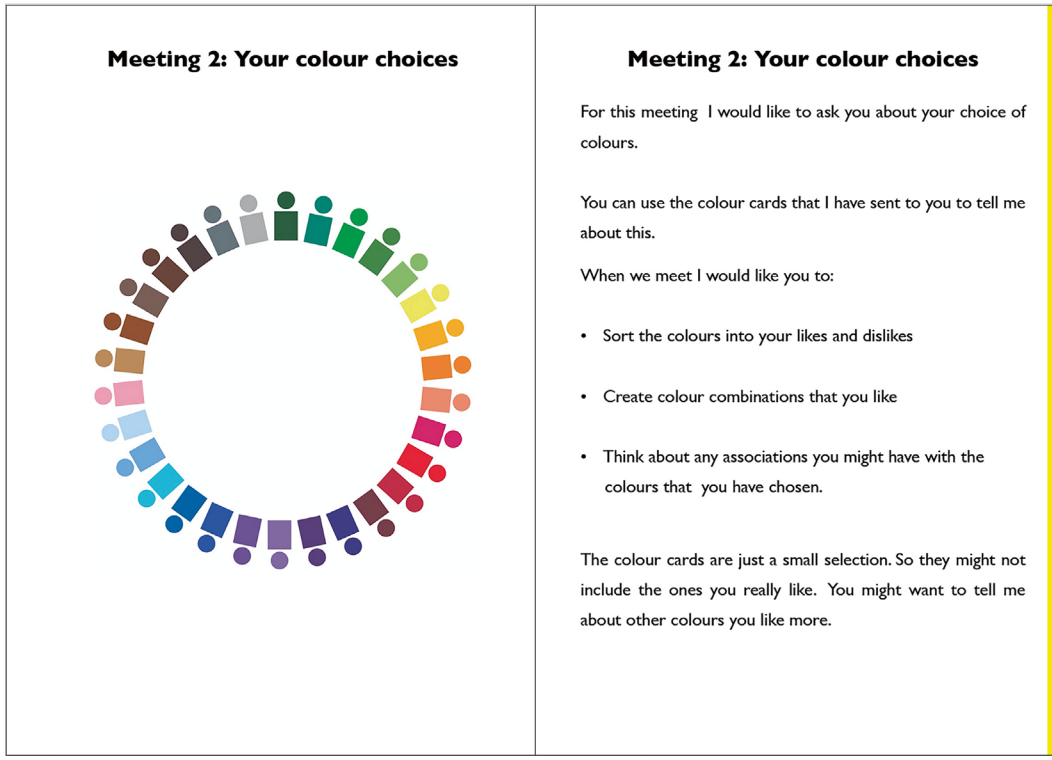

Fig. 8 Topic guide

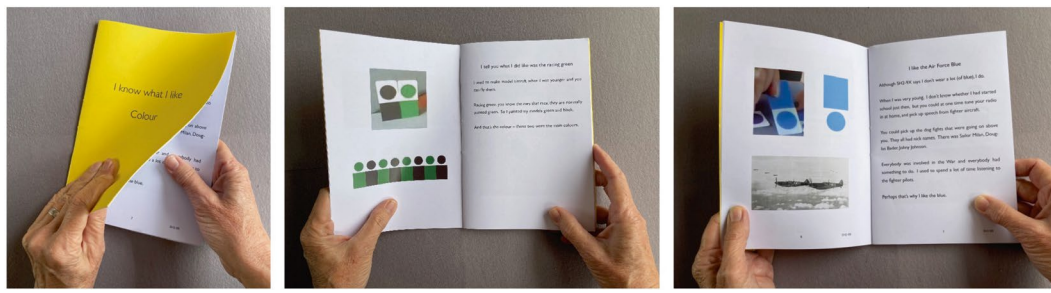

Fig. 9 Personalized booklets

3.5 Recruitment

The phased approach to this study involved testing different ways to support expression of everyday aesthetic preferences with people with and without a diagnosis of dementia. Table 1 summarizes the participant profiles in each phase. The focus of this paper is on the observations of what happened when participants in Phase 3 were invited to share their colour choices in the second of the three meetings. Inclusion criteria in Phase 3 was for people living with early to moderate stage dementia who were self-selecting, still living at home, and could be accompanied by a person nominated by them, if they chose. They needed to be comfortable with and

Table 1 Participant profiles

	Phase 1 LovelyMug UglyMug	Phase 2 Shared looking	Phase 3 Shared looking
Data generation	Survey	Videoconferencing	Videoconferencing
Participants	25 participants without a diagnosis of dementia	14 participants without a diagnosis of dementia	10 participants mild to moderate dementia
Gender	16 female, 9 male	10 female, 4 male	2 female, 8 male
Age range	Not known	23–95	50–85
Meetings	N/A	3 meetings with 12 of the participants 2 meetings with 2 participants	3 meetings with 9 of the participants 2 meetings with 1 of the participants

able to communicate via videoconferencing or be assisted to do so and have capacity to give informed consent using the approach outlined above. In Phase 3 participants were recruited from the DEEP Dementia network[2] and Join Dementia Research[3] a database of people living with dementia who have volunteered to take part in research.

4 Observations and Findings

Observations from participants' interactions with the colour cards demonstrated that both people with and without dementia were equally able to choose and organize the colours into likes and dislikes. Participants made immediate and decisive selections, that provoked reflections on what they had chosen and why. Participants recalled comparisons and associations with possessions, environments and experiences that had personal significance.

A process of sourcing and exchanging images between the researcher and the participants to find examples that represented what they recalled evolved. This involved searching for images that were the nearest equivalent to what they recalled. The images sourced were solely for use by the participants to support a continued engagement and exchange with the participants. As permissions were not sought to use these images for publication the following account only includes the anonymized images that participants gave their consent to share. As screenshots from videoconferencing recordings, the quality of some of the images is inevitably degraded but represent what was shared in the personalized booklets sent after each meeting.

An account of observations of three of the participants in Phase 3 documented below present the diversity of individual differences and associations that emerged from their preference for one colour: green. SH2-9 was accompanied by his care partner (SH2-9X). SH2-14 and SH2-16 were not accompanied. Participants have given permission to use the images they shared.

4.1 Green Suit

SH2-9 initially selected all the shades of green from the colour cards, and then selected one that he said he would wear (Fig. 10). Images were exchanged between the researcher, the participant and his care partner (SH2-9X). This included images of what SH2-9 wears now and images found by the researcher that might represent the suit that was described.

SH2-9X "*(he) wears a lot of green. You've got green trousers, green coats, green shirts.*" and sent an image to illustrate this (Fig. 11).

This led to an exchange about a suit that SH2-9 had as a young man:

[2] Dementia Voices https://www.dementiavoices.org.uk/deep-groups-news/participants-wanted-for-research-into-how-design-can-help-people-with-their-personal-preferences/ (accessed 17–11-24).
[3] Join Dementia Research https://www.joindementiaresearch.nihr.ac.uk/content/about (accessed 26–10-24).

Fig. 10 SH2-9: "*That one, I'd be more inclined on clothing, to wear*"

Fig. 11 SH2-9 wearing green jacket

SH2-9X: "*You had a sort of sage green suit didn't you when I first knew you?*".

SH2-9: "*Yes, it cost me a fortune!*".

An example from images sourced online using was sent to the participant. Looking at this image together at the next meeting SH2-9X wondered "*was it more of a tealy green?*" Another image of a teal green suit was sent. Looking at this second image provoked further recollections for SH2-9 about the process of acquiring the suit. He turned to his wife:

SH2-9: "*I'll tell you a secret there, I didn't buy that suit all in one go. I bought the pair of trousers, and I liked the green so much I went and ordered the jacket made up as well. So first off with the trousers, and then the jacket.*"

For this couple who had been married for over fifty years, the process of choosing the colour green provoked a shared recollection of a significant time in their lives when they first met. For SH2-9 the process of investing in having a suit made, reinforced the memory. For his wife it was what he wore when they first met.

4.2 Green Sofa

SH2-14 explained that he was a keen collector of art deco ceramics and furniture. He selected this colour (Fig. 12) that was the closest to what he referred to as "art deco green".

SH2-14, *"I do love green. That's kind of bit like it. Actually, it's sort of more pastelly than the others. More of an art deco green than the other three.*" This him to recall the process of selecting a suite of furniture for a new home several years before, "*I bought my sofa set, which happened to be quite art deco, with those sorts of Odeon arches type of thing? Not like a shell, you know, like half a saucepan lid*?".

Following the meeting SH2-14 sent a message with a photograph of a sofa that was not the same shape but nearer to the colour he recalled, "*Sorta this colour.*" This prompted an image search to find sofas that might be closer to the style and shape he had described that were sent to him. His immediate response was "*No. lol*" (SH2-14). Several months later SH2-14 sent an

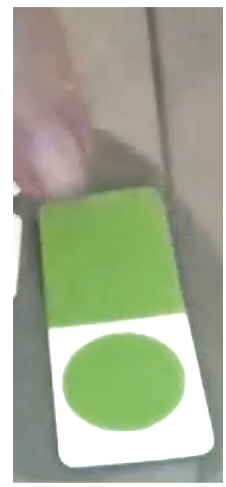

Fig. 12 SH2-14: "*I do love green.*"

Fig. 13 The green art deco chair

image of the armchair that matched the sofa he had described (Fig. 13).

SH2-14, "*That is the chair from the green art deco sofa. I wish I could have that sofa again I really liked it. If I won the lottery I'd have one custom made.*" The significance of this exchange was the extent to which it had provoked recollections that the participant continued to think about and was keen to share some time later.

4.3 Green as Religiously Significant

For SH2-16, one shade of green held an important religious significance as similar to the colour of the Dome at Medina (Fig. 14).

SH2:16, "*It's got a link with the faith. It has a religious meaning to me this has. Because the Dome in Medina, the Prophet's Mosque, is green, and because of that, a dark green colour has a significant part in my life*". He reflected on his experience of visiting Medina several years before, "*When somebody like me ends up at a place like that, it's a blessing. I haven't got the words to explain the feeling that you have. It's overwhelming.*" (SH2-16).

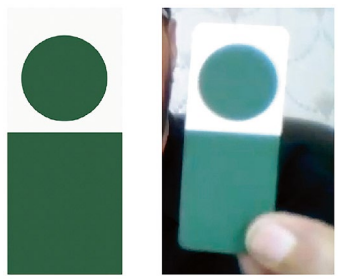

Fig. 14 Religious significance

SH2-16 used the videoconferencing to show me the décor in the room where he spends most of his time is all in shades of green (Fig. 15).

Although he chose green for décor, he emphasized that its religious significance meant that for clothing he would not feel: "*worthy enough to wear it*" (SH2-16). These insights could be important for caregivers, if at later stages of dementia, he becomes reliant on others to make decisions on his behalf. Giving him green pyjamas for instance, might cause resistance that would not be understood.

5 Discussion

Although not everyone has a visual memory, some experience what Ivanovic calls '*memory colour*' [52]. The findings from this study suggest that for those with visual memory, this ability remains intact as dementia progresses, aligning with some evidence that visuo-sensory sensibilities are relatively unaffected by cognitive decline [26, 29]. Participants demonstrated the ability to match colours to visual images in their 'mind's eye', associating them with activities, objects, and environments that had personal significance. If this capability persists in dementia, it suggests colour could support people to contribute to how their environment is personalize.

5.1 Limitations

Whilst it is acknowledged that cultural influences will also influence choices the intention of this study was not to find evidence of universal preferences but whether engagement with a

Fig. 15 SH2-16 green décor (videoconferencing screenshots)

colour palette can support expression of preferences in terms of individual differences. There are several variables that were outside of the control of this small-scale qualitative research study including the participants visual acuity, visual field and contrast sensitivity, and lighting conditions. Videoconferencing also had an impact on how much could be observed and shared.

5.2 The Influence of the Researcher

Whilst participants pointed out that their colour preferences were very much contingent on context, the colour cards worked as a tool to scaffold conversations about their choices. However, some participants remarked on how much the attitude, attention and skills of the person facilitating the conversations influenced their wish to take part, and what they chose to share. A larger study could evaluate the efficacy of the methods with different facilitators.

5.3 The Challenges of Remote Sensory Ethnography

Using a form of remote sensory ethnography, as Barker [51] notes, presents challenges for both the researcher and participants. Not being in participants homes, limited observations and shared insights. Whilst videoconferencing excluded some, it was familiar to the participants with early to moderate dementia in this study, who had adapted to its use during the COVID-19 pandemic. Some were already using it to access a global network of peer support [61].

5.4 Design as a Mode of Interpretation

Using design as a mode of interpretation in creation of personalized booklets provided a tangible record of participants preferences, that could be shared with family and friends. Participants remarked on its value, "*I could relate to it. So therefore, you'd seen it how I'd seen it*." (SH2-2). One of the participants friends observed that the images acted as, "*a portal to reliving the experience. It's not that he was going through the words, he was responding to the pictures.*" (SH2-6XB).

6 Conclusion

As an assets-based approach this study has explored ways that design methods can utilized visuo-sensory sensibilities understood to be retained when cognition is impaired in dementia. The findings suggest that using colour as a stimulus, can be an effective tool to support an immediate and intuitive expression of preferences, that then contributes to provoking conscious recall. Whilst colour is only one aspect of how everyday aesthetics are experienced, the initial immediate responses of participants to the colours became more explicit through sharing and thinking about the reasons for their preference. The colours that participants chose were

contingent on context and revealed associations with objects, environments and activities that held personal significance. This implied that they retained a visual memory of these associations. These preliminary findings suggest that these methods could support people living with dementia to think about and share their preferences at earlier stages of dementia, that could contribute to greater agency at later stages, and times of transitions into care settings.

There is preliminary evidence to suggest that this methodology could be tested in design research with larger and more diverse groups of people living with dementia, but also with different populations. Initial findings shared with dementia care practitioners suggest there is potential to conduct research into how this methodology would work in dementia care practice. It would also be interesting to explore whether these methods could be transferable to understanding how choices related to shape or materiality are made. Given the feedback from participants on their experience of taking part, whether it is feasible to replicate this as a collaborative process between participants and care partners, or care providers could also be considered.

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How Framing Shapes Dementia Research and Design: Subliminal Influences and Considerations

Lisa Bormans and Baldwin Van Gorp

Abstract

Frames are socially shared structures that people use to interpret and meaningfully organize the world around them. These frames shape reasoning, behaviour, and attitudes, and in case of problematizing interpretations, they can contribute to stigma. Therefore, it is essential to recognize the frames that shape people's meaning-making in stigma-sensitive contexts like dementia. However, due to their implicit nature, individuals might be unaware of the frames they adopt. This lack of awareness can lead to a range of issues throughout the entire research process on design projects related to dementia. For instance, presenting dementia as highly problematic may increase the likelihood of securing funding, but it may also risk reinforcing public stigma. During collaborative projects, unawareness of one's own and others' frames can lead to miscommunication and hinder the achievement of common goals. Lastly, the designs themselves or the way results are communicated can reinforce certain frames, further amplifying public and structural stigma. People living with dementia may internalize these frames, thereby increasing self-stigma. Therefore, it is recommended to be aware of frames, including those of people living with dementia, their (informal) caregivers, researchers and the broader society. However, making implicit frames explicit can be challenging. This methodological essay aims to enhance awareness of frames and their influence within dementia design projects. It offers recommendations to promote this awareness while addressing potential challenges and pitfalls.

Keywords

Framing · Personal reflexivity · Methodological essay

1 Introduction

1.1 Dementia as a Social Experience

Dementia is a condition that alters the way people living with the diagnosis perceive, interpret, and respond to the world around them [1]. However, the lived experience of dementia cannot be understood outside of the cultural, historical, and social contexts [2, 3]. For instance, social interactions shape the meaning-making of dementia, which impacts the way others

L. Bormans (✉) · B. Van Gorp
Media, Information & Persuasion Lab, KU Leuven, Leuven, Belgium
e-mail: lisa.bormans@kuleuven.be

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act towards people living with the diagnosis [3, 4]. These behaviors, in turn, influence the sense of self of those with the diagnosis [5]. Moreover, the potential loss of self is primarily caused by the ways in which others treat people with dementia [6]. Media representations reinforce this dynamic, portraying people living with dementia as "living death" [7]. Overall, media representation of dementia evoke catastrophic imagery, such as tsunamis or portrayals of dementia as a fate "worse than death" [8]. Such portrayals reflect "implicit theories" [9] surrounding dementia, encapsulating assumptions about its causes, consequences, and potential responses. These assumptions function as reasoning devices [10], embedding dementia within a framework of shared socio-cultural meanings that contribute to a collective *public culture* [11]. Through a process of internalization, these *collective frames* are absorbed into *personal schemas*, shaping individual perceptions and fostering a *personal culture* [12, 13]. Therefore, frames are "organizing principles that are socially shared and persistent over time, that work symbolically to meaningfully structure the social world" [14].

The influence of frames on individual attitudes and decision-making is well-documented (see e.g., [15, 16]). In the context of dementia, while much remains to be investigated, research has begun to shed light on these dynamics. For example, evidence suggests that emphasizing negative imagery—such as invoking fears of cognitive and physical decline—can effectively capture public attention on dementia-related issues [17]. Conversely, framing that intentionally avoids a strict separation between mind and body has been shown to foster more positive attitudes toward dementia. This effect has been observed across different age groups, impacting both younger and older audiences alike [18, 19]. Given that these frames influence personal attitudes and behaviours toward individuals living with a dementia diagnosis, it is essential to recognize how specific framings shape both personal and societal perspectives. When a narrow set of frames dominates collective discourse, a belief-maintenance effect arises [20], which contributes significantly to the stigma and self-stigma associated with dementia [21], and the loss of self and personhood of the people living with the diagnosis [4].

1.2 Framing in Dementia Research and Design

As frames play a role in everyday interactions and the broader culture, they also have a profound impact on research and design projects concerning dementia in three different ways.

First, the framing of dementia can influence a project right from the start, as it may already be present at the funding stage. Funding agencies are believed to base their decisions on the (societal) impact and urgency of research. Consequently, to obtain funding, it is advantageous to emphasize the urgency of dementia research by framing dementia as problematic. However, this approach can inadvertently contribute to stigma [18, 21]. Therefore, from the earliest stages of formulating a goal and acquiring funding, it is to be considered what frames one is conveying in their communication. This presents a difficult trade-off between avoiding the problematization of the topic and still effectively emphasizing its urgency for research. A similar challenge arises when writing papers, where the aim is to persuade readers of the importance of the contribution without problematizing the topic.

Second, due to the implicit and covert nature of personal schemas [13], people might be unaware of the influence frames have on their perception and reasoning about dementia. This unawareness is further amplified by the tendency to view personal experiences and knowledge as unbiased representations of reality–known as naïve realism [22]. As a result, activated reasoning devices may be perceived as mere common beliefs about causes, solutions and consequences of dementia. In the context of research in design for dementia, however, this can give rise to difficulties, as there may be a lack of clarity regarding colleagues' opinions,

the needs of people living with dementia and their families, or the means of achieving the project's goals. [13]. Failing to question your own personal schemas and those of others can thus jeopardize (research in) design projects. To address this, it is advised to cultivate awareness of the personal schemas held by all parties involved, a practice referred to as interpersonal reflexivity [23], to minimize bias and prevent miscommunication. Additionally, researchers are encouraged to engage in personal reflexivity [23], reflecting on their own schemas to avoid biases such as naïve realism or false consensus bias, which can compromise the validity of their interpretations and conclusions [24].

Third, at the conclusion of design projects, the results are often presented to a broader public or integrated into the daily lives of people living with dementia and their relatives. The way these results are communicated to the public can trigger certain personal schemas by the audience, potentially reinforcing stigma [25]. Therefore, it is suggested to consider the frames conveyed when presenting results concerning dementia. Additionally, it is recommended to be aware of the frames that may be embedded in the design outputs or creations themselves, as they can also trigger personal schemas in the audience [25]. For example, designing a room in a residential care center filled with dolls, large-piece puzzles, and building blocks may reinforce the frame that people living with dementia regress to a childlike state. Similarly, paintings that depict a body with empty eyes can evoke the frame that cognitive deterioration erases the person's identity. When these frames are internalized by people living with dementia, they can lead to self-stigma [26].

The goal of this paper is to provide practical guidance for fostering two types of reflexivity in dementia research and design: personal reflexivity for researchers and designers, focusing on their own personal schemas, and interpersonal reflexivity among all involved parties, focussing on their personal schemas. Additionally, this paper aims to raise awareness about how personal schemas can be influenced by frames in communication and provides practical guidance to address this. The practical recommendations are based on our experiences from an ongoing study in which we aimed to uncover personal schemas associated with dementia. The objective of that study is to gain insight into how individuals living with dementia perceive and interpret their condition, and how these personal schemas are related to the their lived experience and coping strategies. Therefore, one-on-one in-depth interviews were conducted with people living with dementia who attended residential centres for day care services.

2 Considerations for Research in Design

2.1 Awareness of Personal Schemas

As previously mentioned, personal schemas are implicit, remaining unconscious and covert [13]. As a result, people may not always be aware of the frames they adopt. The following recommendations offer guidance on how to make these personal schemas explicit, both applicable to yourself and to your colleagues.

Awareness of one's own schemas. As a researcher, it is recommended to be aware of your own personal schemas, as they can influence your underlying rationale and assumptions, shape your interpretations and, therefore, bias your conclusions [22, 27]. To become aware of the personal schemas you adopt, it is beneficial to first familiarize yourself with the collective frames related to dementia. For instance, you can review research that focuses on how dementia is portrayed in the media, such as newspapers, movies, literature, health care communications, and documentaries. Previous research conducted an inductive framing analysis on a convenience sample of all these type of sources and identified twelve collective frames [28] (See Table 1). These provide insight into the ways dementia is perceived or discussed within some Western European cultures. After familiarizing yourself with these collective

frames, it is advisable to critically reflect on which of these frames resonate with your own personal schemas. You can do this by reflecting on statements based on the underlying reasoning of all collective frames. For instance: '*Cognitive functions define who we are*' (1), '*People living with dementia lose their identity'* (1), '*We should fear dementia.*' (3), '*People living with dementia have to be brave and need to fight against the condition.*' (3), '*The only solution to dementia lies in medical science*' (5), '*Dementia is something we need to fear for*' (7), '*It's better to die, than live a life with dementia*' (7), '*People living with dementia should be institutionalised, so they are out of our sight*' (9), '*Happiness can be found in little things*' (8), '*Dementia is primarily a heavy burden for the caregivers*' (11), '*People living with dementia should be able to count on their closest friends and family for care and understanding*' (12), where the numbers represent the associated collective frame in Table 1. These examples suggest some possible statements, but they do not limit the range of possibilities.

Furthermore, if you are aware which personal schemas you use to interpret the world around you, it is recommended to communicate them transparently to the readers of your research. For example, you can include a positionality statement (see below) in your paper, where you reflect on your own personal schemas, personal experiences with dementia, and how you believe

Table 1 Vignettes based on the 12 collective frames of Van Gorp et al. [17], Van Gorp [28]

Frame	Vignette
(1) Dualism of body and mind	Dementia causes people to gradually lose their identity and humanity. People with advanced dementia are like an 'empty shell' or a 'plant'
(2) Unity of body and mind	Dementia gradually affects a person's thinking abilities but leaves their sensory and emotional capacities intact. It does not take away their humanity
(3) The invader	Dementia is like a thief or intruder, gradually stealing away a person's life as they know it. That's why it must be fought against
(4) The strange travelling companion	Dementia is like a travelling companion that crosses people's path and stays for the rest of their life. People living with dementia must learn to accept it
(5) Faith in science	Dementia is a brain disease, and medical treatment is the only way to manage it. Medical science is our only hope, so we must invest in it and have faith in it, even though the condition is currently incurable
(6) Natural process of ageing	Dementia is not a disease but a variation of the natural aging of the brain. We should focus on having a healthy lifestyle and staying socially engaged
(7) The fear of death and degeneration	Dementia is like a death sentence, signaling an irreversible and incurable process of degeneration. Only death can bring deliverance
(8) Carpe diem	Dementia still leaves some good years. People with dementia should make the most of this time by finding happiness and comfort in the small things
(9) Reversed roles	Dementia makes it hard for people to behave as adults, so their children must look after them. These reversed roles place a heavy burden on the children
(10) Each in his/her turn	Dementia brings people back to the carefreeness and happiness of their childhood. Their children take turns to care for the parents, just as the parents once cared for their children
(11) No 'quid pro quo'	Dementia primarily affects close family members. They bear the heavy burden of caring for a person with dementia, without getting anything in return
(12) The Good mother	People with dementia should be able to count unconditionally on their (informal) carers. They should be surrounded by love, patience, and respect

these factors may impact your perceptions and conclusions [29]. This approach helps readers understand the researcher's perspective and encourages them to reflect on their own personal schemas as well.

Awareness of others' schemas. Even when you are aware of your own personal schemas, collaborative projects can still be hindered by the belief that colleagues adopt the same frames as you–known as the false consensus bias [30]. By underestimating differences in worldviews during collaborative projects, one is unaware of the variation in opinions on (how to achieve) the project's goal. If you are not aware of each other's perspectives or beliefs, collaboration can be hindered. To minimize this bias and its effects on the project, it is highly recommended not only to be aware of your own frames but also gain insight into those of your colleagues.

In a team setting, it is advisable to engage in a similar reflection as described above. This involves collaboratively discussing the collective frames (and their underlying rationale and assumptions), reflecting on how they resonate with the team members and zooming in on how differing viewpoints might impact the project. If hierarchical disparities are present within a team, solely presenting collective frames to others and asking which ones they resonate with, could potentially introduce a social-desirability bias. People may sense that certain frames can contribute to stigmatizing views of dementia and, as a result, consider them less acceptable. To appear more socially desirable, they might then choose to conceal their recognition of these frames. Therefore, it may be necessary to discuss the purpose of the assignment and the importance of transparency in advance.

It is not essential to achieve complete consensus when it becomes clear that individuals hold different personal schemas towards dementia. Simply recognizing these differing perspectives might help reduce miscommunication. However, further alignment may not always be necessary, as personal schemas are deeply ingrained and not easily adjusted [11]. In the context of research or design, however, teams may elect to adopt a particular (set of) frame(s) of reference, with the objective of achieving the desired outcomes. Such matters can be discussed in a collaborative manner, with mutual respect for all parties involved.

Specific considerations for people living with dementia. In our study, we aimed to uncover the personal schemas of individuals living with dementia. While initial expectations suggested this might be challenging due to significant difficulties in reasoning about abstract concepts and changes in language abilities among individuals with dementia [31], our participants were eager to share their experiences, and communication generally proceeded smoothly. However, several interviewing approaches were necessary to support them effectively, such as providing reassurance that they could take their time to reflect and search for words, assisting in finding words with minimal guidance, repeating questions or statements when needed, and maintaining sensitivity to signs of fatigue or overstimulation [32, 33]. Although the conversations progressed reasonably well overall, we did encounter some specific challenges related to the particular subject of framing and personal schemas.

During our research interviews, we encountered some challenges with the aforementioned recommendations. Specifically, we noted that the concept of framing can be too abstract, the statements to discuss collective frames can be emotionally triggering or overwhelming and reflecting on their personal schemas can be cognitively demanding. Therefore, when working with people living with dementia, whether they are colleagues or participants, it is advised to adapt your methods. Instead of discussing collective frames one by one, you might begin your teamwork by simply having a conversation about dementia. Engaging in a discussion on a specific topic can help bring implicit personal schemas to the surface [13, 34], and may feel less threatening or overwhelming. During this conversation, you could indirectly ask about a person's opinion on dementia, which can reveal their underlying rationale and assumptions and provide insight into their personal schemas: 'How would you explain dementia towards others', 'Can you compare dementia

to anything, and why this comparison?', 'What causes dementia to develop?', 'Can you prevent the development of dementia?', 'What are the main effects of dementia?', 'Are there any positive consequences?', 'What is the prognosis of dementia'. It is recommended to listen carefully to the responses, as the interpretations may not always align with the intended meaning. For example, during an interview in our research, a man living with dementia stated: 'Yes, at a certain point, we still live, but in what state do we live?', suggesting that he felt more dead than alive. At first sight, this seemed to align with *The fear of death and degeneration* frame. However, as we got to know him better, we discovered that he had been a driver his entire life and had recently lost his driver's license. This loss made him feel as though he was losing a part of his identity, which, in turn, made him feel less human. This example underscores the importance of asking follow-up questions and avoiding hasty conclusions to accurately grasp the personal schemas at play. Moreover, failing to do so can leave the person living with dementia feeling misunderstood.

When it is necessary to gain a complete understanding of how people living with dementia resonate with each collective frame, vignettes can be a useful tool (see Table 1). These are fixed descriptions that encapsulate the cultural themes within frames in a comprehensive yet concise manner. In our research, we utilized vignettes after noticing that people living with dementia struggled to grasp the full scope of a single frame. By distilling the essence of each frame into two sentences, we made it more digestible. It is advisable to have a few synonyms or alternative phrasings prepared to further clarify the vignettes, especially when aphasia, for example, makes it more difficult to grasp the content.

2.2 Awareness of Frames in Communication

Individuals tend to adopt frames that are readily accessible, such as those presented through media, design, or communication with peers or (informal) caregivers, a tendency known as availability heuristics [22]. This shows how exposure to communication, or collective frames can influence which personal schemas are adopted. Therefore, it is to be carefully considered which image of dementia you want to convey.

In the context of written communication, reflecting on the frames represented in your text might help avoid stigma, as these can activate personal schemas in your audience [11, 29]. These frames are conveyed through communication via specific metaphors and word choices. For example, previous research on dementia has shown that more warlike vocabulary aligns with *The invader*-frame, while appeasement-vocabulary relates to *The strange travelling companion*-frame [28]. Additionally, metaphors such as 'the living dead' and 'life as a gift' are associated with frames *The fear of death and degeneration* and *Carpe diem*, respectively. In the context of design outcomes, the focus shifts from a verbal aspect to visual triggers and underlying meanings that evoke personal schemas. For example, if a designer creates a virtual reality experience that allows users to digitally revisit their old neighbourhood, the resulting message aligns with *Each in his/her turn*-frame, which focuses on the carefreeness of the childhood.

Once you are aware of how your messages may be perceived and which frames they might trigger, you can consider if and to what extent the message needs to be adjusted. It is advised to note that while problematizing frames can indeed contribute to stigma, this does not mean they should be entirely avoided. While this paper consistently advocates for a critical and thoughtful approach to problematizing frames, it does not propose a complete shift to de-problematizing frames. Living with a condition like dementia can bring many challenges. It is important to recognize these, especially in validating individuals' emotions. For instance, focusing exclusively on maintaining autonomy (see Table 1, frame 12) might lead individuals living with dementia to feel that the impact

of their condition is not adequately acknowledged ('It can be managed with a few tools'). Moreover, maintaining trust between caregivers and patients is crucial, as emotional distress can further exacerbate cognitive decline. Therefore, it is essential to balance the use of counter-frames with problematizing frames in communication.

3 Conclusion

This paper provides guidelines for uncovering the personal schemas of researchers, their colleagues, and people living with dementia involved in research and design projects, aiming to reduce the risk of miscommunication and bias. Additionally, the paper focuses on guidelines for language use within these projects and communication to the broader public. The primary goal of these recommendations is to raise awareness of how dementia is perceived, how these perceptions can influence projects, and how, without this awareness, one may unintentionally perpetuate stigma.

This paper offers guidance on how to adapt discussions about frames to meet the needs of individuals living with dementia, who may struggle with abstract concepts, reflective reasoning, and understanding and using language. This latter aspect remains a gap in the research. It is recommended to regularly reassess the frames shaping the worldview of both others and your own worldview, as this worldview continuously evolves through a learning process that involves negotiating, selecting, or discarding various personal schemas [13, 25]. However, as dementia progresses, there is a decline in cognitive reasoning abilities and verbal communication capacities, which manifest as difficulties in retrieving words, recalling questions and their responses, or maintaining insight into their condition Therefore, the method of investigating frames proposed in this paper has its limitations, as it relies on individuals reflecting on their inner world–such as their interpretations of the condition and their attitudes towards it–and expressing these reflections verbally.

Another caveat of this paper is that the research underlying the recommendations, as well as the study revealing the collective frames, was conducted in Western Europe. Given the cultural dependency of frames, we cannot guarantee that these findings are fully generalizable to other cultures, although the core ideas are likely to be relevant across different contexts. Further research is also needed in this area.

3.1 Positionality Statements of the Researchers

Lisa's positionality. Lisa is a psychologist with clinical experience in geriatric and palliative care within hospital and residential settings. She does not have personal experience with dementia in the context of family or close friends. Consequently, her interactions with individuals living with dementia have primarily been in a professional capacity, only involving those requiring specialized care and support. Her background in psychology and solution-focused practice has shaped her primary goal of enhancing the quality of life for individuals with dementia and providing compassionate care. Through her professional experiences, Lisa came to appreciate that people living with dementia are far more than their cognitive challenges, embodying a richness of identity, and humanity. Lisa's personal schemas are predominantly grounded in *The Good Mother* and the *Unity of Body and Mind*. She actively reflected on these frames while conducting interviews to minimize their potential influence on shaping participants' responses.

Baldwin's positionality. Baldwin is a professor of communication sciences. At the time of writing, Baldwin has engaged with persons with dementia exclusively within a professional context. His research focuses on vulnerable populations, including children, older adults, individuals with mental health conditions, those experiencing poverty, and refugees, with particular attention to issues of perception and stigma. As a Western European, white, cisgender male, and highly educated individual, he

acknowledges the privileges and potential biases inherent in his positionality. Recognizing these influences, he prioritizes open-minded engagement and actively seeks to understand the lived experiences and perspectives of those he studies. In relation to dementia, he has gained an appreciation for the diverse manifestations and impacts of the condition, moving beyond the common perception of it as solely an issue of memory loss. He advocates for empowering persons with dementia by emphasizing their agency and the importance of centering their voices in both research and practice.

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Multi-user Virtual Reality for Social Connectedness: Exploring the Design Preferences of People Living with Dementia and Their Support Persons

Aisling Flynn, Gearóid Reilly, David Healy, Attracta Brennan, Sam Redfern, Marguerite Barry, and Dympna Casey

Abstract

Virtual reality (VR) is increasingly being adopted in dementia research. However, much of the research to date has focused on single-user VR applications with limited attention paid to how multi-user VR (MUVR) applications may be designed to promote or maintain social connectedness. This paper explores the design preferences of seven people living with dementia and their seven support persons to inform a MUVR application for social connectedness. The qualitative data obtained from four focus groups were analysed thematically and resulted in two main themes. The first theme, promoting social connectedness through familiarity, described people living with dementias' need to experience MUVR with someone familiar, including familiar avatars, activities, and multisensory content. The second theme related to the need for an easy-to-use MUVR application to enrich social experiences and improve the quality of the shared MUVR experience. These findings provided design guidelines which supported the development of a MUVR application to promote or maintain the social connectedness of this population. The paper also provides information to support future MUVR design research in this area.

Keywords

Virtual reality · Dementia · Social connectedness

1 Introduction

As the number of people living with dementia continues to increase globally with no present cure, people living with dementia must be supported to live well with the condition [1, 2]. Digital technologies present one alternative means of supporting the social health and wellbeing of people living with a diagnosis of dementia and their support person [3–5]. This paper charts the design process for a multi-user virtual reality (MUVR) application *with* and *for* people living with dementia and their support persons. The bespoke MUVR application explicitly aims to promote or maintain social connectedness.

A. Flynn (✉)
Bournemouth University, Bournemouth, UK
e-mail: aflynn@bournemouth.ac.uk

G. Reilly · D. Healy · A. Brennan · S. Redfern · D. Casey
University of Galway, Galway, Ireland

M. Barry
University College Dublin, Dublin, Ireland

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1.1 Social Connectedness and Socially Assistive Technologies

People living with dementia experience changes to their social health and wellbeing as their dementia progresses, this may manifest as withdrawal from or avoidance of social situations and interactions or decreased confidence communicating with others [6]. In particular, people living with dementia often report experiencing social disconnectedness [7]. Social connectedness is described as the momentary feeling of belonging to a social group or network. Dimensions of social connectedness may include relationship saliency, closeness, understanding each other's experiences, shared understanding and contact quality [8]. This conceptualisation of social connectedness has underpinned previous technology design research with older adults [9, 10] and the broader Human–Computer Interaction (HCI) landscape [11, 12]. Dementia-related changes impact the social connectedness of people living with dementia, which is an important contributor to overall quality of life, mental health and wellbeing. Despite the importance of social connectedness to health and wellbeing, there are often limited opportunities for people living with dementia to engage in social activities suited to their needs and abilities [13]. This highlights the need for novel opportunities to enrich social connectedness. Enriching social connectedness closely aligns with previous dementia and design efforts aimed at fulfilling a social or emotional need for people living with dementia, shifting the focus from disability to embracing their unique abilities [14–16]. Socially assistive technology may be one novel means of supporting social connectedness [4].

Within the context of this paper and previous publications [4, p. 596], socially assistive technology refers to: "assistive technology that is specifically designed for and/or used to promote social health among people living with dementia by enhancing their capacities to (1) fulfil their potential and obligations, (2) manage life with some degree of independence, and (3) participate in social activities" [4], HCI research has explored how best to support the social health outcomes of people living with dementia harnessing socially assistive technologies [16, 17]. The application of socially assistive technologies in gerontology and dementia research is vast and ranges from social robotics to virtual experiences [4, 5, 18, 19]. Exacerbated by the COVID-19 pandemic, research exploring the role of digital technology for social connectedness has gained additional traction in recent years [20, 21]. One particular social technology is MUVR [22–25].

1.2 Multi-user Virtual Reality (MUVR)

Fully immersive VR is described as a computer-generated virtual environment that can be interacted with as if it were real, using a head-mounted display (HMD) [26–28]. MUVR enables two or more people to simultaneously be present in the same virtual world, whereby they can engage and socialise with one another [29]. Recognising that people living with dementia may face technology-related unfamiliarity and dementia-specific challenges [30], MUVR design must accommodate their unique experiences. Despite the commercial availability of generic MUVR applications such as 'VR Chat' and 'Rec Room', there is a paucity of research surrounding MUVR design *with* and *for* older adults. This is particularly true for older adults living with dementia [31].

A multi-site observational study by Kalantari et al. [32] used a collaborative MUVR environment with older adults consisting of a 360-degree travel videos, group puzzles and creativity tasks. When trialled with older adults dispersed across two locations, the application was considered usable by and resulted in increased social engagement and enjoyment [32]. Moreover, engaging with the application in pairs provided a sense of social presence (e.g. a feeling of being in the same space as another person) for people living with dementia. In another MUVR study, reminiscence activities were

perceived to address the social needs of older adults [23]. The co-designed MUVR scenarios aimed to facilitate reminiscence, support healthy ageing and address ageist stereotypes. Similarly, Wei et al. [25] highlighted that co-designed MUVR activities such as travel, reminiscence or experiencing familiar family events supported equal relationships between grandparents and their grandchildren. While the aforementioned studies focused on older adults more generally, it is important to acknowledge the scarcity of research explicitly focused on MUVR design for older adults living with dementia. To date, few studies have explored this intersection, with fewer still explicitly designed for social connectedness. Afifi et al. [22, 33] explored the design and implementation of a MUVR application in partnership with people living with mild cognitive impairment (MCI) or dementia. Their application consisted of 360-degree videos and personalised family photographs and videos. Using the application enriched the social relationships between users and demonstrated the need for future MUVR research in this area.

1.3 MUVR Design and Dementia

Broader MUVR research has identified design choices which encourage social interaction [34]. Some of these considerations include aesthetics, avatar-mediated communication, social mechanics and activity preferences [34]. As noted by Handley et al. [35], MUVR design taxonomy is organised into three design areas: the self (avatar representation, customisation, manipulation and locomotion), interaction (communication privileges, types, activities to scaffold interaction) and the environment (user manipulation of the environment, spawning area, openness of environment).

As reported by Houben et al. [16], the aesthetics of design is important to facilitate meaningful technological experiences for people living with dementia. Although often overlooked in dementia and technology design, aesthetics plays an integral role in how such technologies are accepted and scaffold multisensory experiences [36, 37]. Research with older adults also suggests that the aesthetic appeal of the virtual space contributes to one's sense of presence in VR [38]. This, in turn, may influence one's social experience. Avatar aesthetics and avatar-mediated communication are other key aspects of MUVR design which strengthen social engagement [23, 25, 35, 39, 40]. Avatar-design plays an important role in facilitating social presence [40, 41]. Despite this, limited MUVR research describes avatar design with older adults or people living with dementia [25, 32, 40, 42].

While the previous studies provide frameworks for MUVR design more generally, there remains a lack of consolidated guidance for dementia design that considers the self, interaction and the environment [22, 33]. Moreover, given the subjectivity of experience, the design of digital technologies such as MUVR and their aesthetic must be elicited through the active involvement of people living with dementia and their support persons. Drawing on previous literature, this paper focused on identifying the overall aesthetics, multisensory design features, content and activity preferences of older people living with dementia to inform the development of the MUVR application. This work therefore aimed to expand the evidence surrounding MUVR design for people living with dementia through the lens of social connectedness.

This paper outlines the design, methodology, methods of data collection and analysis used to address the research aims. The qualitative findings are presented and discussed in relation to wider literature in the dementia and design field. Implications for future research are also noted.

2 Method

People living with dementia must be involved in the design of socially assistive technologies, facilitated through the adoption of participatory methods and approaches [15]. This research formed one phase of a larger participatory action research (PAR) project [7, 43, 44]. This study

adopted an explorative approach, using qualitative online focus groups to elicit the MUVR design preferences of people living with dementia and their support persons. The value placed on online design research with people living with mild dementia has been noted by Dixon et al. [45] and informed the design of this study. Given the COVID-19 pandemic and geographical distance between members, focus groups were completed on Zoom between January and April 2022. This research was approved by the University of Galway Research Ethics Committee (reference number 2021.03.007).

2.1 Recruitment and Sample

People living with dementia were eligible for inclusion if they were over 59 years of age, self-reported a formal diagnosis of dementia, resided at home and had a nominated support person who consented to participate in the research. The nominated support person had to be over 18 years of age. All people living with dementia and their support persons were relatives, had participated in previous project phases, had experienced a single user VR application and understood the interactive capabilities of VR [43]. Additional details of the recruitment procedures are available in previous publications [7, 44].

Each person living with dementia participating in this study was considered to have either mild or moderate dementia, with a range of 1–7 + years since experiencing initial memory difficulties. The stage of dementia was guided by the National Institute of Aging-Alzheimer's Association [46] and the Diagnostics and Statistics Manual of Mental Disorders (5th edition) stages of dementia (i.e. mild, moderate, severe) [47]. Table 1 presents demographic information related to the people living with dementia and support persons participating in this study.

Table 1 Demographic information related to people living with dementia and support persons

Characteristics	Number of people living with dementia	Characteristics	Number of support persons
Gender		*Gender*	
Male	5	Female	7
Female	2	*Age Range (years)*	
Age range (years)		30–39	1
59–69	3	40–49	1
70–79	3	50–59	4
80+	1	60–69	1
Current Support Person		*Person living with dementia relationship*	
Spouse/Partner	4	Spouse/Partner	4
Daughter	3	Father	1
Years living with memory difficulties		Mother	2
1–3	4	*Years supporting the person living with dementia*	
4–6	2		
7+	1	0–4	5
		5–9	2

2.2 Procedure

Seven people living with dementia and their seven nominated support persons participated in one of four online focus groups. Each involved a maximum of four attendees, alongside the first author (AF) and the games developer (GR) who assisted with any technical issues. The focus group distribution is reported in Table 2.

For design research, people living with dementia must be supported and empowered to express their needs and preferences [48, 49]. Aligned with PAR, the group co-produced the

Table 2 Focus group distribution*

Focus group	Number of people living with dementia	Number of support persons
A	2	2
B	2	2
C	2	2
D	1	1

* Each person living with dementia and their nominated support person attended the same group

focus group schedule at the end of the previous study phase. People living with dementia expressed a preference for small group sizes, pre-circulated materials (one week prior), comfort breaks and a 90-minutes duration for each session.

Images and worksheets were circulated in advance of the focus groups to aid preparation, reduce some anxieties associated with answering questions and facilitate meaningful discussion. Images included a basic multi-user virtual environment (MUVE) (Figs. 1 and 2), sample avatar designs (Fig. 3) (using MakeHuman and Ready Player Me applications), alongside two worksheets to record shared music and activity preferences.

The choice of such strategies to increase engagement were closely aligned with Shastri et al. [50] and provided implicit cues for people living with dementia and their support persons to spark discussion related to abstract topics, such as avatar design, MUVR aesthetics or the scale of the MUVE.

Verbal informed consent was obtained from each person living with dementia and their support person prior to each focus group. These followed a semi-structured format to support flexibility, an important consideration for people living with dementia. These discussions focused around the previously circulated images and worksheets and a video of a basic MUVR prototype. The structure consisted of (a) introductions, (b) an update on the current work to date and outcomes from previous study phases (reviewing the images provided), (c) a discussion of shared activities and music preferences (using the worksheets to prompt discussion), (d) a discussion on the social aspects of avatar representation and communication methods (verbal, non-verbal communication and avatar design preferences, guided by the avatar images), (e) a discussion of controller interaction and the methods of navigation in MUVR.

2.3 Data Analysis

The qualitative data gathered from each focus group were audio-recorded and transcribed verbatim. NVivo 20 software was used to store and

Fig. 1 Images presented to spark discussion

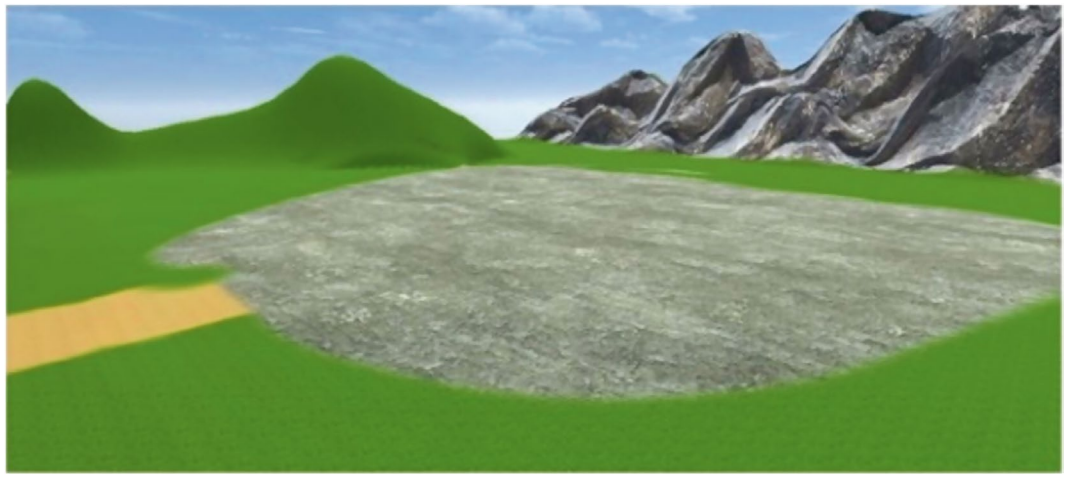

Fig. 2 Image of an open space within MUVR to spark dicussion regarding the content, shared activities and aesthetics

Fig. 3 Avatar design examples (full and partial-bodied)

manage the analysis process, ensuring an audit trail. Braun and Clarke's [51] reflexive thematic analysis approach guided data analysis of each transcript. This approach enabled the construction of themes drawing on the lived experiences of people living with dementia and their support persons to address the research aim and identify their MUVR design preferences. This involved an iterative process of (a) familiarisation, (b) coding, (c) initial theme generation, (d) developing and reviewing themes, (e) refining, defining, renaming themes and (f) report writing [51].

Transcripts were read and re-read to become familiar with their content and AF made some initial notes and observations. Relevant passages from all four focus groups were coded by AF,

capturing the views of both people living with dementia and their support persons. Codes were then grouped into initial candidate themes which reflected the patterns in the focus group data. These themes were then further developed and reviewed by the wider research team (AF, GR, AB, SR, MB, DC) to ensure coherence within each theme and the entire data set and alignment with the overall aim of the study. Moreover, a video presentation of the preliminary themes was circulated to people living with dementia and their support persons to reflect on and confirm whether they felt they accurately reflected their discussions. The feedback received was inputted into NVivo and themes were then further refined and defined. The findings were then drafted, critically reviewed and agreed by the research team (AF, GR, DH, AB, SR, MB, DC).

Several strategies were adopted to enhance trustworthiness including, member reflections, peer debriefing and reflexive journalling. Focus group discussions promoted the triangulation of perspectives between people living with dementia and their support persons. Regular meetings also supported reflectivity, whereby the research team, people living with dementia and their support persons reflected on their experiences and how their worldview influenced the research. The findings are supported by illustrative quotations to ensure that the experiences of people living with dementia and their support persons are to the fore. Demographic details are also provided for people living with dementia and their support person, which may aid transferability of the findings to other contexts.

3 Findings

Two main themes were developed relating to the design of MUVR for social connectedness, (i) promoting social connectedness through familiarity and (ii) an easy-to-use and adaptable MUVR design to enrich social connectedness.

3.1 Promoting Social Connectedness Through Familiarity

This theme related to the importance of a familiar MUVR design to support social connectedness. The idea of familiarity spanned across multisensory content in the MUVE, being in MUVR with familiar others and familiar activities.

Familiar, relatable and easily identifiable multisensory content within the MUVE was considered important to support social connectedness. Such content was considered crucial to evoke memories and spark conversations between people living with dementia and their support persons. Colourful, vibrant visuals and ambient sounds were perceived as focal discussion points by people living with dementia and their support persons while using the application. For example, emphasis was placed on incorporating bright colours, bird song and water sounds into the nature elements and outdoor forested areas. A colourful aesthetic and theme was positively perceived when reviewing the MUVE images (Figs. 1 and 2) and video as evidenced in this excerpt: "*I think that they [images of the MUVR application] are lovely, I really think it's great. I like the colours*" (Person living with dementia 9). When viewing the prototype video, a support person suggested adding more sounds: "*I would love the sound of rustling leaves*" (Support person 3).

Across all focus groups, people living with dementia and their support persons agreed that to promote social connectedness, the MUVE should have a familiar layout and theme each time. They noted that the application should portray an open, communal virtual space relatable to a real-life social environment. Ideas proposed during the focus groups included a village scene with various stores, a community centre, a carnival or funfair. People living with dementia and their support person also reiterated that in order to support social connectedness, there was a need for mutually familiar, interesting and fun

shared activities and music. Music and dance, nature, sport, travel, virtual vacations, cognitive stimulation activities (such as word searches or word games), fantasy and role-play games, meditation and mindfulness activities were common suggestions which held mutual interest for both people living with dementia and their support person. These activities were considered meaningful and resonated with participants' current or past interests. Additionally, they were also regarded as a means of reconnecting to activities which were no longer accessible due to dementia-related challenges, or presented a novel activity that they "*wouldn't normally get to do*".

Using MUVR with those whom people living with dementia had a pre-existing, close relationships with or with those who shared a common interest was seen as a source of comfort and encouragement. This was a consistent finding across focus groups. Familiarity between users was perceived to make the experience more engaging. This included how one was represented in the MUVE and avatar design. There was mutual agreement among people living with dementia and their support persons across all focus groups that to support social connectedness, the avatar designs must be familiar, friendly and approachable. Full-bodied, human-like avatars were universally favoured, attributed to their resemblance with real-life humans as opposed to half-body or partial-body options which were considered "*too abstract and unappealing*". One person with dementia noted: "*I'm not really into the head and hands [half-bodied avatars] [..] It just doesn't look like a person*" (Person living with dementia 6). Similarly, the MakeHuman avatar designs were considered "*menacing*" and unapproachable while the Ready Player Me options were perceived as "*brighter*" and "*friendlier*". Other suggestions to enhance the familiarity of avatars in the MUVE included having the option to account for age (when preferred), to include nametags close to each avatar and to highlight avatars when they are speaking in MUVR.

3.2 An Easy-To-Use and Adaptable MUVR Design to Support Social Connectedness

A common thread across all focus groups was the desire for an adaptable and intuitive application design to support social connectedness. An easy-to-use application, designed for sustainability, that could adapt to the changing needs of people living with dementia was also favoured. This included preferences for natural and accessible communication methods, minimal controller use and navigation, various activity levels and an undemanding aesthetic. Natural and accessible means of communication such as simple lip-sync and speaking into the HMD were perceived to facilitate shared experiences and reciprocal interaction between avatars in MUVR. One person living with dementia noted: "*I don't think it [verbal communication] has to be so perfect. I would be quite happy with that [talking through the HMD]*" (Person living with dementia 7). Adaptive sound and volume to accommodate the sensory needs of people living with dementia, such as those wearing hearing aids, was another key finding. In addition to verbal communication, simple non-verbal interactions through avatars were also perceived as important to support social connectedness. A support person emphasised the importance of physical gestures in MUVR and the ability to observe each other's avatar movements in the MUVE: "*The physical gestures are important; it's a big part of the novelty of being in the VR environments that you could express with your arms and that it will be seen by the other person*" (Support person 6).

In a bid to support the dynamic needs of people living with dementia and to support their agency, people living with dementia and their support persons desired "*to have a choice*" (Person living with dementia 6) between interactive and less challenging, passive activities in MUVR. A support person reported: "*One day you might be in the mood just for listening to a*

concert and relaxing. Another time, you might be in the mood for something more energetic, and so a mix [of activity levels] will be perfect" (Support person 1). To also account for dynamic needs, people living with dementia consistently emphasised the importance of simple and intuitive menu options and user interface panels. This included clearly labelled and "*easy-to-find*" activities, accessed by one main controller button. Another popular suggestion for easing navigation and reducing navigational stress was to clearly signpost shared activities by mapping each to a relevant storefront in the MUVE. For example, music activities could be hosted within a dancehall storefront, so that clicking on the dancehall would directly load the music activities.

These features were considered crucial for simplifying interaction and navigation, allowing more focus on the social elements, thus promoting social connectedness. This was mirrored by a support person, who made the connection between ease of navigation and overall enjoyment of the MUVR experience: "*I think make it [navigation in MUVR] simpler and you would get much more from it. My mom would have much better enjoyment of the whole thing*" (Support person 5).

4 Discussion

This paper explored the design preferences of people living with dementia and their support persons to inform a MUVR application for social connectedness. When usability difficulties arise, it impacts the overall social experience. Therefore, to support positive social experiences such as social connectedness, the findings suggest that MUVR must be designed with familiarity, ease of use and adaptability at the fore. The findings of this paper and the derived design preferences discussed below contribute to the existing paucity of research pertaining to MUVR design in this area.

4.1 MUVR Design Preferences for Social Connectedness

Relatable avatar design and representation. People living with dementia and their support persons expressed a preference for relatable, full-bodied, humanistic avatars as opposed to more abstract half or partial-body options, reflective of other VR research with older adults [32]. Avatar relatability was considered important to assist people living with dementia to associate the avatars in MUVR with themselves and others [25, 53] and may contribute to key dimensions of social connectedness, namely closeness, social presence and awareness [8, 9].

Natural and easy means of avatar-mediated communication. People living with dementia and their support persons preferred simple avatar-mediated communication, speaking into the headset microphone as you would in real-life. Likewise, the value placed on authentic verbal communication in VR is mirrored in previous work by Baker et al. [40], O'Connor et al. [54] and Waycott et al. [55]. However, positive avatar-mediated communication was considered contingent on lip-sync functionality and clear representation of which avatars were speaking to avoid unnecessary anxiety or confusion.

Facilitate MUVR use with familiar others through familiar activities. Having the person living with dementia use the MUVR application with someone familiar was considered a means of promoting or maintaining social connectedness, by using knowledge of one's life story to scaffold conversation and interaction in MUVR. Previous research has also noted that designing VR for shared use with people living with dementia and their family members had social benefits [22, 33, 56]. This existing familiarity with one another must translate to the virtual world, where the person living with dementia can recognise their support person's avatar. Nametags and a variety of avatar design options should be implemented to facilitate this, alongside the aforementioned need for verbal communication.

Drawing on the focus group findings, it is recommended that MUVR designs include activities that are *familiar* and *mutually meaningful* for both people living with dementia and their support person. Mutual engagement in shared activities may play a crucial role in fostering social connectedness by addressing key dimensions such as 'knowing one another's experience' and 'shared understanding' [8]. Such activities may also provide opportunities to converse about the content and share personal life stories, a finding supported by Kolasinska et al. [17]. Moreover, this aligns with other VR researchers [25, 39, 57, 58], who found that meaningful activities, aligned with real-life interests, contributed to positive experiences for older adults and people living with dementia. While some of these studies focused on single-user environments, this paper extends these findings to a MUVR context, highlighting that the positive impact of tailored activities may persist even when multiple users are involved.

Familiar and multisensory aesthetic. The findings propose a MUVR design that is familiar and multisensory for people living with dementia and their support person. Consistent with previous work [53, 59], the findings support the incorporation of a natural aesthetic, with colourful nature scenes and ambient sounds. The value of aesthetics in supporting engagement in VR has been acknowledged in previous VR design guidance for older adults [38, 53]. Moreover, this design preference closely aligns with other HCI research which signposted the link between aesthetics and technology acceptability for people living with dementia [60, 61].

Easy-to-operate and adaptive MUVR design. Considering the focus group findings, it is advisable to implement easy-to-operate and adaptive means of interaction, navigation and communication within the MUVR application. This may include natural verbal communication, one-button controller interaction and navigation, various activity levels (ranging from passive to more interactive), clear and intuitive user interface panels and signposting. Sanders et al. [62] similarly offered design guidance, emphasising the importance of incorporating varying levels of complexity and interactivity when developing VR for users of different ages and cultural backgrounds. While this design recommendation is novel to MUVR design for social connectedness, the need of adaptive design is widely supported by previous dementia researchers to ensure sustainability of technological solutions [4, 63].

4.2 Limitations

This paper shows that, with appropriate procedures, people living with dementia can meaningfully contribute to MUVR design through online focus groups. The co-produced focus group schedule fostered group synergy, enabling collaborative idea exchange from the comfort of home. Furthermore, using tangible prompts helped guide people living with dementia and their support persons to lead the conversation, foster collaborative dialogue and promote idea generation, particularly on abstract topics like avatars [62, 64]. As people living with dementia and their support persons were involved in earlier study phases, their existing familiarity with the research process, design methods, technology and each other strengthened data collection for this study. However, some limitations are noted.

The sample size may be considered small. However, this is not uncommon in early-stage technology design and dementia research [50]. Support persons occasionally dominated discussions, a challenge noted in dementia research [51]. The first author addressed this by gently verifying support persons' viewpoints with individuals with dementia and allowing time to review and feedback on early findings. Additionally, the focus group with one couple, due to scheduling conflicts, may have limited the depth of insights because of the lack of group interaction. Finally, people with dementia and their support persons based their discussions on images and a video of the MUVE rather than experiencing it firsthand through a VR headset.

Using the headset may have offered a more detailed perspective of the avatar designs and MUVR content, potentially eliciting more comprehensive feedback.

4.3 Implications for Future Research

As evidenced in the discussion, there is limited MUVR design research focused on people living with dementia and fewer still focused on social connectedness. This paper is the first of its kind to describe the preferences of people living with dementia and their support persons with respect to MUVR design for social connectedness. This paper provides evidence to support future MUVR development not only for social connectedness, but for MUVR design more generally. This is particularly pertinent given the increased global prevalence of dementia, rapid technological advancements and increased social disconnectedness [7].

As previously noted, the design preferences shared in this paper have been translated into a bespoke MUVR application to promote or maintain social connectedness [44]. Future research should build on this work to investigate how to optimally design MUVR to accommodate shared experiences across geographical distance or with different groups such as people living with dementia and their grandchildren or friends.

5 Conclusion

In conclusion, this paper contributes to addressing the paucity of research on MUVR design for people living with dementia. It further informs the development of MUVR technologies aimed at promoting or maintaining social connectedness for both individuals living with dementia and their support persons. The findings highlight two key themes: promoting social connectedness through familiarity and an easy-to-use and adaptable MUVR design to enrich social connectedness. These themes suggest design preferences that can guide the future development of MUVR applications for social connectedness. Specifically, these preferences include: relatable avatar design and representation, natural and intuitive means of avatar-mediated communication, facilitating MUVR use with familiar others through familiar activities, a familiar and multisensory aesthetic and an easy-to-operate and adaptive MUVR design. In summary, these findings aim to address the limited research on MUVR design for people living with dementia, particularly in the context of fostering or maintaining social connectedness. By highlighting these gaps and insights, this work seeks to encourage additional research in this field to advance the design and application of MUVR technologies.

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Including Design in Dementia Care

Social Robots at Play: Enhancing Social Interaction and Well-Being for People with Advanced Dementia and Their Ecosystem in a Secured Care Context

David Unbehaun, Elisabeth Raß, Jutta Tandler, Gaby Lenz, and Volker Wulf

Abstract

This paper presents a social robot-based intervention to playfully increase physical activity, cognitive capabilities, and socio-emotional interaction of people with advanced dementia and their caregivers. Furthermore, we present preliminary results that demonstrate the impact and appropriation of using the system in a secured care environment over 10-months with overall 23 participants, including 13 people with advanced dementia, their family members, and professional caregivers. Our early findings indicate that the use of the social robot supported well-being, engagement, and social interaction of people with advanced dementia, even demonstrating the ability to create new memories and experiences. We discuss future challenges for research aiming for socially embedded innovations that address the social actors involved and thus contribute to practical and playful solutions for people with advanced dementia and professional care.

Keywords

Dementia · Social robots · Health

1 Introduction

Europe's demographic shifts, particularly in Germany, present growing challenges as life expectancy increases and birth rates decline, resulting in fewer skilled workers. These changes impact families, the labor market, social security, and politics. An aging population correlates with a higher demand for long-term care, expected to rise from 3.5 to 5.3 million by 2050 in Germany. Additionally, the risk of dementia, traditionally viewed as a medical issue, is rising. Recent shifts advocate for a holistic perspective on dementia, acknowledging its socio-emotional and psychological impacts [9, 10, 27]. Appropriate interaction with individuals at different dementia stages requires understanding of their experiences and social context [47, 55].

D. Unbehaun (✉)
Clausthal University of Technology, Clausthal-Zellerfeld, Germany
e-mail: david.unbehaun@tu-clausthal.de

D. Unbehaun · E. Raß
Institute for Digital and Sustainable Cooperation, DNZ gGmbH, Siegen, Germany

J. Tandler
Diakonie Nord-Nord-Ost, Lubeck, Germany

G. Lenz
Kiel University of Applied Sciences, Kiel, Germany

D. Unbehaun · V. Wulf
University of Siegen, Siegen, Germany

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Studies show that physical training and meaningful activities can enhance the mental health, cognitive function, and physical abilities of people with dementia, helping them cope with daily challenges [5, 6, 15, 60]. Music-based activities, in particular, engage brain regions less affected by dementia, evoking memories and improving well-being for both people with dementia and their caregivers [4, 41, 42, 58]. Digital interventions, such as conversational user interfaces, wearables, social robots, and exergames, have shown promise in improving fitness and well-being across age groups [11, 12, 27, 54, 59, 62, 64]. These activities can alleviate depression, anxiety, and stress in people with advanced dementia [14, 23, 28].

However, research on long-term technological interventions for advanced dementia is limited, highlighting the need for studies focusing on the individual and socio-emotional impacts of such technologies. The study is part of the German research project ROBUST, which focuses on robot-based support for prevention and health promotion in care facilities. This project is funded by the Association of Substitute Health Funds (in German: Verband der Ersatzkassen e.V. (vdek). This work presents early insights of a 10-month exploratory study in a secured care environment, examining the long-term use of a robotic system designed to promote physical, cognitive, and socio-emotional activities for people with advanced dementia and their caregivers. We observed 13 people with advanced dementia and their caregivers, conducting 43 observation sessions, eight semi-structured interviews, and two group discussions. Our findings indicate that the robotic system fostered memory creation, social interaction, and positive emotions. The work presents a robotic-based system, consisting of several applications that we partly incorporated based on classical evidence-based interventions and activity programs as well as integrated from individual preferences and socially established activities within the participating care-facilities.

Our study addresses the following research questions: (1) How do people with advanced dementia perceive and interact with the humanoid robot Pepper? (2) What are the socio-emotional and ethical challenges of using social robots in this setting? These insights aim to inform future research and development in Human–Computer Interaction and Human–Robot Interaction to create appropriate and inspiring technologies for people with advanced dementia and their caregivers in secured care environments.

2 State of the Art

2.1 Challenges in Care in Advanced Dementia Settings

Due to demographic shifts and aging populations, the demand for long-term care is increasing, with dementia being prevalent among those needing care [32]. Dementia often forces individuals to leave their homes and social surroundings. From a biomedical perspective, dementia poses challenges in daily care due to symptoms like memory loss and disorientation [2, 49, 67]. Early-stage dementia causes temporal disorientation, leading to missed appointments, disturbed sleep patterns, and difficulties in estimating time, often resulting in depression and social isolation. Advanced dementia may impact on orientation, can impair verbal communication, hinder performing daily activities independently, and may lead to behavioral changes which often results in requiring 24-h care. In late stages, loss of motor control leads to immobility and bedriddenness [7, 21, 39].

Recent focus on the social aspects of dementia highlights the daily challenges faced by people with advanced dementia and their families. Creating environments that foster positive communication and interaction is crucial. Kitwood's person-centered care approach emphasizes viewing people with advanced dementia as individuals with unique needs [31]. Despite academic progress, there is a need for more interdisciplinary research to bridge the gap between quantitative and qualitative findings

in ICT development for advanced dementia care. Kitwood's holistic perspective on dementia, considering both neurological implications and the psychosocial environment, is gaining more and more attention in Human–Computer Interaction (HCI) circles [10, 26, 30, 34, 35, 40, 41, 65]. This perspective underscores the complex interplay between individuals, their relationships, and care structures. The shift towards a broader view of dementia, acknowledging the emotional and organizational challenges faced by caregivers, advocates for moving away from deterministic views and focusing on well-being and individual needs to improve understanding and care for people with advanced dementia and their families [51, 52].

2.2 Beneficial Activities, Social Robots, Digital Interventions in Dementia

Many studies highlight the positive effects of exercise in dementia, particularly programs focusing on motor skills training for activities like standing, dressing, and balancing [5, 22, 33, 46]. These exercises improve physical and cognitive functions, benefiting all stages of dementia by enhancing walking speed, functional mobility, and balance. Creative activities like art and music therapy also positively impact sociability, self-esteem, and cognitive function [17, 36, 38, 48, 50]. Human–computer interaction (HCI) research in dementia care has grown, focusing on social participation, autonomy, and quality of life [9, 10, 13, 18, 29, 35, 42, 53, 57]. Technologies such as exergames and virtual reality can enrich experiences and support interaction and emotional well-being. However, the integration of humanoid social robots (SR) in (advanced) dementia care remains controversial due to concerns about the authenticity of interactions and the awareness of people with dementia [45]. Robotic technologies have shown promise in assisting with daily activities and reducing symptoms like agitation and depression. Studies indicate that robots can improve engagement, mood, and quality of life, but their effectiveness in assisting with basic activities of daily living (ADL) is less clear. There is a need for more comprehensive research to understand the long-term effects of using robots in advanced dementia care. Various literature reviews and meta-analyses suggest that social robots can reduce loneliness, enhance social connectedness, and motivate people with dementia to engage in activities suggesting that this might likely be the case for people with advanced dementia [1, 3, 47]. However, the acceptance and effectiveness of these technologies vary, and further research is needed to optimize their use and address potential limitations. In summary, while robots and creative activities hold promise for improving the well-being of people with advanced dementia, more research is needed to fully understand their impact, particularly in secured care environments for those with advanced dementia [47].

2.3 Designing Playful Robotic Interactions in the Context of Advanced Dementia and Secured Care Environments

Bouchard et al. [8] recommend creating suitable interaction mechanisms for cognitively impaired individuals and adapting serious game designs to their cognitive abilities [8]. Involving all stakeholders, including people with advanced dementia, in the design, development, and evaluation processes is crucial. Hendriks et al. [20] found it challenging to develop universal guidelines for people with advanced dementia due to the individualized nature of dementia [20]. More research is needed to determine basic requirements for dementia care. Long-term ethnographic studies with people with advanced dementia and their caregivers provide deep insights into their unique needs and inform collaborative design decisions. Mayer and Zach have raised concerns about the limitations of traditional participatory methods for people with advanced dementia, emphasizing the importance

of building trust and caregiver involvement in the research process [37]. Ethnographic methods, combining observations, interviews, and group discussions, enhance the understanding of complex care settings. Including co-researchers in care facilities helps access difficult environments and offers valuable insights into the impact of social robots. A comprehensive approach is necessary to understand social robots in care settings, considering the needs and preferences of both people with advanced dementia and caregivers [12, 43]. Wan et al. [63] demonstrated the importance of stakeholder contributions in designing a GPS monitoring system for dementia care [63]. Foley et al. [16] emphasized the value of interactions with people with advanced dementia through tangible objects [16]. Soler et al. evaluated the therapeutic effects of a humanoid robot (NAO), an animal-like robot (PARO), and a real therapy dog in dementia care, revealing mixed results [61]. Both robots reduced apathy but also had some negative effects, such as increased delusions and irritability. These findings highlight the potential and challenges of using robots and therapy dogs in dementia care, indicating the need for further research and refinement to confirm their effectiveness.

2.4 Research Question and Contribution

As explained a variety of activities can positively impact people living with dementia and their caregivers, but there's a need for innovative solutions that integrate meaningful experiences into daily routines. Currently, there is a lack of empirical research on the challenges faced in secured care environments for people with advanced dementia. More studies in Human–Computer Interaction (HCI) and Human–Robot Interaction (HRI) are necessary to develop innovative and playful systems like Social Robots (SR), informed by practical insights from people with advanced dementia and their care networks. This study examines the impact of a robot-based system, focusing on the role of people with advanced dementia, relatives and professional caregivers in daily life. It explores the system's effects on people with advanced dementia and their social care networks, aiming to improve quality of life and well-being in assisted care environments.

3 Project Background, Methods and Research Design

The study setting and framework is part of the German research project “ROBUST”, that focusses on robotic-based support for prevention and health promotion in care facilities and is founded by the Association of Substitute Health Funds (in German: Verband der Ersatzkassen e.V. (vdek)). This Association represents the interests of overall six substitute health funds in Germany and also acts as their service provider. This research initiative is part of prevention strategy of the National Association of Statutory Health Insurance Funds (in German: GKV-Spitzenverband). The aim of the research project is to design and develop a prevention-oriented robotic-based system for people in need of care. Over a ten-month period, we conducted a case study in a secured care area for people with advanced dementia in a major care facility in Lübeck, Germany. Employing an ethnographic approach, we accompanied people with advanced dementia, their relatives, and caregivers in their daily lives to gain rich insights into their activities and interactions. Our study aimed to understand their biographical backgrounds, memories, social contexts, and attitudes toward technology.

Notably, the work we report on here was supported by one funded half-time co-research positions in the care-facility in Lübeck. We trained and qualified the co-researcher, who has a background social care, fostering a collaborative approach. This allowed us to access a vulnerable population often overlooked, building upon existing trustful relationships. Inspired by prior exploratory studies in general, we conceptualized and designed a playful set of application for a long-term case study to explore how Social

Robots (SR) may impact the socio-emotional well-being of people with advanced dementia and the care environment.

3.1 Participants and Setting

Within the secured care environment residents are not allowed to leave without being accompanied by a caregiver or relative. It is in a side wing of the care facility on the second floor. Within the confines of the closed accommodation, a unique protocol secures entry for both professional caregivers and visitors seeking access to this particular section of the nursing facility. To gain access via the stairwell, individuals must engage a locking mechanism on the door. The secured nursing area, with 27 individual patient rooms, is centered around an atrium. Room doors are typically unlocked, except for storage, the kitchen, and the office if unstaffed. Collages of residents' names, photos, and biographical information are displayed next to the room doors.

In our study, 23 participants, including people with advanced dementia, their relatives, and professional caregivers, were involved (n = 23). They engaged in robotic-based group sessions, interviews, and discussions. Among the 32 residents in the Secured care-area during the ten-month period (n = 32), 13 residents participated in 25 regular robotic-based group sessions (n = 13). The participants, aged between 65 and 90, included seven males and six females. All had advanced dementia symptoms, including disorientation and high-risk behavior. Unfortunately, one participant passed away after eight months (n = 1). The participants were chosen on a voluntary basis and showed interests through participation if SR was used in the group sessions. Mrs. C., the caregiver and responsible co-researcher in the facility within this study, organized and managed the SR-based group sessions. As a long-term professional caregiver in the care facility, she could already build trustful relationships to the residents and had the experience and professional background as well as the sensitivity that the use of SR in interaction with this vulnerable target group requires. Three family members (n = 3) gave interviews or participated in robotic-based group session. We furthermore conducted group discussions and interviews with overall seven professional caregivers (n = 7), one was the manager of the care facility (n = 1), four of them worked as social caregivers (n = 4) and two as nursing caregivers (n = 2),six were female (n = 6) and only one was male (n = 1).

3.2 Data Collection

To ensure a comprehensive understanding of the implementation and impact of socially assistive robots in nursing facilities, we employed a combination qualitative data collection methods. Central to this approach was the involvement of a professional caregiver as a co-researcher, which allowed for trust, accessibility, and practical expertise to enrich the research process. The Co-Researcher, Ms. C. was introduced to research methods and field notes at the beginning of the study, enabling her to provide observation protocols after each session with the SR. These field notes provided first-hand material of the real-life environment, how people with advanced dementia use and adapt to an SR, and how its use affects the living conditions, daily routines, and social practices of residents, as well as the interaction between residents and caregivers.

In addition to the co-researcher's contributions, researchers employed various qualitative methods to ensure data triangulation and maintain data quality: Researchers conducted on-site observations of the social robot-based interventions, focusing on interactions between residents and the social robot in real-time. The residents were encouraged to provide situational feedback during their direct interaction with the social robot. The researchers also informed relatives in advance, conducted interviews with family members, and incorporated their insights into the evaluation process. Furthermore, professional caregivers participated in group discussions to share their perspectives on social

robots integration into workflows and its impact on resident care. A rich dataset emerged from these efforts, comprising more than 150 pages of field notes, observation protocols, interview transcripts, and group discussion transcripts. To analyze this data, the research team employed a deductive coding approach as advocated by Kuckartz.

Moreover, researchers conducted additional participant observations, collected situational feedback from oriented residents, and informed relatives in advance and interviewed family members to ensure they are involved in the process. As mentioned above, group discussions with caregivers were also held.

3.3 System Overview and Applications

The care facility's final technical setup featured the humanoid robot Pepper, known for its social interaction skills and expressive design. Pepper, equipped with cameras and lasers for autonomous navigation and emotion recognition, was programmed using Choregraphe and Android Studio. Git for the code repository, Figma for mockups, Jira for management and we have used a Linux-VServer for the distribution of data. In addition, we have used various self-written scripts for the data conversions.

Initially, a basic prototype of Pepper and applications for social-emotional, cognitive, and physical activation were co-designed with residents, caregivers, and therapeutic experts, based on evidence-based interventions from fields like sport-gerontology and training sciences. These interventions were iteratively tested in heterogeneous group settings with residents without dementia or in early stages of dementia before the study with people with advanced dementia. All applications were developed based on resident needs, caregiver input, and existing non-digital health promotion interventions. They aimed to improve overall well-being through movement exercises, cognitive games, and a jukebox for musical entertainment. The design and development process involved collaborative workshops with caregivers, researchers, and developers, incorporating feedback and iterative refinement. Remote testing provided valuable insights, and applications were tested in various care settings before use with people with advanced dementia.

3.4 Ethical, Legal, and Social Considerations

Based on the approval of the Gernan Association of Social Work (DGSA) ethics committees, we ensured the privacy and data security of the participants, the interviews with people with advanced dementia and their relatives were conducted in consideration of various documents to respect and guarantee the privacy of personal data. These documents were prepared according to legal provisions and valid only when combined with a personal declaration of consent, which the participants could revoke at any time. Special attention was given to obtaining informed consent from participants, ensuring their dignity and autonomy were respected while balancing this with the consent of their legal guardians. Participants were asked for their informal consent both prior to and during the activities. Researchers and caregivers demonstrated heightened sensitivity to recognize and interpret how persons with advanced dementia might express their willingness to participate—whether verbally or nonverbally. Additionally, to avoid medical complications, a medical declaration of no objection, in which each participant excludes certain medical risks, was prepared. The mentioned documents were part of the ethical approval. Because of its sensors, especially Pepper's cameras, the system was only connected to the Wi-Fi for updates in non-public areas to protect the privacy of residents, staff, and visitors. Regarding the vulnerable target group, relatives and legal guardians were informed and gave their legal consent. Special attention was paid to the informed consent of the participants' meaning that their situational will and their reaction were respected and overweighed the consent of the legal guardian. Informal consent requires a high sensitivity of the caregivers so that they can

see and understand how people with advanced dementia declare verbally or nonverbally their intention to participate or not.

3.5 Interactive Sessions

In the secured care environment for people with advanced dementia, Pepper was used primarily in group sessions held in the community room, where residents formed a circle around Pepper. A staff member operated Pepper using a tablet, with the robot either standing in the center or joining the circle. Some non-participating residents moved around the lounge during activities causing an agitated atmosphere. Pepper was also used for one-on-one interactions with interested or bedridden residents, with the Jukebox app being particularly popular for its familiar songs and cognitive exercises (Fig. 1).

The group sessions were performed in groups of 4–10 participants 2–3 times a week with 30 min per session for overall 10-months in a group area so that also other residents can if they want. The social collaboration during group sessions often encouraged all participants and thus generated a cooperative, respectful, and motivating atmosphere. Relatives and professional caregivers reported having noticed the positive emotions, collaboration, and expressions that the people with advanced dementia exhibited while using the system and that the games were a starting point for further discussions, even after the sessions. During the moderated group sessions, we observed how participants interacted with the system and how collaboration and social experiences were facilitated by its use.

4 Preliminary Results

After the system had been deployed, the impact of the system was continuously assessed, refined and extended to reflect insights arising from observations of its use and feedback. Below we present the preliminary findings focusing on the perception and interaction of people with advanced dementia with SR, taking into account the ethical and social challenges within the deployment of SR in the context of people with advanced dementia.

4.1 Positive Perceptions and Social Engagement

When the SR, Pepper, was introduced by professionals, residents responded mostly positively. They often commented on its human-like appearance or tried to make physical contact with the SR, like touching its hands or its head. Playful games and activities with Pepper, such as singing and dancing, fostered social engagement and joy. Residents turned sessions into interactive experiences, like guessing song performers during the jukebox app. Humor, especially

Fig. 1 Impression from Group-based Sessions and Individual Interaction

through Pepper's "giggle" feature, contributed to a positive mood and social interaction with residents creatively exploring new ways to interact with Pepper. Sharing their experiences after a session with the robot, Ms. E. mentioned that she liked „*the way it laughs*". Another participant, Mrs. W. also described Pepper's giggling during a robotic assisted group activity as a pleasant experience: "*When it giggles like that. It moves its head and laughs so nice (imitates giggling)*". The facility manager also highlighted "giggling" as a positive example of human–robot interaction in the context of advanced dementia, telling the story of one resident: "*She didn't stop at all, she just kept touching his head and responding to that warm smile by smiling back*".

4.2 Mixed Reactions and Challenges

Despite positive interactions, some residents showed ambivalence or rejection toward the SR. A few residents expressed fear or discomfort, while others displayed aggression. For instance, Mr. M. attempted to hit Pepper, and Mr. B. tried to knock it over with a chair. Professional caregivers described the need to moderate the interaction of the SR with the residents as stressful. These mixed reactions highlight the necessity for careful and sensitive integration of social robots in dementia care. However, the systems and it´s biographical-oriented applications helped activate both old and new memories among residents. Playful interactions with the robot reawakened technical knowledge and personal history, as seen with Mr. N. Sr., a former engineer who recalled his work experiences. Music and proverbs games triggered discussions about personal experiences, like Mrs. W. recalling her brother's horses.

4.3 Ambivalence in Perception of the Robot

Residents had mixed perceptions of Pepper, seeing it both as a machine and a social entity. Some recognized it as technology and game-moderator, while others interacted with it as if it were a person. This ambivalence was reflected in their speech and behavior, such as using child-directed speech.

Family members were consistently positive about the social robot's deployment and playful interaction. They appreciated the researchers' recognition of their relatives' lives and the design effort for often-overlooked individuals. Relatives could also join robotic-based game sessions, enhancing their connection with their loved ones. For example, Mrs. D. Jr. valued the chance to participate with her mother, noting it was a better option than staying in her mother's room. The N. family exemplified how social robotics fosters intergenerational bonding. Mr. N. Jr. mentioned his father's lifelong interest in technology, shared by him and his son, highlighting the joy it brought to his father and the meaningful connection it provided. However, relatives emphasized that technology should not replace personal interactions, especially for those with advanced dementia. The robot, seen as a "cool gadget," (Mr. N. jr.) that playfully supported physical and cognitive activities while stimulating social dynamics.

4.4 Professional Perspectives on Social Robots in Secured Care Environments

Professional reactions varied based on residents' attitudes. Positive resident responses during and after the games facilitated the acceptance among staff, as Ms. G., a nurse, noted "*I think Charlie [the robot was called Charlie by the residents and the staff] is beneficial. Resident perception is key, and I think it's good because the residents are accepting it.*"

Some staff were surprised by the residents' positive reactions, though concerns were raised about the constant presence of the robot and its interaction limitations.

Caregivers had mixed feedback on the robot's usefulness. Some, like Mrs. C., had frequent contact with it, while others, like Mr. D., had minimal involvement. Mrs. A., the care facility

manager, saw the robot as a support tool rather than essential. Some staff felt the robot added complexity to their work, with Mrs. X. stating "*For me, it's not a relief. It's supposed to make my job easier, but it ends up being more work for "Charlie" than for the resident, in that moment*".

Staff suggested the need for a more autonomous interactive sequences to interact with residents without close supervision. Funding and resource challenges were acknowledged, and care managers noted that robots do not address staff shortages directly. However, the robot showed potential for supporting group activities, allowing caregivers to focus on individual needs without disrupting group-activities.

From an ethical standpoint, caregivers emphasized equal treatment for people with advanced dementia, ensuring they have access to the same services and game opportunities. They stressed the importance of incorporating residents' feedback in the design process and ensuring informed consent in care decisions. Positive resident responses were seen as crucial for justifying the use of social robots and the games.

5 Discussion

Observations indicate that while not all residents immediately engaged in the games and with the social robot, it consistently captured their attention, which is crucial in facing social isolation among people with advanced dementia. The robotic-based game sessions facilitated social connections and provided a break from the monotony of daily life. Participants enjoyed interactive and playful group activities, fostering a sense of camaraderie and rapport, as seen when Mr. N. sought the robot's companionship in the absence of a caregiver. These sessions became routine, offering new experiences and fostering trust and mutual interest among people with advanced dementia, caregivers, and researchers. Notably, residents formed meaningful connections with the robot, even recalling it despite memory loss. The robot served as a focal point during sessions and provided support to caregivers, facilitating conversations and evoking positive emotions among residents. Although the robot and it´s games cannot replace human interaction, it complements caregiver support, especially in memory activation and activities in times where no one is around.

The design of the system, particularly its humanoid appearance, influenced residents' responses, blurring the line between perceiving it as a machine, a game-moderator or a social entity. While some participants treated the social robot as a technological gadget, others engaged with it socially, experiencing joy and laughter.

Ethical considerations are paramount in integrating social robots into care environments. The humor, joy, and laughter associated with using social robots (SR) to create a sense of detachment can be understood within the challenging living conditions of people with Advanced Dementia. Building on previous findings, we emphasize the potential drawbacks of strict ethical protectionism, as noted by Hodge et al. [24], and urge careful consideration of ethical issues in human–robot interaction [24]. Concerns about recognizing SR as machines or the lack of reciprocity should be balanced against the meaningful social engagement they provide. While humanoid robots may enhance acceptance and interaction, they also risk misunderstanding and over-anthropomorphism. However, given the restrictive environments and limited life expectancy of people with advanced dementia, excluding them from SR interactions altogether may also be unwarranted. Our methodological approach highlights the importance of ethical methodologies and collaborative efforts in enhancing the lives of people with advanced dementia [11, 35, 56, 63, 66]. Although caregivers may have their own agendas and thus bias the advocated interests of people with advanced dementia, we commented in the findings that having professional and informal caregivers as well as relatives to advocate for people with advanced dementia is crucial in design and ethically mandatory [44, 55]. Building trust with professional and non-professional caregivers is essential for successful implementation and appropriation of

SR technology as it enables researchers to gain invaluable insights into their biographical backgrounds and personal preferences without overburdening vulnerable populations [18, 19, 25]. Developing strong relationships with caregivers is equally vital, as they play a crucial role in managing and maintaining SR systems.

6 Conclusion

Overall, the use of social robots and it´s playful applications in advanced dementia care shows promise in enhancing social engagement, joy, and memory activation. However, the mixed reactions and challenges highlighted the need for careful planning and sensitivity in their integration. The study underscores the importance of considering individual responses and the potential for robots to contribute to the well-being and quality of life for people with advanced dementia. In summary, our discussion underscores the complex integration of social robots and games into dementia care, revealing their potential positive impacts on well-being, quality of life, and social engagement within secured care environments. While social robots can activate memories and create positive experiences for some individuals with Alzheimer's disease it's crucial to acknowledge that reactions such as fear, rejection, or aggression are not uncommon and require personalized solutions tailored to each person's needs. This highlights the importance of thorough evaluation, the pivotal role of professional caregivers, and the ethical imperative of informed decision-making to optimize care for people with advanced dementia. The importance of the role of professional caregivers is also reflected in the data collected during this study as many results would not be found without the caregivers input (co-researcher).

Moving forward, further research and practice should explore these aspects in more depth to ensure inclusive and compassionate care outcomes. Additionally, considering the ethical dimension of how people with advanced dementia perceive social robots and moderated game-sessions raises questions about prioritizing their happiness while mitigating potential issues associated with humanoid designs. Exploring alternative robot designs that are less human-like yet interactive could offer a balanced approach, fostering engagement while minimizing confusion or emotional disruption.

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Leveraging Co-Design Activities in a Learning Community to Enhance Technology Acceptance in Dementia Care

Sanne Beijer, Karlijn van Rijen, Leonie Copraij, and Rens Brankaert

Abstract

Healthcare technologies are often considered a solution for better and more efficient dementia care; however, these technologies are frequently abandoned over time. Improving user acceptance is vital to increasing the use of healthcare technology by care professionals, but achieving this attitude change is a complex challenge. Learning Communities provide a form of organized collaboration that can help to accelerate innovation by involving stakeholders from multiple disciplines such as care practice, education, and research. Co-design methods have shown promise for multi-stakeholder involvement, helping them make sense of complexity and leading to new proposals and ideas. This paper showcases how co-design activities in an existing Learning Community were employed to address challenges surrounding the technology acceptance of care professionals in dementia care. Over three sessions, twenty Learning Community members were guided into designing three serious games to discuss, share, and reflect on technology use in dementia care practice. This paper describes the co-design process, demonstrating promise for using co-design activities to create solutions for shared challenges and using gamification to create attitude change in context.

Keywords

Co-design · Dementia care · Multidisciplinary collaboration · Learning communities · Technology acceptance

S. Beijer (✉) · R. Brankaert
Department of Industrial Design, Eindhoven University of Technology, Eindhoven, The Netherlands
e-mail: s.g.beijer@tue.nl

K. van Rijen
Department of Industrial Engineering and Innovation Sciences, Eindhoven University of Technology, Eindhoven, The Netherlands

Luckt B.V, Eindhoven, The Netherlands

L. Copraij
Department of Health and Well-Being, Research Group 'Living Well With Dementia', Windesheim University of Applied Sciences, Zwolle, The Netherlands

Utrecht School of Governance, Utrecht University, Utrecht, The Netherlands

R. Brankaert
School of Allied Health Professions, Fontys University of Applied Sciences, Eindhoven, The Netherlands

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1 Introduction

With nearly ten million new cases each year, one of the most pressing issues in our society is providing proper care and support for people living with dementia [1]. The World Health Organization highlighted dementia as a public health priority and aims to substantially decrease the global health burden of dementia while improving the lives of those living with dementia [2].

In a time when our care system is under pressure, facing an increasing demand for care, staff shortages, and budget cuts, healthcare technologies offer valuable ways of supporting people with dementia and professional caregivers [3]. Healthcare technologies can support individuals with dementia by promoting safety, fostering communication, providing multi-sensory stimulation, and reminiscence [4]. Professional caregivers can be supported to initiate and spark social connectedness by providing accessible interfaces for digital media [5] or through information, communication, and technological innovations that support and improve care process management [6]. Healthcare technologies are often considered a solution for better, safer, and more efficient dementia care [6–8].

Nonetheless, dementia care professionals often experience barriers to technology use in practice, and many implemented technologies are abandoned over time [9]. One specific barrier is the lack of technology acceptance, which has been attributed to different factors in literature, including technology anxiety, resistance to change, and low perceived ease of use [10, 11].

Literature shows that stakeholder collaboration, such as a Learning Community (LC), can help address complex issues by shaping structural collaboration involving various stakeholders from different disciplines and sectors [12–16]. In this paper, we use the term Learning Community to describe a form of collaboration in which stakeholders from design, research, education, and practice work together to learn, develop, innovate, and work on complex, wicked problems in dementia care [17–20]. LCs can be described by four essential building blocks: strategy, structure, process, and culture [16]. When looking at the processes, LCs typically utilize collaboration techniques such as presenting, knowledge sharing, and experimenting with technology in practice [21, 22].

In the context of a LC, co-design may be a promising way of working on shared problems or goals because it allows for identifying user needs with relevant stakeholders and generating novel proposals and ideas [23, 24]. Moreover, practical and visual co-design methods such as making prototypes, designing probes, and developing games can support stakeholders within a LC to make sense of complexity and articulate personal values, knowledge, experiences, and feelings [14].

This paper showcases a co-design process within a LC to address technology acceptance in dementia care. The process resulted in three serious game prototypes [25] for discussing, sharing, and reflecting on technology attitudes and usage among care professionals. Dementia care experts evaluated the three designed games at a public conference.

This work explores how to address the challenges of technology acceptance collaboratively and contributes by demonstrating and discussing how co-design activities can be used to achieve shared goals on complex problems. In addition, examples show the promise of using gamification to change attitudes regarding technology acceptance in dementia care.

2 Background

2.1 Technology Acceptance in Care Practice

Healthcare professionals often experience barriers to technology usage [6, 10, 11, 26]. Using healthcare technology in practice implies a change in organizational processes and culture, and professionals, as a result, must evaluate their intentions and may find switching to new habits challenging.

Within the Technology Acceptance Model (TAM) and model for Unified Theory of Use and Acceptance of Technology (UTAUT), technology acceptance is posited as the key determinant of technology use and, therefore, technology adoption [10, 11]. The models provide different factors to explain the barriers to technology acceptance, including perceived ease of use and usefulness, resistance to change, technology anxiety, technical skills, and personal innovativeness [6]. The social environment also plays a role in overcoming barriers, as individuals are likely to conform to prevailing norms. In addition, education is crucial for accepting innovation, understanding the benefits of technology, diminishing fears and negative thoughts, and changing attitudes that could detour technology acceptance [26].

2.2 Co-Design to Achieve Shared Goals

In the last centuries, design methodologies have grown in awareness and popularity and are used across industries such as business and management, strategy, community services, and social and healthcare innovation [15, 27–29]. These methodologies are "*drivers for guiding people, teams, organizations, and coalitions toward change and transformation*" [30].

According to Sanders and Stappers' [24] definition, co-design entails collective creativity across the whole span of a design process, where both designers and people who are not trained in design work together in the design process.

In co-design sessions, participants with various disciplinary backgrounds collaborate to envision the future by interacting with each other and with physical materials, creating, for example, lo-fi prototypes, sketches, posters, and stories [13, 31–33]. These activities stimulate engagement, facilitate collaboration, unlock empathy, and create a shared understanding of values while generating beneficial opportunities in shared problematic situations among stakeholders [30].

In healthcare and dementia care, innovation is essential for finding strategies to improve the quality of life for people living with dementia while balancing costs and quality of care in a climate of restricted healthcare resources [28, 34, 35]. Because of this, dementia is a complex design space with many different stakeholders and domain experts. Therefore, it is crucial to understand and involve all these perspectives in finding and evaluating new solutions [15, 36], which can be achieved through co-design.

3 Design Process and Results

This section reports on the co-design process that was conducted within a LC to address technology acceptance in dementia care. The process can be divided into four phases: (1) the definition phase to form a design question; (2) co-design session 1 to establish early concepts; (3) co-design session 2 to design prototypes; and (4) the final prototypes to pilot-test them. We first give a broader overview of the research context, followed by a description of each phase, detailing the materials, procedures, and results.

3.1 Learning Community Context and Participants

This study was conducted within an existing Learning Community in the Netherlands that focuses on dementia and technology. The Learning Community was founded in 2022 and comprises stakeholders from design, research, dementia care practice, residential care, and education (Table 1).

The LC was set up to collectively address technology implementation, discuss new innovative and technological developments, and facilitate knowledge sharing. The community features quarterly meetings in which different challenges provided by the members are discussed and worked on. The co-design sessions

Table 1 An overview of participants in the two co-design sessions

P#	Profession	Organization type	Session#
1	Innovation manager	Care organization A[c]	1
2[a]	Innovation manager	Care organization B[c]	1
3	Innovation manager	Care organization C[c]	1
4	Innovation manager	Care organization C	1
5	Social designer	Care organization D[c]	1
6	Program coordinator	Regional care innovation network	1
7	Lecturer and researcher technology and ageing	University of Applied Sciences	1
8	PhD researcher dementia and technology	University of Technology	1
9	Lecturer and researcher human and technology	University of Applied Sciences	1, 2
10[b]	PhD researcher	University of Applied Sciences	1, 2
11[b]	PhD researcher and program manager	University of Technology and regional healthcare innovation network	1, 2
12[a]	Innovation manager and nurse	Care organization B	1, 2
13	Nurse	Care organization B	2
14	Project lead innovation	Care organization E[c]	2
15	Network coordinator	Regional dementia care network for case managers	2
16	Project coordinator vulnerable older adults	Regional care innovation network	2
17	Board member	Alzheimer advocacy organization	2
18	Innovation advisor	Residential care organization	2
19[b]	Lecturer and fellow dementia and technology	University of Technology and University of Applied Sciences	2
20	Lecturer care and wellbeing	Secondary vocational education	2

[a]Participant 2 and 12 provided input in the definition stage (see Sect. 3.2)
[b]Three of the four authors of this paper also participated in the co-design sessions
[c]These organizations all offer residential care (long-term care in nursing homes) and home care (care provided in the individual homes of people) for older adults and individuals living with dementia

described in this paper address one of these challenges: technology acceptance by professionals. Therefore, the co-design sessions were integrated into the pre-existing LC's quarterly meetings.

The participants of this study are all part of the above-described LC and, by participating in the community, agree that the work that is done can and should be used for research purposes. The participants are, therefore, not study subjects but peers as they are experts in different challenges surrounding healthcare technology implementation in dementia care. While conducting the co-design sessions and writing this paper, participants were informed and updated about this academic contribution and allowed to withdraw at any time.

3.2 Setting the Stage (Definition Phase)

In this phase, the authors met with two other LC members (Participants 2 and 12, Table 1) to define a specific co-design challenge. Participants 2 and 12 both work as innovation managers at a care organization offering residential, outpatient, and home care for older adults at different locations. They are responsible for stimulating, managing, and implementing innovations in the day-to-day care practice. More specifically, they try to foster positive attitudes and reduce apprehension toward technology among frontline care professionals who work with people with dementia. One of the main challenges they faced was the variety

of attitudes toward technology usage among these professionals, both organization-wide and within location-specific teams. While conveying technology to people with a negative attitude towards technology was a challenge, this variety of attitudes also challenged the innovation managers in adapting their communication and approaches to these various beliefs. Given these differences, they wished to gather input and inspiration from the other LC participants on addressing the technology acceptance issues. The innovation managers planned to use the outcomes of the co-design sessions to develop a one-hour training session for their frontline colleagues, which was already planned, aiming to discuss technology acceptance and use in their daily work. Based on this preparation session, the following design question was formulated: *How can we convey the benefits of healthcare technologies to various care professionals in a training of 60 minutes?*

3.3 Co-Design Session 1

This session aimed to answer the design question from the definition phase. Participants were asked to develop solutions and concepts based on their ideas for the design question (Fig. 1). The session took about one hour. In this session, twelve participants of the LC took part (Table 1).

Procedure. At the start of the session, the participants split into three groups. People from the same organization were asked to join different groups. The first activity addressed the question: *How can we convey the benefits of healthcare technologies?* Participants took part in a brainwriting activity [37, 38] in which participants had to write down one idea on a sticky note individually and then collectively expand on these ideas in a circular motion. After brainwriting, participants discussed the resulting ideas within their groups and formed an initial concept (Fig. 1a).

Fig. 1 Schematic overview of the corresponding co-design activities utilized during session 1: namely **a** twenty-three minutes of brainwriting; **b** fifteen minutes of brainstorming; and **c** twenty minutes of pitching

As attitudes to technology vary among care professionals, the challenge was modified into: *How can we convey the benefits of healthcare technologies – to various care professionals?* In the second activity, participants were asked to brainstorm individually, allowing participants to generate ideas in a 'safe' setting by building upon the ideas of others without being influenced by group dynamics that might arise when collectively brainstorming [37], discuss their ideas amongst their group, and expand their previously formed concepts (Fig. 1b).

In the third activity, a final challenge was added to the design question, modifying the challenge into: *How can we convey the benefits of healthcare technologies – to various care professionals–in a training of 60 minutes?* Participants were asked to form one concept with their group and give a pitch to the other groups to inspire and educate each other (Fig. 1c).

Sticky notes were collected, and one member of each group was asked to write a summary of what was concluded by the end of each activity.

Results. At the end of co-design session 1, each group proposed a concept activity to convey the benefits of healthcare technology to care professionals. Based on the summary provided by the group members, four different directions were deduced through which the concepts aimed to achieve their goal.

Create space for doubts, objections, and feedback. Different groups discussed that fears and frustrations should be addressed first to be able to change attitudes. They suggested doing this through group or individual conversations, collecting information during a coffee break, using an idea tree, interviews, a physical or digital bulletin board, or in a 'Pessimist Pot', asking professionals to fill it with as many doubts as possible.

Stimulate dialogue between positive and negative attitudes. Another insight from the gathered data is that reflections on attitudes over time and dialogue between professionals with different perspectives are crucial. The participants brainstormed on different reflection assignments. For example, exercises in which professionals must name six technologies they use daily, of which three they were optimistic about and three they would never want to use again, asking professionals to describe their day if they could not use technology, or a 'Cross the line' exercise, where a leader calls out an experience, and participants have to cross the line if they had that experience. In this case, the experiences would be tailored to experiences regarding the benefits of and barriers and facilitators to using healthcare technology. This exercise gauges different opinions in a group.

Share positive stories. According to the participants, success and failure stories should be shared and celebrated with different teams and care units through social media or video databases. While sharing stories, it is essential to involve different perspectives, such as the residents, healthcare professionals, management, and board of directors.

Experience technology before applying it in practice. Another insight is the need for more experiential knowledge regarding technology use among care professionals. One solution given by the participants is to increase knowledge of the accessibility of technologies through firsthand experiences and demonstrations to professionals.

Further analysis of the results by the authors afterward revealed that multiple concepts consisted of game- or playful elements, leading to the development of 'serious games' in the next phase. Serious games are used for purposes beyond mere entertainment, containing an implicit objective typically related to skill improvement, knowledge gathering, or (experiential) learning, such as education and training [25, 39]. Since serious games could work as a form of team building and inspiration [40] and are becoming increasingly popular for training healthcare professionals [41], the four defined directions and the game element were used as input for co-design session 2.

3.4 Co-Design Session 2

In this session, participants developed a game format that care teams could use to convey the

benefits of healthcare technology based on one of the four directions from the previous session. In this session, twelve participants took part, and it lasted approximately one hour (Table 1).

Procedure. Before starting the activities, the participants split into four groups, separating those from the same organization. Each group was asked to choose one of the provided visual story cards representing the directions from co-design session 1 (Fig. 2).

In a guided, fast-paced brainstorming session (Fig. 3a), participants had to individually brainstorm five ideas for their chosen direction while imagining they were superheroes (i.e., Superman, Wonder Woman, etc.) and use their characteristics to develop ideas [42]. This method was chosen because the skills of the superheroes break the bounds of 'normal' behavior and help people go beyond their underlying norms and assumptions [42]. A brainwriting exercise was held after the individual brainstorming session, like the one in co-design session 1, which challenged participants to build on each other's ideas (Fig. 3a).

After the brainstorming activity, participants discussed the outcomes and created one game concept. To help concretize the groups' ideas, they filled out a game manual and storyboard template (Fig. 3b). In the game manual, groups had to define the aim of the game, duration, number of players, target group, necessary materials, preparation, how the game would be played, the end of the game, and scoring. The storyboard aimed to give an impression of the context in which the game would be played. Figure 4 provides an example of a storyboard one of the groups created, describing an escape suitcase that should be solved using existing care technologies. The session was closed with pitches. Each group created one game concept in co-design session 2, aligning with one of the four directions from Fig. 2. The four resulting

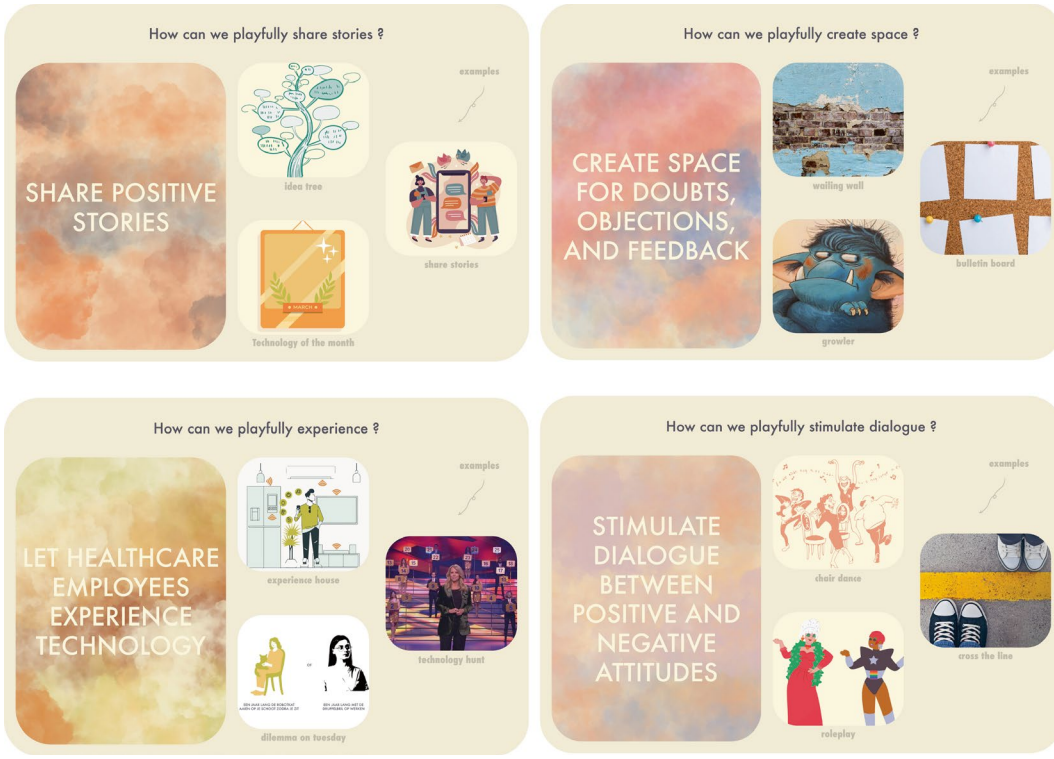

Fig. 2 Visual story cards used to direct groups in the design process

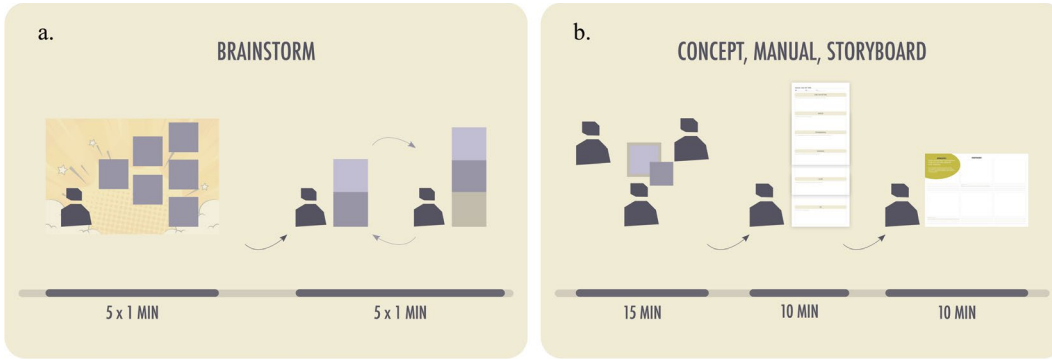

Fig. 3 Schematic overview of the corresponding co-design activities utilized during session 2: **a** five minutes of individual brainstorming and five minutes of brainwriting; and **b** thirty-five minutes of co-creating a concept, game manual, and storyboard

Fig. 4 Example of a filled-in storyboard created by one of the groups to experience technology

concepts contained elements such as cooperation, discussion, reflection, time pressure, achievements, scores, and feedback. The authors decided to develop three of these concepts into final prototypes to be played at the conference, which will be elaborated upon below. One of the four resulting concepts was not chosen for further development due to practical restrictions. This decision was made because the concept required multiple tailored healthcare

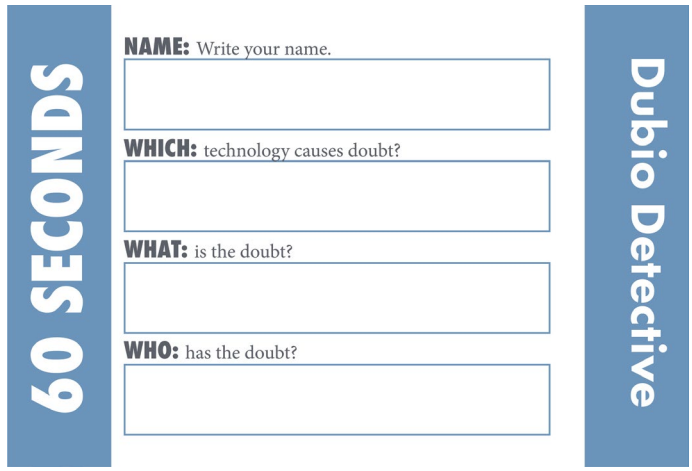

Fig. 5 DubioDetective game card

technologies that would be used by care professionals to solve a puzzle. The magnitude of this concept was beyond the scope of this project.

3.5 Final Prototypes

This section will describe three games developed into prototypes. These are DubioDetective, Step-by-step, and TechTalks.[1]

DubioDetective. This game aims to provide insight into doubts, objections, and feedback regarding technology through team discussion. Care professionals can be afraid of, distressed by, or worried about using new technology, its reliability, and the necessary competencies to use it, which can hamper technology acceptance [26]. DubioDetective aims to address these worries in a lighthearted and accessible manner by allowing care professionals to express and team leaders to be informed about these objections, potentially addressing them to increase technology acceptance.

The necessary game materials include a manual, fill-in cards, scorecards (Fig. 5), and a timer. Each player fills in at least one card (Fig. 5) containing (1) their name, (2) which technology causes doubt, objection, or dilemma, (3) what doubt, objection, or dilemma is at play, and (4) who is the subject (e.g., the client or resident, co-worker, medical specialist, etc.). Other players must guess these elements by asking questions that can only be answered with yes or no. After 60 seconds, the player that filled in the card explains their reasoning, the team discusses the doubt, and a score is given based on how many elements were guessed correctly.

Step-by-step. This game stimulates dialogue between positive and negative attitudes towards a specific care technology. Players are persuaded to formulate their opinions of healthcare technology and consider possible benefits and disadvantages by completing reflection cards (Fig. 6). Additional materials include a game manual, technology inspiration cards, scorecards, and a staircase.

For this game, a physical staircase visualizes people's attitudes, meaning that the players divide themselves over the stairs according to the attitude score on their reflection cards (i.e., positive attitudes at the top and negative at the bottom). After that, other players are challenged to counteract doubts and increase the player's positive attitude by discussing counterarguments and benefits of the technology at play. Again, the staircase represents players' attitudes as they must change position when

[1] For more information and access to the three prototypes, please e-mail the corresponding author.

Fig. 6 Step-by-step scorecards to be filled in before and after playing the game

convinced by an argument. This way, the leading player will learn about possible benefits of the technology they may not have been aware of before, while other players are forced to provide positive counterarguments that may or may not match their beliefs. This way, players continuously reflect on their attitude while playing the game. In addition, potential drivers and barriers to using the chosen technology will arise.

TechTalks. One of the drivers of technology use is its perceived benefit by care professionals [43]. This game challenges healthcare professionals to build and share positive stories and experiences with technology with colleagues in a pitch competition. This way, players share their best practices and collaboratively expand knowledge while exerting social influence.

For this game, duos must create an elevator pitch about a technology of choice or from the provided inspiration cards that contain commercially available and commonly used healthcare technologies in dementia care. Players are provided with the building blocks of a successful pitch (Fig. 7). Then, each duo holds their pitch and, while pitching, receives a score (Fig. 8). The care organization can share the winning pitch among its employees for inspiration and motivation.

Prototype evaluation. The three prototypes were pilot-tested during a conference on

Fig. 7 TechTalks pitch template. Participants must consider an introduction, experience, purpose, solution, and plan. Each of these elements is one sentence

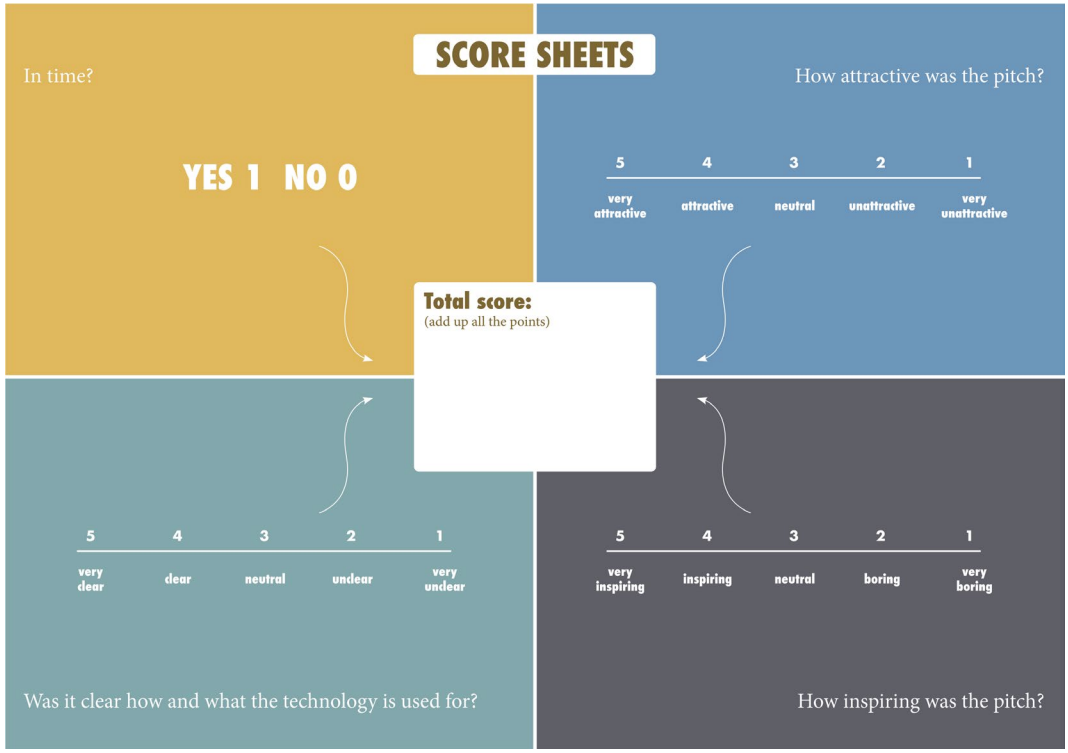

Fig. 8 TechTalks score sheets. Participants can score points by timekeeping, attractiveness, clarity, and inspiration. The other players give the score

dementia and technology with about 180 attendees ranging from researchers, entrepreneurs, (in) formal caregivers, care professionals, designers, developers, students, and people with dementia. During a roughly thirty-minute session, DubioDetective and TechTalks were played by three groups of twelve, and Step-by-step was played by two groups of twelve. Eight game leaders were assigned before the event to facilitate the gameplay and write a reflection afterward.

The written reflections provided a generic description of how the games were received. In general, the games were perceived as fun, engaging, active, and relevant. They functioned as lighthearted conversation starters to spark more profound discussions on values surrounding technology in dementia care and enabled participants to share personal stories and experiences.

Nonetheless, two considerations were brought up: goal achievement and transferable game experiences. The first is whether the discourse that emerged in the groups when playing the games contributes to the intended goal. The second is the extent to which the positive experiences conference attendees had while playing the games would, in practice, translate to the intended user group in the intended setting. We will elaborate on this in the next section.

4 Discussion

This paper illustrates how challenges in dementia care and support can be addressed in a Learning Community and how co-design activities can be leveraged to generate support tools. The LC offers an already established longitudinal collaboration of committed professionals who are familiar with each other outside the scope of this study and work on relevant contemporary dementia care issues. This provided practical benefits, as participants met regularly,

allowing for rapid design cycles. The shared enthusiasm towards the potential of technology led to a collaborative atmosphere, which promotes interest and involvement throughout the co-design process. The resulting feelings of ownership led to having a personal stake in the quality of the solutions provided. However, this positive tendency might have caused a potential bias in the results. In addition, even though many LC participants have previously been frontline care practitioners, the current participant sample of the co-design sessions should contain more direct representatives. Including these practitioners in future revisions ensures that the outcomes align with their needs and experiences. This first attempt at leveraging co-design activities in the LC shows promise to facilitate multidisciplinary collaboration on complex problems, designing solutions, and using gamification in dementia care and beyond.

4.1 Co-Design Activities to Achieve Shared Goals on Complex Problems

Throughout two co-design sessions, we demonstrated that brainstorming activities used for ideation in co-design session 1 facilitated stakeholders from various disciplines to utilize their personal and professional experiences and collaboratively generate ideas for a shared problem. This aligns with previous research on the opportunities for co-design to involve different stakeholders, especially in the context of wicked problems [14, 23, 24, 30].

We noticed that participants from each domain contributed differently to the process. For example, participants from care practice provided content-related experiences, example cases, and opportunities for directly applying the ideas of the LC into practice. Participants from education utilized their experiences with learning strategies, and participants from research used their critical thinking and reflections to support the process. Participants with a design background showed initiative to guide group members effectively through the design process and facilitated creativity by quickly generating ideas. This aligns with previous research in which the role of designers is described as facilitators of multidisciplinary projects [44] and communities [45] in the context of complex design spaces [27].

The co-design methods handed to participants subsequently assisted them in engaging with each other and led to concrete solutions. Participants indicated they valued the co-design activities for emphasizing the perspectives of different participants outside their organization or domain, which aligns with previous studies [31, 46]. Moreover, two innovation managers from care organization B (P2, 12) appreciated the co-design methods. They used several of them, such as brainwriting, to collect doubts, objections, and colleague feedback.

The co-design activities were nonetheless only appropriate for some participants. In co-design session 2, one group struggled with brainstorming methods and got stuck. This might be due to the absence of a group member with a design background who could have helped guide this group through the process. While this illustrates the added benefit of designers as participants in co-design sessions, it also poses a risk and dependency [47]. To overcome this, we recommend dedicating time to future co-design sessions to educate the participants in design thinking. With this, the reliance on designers decreases, and participants are empowered to use these activities in their daily practice.

4.2 Gamification to Convey the Benefits of Healthcare Technology

Unintentionally, most ideas generated in co-design session 1 contained playful elements, suggesting a natural tendency for the participants to choose games to convey certain beliefs and lessons to others. The value of play that the participants implicitly brought forward is confirmed in literature. Gamification is denoted as an effective method for inducing attitude change. Games can foster thinking about

technology and increase empathy by changing perspectives and engaging in storytelling, thereby evolving attitudes, behaviors, or beliefs [40, 48]. Moreover, playful experiences keep players motivated and engaged and increase their activity, social interaction, quality, and productivity (e.g., teamwork and cross-functional collaboration) [49]. Gamification has already been used to support companies' innovation processes, especially in the early stages, to increase team alignment and coordination and mitigate the issues related to feelings of anxiety and overload in innovation teams [40, 50].

There is a need for novel approaches to increase technology acceptance, and games like the ones designed in this paper provide playful ways to understand the benefits of technology and diminish fears and negative thoughts. We know from the literature that healthcare professionals experience barriers to technology usage and need to get used to a continuously changing environment necessary for innovation [6, 10, 11, 26]. With these games, we aim to facilitate the investigation and reflection of attitudes by care professionals and to create time and space to consider the pros and cons of technology. Organizations can use the games to facilitate the involvement of care professionals in their decisions on which technologies are deemed worthwhile and what the general attitudes of their employees are.

Even though the games were positively experienced at the conference, some limitations remain. For example, the conference attendees' expertise varied widely, and it remains unclear how their experiences translate directly to frontline healthcare professionals who are envisioned to play the games. In addition, does the discussion surrounding technology in dementia care brought up in the game contribute to improving technology acceptance among players? From literature, we know that changing attitudes is quite complex. As the attendees at the conference were not asked to reflect on the games afterward but merely played the games, we need more findings on whether the games can contribute to changing attitudes in this context, and further research is required.

Nevertheless, we learned that the games contributed to profound discussions on values surrounding technology in dementia care and enabled participants to share personal stories and experiences. Combining this with research on gamification in this context [32, 48], we see the relevance of further exploration into the actual application of these or similar games in care practice. This way, we hope that technological aids and devices are better adopted, contributing to the general well-being of people with dementia and their caregivers.

5 Conclusion

In this study, we present co-design activities in a Learning Community to address the challenges of technology acceptance in dementia care. Together with stakeholders from design, research, dementia care, and education, we created solutions to convey the benefits of technology. The use of co-design activities, such as brainstorming, brainwriting, conceptualization, and game development, in the multidisciplinary setting of the LC contributed to the design outcomes by inspiring and engaging participants to utilize their professional experiences to create ideas and learn about others' perspectives. The activities yielded three games, each containing different elements to spark discussion and reflection on technology usage in care practice: DubioDetective for sharing doubts; Step-by-Step for stimulating dialogue between differing attitudes; and TechTalks for sharing positive stories. A pilot test showed promise for the games, which need further development and more thorough evaluation to assess their effectiveness in achieving their goal.

Author Contribution Statement

In the design process, the authors contributed in different ways. All authors were responsible for organizing and facilitating the co-design sessions as part of their regular responsibilities within the LC. The first author facilitated the co-design sessions and guided the groups. Authors 2–4 participated in these sessions. The first author took the lead in designing the final

prototype games, as presented in this paper, with feedback from the other authors. Authors 1–3 collaboratively discussed and interpreted the results of all co-design sessions. Authors 1–2 were mainly responsible for executing the conference pilot test, which author 3 supported in the preparation. The first author took the lead in writing this paper; the second and third authors contributed equally to revise the paper. Authors 1–3 were under the supervision of the fourth author during the entire project.

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Artefacts in Action: Facilitating Positive Person Work in Dementia Group Living Environment

Rising Lai, Niels Hendriks, Andrea Wilkinson, and Sara Laureen Bartels

Abstract

This study investigates how artefacts facilitate Positive Person Work (PPW) in dementia care, with a focus on facilitation and collaboration within group living environments. Using short-term design ethnography in a care home in Belgium, we explored how artefacts act as mediators of non-verbal communication, enable collaboration, and foster inclusivity. We used Actor-Network Theory (ANT) to map the interactions between residents, staff, and artefacts to understand how these interactions create a supportive environment for PPW. Additionally, by integrating Material Engagement Theory (MET), we identified the material agency of artefacts in these processes. These insights informed the development of a design toolkit based on the 5E Experience Design Model, offering caregivers a practical guide for creating activity experiences that enhance facilitation and collaboration. This research provides practical design-related considerations for improving care practices and enriching the daily experiences of people with dementia.

Keywords

Dementia care · Artefacts · Facilitation

1 Introduction

Renowned dementia care researcher Kitwood [1] identified twelve types of interactions to address psychological needs, preserve personhood, and enhance well-being of people with dementia. These interactions are celebration, collaboration, facilitation, holding, negotiation, play, recognition, relaxation, timalation, validation, creation, and giving, collectively referred to as Positive Person Work (PPW). The first ten interactions are typically initiated by caregivers, while the last two are initiated by the people with dementia themselves. Facilitation empowers people with dementia to undertake actions, while collaboration emphasises working together, treating people with dementia as equal

R. Lai (✉) · N. Hendriks · A. Wilkinson
LUCA School of Arts, C-Mine 5, 3600 Genk, Belgium
e-mail: rising.lai@luca-arts.be

N. Hendriks
e-mail: niels.hendriks@luca-arts.be

A. Wilkinson
e-mail: andrea.wilkinson@luca-arts.be

S. L. Bartels
Department of Psychiatry and Neuropsychology and Alzheimer Centrum Limburg, Mental Health and Neuroscience Research Institute, Maastricht University, Dr Tanslaan 12, 6229 ET Maastricht, Netherlands
e-mail: sara.bartels@maastrichtuniversity.nl

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partners rather than passive recipients of care [1–3]. Previous research has underscored the importance of facilitation and collaboration in dementia care [4–6]. These two interactions are noteworthy, since they are often interconnected and actively involve residents in the care environments, not just in the physical spaces but also in the social contexts for working and living. Facilitation and collaboration aim at supporting the autonomy and agency of people with dementia, which encourage meaningful participation in daily activities. In group living environments, which a prevalent form of dementia care and represent the practical context of this study, the need for facilitation and collaboration is particularly pronounced. Group living environments are a prevalent form of dementia care that consists of small, homelike units, supported by full-time staff who assist with daily living and create a supportive, familiar community environment [7].

How can a dementia group living environment become more supportive of PPW? Previous studies suggest that PPW can be enhanced by the intentional use of artefacts [8, 9]. Artefacts can mediate social interactions and contribute to well-being [10, 11], supporting positive psychology and interactions for people with dementia [3]. Importantly, the adaptability of artefacts throughout the dementia journey, considering both individual and communal capacities and willingness, is crucial to implementing PPW effectively. This dynamic understanding of artefact use is supported by Material Engagement Theory (MET), which views artefacts not as passive objects but cognitive and emotional mediators [12]. This perspective guided our choice to conduct short-term design ethnography in a care home in Belgium, allowing us to observe how artefacts actively support PPW in action. Our short-term design ethnography approach aimed at providing design-related considerations for creating a supportive environment conductive to PPW for people with dementia. These considerations extend to experience design, where the focus lies not only on functionality but also on enriching experiences for people with dementia.

This study constitutes part of the first author's PhD, which focuses on supporting the autonomy of people with dementia through decision-making in daily activities, including food-related activities. Overall, daily activities are important because of their routine and familiarity, providing regular opportunities for intervention and reflection. By observing high-quality dementia care practices, where PPW is actively encouraged, we applied Actor-Network Theory (ANT) to map the complex actors involved. ANT helps us understand the intricate relationships between people and artefacts [13], identifying where critical interactions occur. This understanding can inform our decisions on artefact placement and activity structuring, improving an effective implementation of PPW. By integrating ANT, we can design environments where artefacts play key roles in helping people with dementia stay engaged and supported [14].

2 Related Work

Through the association of PPW, ANT and MET, the key role of artefacts in dementia care is emphasised. PPW guides the goal of using artefacts to support personhood and active participation. ANT allows us to map the interactions during activities that contribute to achieving PPW, while MET helps explain how certain artefacts are more effective than others in triggering meaningful interactions (see Fig. 1).

2.1 Design for Positive Person Work

Branco et al. [3] discuss how artefacts can promote PPW in dementia care by preserving personhood and fostering social relationships. The authors emphasise the need for real-world evaluations of artefact designs to ensure the artefact's impact on enhancing well-being and engagement. Hobson [15] further explains that artefacts supporting PPW can empower people with dementia by enabling engagement in meaningful activities, retainment of control, and validation.

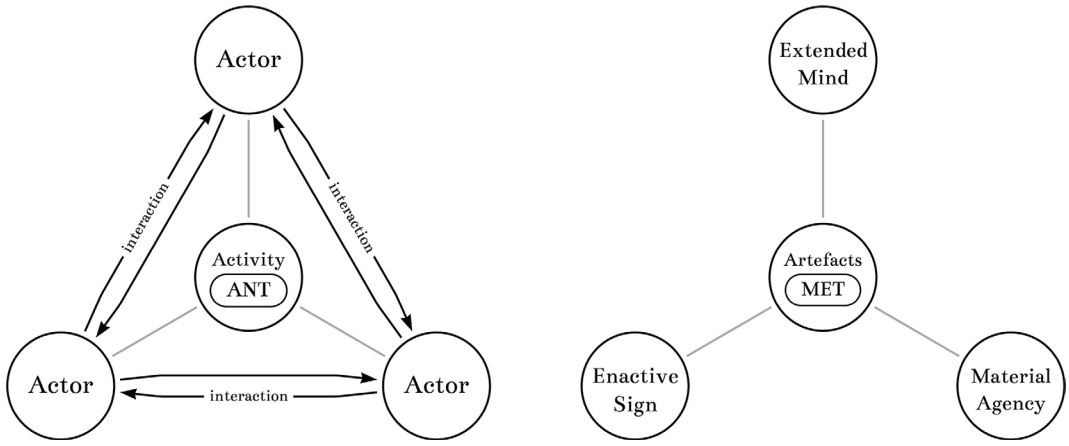

Fig. 1 Visual representation of ANT and MET

Foley et al. [16] and Bosco et al. [17] add that artefact designs should foster mutual recognition and support the agency of people with dementia, ensuring active participation in care and social interactions. Thus, designed artefacts can facilitate recognition and validation, which are crucial for maintaining dignity and social connections.

2.2 Mapping Actors in Dementia Care

ANT offers a valuable framework for examining the various actors, including people (residents, staff) and non-human actors (artefacts), involved in dementia care, with a particular emphasis on the performative agency of design elements [18, 19]. The performative agency of design elements actively shape interactions and outcomes by structuring environments and influencing behaviors [18]. Schillmeier [14] highlights how dementia reshapes the intermediary role of cognitive abilities, turning it into a complex mediator that distorts interactions. This transformation necessitates a more profound investigation into non-human actors such as artefacts that play a role in mediating the experience of people with dementia. These perspectives underscore the need for continued research to map and optimise interactions, thereby enhancing care practices.

2.3 Material Engagement Theory in Dementia Context

MET emphasises the interaction between people and their physical environments and can guide the creation of supportive environments by recognising the roles that artefacts play in shaping meaningful experiences [12]. Malafouris [20] explores how the MET approach helps researchers to understand the effects of everyday artefacts on people with dementia. He describes how people with dementia interact with material environments, including artefacts, and how these engagements influence agency, cognitive abilities, and selfhood throughout the dementia care pathway. Recognising the significance of artefact memories can inform care strategies that actively promote continuity, stability, and comfort [20, 21].

3 Method

3.1 Study Design

This observational study consisted of a three-month fieldwork at the care home, where the first author of this paper engaged in extensive observation and interaction through a short-term design ethnography approach to gain a deep understanding of daily operations, activities, and

interactions among residents, staff, and artefacts. This approach was chosen because it fosters short-term research engagements and establishes a focused dialogue [22]. The first author followed the principles outlined by Pink and Morgan [22] and Vindrola-Padros [23], including:

- Active Participation: The researcher positioned themselves at the centre of the actions taking place at the field site from the beginning of the study, avoiding more passive forms of fieldwork.
- Use of Prior Knowledge: The researcher drew on past experiences and knowledge, such as prior interactions with people with dementia, to better understand what participants were trying to convey or achieve in practice.
- Iterative Engagement: The researcher engaged in active dialogue with participants, supervisors, and other researchers throughout the period of the fieldwork, using these interactions to guide the research and engage with theoretical discussions.

The observational study adhered to and was approved by the ethical guidelines of the KU Leuven Social and Societal Ethics Committee (G-2023-7351). It involved non-invasive qualitative shadowing at the care home, observing interactions in shared spaces without disrupting participant activities or collecting personal data. No informed consent forms were required, as the study was designed to ensure full anonymity and confidentiality of all participants.

3.2 Environment and Setting

This study is based on the fieldwork in a care home in Belgium. This care home is part of a non-profit organisation that provides care services, daycare, and permanent housing for people with dementia. The organisation considers each personal story as unique, encouraging individuals who provide care to reflect on the residents' desires, fears, and mortality. As such, this organisation prioritises capabilities of individuals, rather than focusing on deficits.

This organisation creates an environment that feels familiar and similar to the home situations prior to the onset of dementia by using artefacts and interior designs that are typical of a domestic setting. For example, the furniture and artefacts in the care home where this study is based are not specialised products designed specifically for people with dementia or dementia-related behaviours, nor do the artefacts function differently from those found in any typical home. This approach means that the difficulties residents might face require more attentive support and adjustment from staff. The philosophy of maintaining "home life," along with the daily evolution of the environment, is rooted in the core concept of a holding environment [24] that this organisation adopted.

The approach at this organisation emphasises respecting the inner experiences of people with dementia within both their material and immaterial environments. This respect is maintained through small-scale living arrangements that mimic family-like settings, deeply integrated with the surrounding community. For instance, residents dine together at a large communal table and decorate shared spaces with personal items, creating a homelike atmosphere. This environment allows staff to connect emotionally and personally with residents, further enhancing the familial feel. Additionally, weekly reflections from all staff members are documented, focusing on how each resident's capacity, emotions, and living experience are being supported and upheld. These reflections foster ongoing conversations and exchanges of observations among staff with the goal of continuously improving care practices and adapting to the evolving needs of residents.

3.3 Participants

The participants of this study, referred to as "residents" in this paper, included the fourteen people with dementia who lived permanently in this care home, and one or two individuals attending daycare once a week, from breakfast until dinner. One individual who did not have

dementia but resided in this care home was excluded as participant in this study. Staff were not classified as participants but rather as facilitators within the care environment.

During the three-month study period, residents, staff, and residency situations changed (see Fig. 2). Between periods one and two, one resident passed away, and another entered palliative end-of-life care and later passed away. During period three, one person with dementia who had been attending daycare became a resident, and an additional new resident moved in. Moreover, the first author of this paper, a design researcher, temporarily lived in the guest room of this care home during these periods, which allowed a deeper understanding of the daily operations and interactions.

All residents who participated in the activities during this study demonstrated independence or required only mild support in terms of motor abilities, for example, assistance when standing up from a seated position. Residents were able to engage in activities without the need of wheelchairs or walkers. While the conclusions of this study may not be fully generalisable to all people with dementia, they can highlight the significant potential of actively participating in meaningful tasks and social interactions.

3.4 Data Collection and Analysis

Comprehensive fieldnotes were written during this fieldwork, capturing the subtle nuances of interactions. The first author closely observed residents' gestures, body movements, and both verbal and non-verbal interactions with artefacts–"*She uses one hand to hold the melon and uses the other hand's finger to touch against the melon to peel (with a knife).*" (fieldnote taken by the first author). Detailed notes were taken, including time stamps to document the sequence and duration of events. Thorough descriptions were provided of what occurred and how residents reacted through facial expressions and other behaviours. Additionally, sketches were made to capture the gestures of residents and the shapes of the artefacts in the environment for mind revisiting in the later process of the study. Statements of staff were written down in the fieldnotes to capture aspects of residents' well-being from a broader perspective. This included viewpoints that might initially appear inconsistent with the researcher's observations, ensuring a balanced representation of different perspectives. These fieldnotes underwent a thorough review process, including clustering, to identify activities that were driven by the concepts of facilitation and collaboration within the context of PPW.

Eligibility Criteria for Fieldnote Selection. The following eligibility criteria were used for fieldnote selection:

1. Fieldnotes taken during specific activities, namely food preparation and the cleaning of artefacts used during food preparation and mealtimes (breakfast, lunch, and dinner), in which residents participated. Activities carried out solely by staff were excluded.
2. Fieldnotes that mentioned the use of communal artefacts during food preparation, cleaning, and mealtimes, specifically noting the use of these artefacts by residents, either independently or in collaboration with staff.

The selected fieldnotes were then analysed further through the ANT mapping, which visualises the relationships and interactions among residents, staff, and artefacts. More details and an example of these maps (see Fig. 3) is provided in Sect. 4.2. We further interpreted and aggregated the maps and discussed the material agency of artefacts through the lens of MET.

4 Mapping Food-Related Activities

4.1 Food-Related Artefacts

Table 1 shows the groupings of food-related artefacts based on utility categories and associated activities. Food items, including ingredients

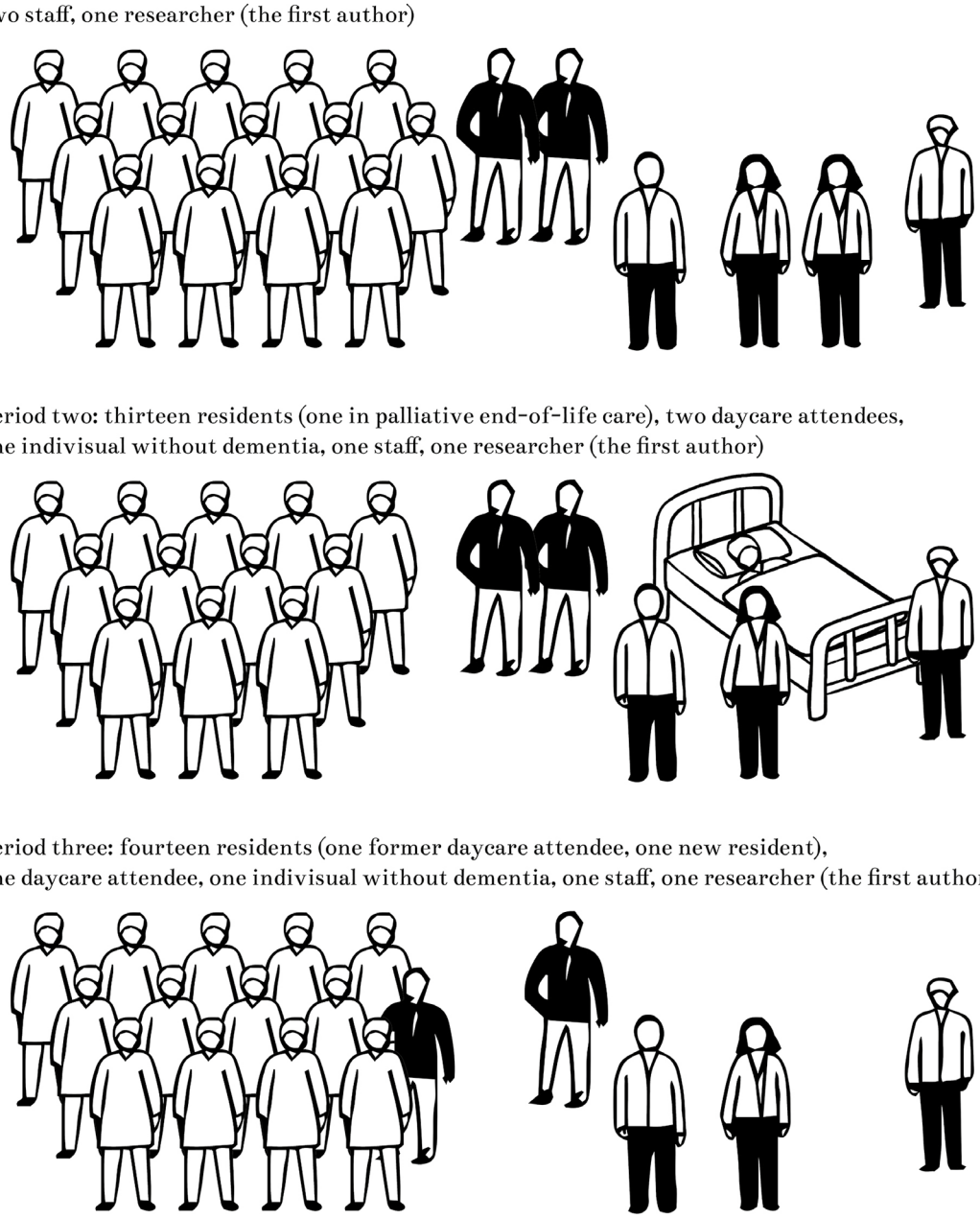

Fig. 2 Change of population in the care home during the fieldwork duration. Period one was two weeks, period two was one week, and period three was nine weeks

and cooked dishes or meals, were not considered artefacts but rather actors in the ANT mapping process. Elements of spatial construction, such as the ground, walls, and doors, were also excluded from being classified as artefacts.

4.2 Food-Related Activities

Actor-Network Mapping. This study mapped out the activities observed during fieldwork using ANT. Activities that are food-related were

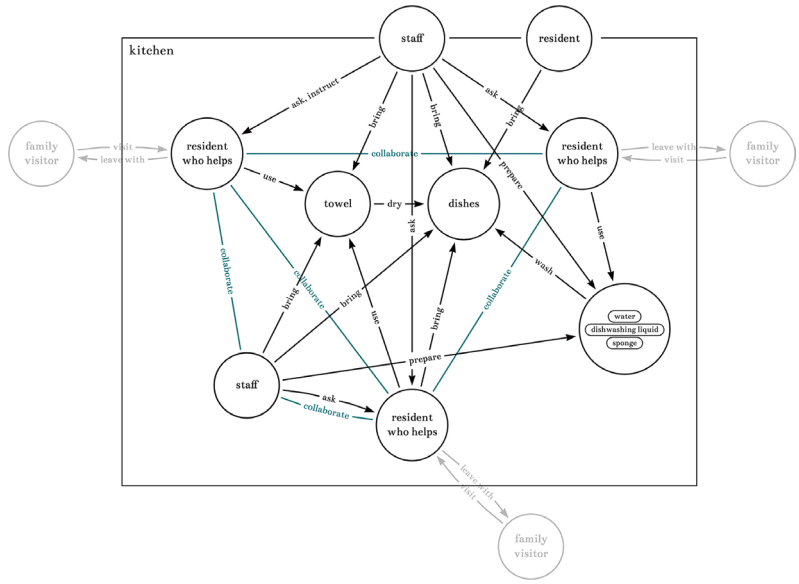

Fig. 3 Exemplary Actor-Network map of dishwashing and drying

selected because they are routine in the care home and involve multiple residents. The Actor-Network of these activities was mapped to show how artefacts are involved and to highlight the artefacts' roles. Our mapping approach extends previous related work by focusing on practical, routine food-related activities, going beyond merely describing interactions to emphasise how artefacts actively facilitate collaboration and participation.

Participants would occasionally leave and return to the activities for various reasons, such as losing interest or patience, receiving a visitor, or needing to use the toilet. In this study, the ANT mapping proposed cannot fully represent the dynamic nature of the entire activity process. Instead, the ANT maps represent a repetitive and aggregated version of interactions observed during the study period.

We mapped activities of food-related activities, including food preparation, table setting, dishwashing, and cutlery cleaning, with a focus on facilitation and collaboration. These activities were mapped by extracting the actions and interactions described in the fieldnotes. Upon reviewing the maps, we discovered that many of the interactions could be viewed as intentional interventions. Here, we would like to highlight one activity as an example.

Dishwashing and Drying. This activity emphasised teamwork, with the participation of each resident being crucial (see Fig. 3). Therefore, it was essential to ensure that every participating resident could contribute according to their abilities. Staff assisted residents in navigating the task, ensuring that it was manageable. Given the variety of artefacts involved (G7) in dishwashing and drying, staff simplified the process by, for example, sorting and stacking plates to make it less overwhelming for residents.

The involvement of residents in dishwashing and drying activities is a form of guided participation. Residents remain active and engaged in this activity daily. The facilitation of this activity, illustrated through the actions and captions on the arrows, aims to create an inclusive atmosphere where residents feel encouraged to participate and support one another. The division of tasks—washing, drying, and returning artefacts to storage—requires effective communication and coordination by staff. The artefacts themselves also play a role in the division of tasks, following a clear sequence that drives the activity forward and signals the beginning

Table 1 List of artefact groups involved in food-related activities

No	Group	Artefacts	Photo
G1	Food and beverage containers	Small plate, soup plate, food plate, dessert bowl, coffee cup, coffee plate, glass	
G2	Cooking utensils	Pot, bowl, colander, basin, food waste box	
G3	Cutlery	Table knife, fork, small fork, soup spoon, small spoon	
G4	Food preparation	Paring knife, chopping board, cooking utensils (G3)	
G5	Table setting–Breakfast and dinner	Placemat, napkin, some eating utensils (G1), some cutlery (G3), thermos jug, tea jug, breadbasket	 

(Continued)

Table 1 (Continued)

No	Group	Artefacts	Photo
G6	Table setting–Lunch	Placemat, napkin, some eating utensils (G1), some cutlery (G3), glass jug	
G7	Dishwashing and drying	Used eating utensils (G1), used cooking utensils (G2)	
G8	Cutlery washing and drying	Used cutlery (G3), wash basin, towel	

and end of each stage. For example, when a resident requests an artefact, such as a dry towel, it prompts a staff member to continue engaging with residents and keep them informed, maintaining involvement in the process.

5 Findings

We compiled all created maps, integrating key actors and their interactions to create an aggregated Actor-Network map (see Fig. 4). This generalised map helps clarify the roles of each actor, hypothesising an Actor-Network map where artefacts structure the activity, residents participate and collaborate, and staff facilitate the process.

This aggregated Actor-Network map was developed within the context of food-related activities. It revealed fresh perspectives on how artefacts, routine activities, and social dynamics shape dementia care in a group living environment, which can be relevant to various types of activities in dementia care.

5.1 Facilitation Through Artefacts

Artefacts used during food-related activities served as mediators, enabling non-verbal communication and fostering connections between residents and staff. In this sense, the artefacts' role within the activities went beyond utility, offering opportunities for meaningful interaction. This finding reframes the role of everyday artefacts, highlighting their potential to enhance engagement. The division of tasks created a tiered system where residents participated at their own capacity, ensuring even those residents with limitations could contribute meaningfully,

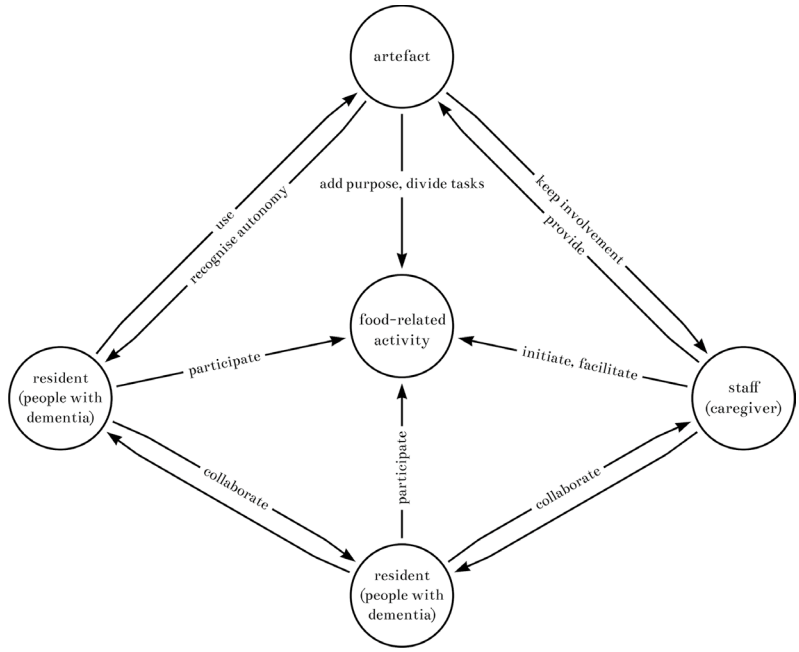

Fig. 4 Aggregated Actor-Network map of food-related activity involving residents with dementia and staff in a group living environment

preserving their dignity and agency. Routine activities like food preparation and cleaning provided multisensory experiences with tangible outcomes, such as a shared meal and a clean table, offering a sense of accomplishment, social connection, and home. Transforming the activities into experience interventions and care that emphasises routine and familiarity, helps residents stay connected to their environment while reinforcing a sense of purpose.

5.2 Collaboration as Empowerment

Staff actively collaborated with residents, treating them as equal partners in activities like food preparation and table setting. This shift from passive care to active collaboration highlighted the empowering potential of fostering inclusivity. Activities like cutlery washing were adapted for residents with physical limitations, demonstrating how daily activities could be modified while maintaining engagement. Residents not only worked with staff but also laughed, chatted, and emotionally connected, transforming routine activities into enriching social experiences–"*Some residents are cutting vegetables. The atmosphere feels nice because they are talking and laughing.*" (fieldnote taken by the first author). These activities strengthened relationships between residents and staff, reinforcing a sense of belonging and community.

5.3 Meaning of Housework

Participating in housework activities, such as food preparation, table setting, and cleaning, is an effective and meaningful strategy designed to be accessible. Yet, it is important to recognise that housework is also a form of labour. When considering the quality of life, there may be debate over whether such labour is viewed positively or negatively. However, this study places greater emphasis on the participation aspect of these activities, focusing on fostering involvement and cooperation, rather than on the completion of work. In the care home where this

study took place, housework was considered a meaningful occupation, imbued with personal significance and a source of satisfaction–"*We do things together here*," "*As long as I can help, [it is] a pleasure to do it.*" (fieldnotes taken by the first author). Residents had the autonomy to quit or decline participation at any time, and both male and female residents were involved. Staff encouraged residents to engage, assist, and collaborate with one another, rather than simply taking on the workload themselves. The opportunity to participate in housework activities allows residents to continue engaging in the group living environment in a supported manner.

6 Discussion

6.1 Material Agency of Artefacts

We now determine that artefacts support facilitation and collaboration by acting as mediators beyond mere utility, dividing tasks, building a tiered system, and adding purpose through routine. But how do artefacts achieve this? To explore this, we further examined their material agency using MET.

According to Malafouris [20], mundane artefacts hold memories of our past, embodied through our interactions with the material world. In the care home where this study was based, the artefacts were familiar to residents, but what stood out was that "the past" referred not only to residents' life before residing there, but also to recent routines. This perspective highlights the potential for designing artefacts that not only evoke memories from a person's distant past but also reinforce the continuity of their more recent life experiences.

Some residents adopted routines at the care home and continued to participate in certain activities regularly, and staff often invited residents to join in certain activities repeatedly. Conversely, when residents encountered unfamiliar artefacts, they often refused or struggled to engage with the given task within an activity. For example, a resident "… *struggled to understand where to put the washed cutlery (the wash basin) because she usually washes the dishes and not the cutlery.*" (fieldnote taken by the first author). This observation highlights the potential for the experience design of the activities to be informed by the familiarity of artefacts and routines.

Malafouris [20] also emphasises that former enactive capacities of people with dementia remain largely intact and can be reused or developed to compensate for lost abilities. During the present fieldwork, we observed that some residents, despite having difficulties in simple manual tasks like folding a towel or turning a book page, could still participate in specific activities that involved certain artefacts they were familiar with. Based on the authors' observations, even when a resident could engage with only one artefact, it was enough to facilitate meaningful participation. Staff would invite new residents to different activities and assess their abilities by observing how they interacted with artefacts, which then informed future facilitation decisions.

Some residents were insistent on specific roles, including the positions they occupied and the artefacts they used during activities. It was observed that these artefacts supported residents' autonomy by offering a sense of continuity. Significant artefacts and personal possessions, accumulated over the course of life, serve as material memories and anchors of self-identity [20].

In summary, it was observed that there are clear benefits to keeping daily activities and artefacts as familiar as possible, resembling a regular (home) environment. This finding is coherent with existing dementia research such as [25, 26]. Excluding residents from daily operations of communal living, such as by using catering services, could eliminate opportunities for meaningful participation. Additionally, the use of mundane artefacts helps recognise and preserve the autonomy of people with dementia.

6.2 From Research Insights to Design Toolkit

PPW collaboration emphasises the importance of treating people with dementia as equal

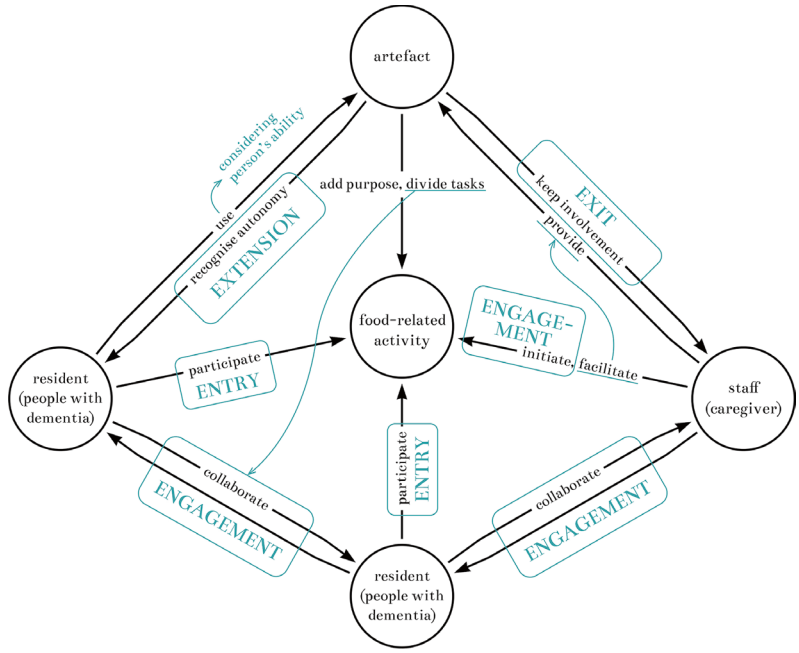

Fig. 5 Applying the 5E experience design model to the aggregated actor-network map of food-related activity involving residents with dementia and staff in a group living environment

partners and fostering social experiences. The aggregated Actor-Network map (see Fig. 4) clarifies the actors, their interactions, and how actions are enacted. MET helps us understand the material agency of artefacts, which is crucial for designing activities that support people with dementia. These insights are inspirational for experience design, providing clarity on the meaning, design interventions, and purpose of supportive environments for people with dementia. Our goal was to translate these insights into practical design-related considerations by developing a toolkit for caregivers (including staff and informal supporters) to create activity experiences that promote facilitation and collaboration.

To develop this toolkit and incorporate the insights from PPW, the Actor-Network map, and MET, the 5E Experience Design Model was used as a framework. This model includes the stages of excitement, entry, engagement, exit, and extension – the "5Es" and is a framework for creating holistic and meaningful experiences [27], aligning closely with our goal. The 5Es represent steps through time, providing a sequence of the experience.

6.3 Applying 5E Experience Model

First, we mapped the interactions from the aggregated Actor-Network map onto the 5E stages, matching each stage with the order in which the interactions occurred (see Fig. 5). Next, we listed the actors and their interactions in sequence, specifying who initiated each step. Then, we illustrated the steps in a circular loop to represent the routine nature of the activity, which can be re-initiated. Finally, we developed a practical toolkit for caregivers based on the result of applying the 5E Experience Design Model.

Artefacts in Action Toolkit. This toolkit[1] guides caregivers in creating activity experiences for people with dementia. It helps outline

[1] To request the full toolkit, please email the first author.

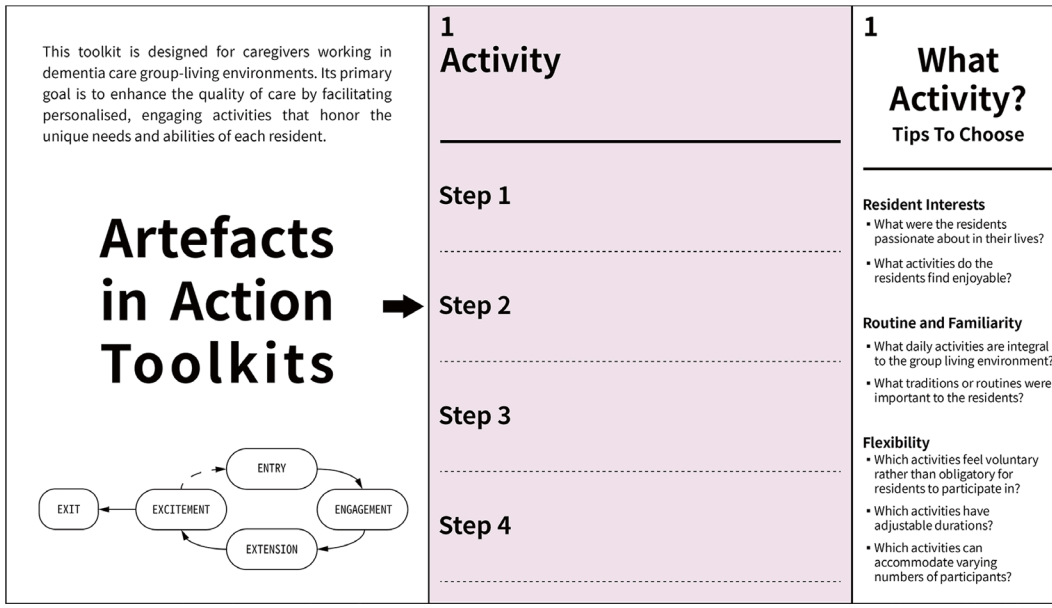

Fig. 6 Artefacts in action toolkit–activity

the steps, identify involved artefacts, and consider factors like motivation, engagement, challenges, and how to adapt as a person's capacities change, as explained in the following instructions:

1. Start by selecting an activity you wish to facilitate (see Fig. 6). Break down this activity into clear, manageable steps.
2. List all the artefacts needed for each step of the activity (see Fig. 7). Provide a description or sketch of each artefact, specifying which residents can use them and how they are used. Record any additional notes and dates to track changes in the residents' conditions and adjust the activity as needed. Consult the instructions for detailed tips.
3. Review and refine the activity steps to create clear, practical instructions for facilitation (see Fig. 8).

While this toolkit was developed in the context of food-related activities, activities common in group living environment or other care settings, like decorating a shared space, can potentially be applied. For example (see Figs. 9 and 10), making paper ornaments to decorate a Christmas tree could be an activity where different actors and artefacts interact. Stationery artefacts like scissors, glue, glitter, and paper are involved. One resident might cut the paper, while another glues glitter afterward. A resident who enjoys bright and colourful aesthetics might be motivated to glue the glitter. For staff, pre-drawing cutting lines on the paper is the indication to facilitate participation in this collaborative activity. This toolkit was not formally tested, instead, the example demonstrates how the toolkit could be applied in practice to facilitate meaningful activities, and its potential utility.

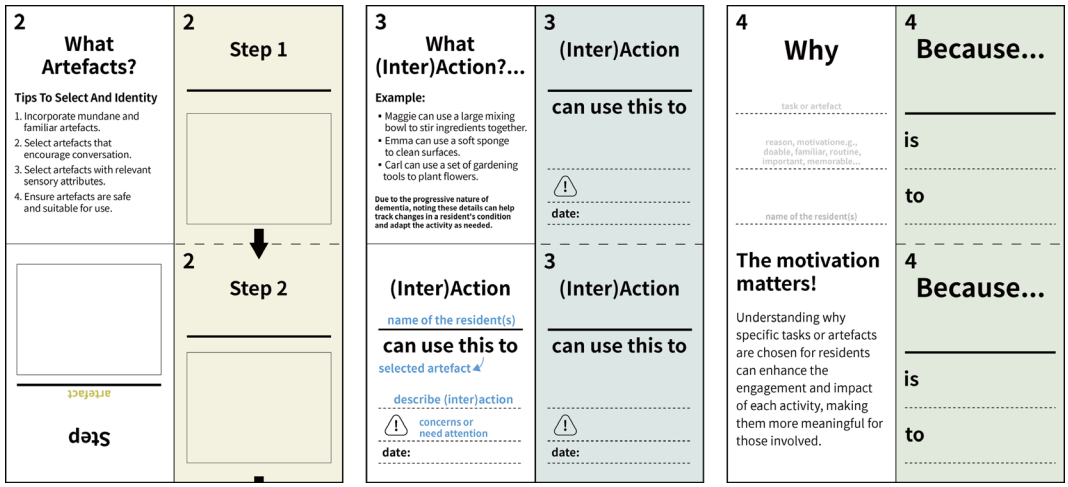

Fig. 7 Artefacts in action toolkit–identify artefact and interaction (with instructions)

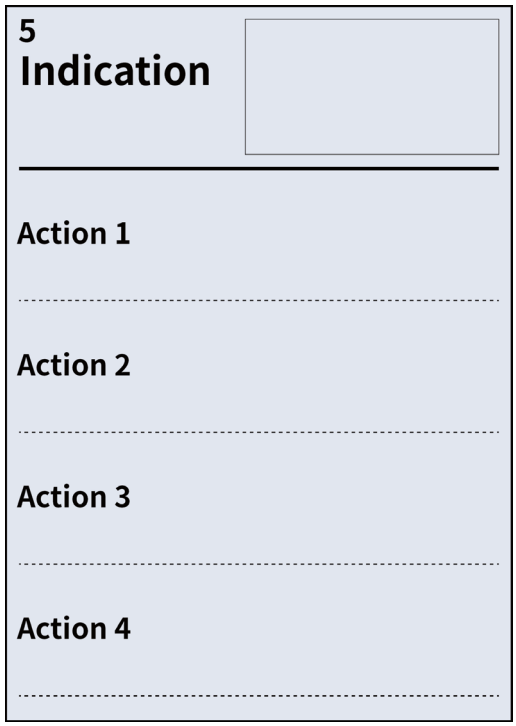

Fig. 8 Artefacts in action toolkit–refine activity steps to practical indication

7 Conclusion

This study explores how artefacts facilitate Positive Person Work (PPW) in dementia care by fostering facilitation and collaboration within group living environments. Through short-term design ethnography in the care home, we examined the critical role of artefacts as mediators of non-verbal communication, enabling social interaction and participation. Using Actor-Network Theory (ANT), we mapped relationships between residents, staff, and artefacts, revealing how these interactions shape a supportive environment for PPW. Additionally, Material Engagement Theory (MET) provided insight into the material agency of artefacts, showing that they are not passive objects but active actors in creating meaningful experiences for residents.

Our findings led to the development of a practical design toolkit for caregivers based on the 5E Experience Design Model. This toolkit offers a structured guide when designing activity experiences that promote collaboration and facilitation for people with dementia. Artefacts

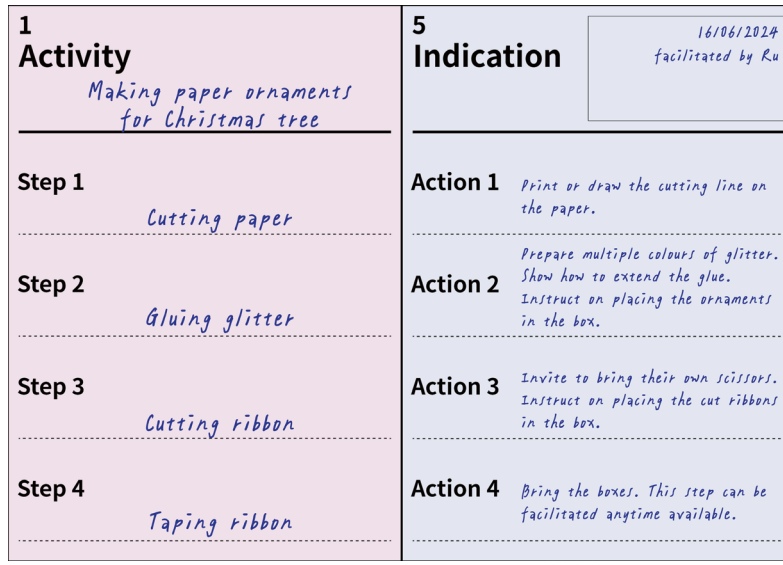

Fig. 9 Example of using artefacts in action toolkit for making paper ornaments

and routine activities serve as mediators and opportunities to enhance residents' autonomy, agency, and social interaction, while fostering meaningful interactions between staff and residents. While our study initially focuses on food-related activities due to their routine nature and familiarity, the toolkit developed is designed to be adaptable to a broader range of daily activities within dementia care.

The study also provides several design-related considerations for dementia care. Artefacts should be selected not only for their utilities but also for their ability to evoke memories, engage former enactive capacities, and facilitate interaction. Moreover, involving residents in daily activities such as food preparation, table setting, and dishwashing offers valuable opportunities for meaningful engagement, reinforcing a sense of accomplishment and purpose.

7.1 Future Research

Future research should explore the broader applicability of facilitation through artefacts and collaboration as empowerment across diverse dementia care settings, including residential care homes and daycare centres. The ongoing refinement and formal testing of the developed toolkit, including further evaluation for caregivers of people with more advanced dementia or motor abilities, are planned as next steps in this research. Additionally, longitudinal studies could investigate the long-term impact of artefact-based interventions on the well-being and cognitive abilities of people with dementia. By continuing to examine how artefacts and activities can support PPW, future research can contribute to the development of more supportive and inclusive dementia care environments.

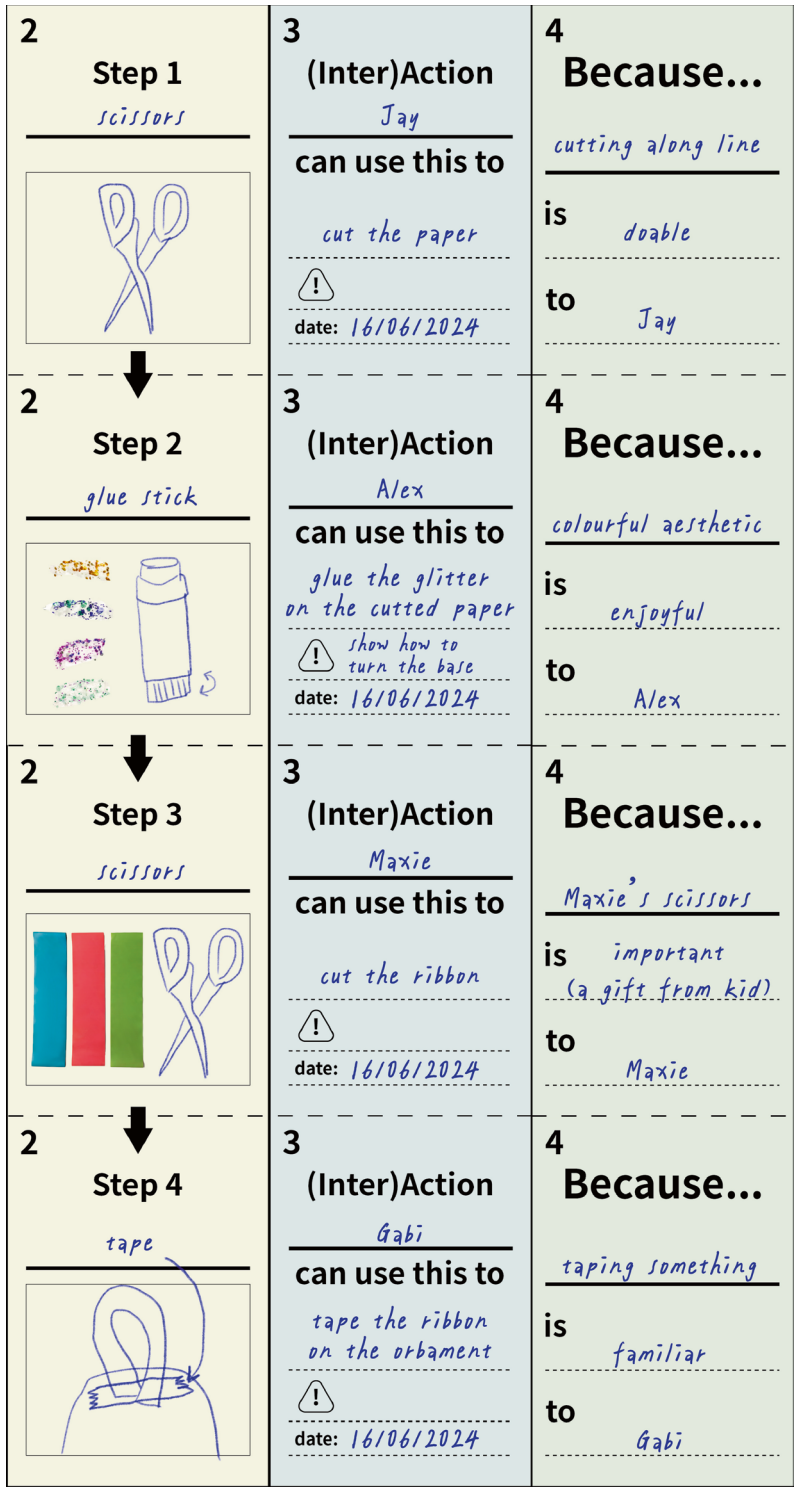

Fig. 10 Example of using artefacts in action toolkit for making paper ornaments

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Design within Cultures of Care

One Lovely Hour: Food as a Tool for Empathy in Designing for Culture, Aging, and Care

Amanda Huynh and Ranee Lee

Abstract

More than a necessity, food can be a way to create a connection to identity, culture, and a sense of belonging. In this study, we investigate the impact of lived experience on the perception of food based on the form, colour, and texture of what is presented to us. These workshops were undertaken in academic settings: a conference on dementia (3 participants) and a design studio classroom (10 participants). Our findings point to the connection between lived experiences and the perception of food. The workshops heightened participant awareness and empathy regarding how food affects memory and emotional well-being, particularly for immigrant older adults living with dementia in long-term care (LTC). The findings contributed to (a) a design brief for culturally specific assistive tableware and (b) suggested that experiential food workshops are a valuable, low-barrier method for enhancing caregiver empathy for improving LTC quality. Further studies will evaluate the resulting tableware design and its impact on LTC mealtime.

Keywords

Culture · Dementia · Long-term care

1 Introduction

Food is a connection to comfort, safety and home [1–3], concepts which are critical to older adults living with dementia. These older adults can experience poor appetite, decreased sensory experiences in smell and taste, self-feeding difficulties and other factors that result in poor food intake and weight loss. [4] We place a focus on the mealtime occasions when food is connected to one's culture, giving a sense of safety and belonging that is especially important for older adults experiencing cognitive decline. Improving food intake in LTC has been previously identified as a priority by other researchers, yet it remains an area that has been neglected in intervention research. [5] Mealtime is often the highlight of the day for LTC residents, providing opportunities for social interaction and the development of social relationships with their caregivers. [5] "One lovely hour" refers to the chance to make positive design interventions in the daily mealtime for LTC residents, allowing older adults to reclaim one lovely hour each day.

The authors are first- and second-generation Canadian immigrants of East Asian descent,

A. Huynh (✉)
The Ohio State University, Columbus, OH, USA
e-mail: huynh.310@osu.edu

R. Lee
OCAD University, Toronto, ON, Canada

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trained industrial designers, and post-secondary educators in the design field. Amanda Huynh has expertise in food design and teaches design research, while Ranee Lee has an ongoing human-centered design course that partners with Baycrest Health Sciences (research and teaching hospital for older adults) designing with older adults living with dementia. Living in urban North American cities with dense populations of diverse cultural backgrounds, we have firsthand experience with older family members living with dementia. Through our own lived experience involving older adults and food, we separately observed how Western hegemonic food was still the cultural standard served in LTC homes serving diverse residents. Immigrant LTC residents in Canada have found themselves cut off from their traditional foods, which many residents consider the last link to their culture [6]. Prior to moving into LTC, immigrant older adults may access their cultural foods through family, and culturally-specific restaurants and grocery stores. This access can become much more limited in culturally dominant LTC contexts. Through our participatory design practices with community groups, we saw the opportunity to improve the day-to-day food service for LTC residents of all cultural backgrounds, particularly for older adults living with dementia experiencing diminished sensory and memory experiences. Food is relevant to culture and memory, and those connections can be few and far between for immigrant older adults, making this area of study critical for those living with dementia [7]. While this impacts other non-hegemonic cultures, we center the food of immigrants from East Asian cultures in this first pilot study given our own experiences and cultural positionality.

The study explores two research questions:

1. How do our visual perceptions of colour, form, and texture impact our expectations and experiences of food?
2. How might we design workshops for stakeholders (such as caregivers) from different cultural backgrounds to build empathy and capacity to understand the value of cultural food considerations for older adults living with dementia?

1.1 Context: Culture and Identity

The world's population of people aged 60 years and older will double between 2020 and 2050 [8], with immigration making up the largest share of this increase in urban cities like Toronto and New York City, situating us at the important juncture of aging and culture. As of 2021, Toronto's population consists of 52.9% first generation Canadians [9]. This illustrates the increasing importance of cultural considerations in aging and care. In this research, we focus on Canada's LTC system, a social system offering assistance with the basic personal tasks of everyday living, and focusing the design inquiry on the experiences around foods for older immigrant adults. When a group is marginalized by race, ethnicity, or language, food often takes on distinct meaning as a vehicle for transmitting cultural traditions and identities [10]. There are existing leaders in culturally-specific healthcare in LTC serving culturally-appropriate foods for their residents. However, the need far outpaces the available resources. On a provincial level, only 56 out of 627 LTC homes in Ontario offer culturally-sensitive care, resulting in longer wait times than the culturally dominant LTC homes [11, 12]. In an already stressed social system, the LTC homes were distinctly affected during the COVID-19 pandemic, which brought food service issues to the foreground.

For older adults to age well, especially for those living with dementia, food and eating rituals are particularly important. Eating culturally appropriate foods allows for recognition, supports mental well-being, promotes joy, and creates a sense of belonging and comfort [13–15]. Mealtime for older adults with dementia in LTC is a complex issue, at the intersection of factors such as resident physical and cognitive abilities, cost, and local regulations. We are proposing a low-barrier empathy tool to address just

one aspect of the issues that can be presented: cultural considerations in LTC mealtime, a factor that we found underrepresented in prior research.

1.2 Context: Form

Lee cares for her mother, who lives with advanced Alzheimer's in a private home residence. An Asian immigrant, she is frequently served plates of food that are unrecognizable to her. For example, lunch is often served in the form of a sandwich on a cold plate (Fig. 1), favouring Western hegemonic food as the cultural norm. Coming from a culture where hot lunches are the standard and having little experience with a typical sandwich, the food is meaningless and lacks any joyful connection to her memories or identity [16]. Food characteristics that present visually are of great importance to appetite for older adults. Colourful food, "eating with your eyes" can stimulate appetite, which is crucial for nutrition and health [17]. In latter stages of dementia, where older adults may experience swallowing difficulties, shapeless or scooped purees are the norm [18]. This removes formal visual reference altogether, and no connections can be made to one's existing understanding of food.

There is potential for a positive impact in long-term care through products designed for the visual appeal of foods. Biozoon, a food company in Germany, focuses on older adults and their quality of life by using gels and thickened liquids formed with moulds into recognizable shapes to look like German cultural plated foods such as sausages, peas and roast beef. In

Fig. 1 Cold sandwich lunch with two slices of beets served in a private care home, 2021

a 2019 study of older adults living with swallowing and/or mastication disorders, 62.5% of the participants reported that the appearance of the pureed food is the most or a very important aspect of the food [18]. Similarly, other advances in 3D-printed food are being developed with a focus on improving appetite and dietary intake for older adults [19]. The correlation between older adults recognizing food and their overall health crosses all cultures.

Aging experiences can be designed with greater consideration to the cultural background of older adults in LTC. Such considerations might allow these adults to bring more aspects of their lived experiences into their day-to-day care. Studies show that beyond its functional role of nourishment, food's social and psychological impact can be used as a tool for comfort [3]. Furthermore, food can be a connection to home, culture, and a reinforced sense of identity [2]. Ultimately, when older adults do not recognize the foods served to them, there is a sharp disconnect from their identity, home, and culture. This study is important for those in roles of caring for those living with dementia, who have more control over the decision-making around food service.

This research explores food as it relates to memory and identity, and the impact of form, colour, and texture on our expectations of taste. Originally conceived as an exercise in design exploration, we now see the value of the workshop activities as empathy-building exercises for formal and informal caregivers of older adults living with dementia for a more effective care practice.

1.3 Context: Empathy Tools

Effective caregivers require a level of empathy and understanding of older adults living with dementia. This is especially true when the caregivers and older adults are from different cultural contexts. From this study, using food as a tool for empathy can be an accessible and effective way to highlight differences and bridge the connection needed for more empathetic and effective care. Currently there are several studies about the feasibility of effectiveness of virtual-reality based training for dementia care for both informal caregivers and people pursuing nursing education [20–22]. Given the increasing trend in employing novel technology such as VR in caregiving empathy training [21] which can be costly, there is value in proposing low cost and low barrier alternatives to experiential empathy tools. Using food as a tool provides an experiential, embodied empathy-building experience with minimal training requirements and no need for technology or technological onboarding. Existing empathy tools have proven to change attitudes and behaviours towards a better understanding of older adults living with dementia.

2 Culture and Identity

"[E]thnically and linguistically diverse communities may experience longer wait times than others in getting into a LTC home of their choice" [11, 12]. Securing placement within a LTC facility that aligns with one's linguistic and cultural requirements is challenging, resulting in many older adults settling for a mainstream LTC that may not deliver services to sufficiently meet their ethno-specific needs [11]. Only about 9% of LTC homes in Ontario offer culturally appropriate accommodation and care, even as studies show an important link to "health, well-being and quality of life of LTC residents" [12].

The increasing number of older adults brings challenges of caring for an aging generation. Society will potentially face a shortage of LTC facilities and caregivers [23]. With this aging population and the rate of immigration in urban cities, addressing culturally tailored care is becoming increasingly urgent. Within this context of a multicultural society such as Canada, culture is transmitted through food practices [10] and through references to food. Rituals around food play a critical role "in the creation and maintenance of socio-cultural identities" [2]. Spending more resources on intentional meal time experiences is the most straightforward way to connect to an older adult's sense of

self and belonging [24]. "The food we eat, the way we eat it, and who we eat it with are deeply embedded cultural practices that say much about who we are, where we are from, and what we value" [2].

Previous studies on food in long-term care have taken place directly within the LTC facilities and have focused on quantitative health-related metrics such as nutrition and intake values [4, 25]. There have been few studies in LTC that focus on the visual and cultural aspects of the food served. "[M]odifying the psychosocial aspects of mealtimes is proposed as a means of improving food intake and quality of life and, to date, is a neglected area of intervention development and research" [4]. Due to the difficulties posed by unpredictability in participants, including diminished the performance of cognitive functioning such as reasoning, memory and communication, and a compromised ability to conduct daily tasks, there is room for more qualitative research that involve other stakeholders in a participatory way [26].

In this study, we see an opportunity to design a tool for empathy that crosses cultures for stakeholders to gain a deeper understanding about the dining experiences of older adults.

3 Research Methods

We designed the Colour, Form & Texture Workshop as a tool to create empathy and understanding in participants for older adults being served foods they don't recognize by presenting various food samples selected for their abstract appearance—the taste of each were not obvious through visuals alone. The workshop investigated the relationship between the visual assessment and expectations of the food samples based on the participant's lived experience and own cultural backgrounds. For this study, we facilitated two sets of experiential workshops on two continents (Europe and North America) in autumn 2022 for the purpose of gaining insights from differing groups of people. In each workshop, participants were informed that their input and photographs would be collected for academic use and may be used to inform the next iteration of our design process. They provided their consent through a sign-in, which also provided an opportunity to opt out of any activities and documentation. Participants were asked to reflect on their cultural experiences of food and what they learned through the workshop activities and to only share as much as they were comfortable and willing to.

To explore our research question regarding the properties of food (colour, form, texture) and their impact on diner expectations and intake, we devised a 60-min workshop session (Table 1).

We introduced and facilitated two activities, but are only analyzing the results of Activity #1 in this paper. In Activity #1, participants were asked to assess packaged food samples first visually and then through taste (Fig. 2). The food samples were chosen from common Asian snack foods based on their ambiguous colours and abstract forms, to simulate the experience of older adults with dementia being presented with unrecognizable food. We ran the workshop once in a conference setting in Belgium (3 participants), and once more in a studio classroom setting in the United States (12 participants). Participants in Belgium consisted of healthcare research and design professionals recruited from conference attendees, who self-selected based on their own interest through a brief workshop description about food and memory, while participants in the studio classroom were international design students interested in participatory design and aging.

Before participants arrived, we set out for each person: 7 individually packaged samples

Table 1 The colour, form and texture workshop

Order	Time (min)	Description of activity
1	5	Introduction pre-questionnaire
2	10	Introduction to workshop (colour, form and texture in food)
3	20	Activity #1 colour form and texture expectations
4	15	Activity #2 future of food discussion
5	5	Closing reflections
6	5	Post-questionnaire

Fig. 2 The colour, form and texture workshop at a conference

of food, two questionnaires, and a page for responses to the food sample activity indicating the order in which to taste the foods. At the outset of the workshop, participants completed a workshop pre-questionnaire, outlining their relationship to dementia and LTC, ethnicity and cultural background, and about prior understanding of cultural food. All questions were made optional.

An introduction was given to the participants explaining our backgrounds as product designers, and thus our focus on the visual aspects of food. We asked general questions about food and comfort, personal memories associated with food, and whether we perceive these foods to be tied to their cultural backgrounds. We also shared that although the food samples were common Asian snack foods, the workshop was intended to build empathy around unrecognizable foods rather than center Asian eating and dining culture. We also gave cursory background information on the state of the dining experience in North American LTC facilities.

Activity #1: Colour, Form, Texture and Expectations

In front of you are 7 packages of food.

Please fill out the slip of paper that corresponds to each:

1. What does the form remind you of?
2. What do you expect it to taste like?
3. What do you expect its texture to be?
4. What did you actually taste and experience?

Participants were asked to visually examine and write their impressions of each packaged food sample, answering questions about the form, and their expectations of the taste and texture of what they saw. After writing, they tasted each sample and noted the experience. Following the activity, we reflected on their experiences sampling the food and the surprises that arose. We will discuss more in the findings. The workshops ended with a post-questionnaire, asking similar questions as the pre-questionnaire, in order to gauge any change in participant understanding.

4 Results

4.1 Colour, Form and Texture Workshop Results

In Workshop 1, September 2022, we had a total of 3 participants. In Workshop 2, October 2022, we had a total of 10 participants. Due to

the low number of participants in Workshop 1, we are evaluating the results of both workshops together. In the pre-questionnaire, participants were asked:

1. What is your relationship to dementia and long-term care? (Designer, educator, caregiver, etc.)
2. What ethnicity/cultural background do you identify with?
3. On a scale from 1 to 5 with 5 being the most/highest, please circle:
   a. How often do you consider food in your own day-to-day?
   b. How would you rate your knowledge about food in long-term care?
   c. How important do you think it is to consider cultural relevance in food?
4. What excites you, if anything, about the role that food can play in long-term care?
5. What concerns, if any, do you have about the current state of food service in long-term care?

Table 2 Participant relationship to dementia and ethnicity/cultural background (self-identified)

Participant	Relationship to dementia	Ethnicity/Cultural background
P1	Family member and designer	European (French)
P2	Designer	Western European
P3	Occupational therapist	European
P4	Family member	Unknown
P5	No relationship	White/Middle Eastern
P6	No relationship	Chinese-American
P7	Personal interest	Korean
P8	No relationship	Southeast Asian
P9	No relationship	Chinese
P10	No relationship	Chinese
P11	Family member	Asian–Chinese
P12	Family member	Chinese
P13	Some familiarity	East Asian–Korean-Japanese

Results showed that participants' expectations of food based on its appearance is heavily influenced by their own lived experiences and cultural contexts. Based on the responses to Question 1: What does the form remind you of? For example, with the haw flake, a circular pink wafer, a European participant, P3 responded "Communion wafer" (refer sample at top left, Fig. 2). Another participant looking at the same disc-like food says that "it's something (felt pads) you put under a chair to not scratch the floors"; while P1 wrote "sausage (German)", specifically. These responses show how expectations of particular food shapes are determined by lived experiences and contexts (Table 2).

Participants came to understand the connection between ambiguous or unfamiliar food being served to immigrant adults in LTC as a potential issue for health and quality of life. A triangular half sandwich served cold on a plate might not register as food for someone who did not eat sandwiches before living in a dominant culture LTC facility. Participants shared that they were at times unpleasantly surprised by the flavour and texture of the food sample contrasted with their expectations.

Participants were asked about their expectations about the food samples for Question 2: "What do you expect it to taste like?" and Question 3: "What do you expect its texture to be?". Question 4: "What did you *actually* taste and experience?". Below is an illustration of responses from Participants 1 and 2 to give an example of the range we were presented with (Table 3).

P2 was expecting the food to be "salty" and after sampling wrote "cranberry, hard candy, it was very shocking". Furthermore, P2 had an expectation the food sample was "bland" and wrote "crunchy, salty, it has a lot of taste" upon tasting. These varied experiences achieve our goal of simulating the experience older adults can have when served foods they do not recognize. For the participants, it was a new way of engaging with experiences in LTC.

Table 3 Sample participant responses to unlabeled samples of food

	P1		P2	
Sample	What do you expect it to taste like?	What did you actually taste and experience?	What do you expect it to taste like?	What did you actually taste and experience?
1	Communion wafers, dry	Sugar with fruits candy	Candy-like sweet and sour	Salty soft
2	Spicy	It is as expected	Salty crunchy airy	Roasted snacks, peas?
3	Cat food, soft	Didn't expect that!	Cat food, salty	Food stock (bouillon) with licorice inside. Soy sauce
4	Sugar for coffee	Crackers, very good with bacon and spicy maybe	Salty soft (milky) or caramel	–[a]
5	White chocolate, I don't want to eat it	Remembered Kinder chocolate	Mayonnaise, eggy fat	Kinder Surprise
6	Fruit sugar	Apricot candy	Fruity candy or ham	Fruity berry carrots
7	Candy	Ginger–very good	Sweet, dates	Spicy ginger eucalyptus minty

[a]Participant could not respond due to a food allergy

4.2 Questionnaire Results

Participants from Asian backgrounds (P6–P13) were already familiar with some of the snack foods that were presented, so the gap between their expectation and reality was not as wide as that of participants from European and Middle Eastern backgrounds. P10 shared that, while their own expectations of taste were not challenged, they were "quite surprised to see how people from different cultures experienced the food differently." Still, the understanding of the connection between food and memory in LTC was made more apparent. With these participants, the greater results came from their written responses to our pre-and-post workshop questionnaires.

We gathered and organized the data according to mental and emotional shifts towards the topic of culture, care, and dementia. There is evidence that the workshop heightened awareness and the level of empathy in the participants, as shared in their feedback. These short answer responses can be categorized by: change in perspective on cultural importance of food, shift in self-reflection, and understanding of food in relationship to dementia (Table 4).

5 Discussion and Further Studies

As a result of these workshops addressing form, colour, and texture, we present a contribution to the understanding of how food can be used as an empathy tool to improve effective care and quality of life of immigrant older adults living in North American LTC through its use in introducing and familiarizing the concept of cultural foods to caregivers. When caregivers in LTC understand the perspective of older adults in their care, their attitudes and behaviours may shift to more resident-centered decision making for mealtime experiences. Our study provides insights into the value of using food as an experiential tool for empathy as a low-barrier method of embodied experience for participants, which can provide both design input and promote a higher quality of care from caregivers. The responses reflecting on the workshops showed evidence in a shift in self-reflection and an increased understanding of food in relationship to dementia. These findings have resulted in a design brief for culturally specific assistive tableware which will be evaluated in future studies.

Table 4 Sample questionnaire results by category

Response categories	Short answer responses
Change in perspective on cultural importance of food	"It further enhanced how important I think cultural relevance is in food. It made me realize how much memory, joy, emotional experience it brings. The presentation also made me realize how familiarity relates to appetite." (P9) "I think that this experience not only educated me, but created a great sense of empathy for our connection to food. I think there are so many parts of the food experience that we take for granted. Being able to verbalize it and add value to things like color, texture, and form means we can retain them in experiences like LTC. This was a very emotional experience for me. Thank you for doing this." (P8)
Shift in self-reflection	"I already thought it [food] was important, but by the examples and thinking assignments, it became much clearer and my perspective grew.". (P2) "I think that people who don't really have control over their food, when see the food made by others can have certain emotional reaction and I think it is important to consider these parts when preparing food. I really enjoyed this workshop it made me rethink, reflect, and reimagine what the. future might work like and how we can contribute to them." (P13)
Understanding of food in relation to dementia	"I think that this experience not only educated me, but created a great sense of empathy for our connection to food. I think there are so many parts of the food experience that we take for granted. Being able to verbalize it and add value to things like color, texture, and form, means we can retain them in experiences like LTC." (P8) "I've never thought about how people with dementia can view food differently based on the different shapes of the food and how food can trigger memories. from all 5 senses." (P12) "Never thought about form associations for people with dementia before and how cultural differences might affect that." (P4) I've never thought about how people with dementia can view food differently based on the different shapes of the food and how food can trigger memories. From all 5 senses. (P12)

Based on this study, we found that the food samples provided a tangible connection and understanding for participants that typical surveys or interviews do not. Through a relatively short workshop, it allowed participants to directly experience tasting food when they were unsure of what to expect. The workshop is low cost and easily replicable as an empathy tool to understand the importance of cultural food using similar snack foods from other cultures.

5.1 Further Studies

We recognize the limitations inherent to our workshops engaging the general public rather than direct caregivers of older adults in LTC. The participants recruited were limited to small groups, each with similar cultural backgrounds. We also chose to work with Asian snack foods given our own experiences and positionality, which limited our outcomes. However, we found it to be a valuable pilot study to gain an understanding of public perception around food and aging in a diverse urban community before we engage with older adults and their caregivers directly. It also helped us to understand the high level of interest in the topic. We acknowledge that we have included only studies published in English and relevant literature published in other languages may have been missed.

In the intervening time since these early workshops, we have used the results to connect food, identity, memories, and belonging in product design for LTC. We developed an assistive plate with an experiential dinner to gather further insights on dignified meal experiences within the constraints of LTC institutions. For further validation studies, we plan on testing the plate design in a LTC setting for

general usability as well as perception by older adults. The outcomes will be discussed in a future paper. The proposed model of centering food in empathy workshops to inform the design process also needs to be evaluated in follow-up studies.

6 Conclusion

This series of form, colour, and texture workshops employed experiential methods to engage stakeholder communities in conversations around food and cultural heritage for older adults. From the workshops we found valuable insights that have led to the formation of both a design brief for an assistive tableware product and a proposed method of empathy-building around culturally appropriate food for long-term care residents. Given the affecting feedback from participants, we believe there are many more opportunities to consider lived experiences of older adults in food, product, and service design in LTC. The benefits of using cultural understanding in a design brief for LTC products will ultimately be measured through future studies in LTC settings. We believe that utilizing food and dining experiences as methods of inquiry can be used by other designers and researchers to capture participants' lived experience, gaining deeper insights on aging and those living with dementia.

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Feels like Home: A Participatory Approach to Enhance Care Environments Through Personal and Collective Stories

Silvia Maria Gramegna

Abstract

The concept of 'home' plays a critical role in designing care environments for individuals with dementia, extending beyond physical space to include identity, familiarity, and continuity with life stories. This study explores the intersection of narrative and spatial design, presenting a narrative-based approach to creating living spaces that preserve and support personhood. As dementia progresses, recalling and organizing personal stories often becomes challenging, increasing the importance of environmental cues in maintaining identity. A participatory co-design methodology was employed, engaging individuals with dementia, care staff, and researchers to develop spaces resonating with personal and collective narratives. Narrative elicitation sessions captured participants' life stories, preferences, and sensory experiences, which were translated into tangible design elements. The resulting environments go beyond functionality, becoming extensions of residents' life stories that promote emotional well-being, reduce stress, and enhance belonging. By embedding narrative-driven elements such as familiar objects, textures, and sensory cues, the design approach ensures that care environments remain adaptable and deeply personalized, supporting identity amidst cognitive changes. This study underscores the therapeutic value of integrating narrative into design processes, advocating for care settings that reflect the unique identities of their residents while fostering connection and continuity.

Keywords

Narratives · Participatory practices with people with dementia · Interior design

1 Introduction

As the global population ages, the prevalence of dementia—a group of progressive neurological conditions that impact memory, thinking, and behavior—is becoming an increasingly significant concern in public health [1]. According to the World Health Organization, an estimated 55 million people worldwide are living with dementia, with this number expected to grow to 78 million by 2030 and 139 million by 2050 [2]. The increasing prevalence of dementia makes the design of comfortable, decent and home-like

S. M. Gramegna (✉)
LABIRINT Research Team, Department of Design, Politecnico Di Milano, Milano, Italy
e-mail: silviamaria.gramegna@polimi.it

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care environments for individuals with dementia a critical area of focus [3, 4]. For those living with dementia, the concept of 'home' transcends the mere physical structure, encompassing a deep connection to personal identity, memories, and a sense of continuity with one's past [5, 6]. The home is a repository of habitual activities, familiar objects, and sensory experiences that anchor individuals in their personal history, providing comfort and stability as cognitive functions decline [7]. However, the progression of dementia often necessitates a transition from the familiar home environment to a care facility, a move that can be disorienting and emotionally challenging. This transition highlights the importance of designing care environments that not only meet the functional needs of individuals with dementia but also resonate with their personal narratives [8, 9]. By integrating elements that reflect and reinforce these narratives, such as personalized spaces, familiar textures, and cherished belongings, designers can create environments that actively support the continuity of identity and promote emotional well-being [10, 11]. This paper explores a novel approach to co-designing care environments for people with dementia, merging narratives and interior design. The ongoing study, conducted by researchers from the Department of Design, Politecnico di Milano in collaboration with Equa Cooperativa care staff, focuses on Milan's PIAZZA GRACE Dementia Village. PIAZZA GRACE includes six shared apartments, each with a small kitchen, bathroom, and adjustable bed, housing two residents. Common areas feature a communal kitchen, living space, covered balcony, and garden. These residences are integrated into a broader community environment accessible to the local community, with stores, businesses, and public spaces. Through participatory co-design methods, this ongoing study aims to create interiors that extend residents' life stories, fostering a sense of home within care facilities. It also aims to support homemaking practices for people with dementia in care environments. This paper discusses preliminary results critical to the study's development.

2 Home

An increasing body of research has acknowledged the significance of dementia care facilities providing homelike feelings [4, 6, 11–13] since the establishment of person-centered care [14]. This approach has been shown to enhance social connections [15, 16], cognitive function, and performance in daily activities [17]. Creating a small-scale, home-like environment is one way to foster a sense of home for dementia patients [18], with a focus on residents' autonomy, privacy, and opportunities for fulfilling activities [19, 20]. Research on 'home-likeness' has led to improvements in the physical environment of care facilities, with notable adjustments such as smaller unit sizes, family-sized dining areas, private bedrooms, domestic furnishings, accessible outdoor spaces, and soft finishes on floors and surfaces, along with subdued lighting and personal items on display [21–26]. Organizational elements, such as family-style meals, flexible routines, resident participation in household chores, and discretion over portions, also contribute to a homelike atmosphere [27].

The concept of 'home' extends beyond the physical setting and institutional regulations of a long-term care facility. It emerges from a dynamic relationship between the individual and their environment, encompassing physical, social, and psychological dimensions [28]. For those with dementia, 'home' embodies a deep connection to identity, familiarity, and continuity with past life experiences [3, 9]. With memories and sentimental items that support their sense of self, home is a place where individuals feel secure, comfortable, and in control [10, 19]. The habitual activities, routines, and personal belongings developed over a lifetime provide stability and comfort amid the confusion and unpredictability brought by cognitive decline [29, 30]. Personal items such as family photographs, cherished books, or a well-worn blanket act as tangible links to the past, anchoring individuals in their personal history [31–33]. These familiar items can trigger memories and emotions, helping maintain identity and providing

solace amid change [34]. Sensory experiences tied to familiar smells, sounds, and textures are integral to the experience of home, evoking resilient emotional responses and memories [33].

As dementia progresses, these elements—habits, personal belongings, and sensory cues—become even more critical, providing a foundation for present identity and security [19, 35]. However, as dementia worsens, the ability to live independently often declines, creating an emotionally challenging moment when individuals must move from their home to a care facility, leaving behind familiar routines and people that anchor their identity [36]. Since this transition can signify a major loss of independence and familiarity, it is vital for caregivers to establish a 'home-like' environment that respects the person's individuality [4, 11, 12]. This includes retaining personal items and practices from the person's previous home to help mitigate the emotional impact of this change and maintain a connection to their history and identity.

3 Narratives of Home

Thus, the concept of 'home' is inextricably linked to the stories that mold an individual's identity; it is more than simply a physical location; it is also a storehouse of memories, experiences, and feelings [37]. That's why a well-designed place needs to speak to the experiences and personal tales that define 'home' for each individual, rather than just being aesthetically pleasing and useful. A person's surroundings play a significant role in shaping their life story [38]. This is seen in the integration of recognizable items, the recurrence of routine activities, and the stimulation of senses. Together, these components give a person a consistent feeling of self and stability, especially as life circumstances alter. The way living spaces are designed is even more important for conserving and bringing these unique stories to life for people with dementia [29]. Cognitive abilities may deteriorate with dementia progression, making it more difficult for people to remember and tell their own stories. In this situation, the surroundings themselves become an effective means of preserving a link to the past [39, 40]. Designers can create environments that do more than just meet the basic needs of care by carefully incorporating elements that reflect and reinforce a person's life narrative. Examples of these elements include cherished belongings that hold significant meaning, individualized spaces that evoke fond memories, and familiar textures that provide comfort [31, 41]. As the person navigates the challenges of cognitive decline, these environments take on an active role in their continuing story and support their identity. Because of this narrative-centered design approach, living environments for individuals with dementia are guaranteed to be authentic extensions of their individual lives, not just places where they can receive care. Designers can support residents' emotional well-being by creating environments that are rich in personal significance, which will give them a greater sense of comfort and belonging in their surroundings [7]. In the end, these carefully planned areas aid in maintaining the dignity and personhood of dementia patients, enabling them to carry on with significant experiences related to their identity and life narrative. Hence, this paper introduces a narrative-based approach to spatial design, emphasizing home-making dynamics by integrating personal stories into living environments. By addressing both practical needs and personal experiences, this method fosters a stronger sense of connection and belonging, turning care settings into authentic extensions of individuality.

4 Narrative Environments

The recognition of narratives as essential in care settings has grown alongside the rise of person-centered care models. These models emphasize that care should address not just the illness diagnosed but also the individual as a whole [14]. Consequently, those receiving care are regarded as unique individuals whose life stories should be maintained, and their perspectives and experiences of daily life should be honored and

adhered to [42]. These personal and subjective viewpoints are often shaped through narratives, as people understand their experiences and identities by creating and sharing stories [43]. Some scholars have even suggested that being a person inherently involves having a personal story and the ability to engage in narrative exchanges [44]. Preserving personhood is especially crucial for individuals with dementia, as the disease often impairs their ability to recall, organize, and share stories, particularly in its later stages [40]. To address this challenge, some scholars have introduced the concept of narrative care, which focuses on structuring care in a way that helps older adults maintain their sense of personhood [45, 46]. Different definitions of narrative care reveal a common core that describes a practice, a manner of giving care that places personhood's storytelling aspect at the very center of care activities [39]. In depth, we can see it as a narrative approach to human development, emphasizing that humans are inherently meaning-makers, primarily through language and storytelling. Our sense of identity is shaped by the stories we tell about ourselves, and this narrative identity evolves throughout life. One of the possible approaches in narrative care is the 'big story' one. This approach gives preference to structured narratives, which are stories that place various life events at precise temporal and spatial coordinates. These stories give the narrator a framework and give their lives coherence and meaning [47]. According to Westerhof [48] this method bases itself on the idea that a person's life story is composed of chronologically connected biographical memories that are kept in their mind, constituting a consciously accessible representation of the person's identity and self. Such autobiographical memories may disappear or access to them may be restricted in the case of individuals with dementia, endangering the preservation of individual identity [44]. It follows that the majority of interventions classified as narrative care have used a big story approach, attempting to maintain and refresh the life experiences of individuals with dementia in order to maintain their identity for as long as possible [40]. Another interesting approach related to narrative care is the 'small-story' one. The value of the tiny, everyday narratives that emerge in conversational settings is emphasized by this approach [49]. These short stories are fluid, conversational constructions tied to participants' 'here-and-now' interactions rather than reflections on significant life events. Often rooted in commonplace, seemingly minor moments, these narratives form the threads of an active social life. In institutional care settings, such stories emerge naturally during routine activities like eating or bathing. While dementia can hinder the creation of coherent life stories, limiting the 'big story' approach and relying on biographical input from relatives [50, 51], the situated and co-constructed nature of small stories offers a more accessible alternative. Focused on present needs and interests, small stories provide meaningful, relevant narratives that support connection and engagement for individuals with dementia.

5 Narratives and Spaces

Marie-Laure Ryan, Kenneth Foote, and Maoz Azaryahu's 2016 publication offers compelling insights into the relationship between story and place [52]. Their work identifies potential conflicts between narrative and space, categorizing these into four typologies of textual space: the text's physical space, its spatial shape, its spatial context, and the storyworld's or mimetic space [53]. The third typology, known as spatial context, explores the physical setting or support of a text. In this framework, architectural landscapes and surrounding environments become essential, serving as 'hooks' that enhance audience connection, engagement, and immersion by grounding stories in a physical location.

Spatial context itself can be broken into three categories: 'spatial annotation', which includes programs encouraging people to explore cities for narrative content; 'location-based games', which use the physical environment as the playing field; and 'mobile narrative experiences', where the storyline takes precedence over gameplay. The fourth typology, 'mimetic space', is the 'storyworld space' where characters act and

move in story environments shaped by architecture and spatial design [52]. These storyworlds encourage readers to mentally simulate character actions and movements, making fictional environments feel tangible and relatable, with connections to real-world spaces. Designers working within social spaces can foster this immersion by experimenting with world-building techniques, sense-of-place elicitations, and place-making practices [54, 55].

Using clues such as decorative elements, patterns, and familiar objects, designers can shape spaces that reinforce a person's sense of home and identity, especially for individuals with dementia. The interplay between narrative and space plays a significant role in shaping this sense of home, which is closely tied to both physical surroundings and personal items—crucial anchors of memory and identity [19, 20]. Design decisions like integrating auditory and visual elements allow spaces to resonate with residents' personal narratives, creating environments that support meaningful interactions and activities.

This narrative-driven methodology in spatial design enables the creation of enriched environments that serve as stages for narrative occurrences. In turn, these design elements support homemaking dynamics, acting as both narrative and physical anchors that foster a strong sense of place and identity. Ultimately, the relationship between stories and place highlights the importance of careful, narrative-informed design in crafting healing and meaningful spaces, particularly for people with dementia.

6 Methodology

This study utilized a qualitative, participatory co-design methodology involving individuals with dementia, care staff, and design researchers, with a particular focus on narratives and storytelling to inform the design of interiors in a dementia care environment. The methodology was grounded in narrative and storytelling practices to ensure that the design outcomes were deeply informed by the lived experiences and personal histories of the participants. This ongoing study aims to enhance PIAZZA GRACE interiors, to foster a sense of home even within a care facility by using participatory co-design processes to create spaces that are not simply places of care but also extensions of the inhabitants' life stories. Additionally, the project intends to encourage and improve homemaking practices in individuals with dementia who have moved into PIAZZA GRACE care environment. The on-going study was organized as follows:

Participant Recruitment and Selection: The study recruited 12 participants from PIAZZA GRACE dementia village, including 6 residents with dementia (aged 75–84), 4 care staff members, and 2 design researchers. To further support the residents in recalling memories, two family members, specifically the daughters of two residents, were also involved in select activities. Residents had mild to moderate dementia, diagnosed according to standard clinical criteria, with a balanced gender distribution (4 females, 2 males). Care staff were chosen for their extensive experience in dementia care, ensuring practical insights. The diverse group was selected to represent a broad range of perspectives and needs in the participatory process (Fig. 1).

Narrative elicitation sessions: Narrative elicitation was a critical phase of the research, aimed at capturing the personal histories, preferences, and significant life experiences of PIAZZA GRACE's residents with dementia. These sessions were conducted by researchers as short group interviews with the residents, organized in small groups of 2, lasting between 30 to 50 min each, depending on the participant's stamina and engagement level. Group conversations were conducted in the communal kitchen or in the personal shared rooms of the residents involved. Staff was participating in the interviews, with a supporting role, helping researchers to understand if the activity was becoming too stressful for participants with dementia. Conversations were semi-structured, allowing for flexibility in exploring different aspects of the participant's life story. Key questions included:

Fig. 1 Elderly residents participating in the study. Names are fictional

"Can you tell me about a place that holds special memories for you?"

"What happened in that place?".

"Can you tell me about an important object in your room? Or in your life?"

"Why is it so important for you?"

"Are there certain colors, sounds, or smells that remind you of a happy time?"

To facilitate memory recall, the researchers used a range of sensory prompts such as photographs, music, scents, and familiar objects. In 2 cases, family members were also involved in these sessions to provide additional context and support the residents in recalling and articulating their stories. Conversations were audio-recorded and transcribed for in-depth analysis, ensuring that the narratives were accurately captured and could be referenced throughout the design process. This phase is still on-going.

Participatory iterative design development: Insights from the narrative elicitation sessions were analyzed to identify recurring themes, such as preferred environments, emotional triggers, and personal symbols. These themes will then be translated into design concepts (which will be implemented in the care facility interiors) through a series of collaborative activities involving residents, care staff, and design researchers. Activities include small prototyping and sensory exploration, to translate narrative themes into tangible design elements. In particular, during

sensory explorations, participants will explore various materials, textures, colors, and scents, providing feedback on what resonates with their memories and preferences. This process will help to inform the selection of design materials that could evoke positive emotions and enhance comfort. The activities will be structured to be flexible and adaptive, accommodating the cognitive abilities and comfort levels of the dementia participants. The iterative design process will involve multiple rounds of feedback from all participants, ensuring that the evolving design remained true to the narratives and was responsive to the practical needs of the care environment. This phase will emphasize creating spaces that could evoke positive emotions, support orientation, and provide comfort to residents by integrating narrative-driven elements such as specific color schemes, textures, and familiar objects.

Ethical considerations: Ethical approval was secured from the EQUA Cooperativa Coordination Board before the study began. Informed consent was obtained from all participants, who were fully briefed on the study's purpose, their role, and their right to withdraw at any time without penalty. For those with advanced dementia, consent was gathered through discussions with family members and care staff, adhering to guidelines that protect residents' autonomy and dignity. Confidentiality was rigorously maintained, with all personal data anonymized. Interviews were respectful, non-intrusive, and sensitive to participants' cognitive limitations.

7 Results

The ongoing study presented in this paper, consists of two phases: narrative elicitation sessions and participatory iterative design development. Currently in the second phase, the research focuses on participatory design development. This paper primarily presents findings from the first phase, emphasizing the narrative elicitation sessions. These sessions have revealed how personal stories and lived experiences can inform the design process for people with dementia.

The design method uses the narrative frameworks discussed in Sects. 1.2, 1.3, and 1.4 to integrate daily interactions and personal histories as important components of the participants' identities. Both 'big story' and 'small story' methods are highlighted in this study's participatory co-design technique, which is strongly rooted in narrative-centered care practices. In particular, 'big story' approach is addressed during the narrative elicitation sessions where researchers ask questions aimed at eliciting structured, biographical narratives. In the narrative elicitation sessions, the 'small story' approach unfolds through semi-structured interviews using sensory prompts like photos, music, and familiar scents. These cues encourage participants to share casual, everyday memories that often emerge naturally. While these moments may seem simple, they are vital parts of each person's story. By capturing these 'here-and-now' memories, the sessions ensure that participants' current experiences and small, everyday recollections add meaningful depth to the design process.

To analyse the data gathered from the narrative elicitation sessions, researchers reviewed and organized the stories shared by participants, paying close attention to recurring themes, personal symbols, and emotional triggers. The data were sifted through to identify patterns in the participants' preferred environments and the specific sensory cues that evoked positive memories or comfort. Each narrative is examined for details that revealed deeper layers of meaning—places, objects, colours, and textures that held significance in the residents' lives. Currently, the researchers are developing visual boards, depicting these sensory cues, stories and memories, to be shared with residents, and to provide a base for the design development.

Moreover, the development of the participative phase in this study was greatly influenced by the time factor. To support the cognitive and emotional demands of participants, co-creative and participatory projects—especially those involving people with dementia—need a flexible and extended timeline. The project's narrative elicitation workshops and participatory design

exercises were thoughtfully timed to provide residents enough time to comfortably recollect and share recollections. Researchers occasionally rescheduled sessions to better suit each participant's degree of participation because they understood that everyday well-being can vary. Residents may not feel ready or motivated to participate on certain days; instead of pushing through, the team prioritized flexibility, modifying the timetable to accommodate participants' preferences and rhythms.

Furthermore, the key results outlined below serve as a foundation for the ongoing design development phase.

1. Understanding the Importance of Personal and Collective Narratives
   - Personal Narratives: Memory loss and confusion are common symptoms of dementia in individuals, which can cause a loss of identity. An individual's life history, interests, and experiences can form the basis of a personal narrative, which is a potent instrument for securing their identity. When co-designing interior spaces, these personal narratives assist in guiding design decisions that honor the person's history and promote comfort and familiarity. For instance, including motifs, colors, or items from the subject's history into the design can bring back pleasant memories and improve their emotional state.
   - Collective Narratives: Sharing stories that a community or group shares can go beyond personal accounts and be utilized to build environments that appeal to a wider sense of belonging. These stories can convey significant historical, social, or cultural aspects to the group, fostering a sense of inclusivity and community within the care setting.
2. Narrative as a Tool for Engagement and Communication in Co-Design
   - Promoting Participation: Narratives serve as a link between designers, people with dementia, and their carers during the co-design process. Interviews, memory-sharing exercises, and storytelling sessions might provide details about the needs and preferences of dementia patients. By ensuring that the design process is inclusive, this participatory approach gives voice to those with cognitive impairments who might otherwise find it difficult to communicate their desires.
   - Empathy Building: By learning about the lived experiences of people with dementia via their narratives, designers can develop empathy, which in turn inspires more deliberate and person-centered design choices. This knowledge aids designers in anticipating potential problems that residents may encounter and creating settings that reduce uncertainty and discomfort.
3. Incorporating Narrative Elements into the Physical Environment
   - Memory Triggers and Story Spaces: By embedding narrative elements into the physical environment, designers can create spaces that act as memory triggers. This can include visual cues like photographs, personalized artwork, or themed areas that relate to significant periods in a resident's life, personalized scents in the private spaces, color patterns for certain areas in the walls, application of temporary personalized finishings in the private rooms, personalized spatial layout through furniture. These elements can help individuals with dementia orient themselves within the space and reduce feelings of anxiety.
   - Storytelling Features: Residents and their family can share tales and experiences thanks to interactive features like memory walls and digital displays. These can be dynamically updated to reflect ongoing narratives, offering chances for dynamic involvement and bolstering continuity and identity.
4. Designing for Flexibility and Evolution of Narratives
   - Adaptability: As dementia is a degenerative illness, people's needs and capacities will vary over time. Thus, narrative-driven

design needs to be adaptable so that environments can change as individual and group narratives do. To ensure that the environment stays relevant and encouraging, this may entail using easily updated or replacement modular design elements.

- Preserving Connection: As residents' cognitive capacities deteriorate, it may be harder for them to stay connected to their narratives. Even if verbal communication declines, design techniques that include sensory components (such familiar sounds or scents) might support the maintenance of these ties.

8 Discussion and Conclusions

The findings of this study underline the powerful role of narrative-driven, participatory design in creating home-like environments for individuals with dementia. By incorporating both 'big stories'—significant life events—and 'small stories'—routine encounters and everyday moments—researchers documented a range of experiences central to residents' identities. This process revealed themes such as meaningful objects, emotional triggers, and preferred surroundings, which were translated into design concepts tailored to personal memories and sensory preferences.

This approach extends beyond typical design, emphasizing an ethical commitment to honouring residents' identities and life stories, which are often vulnerable due to cognitive decline. By integrating personal and collective narratives into the care environment, the study fosters dignity, continuity, and a sense of community that is essential for emotional well-being. This alignment of ethics and aesthetics highlights the importance of creating environments that feel like authentic extensions of each resident's life story. The study emphasizes that a true sense of home in care settings transcends functional design, requiring a deep connection to personal and collective narratives. It advocates for spaces that adapt to the evolving identities of residents, supporting their well-being through dynamic, therapeutic, and personalized settings.

However, the study's reliance on verbal methods of engagement represents a key limitation. While effective for this group, it excluded those with advanced dementia or nonverbal communication needs. Future research should incorporate methods such as visual storytelling, body language interpretation, or tactile engagement to ensure inclusivity. Further studies should also examine the longitudinal impact of narrative-based designs, exploring how these interventions evolve alongside residents' cognitive and emotional changes. The integration of technology, like digital tools or augmented reality, may offer new possibilities for narrative elicitation and application in future studies.

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