Design For Inclusion 3

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# Dementia Lab 2022: The Residue of Design

## Proceedings of the 6th Dementia Lab Conference, D-Lab 2022, September 20–22, 2022, Leuven, Belgium

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# Design For Inclusion

## Volume 3

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# Preface

We proudly present the proceedings of the Dementia Lab Conference 2022 that contain the papers presented at the 6th installment of this conference series, hosted in Leuven by LUCA School of Arts and KU Leuven. The Dementia Lab Conference brings together designers, researchers, artists, care practitioners, people with dementia, and people from industry and presents the latest research on the role of design in supporting the needs of people living with dementia and their surrounding context. After a two-year global pandemic, this edition of Dementia Lab returns to the in-person format where experts from academia, industry, and care practice can connect, discuss, and exchange ideas on future challenges related to design and dementia.

Since its first edition in 2016, the Dementia Lab Conference has provided a forum open to all working with people with dementia to share the multifaceted lived experiences of dementia. The number of people with dementia is increasing worldwide, and there is currently no effective treatment. As a result, dementia poses numerous economic and social challenges for society. We highlight the value of design to address these challenges and contribute to the quality of life, care, and wellbeing of people living with dementia. This design perspective offers an alternative view to existing clinical or biomedical approaches and focuses on identity, personhood, and the unique lived experiences of dementia. The Dementia Lab community values inclusive, participatory, and person-centered approaches in design for dementia to be celebrated and shared among like-minded designers, researchers, caregivers, and other professionals working in this context.

The theme of Dementia Lab 2022 is ‘The Residue of Design’, which encompasses the essence and impact of design research in dementia. The previous editions of Dementia Lab have provided numerous examples and cases of how design can benefit people with dementia, their loved ones, and caregivers. Despite positive outcomes, it remains challenging to incorporate these novel solutions into routine care or the everyday lives of people with dementia. This year’s theme aims to address this challenge by focusing on the residue of design, namely what *remains* from participation and engagement with and through design. With this focus, we aim to amplify emerging ethical perspectives on design for dementia beyond exploring the initial impact of design to recognizing the complexity of existing care structures and the challenges of transforming long-term care practices.

We invited original research contributions that report and reflect on design for and with people with dementia in terms of methods, material characteristics, field studies, and critical reflection on ethics. Full papers addressed the value of the participation of people with dementia in design at a *personal*, *product*, or *organizational* level. The personal level of participation addressed how participatory practices can be meaningful for the person with dementia and the designer. For example, by exploring how the design process can facilitate the way people with dementia interact with their close relatives or how design can stimulate intergenerational dialogues. The *product* level looked at what entails 'good' design for people with dementia by inviting contributions that addressed the development of commercial products that embody the enabling qualities of design, for example, by elaborating on what vision of a person with dementia is 'inscribed' into a design and identifying the ethical challenges of how a design can hinder or support the world view of people with dementia. Lastly, we invited papers that contribute to an organizational level that tackle the challenges of how a design process or artifact can support care organizations or influence existing societal views on people with dementia.

This year, we received 17 eligible submissions for the full paper track, of which nine were accepted after a rigorous double-blind peer-review process. The submissions were assigned to a program committee member who coordinated 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 and was extensively discussed during the program committee meeting. After careful consideration by the program committee, nine full papers were accepted for oral presentation and publication in the conference proceedings.

This year's full paper track showcased the diversity and wide range of applications in which design can impact people with dementia and their personal contexts, such as graphic design, technology, commercial products, and architecture. The papers further advanced the field of design in dementia by raising awareness and overcoming stigma, exploring how products and care environments can be better suited for people with dementia, and sharing participatory methods to engage people with dementia in design work. With these proceedings, we aimed to inspire future inclusive, sensitive, and empowering design practices with and for people with dementia.

On behalf of all the proceedings editors, we want to express our thanks and gratitude to the scientific committee for their efforts in providing rigorous and constructive reviews that resulted in the collection of papers presented in these proceedings. We also thank Springer for their ongoing engagement and collaboration in realizing the third edition of the published Dementia Lab proceedings. Lastly, we thank all the authors who submitted their work to the Dementia Lab Conference 2022 and the people with lived experiences of dementia who participated in the research presented at this conference.

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# About This Book

This book presents the proceedings of the ‘Dementia Lab Conference 2022: The Residue of Design’ and gathers the paper contributions presented at the sixth installment of the Dementia Lab conference series hosted in Leuven, Belgium, during September 20–22, 2022, by the LUCA School of Arts and KU Leuven. The proceedings present original and innovative research on how design can contribute to the quality of life of people with dementia, their loved ones, and caregivers. The peer-reviewed papers cover topics such as the development of creative design methods to foster participation and engagement from people with dementia, evaluation studies or critical reflections that reveal the impact of design and the built environment in dementia care, and the ethics and discussion of preconceived or stigmatizing societal views on dementia. These insights and ideas are centered around the theme ‘The Residue of Design’ and go beyond the initial impact of the design itself by looking at what benefits design research brings for people with dementia, such as countering stigma, transforming care practice, and supporting and enriching the everyday lived experiences of people with dementia.

# Contents

# Compassionate Design—HUGs on Prescription

Cathy Treadaway, Jac Fennell,
Abdul Seckam, and Aidan Taylor

**Abstract**

There is a growing need for well-designed innovative products and services for people affected by dementia. Governments and charities are offering a range of business support to encourage the development of commercial products to address this need. This paper describes how HUG, an output from LAUGH and LAUGH EMPOWERED academic dementia research in the UK, has been successfully translated into a commercial product via accelerator start-up business funding. HUG is being used in care homes and hospitals in the UK to reduce anxiety and improve the quality of life of people living with advanced dementia. Compassionate Design methodology has underpinned this work. Personhood, sensory stimulation, and connection with others have been used as three key principles to ensure that the design meets the needs of people living with dementia in the later stages of the disease. Loving kindness for the person living with dementia (product user) has been central to the design process and involvement of people affected by dementia at various stages of the disease has been crucial to the success of the product. The studies described in this paper provide an example of how an output from academic research has been successfully translated into a commercial product that is now improving the lives of people living with dementia.

**Keywords**

HUG · Dementia · Product · Design research

## 1 Context

There is a global need for better designed products and services that help people live well with dementia and maintain their quality of life [1].[1] A growing number of academic research projects focus on understanding how to design appropriately for people living with dementia [2].[2] There is also increased interest in this expanding market sector from the manufacturing and design industries, who seek guidance from academia and the care sector on how to create better products and services. Governments are encouraging researchers and industry to work together

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[1] https://www.ukri.org/opportunity/healthy-ageing-challenge-designed-for-ageing/.

[2] MinD; CertificationD: DesHCA; LAUGH etc.

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to address this global need with catalyst, seed, and accelerator type funding.[3] These schemes bring together design experts with industry to translate good ideas into commercial products. Nevertheless, very few design concepts emerging from academic research, ultimately make it to market at an affordable price and are successfully integrated into dementia care.

This paper focuses on one success story. It describes how an output from academic research in the UK has been translated into a commercial product that is improving the quality of life of people living with dementia [3, 4]. HUG is a soft therapeutic comforter that was originally created for people living with advanced dementia. The product is designed to be cuddled and has a plush textile outer body with weighted arms and legs (Fig. 1). Its soft inner cushion contains a programmable electronics module, which provides the pulsing sensation of a beating heart and can play a person's personalised playlist of music.[4] It is being used in the UK by individuals living with dementia in the community, in residential care and NHS hospitals, where it is now being prescribed for patients within individual care plans. The underpinning research for HUG began in 2015 supported by two government grants: LAUGH[5] and LAUGH EMPOWERED[6] and was completed in 2021.

The LAUGH project (2015–18) sought to investigate the broad principles required to design hand-held playful devices for people living with advanced dementia to support their wellbeing. The design process was underpinned by Compassionate Design methodology, which was developed and tested through the research [5]. This approach places lovingkindness for the individual living with dementia at the heart of the process and focuses design thinking on sensory, personalised and connecting properties of the product. A collection of prototype playful objects was designed and tested through the LAUGH study. HUG was one of six outputs from the research along with the Compassionate Design methodology that guided the creative process (Fig. 2) [6].

Findings from the evaluation phase of the research evidenced a significant improvement in the physical and psychological health and wellbeing of the person for whom the original HUG was designed [7]. Consequently, further government funding was awarded in 2018 for LAUGH EMPOWERED, a much larger study, undertaken in both residential care and hospital contexts over the next three years. This study corroborated findings from the initial LAUGH evaluation study and led to the establishment of a university spin out company, HUG by LAUGH® (See Footnote 7). HUG had been found to make a significant positive impact on the lives of people living with dementia and so it seemed imperative to make the product commercially available [4].

## 1.1 Involvement of People Living with Dementia

People living with and families affected by dementia were included through all phases of the research. Their contribution informed each stage of the design research from initial guidelines, concept development through to packaging and promotion of the manufactured product. The LAUGH project benefitted initially from advice from people living with early-stage dementia through the members of an Alzheimer's Society Service Users Reporting Panel. Twelve people living with advanced dementia and their families also helped to inspire the design concepts for the products that were developed. Portraits of the individuals, containing brief life history information and individual preferences, were developed to ensure the bespoke nature of the design concepts. Six of these individuals living with advanced dementia were involved in evaluating the prototype products that were developed. 40 people living with dementia and cognitive impairment participated in the LAUGH EMPOWERED evaluation study

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[3] Alzheimer's Society Accelerator Funding; Innovate UK Healthy Ageing Catalysts, Design Age Institute Pathfinder Awards etc.

[4] www.hug.world.

[5] Arts and Humanities Research Council grant Ref: AH/M005607/1.

[6] Welsh Government SMARTExpertise European Regional Development Funding Ref: 2018/COL/012/80839.

**Fig. 1** HUG by LAUGH®

including one who was a member of the project Advisory Group.

In the final stages of the research, the HUG by LAUGH Ltd. business was established with support from Alzheimer's Society UK. Product development was guided with the help of their Innovation Team and Dementia Voices focus groups (Fig. 3). These included people living with dementia and their carers, and provided invaluable guidance on the product offering prior to launch, including packaging and product information. Finally, a Dementia Voices group evaluated the launched product as part of a media campaign for Alzheimer's Society. At each stage in the product journey, experiences and insights of people living with dementia helped to inform the design decisions, ensuring the final manufactured product met the needs of people living with the disease. Testimonials from people who have found HUG beneficial are included on the HUG by LAUGH website (www.hug.world).

The participation of people affected by dementia was invaluable, providing unique insights as the product developed (Table 1). For some of those participants living with advanced dementia who were involved in evaluating HUG, engagement in the research was life changing and this was documented via a film broadcast on BBC TV.[7] Staff working in the hospital and care homes reported how being involved and having access to the prototype objects, had brought benefits not only to those they cared for, but also for themselves via increased job satisfaction [7].

## 2 Methodology

Involvement of experts by experience, carers and health professionals has been key to the success of HUG and the underpinning research. Finding ways to capture and exploit their insights has been vital, to inform product development and the design for dementia process. The LAUGH research project used qualitative interpretivist

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[7] https://www.bbc.co.uk/news/uk-wales-50237366.

**Fig. 2** Prototype HUG from LAUGH research

methodologies in which data was collected through collaborative and creative methods in participatory and co-design workshops, semi structured interviews, and focus groups. Storytelling, observation, creative, practical, and playful activities were used to stimulate discussion and generate knowledge about dementia to underpin the later design phases. Video and audio recording of these activities was used to capture participant responses. Data was analysed thematically [8], through a mix of deductive and inductive approaches and in response to existing literature concerning dementia, design, and wellbeing. Compassionate Design principles (Fig. 4). guided the creative process to ensure each design was stimulating to the senses (to keep the person in the moment), highly personalised (to maintain their dignity and retain self-identity) and able to connect (the person to others and the world around them).

**Fig. 3** Alzheimer's Society Dementia Voices focus group with HUG. (*Photo* Alzheimer's Society UK)

**Table 1** Involvement of people living with dementia

| Research stage | People living with dementia involved | Numbers |
|---|---|---|
| *LAUGH research* | | |
| Initial research | Alzheimer's Society Service Users Reporting panel Cardiff | 6 |
| Design inspiration | People living in residential care | 8 |
| Design evaluation | 1 person per bespoke prototype product | 6 |
| *LAUGH EMPOWERED* | | |
| Sunrise study | Residents in care home | 20 |
| NHS Hospital study | Patients in hospital | 20 |
| Product design | Dementia Voices focus group (national) | 6 |
| Packaging design | Dementia Voices focus group (national) | 6 |
| Product evaluation | Dementia Voices (Newport) | 6 |

Participants living with advanced dementia were selected for the research in collaboration with the care home managers who knew the people and their families well. The criteria for selection included a diagnosis of dementia (in the advanced stages) with a family member or caregiver who knew the person well enough to interpret their emotional responses via non-verbal cues such as facial expressions and body language. These carers were involved in the product evaluation with the person living with dementia. 8 individuals living with advanced dementia participated in the design phase of the LAUGH research.

The LAUGH EMPOWERED research (2018–21) involved two evaluation studies: one in a residential care home and the other in a hospital context. Both studies involved 20 participants receiving a HUG. The evaluation tools included the Pool Activity Level Instrument (PAL) [9] and an Adapted Bradford Dementia Wellbeing profile.[8] Staff in the residential care home and

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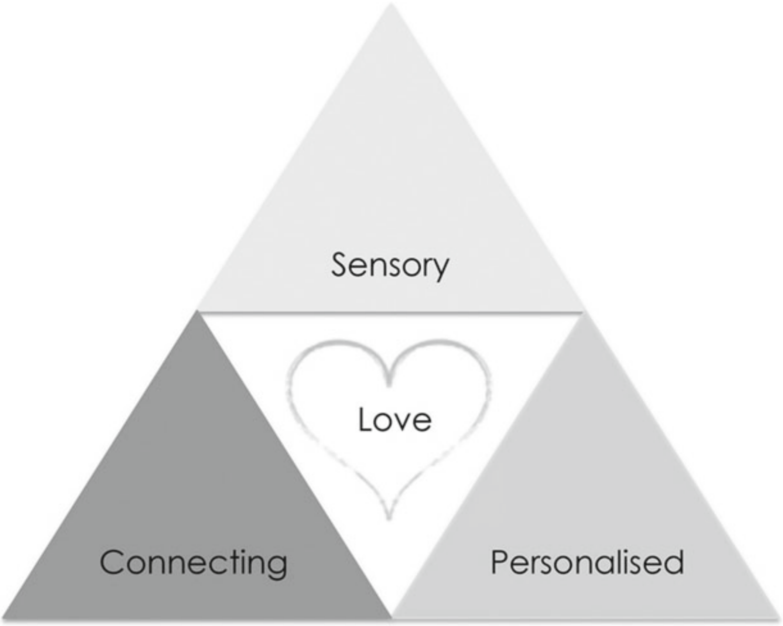
[8] https://www.bradford.ac.uk/repos/health/Bradford-Well-Being-Profile-with-cover-(3).pdf.

**Fig. 4** Compassionate design



hospital were trained in the evaluation methods prior to the start of the research, with the intention that it would be possible to compare the data at the end of the study. Unfortunately, the hospital study coincided with the Covid pandemic,[9] and it was not possible for medical staff to complete the planned outcome measures for the study due to extreme work pressures, or for researchers to enter the hospital. A pragmatic approach was taken to collect data and to ensure that the study did not fail. A series of online qualitative interviews were undertaken with hospital staff, towards the end of the pandemic when the situation had eased significantly. These comprised a series of 5 focus groups with up to four practitioners representing the interdisciplinary medical teams ($n$ = 20 participants).

University ethics approval was gained for both LAUGH and LAUGH EMPOWERED studies. IRAS[10] ethics approval was achieved for the NHS hospital study and an ongoing 'process method' of consent used for research participants living with dementia [10].

## 3 LAUGH EMPOWERED

LAUGH EMPOWERED was funded by Welsh government over three years from 2018 to 2021. The aim of the project was to undertake a larger evaluation of HUG in both residential care and hospital contexts. The project partners were Sunrise Senior Living Ltd and NHS Cardiff and Vale University Health Board (Llandough Hospital). The first task for the research team was to batch prototype 40 HUGs to ensure sufficient identical products were available for evaluation in both contexts [11]. NHS staff contributed to revisions to the design of HUG to ensure that it complied with NHS infection control and safety regulations. The soft textile outer shell and the internal electronic unit were each made by hand, as it was too expensive to manufacture such a relatively small quantity.

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[9] March 2020.

[10] Integrated Research Application System (IRAS)—UK National Health Service (NHS).

### 3.1 Findings from the LAUGH EMPOWERED Care Home Study

While the HUGs were being made, ethics approval was sought, and staff trained in the use of the Pool Activity Level (PAL) instrument and the Bradford Dementia Well-being profile (BDW). Participants were selected by the care home management and consent gained from families for participant inclusion in the study. Baseline assessments were made of participants' cognitive and functional ability (PAL) and wellbeing (BDW) prior to being given a HUG. They were assessed again at 3 months and 6 months into the study. In any dementia study, attrition is inevitable since it is a terminal disease. In the Sunrise study, data was collected at 3, and 6 months for 16 out of the 20 participants. 87% of those participants who had used a HUG for 6 months showed an increase in their wellbeing. Of those, over half the group showed an increase in their functional and cognitive ability as measured by the PAL Instrument. These findings are particularly significant as dementia is generally associated with neurodegenerative decline [4].

Those participants who received a HUG in the study were allowed to keep them. There were many heartwarming stories from family members and care staff indicating ways in which participants had enjoyed their HUGs and formed attachments with them. A BBC film made about this study can be viewed online[11] and includes positive accounts from family members about the benefits of the product experienced by people living with dementia. Media interest in the study led to many enquiries from the public wanting to purchase the product. The university responded to this by supporting the research design team to develop a business plan for a spinout business, and to explore manufacturing and selling the product (Fig. 5).

### 3.2 HUG on Prescription

At the same time as the care home evaluation was underway, the NHS IRAS ethics process was initiated, and hospital staff were trained to use the PAL and BDWP tools. Half of the HUGs were distributed to patients on the inpatient dementia wards ($n = 10$) and the rest to selected patients in the Stroke Rehabilitation unit ($n = 10$). The selection criteria included a diagnosis of cognitive impairment following stroke or dementia and presentation of symptoms of anxiety and agitation. Patients were prescribed HUG with an associated care plan once ethical approval had been gained and consent forms signed by participants and families.

There was some initial delay to the start of the evaluation due to reporting requirements from the funder and lack of NHS staff time to implement the study. This was followed in March 2020 by the beginning of the pandemic when reporting for all research was put on hold by the NHS Health Board. Nevertheless, patients continued to be prescribed HUG and although the evaluation tools had to be abandoned, those staff who worked with patients who had been prescribed HUG during the six-month period, were invited to participate in (post-study) multidisciplinary team focus group feedback interviews ($n = 20$). These took place in April 2021, once restrictions on research data collection were eased and IRAS ethic approval had been obtained from NHS.

The focus group participants represented the different specialisms in the multidisciplinary medical teams who had cared for patients with HUGs. These included: doctors, nurses, psychologists, occupational therapists, speech and language therapists and technicians. The delay between the end of the evaluation and the interview data collection meant that some participants found it difficult to remember details clearly. Nevertheless, collectively they were able to describe ways in which HUG had benefitted patients and helped in their care, as well as making insightful observations, and suggestions about how the product might be improved and implemented in care.

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[11] https://www.bbc.co.uk/news/uk-wales-50237366.

**Fig. 5** HUG being used by a person living with dementia

## 3.3 Findings from LAUGH EMPOWERED Hospital Study

Patients who have been admitted to hospital are inevitably in crisis and experiencing anxiety and agitation. For someone living with dementia hospital admission may exacerbate their underlying anxiety and cause distressing behaviour. For a patient who has had a stroke, the sudden onset of cognitive impairment may be shocking and very frightening [12]. There is reluctance by doctors to prescribe anti-anxiety medication for these patients in the hours after a stroke, due to side effects. Alternative nonpharmacological solutions are particularly attractive option to try to help keep patients calm and reduce their stress. HUG was prescribed for a small number of patients who were recovering post stroke, and a group of inpatients on the dementia wards ($n$ = 20 total).

Analysis of the data collected from the NHS Staff qualitative interviews provides a rich picture, detailing the complexities of introducing a therapeutic playful object into an NHS context with critically ill patients. The interview data provides consensus that HUG was beneficial for some patients, but not all. Some patients rejected HUG immediately and it was recognised that not everyone enjoys receiving a hug or social touch, particularly if they have had difficult life circumstances in which they experienced abuse. When accepted, however, HUG provided a significant positive experience for the patient and those staff involved in their care. The ways in which the product was introduced to the patient, staff personal attitudes towards HUG and time available for practitioners to integrate it into day-to-day care seems to have impacted significantly on how each patient responded.

Findings from the study identified the following positive benefits of HUG on patients in the hospital context:

1. Providing comfort, reducing anxiety, agitation and giving reassurance

2. Improving communication and initiating conversations with staff
3. Providing company and a sense of purpose
4. Increasing oral intake: improving eating and drinking and taking prescribed medication
5. Providing an alternative to medication for anxiety (and lowering the risk of falls)
6. Enabling medical procedures and personal care to take place
7. Modifying distressing behaviours (tapping, shouting, crying)

When patients are hospitalised, they are often frightened, agitated, and disorientated due to the health crisis for which they have been admitted; they have left the safety of home and enter an alien environment, full of unfamiliar people and sensory experiences. For someone with cognitive impairment, sensory loss, dementia, or delirium, this can be devastating. Finding ways to calm patients, so that medical procedures can take place, is vital for positive health outcomes and crucial for their care and wellbeing. One doctor commented:

> I think the situations where people are really withdrawn or they're showing signs of distress and you can't really sort of orientate them, I think it's really useful to be able to give them something to be able to, well, help give them a bit of reassurance and calm them down really, to enable them to engage a little bit more.

HUG was used to help reduce distress, with many of the interviewees referring to having observed the positive way in which HUG was able to help patients in their care. A doctor gave an example of one patient in particular who benefitted:

> She was an elderly lady with a dementia diagnosis who was in a lot of distress…… And so, she was sort of seen as an ideal candidate for somebody to trial with the HUG. From what I remember, it was quite a marked change actually. So, when she did have it, she was pretty inseparable from it to be honest. It did settle her quite a bit and then when people did approach her, say nurses or any other therapist, or the doctors, we'd get a much better response from her.

Patient anxiety, confusion and fear can make communication with medical staff difficult, and this can impact on the quality and timeliness of care that can be provided. People with cognitive impairment or living with dementia can often be very withdrawn and staff can find initiating conversations difficult. HUG was found useful as an icebreaker with patients and as a conversation starter. A doctor commented on how HUG had helped in communication with one patient saying: *'it was easier for her to communicate when she wasn't quite so wound up and banging things and shouting'.*

Anxiety distress, agitation and boredom can accompany hospitalisation for a patient with cognitive impairment or dementia. Wards are busy environments and there is little time for staff to stop and chat with patients when they are lonely, bored, or lacking self-confidence. HUG was described as: *sort of something to cling to, a bit of comfort, so [they] gained a bit more confidence on the ward and were a bit more orientated.*

One doctor described a patient for whom HUG became a companion:

> A companion yeah! She was just much more settled if she had the HUG with her. and to be honest…. we don't have the staffing level to be persistently with somebody like that, constantly.

When a patient is agitated or distressed, they will often decline food, drink, and to take their medication. Various members of the MDT described how patients who had previously refused oral intake were much more inclined to be compliant while they were holding HUG. A physiotherapist described the *'real positives'* of using HUG around the *'feeding and the nutritional side of things'* and remembered *'one particular patient being very difficult and had a very, very poor intake, but actually after we give HUG to her she became more engaged with everything around the ward, and even though we didn't gain anything from a rehab stand point, from a purely physical side, we gained from her being able to have a bit more intake.'*

Encouraging patients living with cognitive impairment or agitation to take medication can prove to be difficult, however HUG was found to help with this aspect of care. An occupational therapist recollected:

> I can remember the HUG with the patients with dementia taking their medication as well. I think it was helping to soothe, calm them down and they were able to take their medication, whereas normally they would decline to take it.

For patients who have delirium, dementia, or post stroke cognitive impairment there are few drugs available without side effects that negatively impact on the conditions being treated, or their quality of life. Medication can make people drowsy and more likely to have a fall, leading to further pain and distress. One nurse commented that a positive thing about HUG *'is it reduces the risk of falls, reduces the risk for medication, lessens the anxiety levels—they've gone down for the patient, and the staff around them going back and forth. So, that was hugely beneficial for the ward and for the patient.'*

Routine procedures can be traumatic for patients who are frightened, agitated, or stressed. Nursing staff commented on how HUG had helped them to administer personal care. This is inevitably difficult and takes more time when a patient is distressed. HUG was also found to help relieve a patient's anxiety sufficiently so that staff could undertake basic medical procedures:

> There was a lady, you know…she'd get quite agitated when she needed her blood pressure taken, and the nursing staff reported the doll would calm her, to allow them to take the blood pressure.

Health professionals described ways in which HUG calmed patients down and 'took away some of the frustration' they were experiencing. The impact of a distressed and anxious patient on others on a hospital ward can be very difficult for staff to manage. Finding ways to help a patient calm down or modify their behaviour can reduce stress levels for all. HUG was found to calm and distract patients for the benefit of everybody on the ward. A physiotherapist technician presented an example of this:

> There's another lady we have who taps on furniture, arm of a chair or table and obviously for everybody in the room, you know it can be quite distracting quite annoying, I think maybe for some of the other patients. So, they give her the doll, and she would tap on the doll instead.

Patients who have had a stroke may lose sensations and awareness of their body within space. These patients can become very anxious due to the sensation of falling they experience, even when they are laid flat in bed. The weighted limbs of HUG and the cuddling sensation that it provides can be very comforting and help give the perception of being 'grounded'. A doctor reflected on this as follows:

> We have a certain group of patients who will only be able to lie flat on their back and even when they are doing that, they still don't feel safe in the bed because of the way the stroke has affected them. They always feel like they're falling, or they are about to fall. So, giving someone some grounding, some weight down through them, can be very beneficial from a physical point of view. I wonder if that is an element of it, that weighted feature and the more sort of sensory stimulus it gives you by hugging it, that is actually a feature that really settled people.

Although not every patient who received a HUG accepted it, the device did have a significant positive impact on the quality of life and care of those who did. It is clear from the interviews with NHS staff that, although HUG may not be the right solution for every patient, it is a useful alternative to prescribed medication to be considered for someone who is anxious and distressed. Doctors interviewed for the study observed HUG to be a useful, low-risk intervention, without the negative side effects that often accompany many of the drugs currently used. Where HUG was helpful, the improvement in the patients' quality of life was significant. For some, this was in the short-term, providing comfort in times of severe illness but, for other patients, HUG became a comforter and companion object that remained useful for the duration of their hospital stay and beyond. Where HUGs were not accepted, a variety of factors are implicated from the interview data, including patient inhibition or dislike of tactile intimacy (hugs and body contact), personal preference (aesthetic appearance), social pressure (fear of infantilisation) and the way the device was introduced by staff to patients. Prior research has found that people living with cognitive impairment and dementia respond to the world at prereflexive emotional level and, even when communication is impaired, will read body language and affective responses of others [9, 13]. For this reason, the manner in which HUG is introduced to a patient will influence its therapeutic benefit. When staff lacked conviction in the efficacy of HUG as a wellbeing intervention, disliked it themselves, or felt it to be infantalising, there was an impact on the way it was introduced and then received by the patient.

## 4 Commercialisation

The LAUGH EMPOWERED evaluation studies corroborated findings from the initial LAUGH evaluation. They found that HUG can be used successfully to help reduce anxiety, agitation, provide a sense of purposefulness, companionship and stimulate communication. A clear argument was presented that the product would be useful and could fill a gap in the market. The LAUGH EMPOWERED project included a scoping study for commercialisation of the product and, during 2019, a business plan was written, and the pre-manufacturing compliance testing carried out. This included CE and UKCA marking,[12] to ensure customer safety and product liability. Funding support from the university and external sources was explored. This included an application to Alzheimer's Society for Accelerator Funding[13] and a crowdfunding campaign.[14] Both yielded positive results. Despite the difficulties of working through the first year of the pandemic, the HUG by LAUGH Ltd. business was registered in 2020 and supported by Alzheimer's Society UK during its first year of trading. The crowdfunding campaign helped to raise public awareness of the product and resulted in two UK awards from Tech4Good[15] and the first sales of the product in the UK.

Alzheimer's Society Accelerator funding provided the business with advice and financial support to manufacture a first batch of the product through 2021. The Alzheimer's Society Dementia Voices group, which includes people living with dementia and caregivers, provided advice and feedback on the product and its packaging. They also played an important role in providing encouragement and help disseminating information about the product. The Alzheimer's Society Accelerator funding was crucial in helping translate the research output into a viable commercial product and underpinning the product with user confidence. Labels attached to the product and its packaging display the Alzheimer's Society UK logo and a percentage of the profit of each product sold, helps raise funding for the charity.

Throughout its development, HUG had benefited from press and media interest, including regional and national television coverage, local and national newspaper stories, web posts and invited blogs. The affiliation with Alzheimer's Society and the university has helped the business to market the product widely, and HUG by LAUGH is now receiving interest from customers globally.

## 5 Discussion

Academic research frequently generates innovative ideas that can be life changing, however there is a huge gulf between a good design concept and a manufactured product. Academic researchers must learn a raft of new skills which may be beyond their expertise. The gap in knowledge involves, amongst other things, manufacturing processes, compliance, intellectual property legislation, business models and planning, marketing, and investment funding. It requires a tenacious and passionate academic research team to navigate these new territories. Start-up funding and business support can ensure that good ideas, founded in and tested through academic research, can make a positive difference to the lives of people living with dementia. HUG is now commercially available in the UK

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[12] CE (European Conformity) and UKCA (United Kingdom Conformity Assessment).

[13] https://www.alzheimers.org.uk/research/our-research/accelerator-programme.

[14] https://www.crowdfunder.co.uk/p/hug-by-laugh-1.

[15] https://www.tech4goodawards.com/finalist/hug/.

and is soon to be available to buy globally. Product users are not only people living with dementia but include adults and children living with diverse disabilities and medical conditions, as well as those receiving palliative and end of life care.

The global pandemic has highlighted ways in which social exclusion results in anxiety and loneliness, and how important affective caring touch is to individual wellbeing. In the research described, HUG was made available during the pandemic to hospital patients 'on prescription' with an associated care package. The evaluation process was inevitably severely disrupted, and the research protocol had to be adapted to ensure that qualitative data from healthcare professionals was gathered post-trial. Continuity of the study throughout the lockdown period ensured patients were able to receive the therapeutic benefits of using the product during a period when there were stringent restrictions on visitors, and individual anxiety levels were particularly high. Acceptance of a product like HUG poses difficulties for health sectors who usually require hard quantitative evidence to prove efficacy.[16] Nevertheless, the pandemic has revealed ways that new psychosocial approaches, outside usual the medical model, can provide successful person-centered solutions that can improve quality of life for people affected by dementia and other disabilities.

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[16] Further hospital studies are currently underway in the UK that will mitigate the limitations of the one reported in this paper.

# Adaptivity in Research Practice with People Living with Dementia: A Designer's Reflection

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## Abstract

Engaging people with dementia in the design of technology is increasingly gaining more attention—and rightfully so. Yet to be sensitive and responsive to the variety of participants with dementia in different contexts and phases of a design process can be challenging. In this case-study, we applied retrospective reporting to elicit information on this topic from an experienced designer. The findings show how a designer practices adaptivity in duration, explanations, and approach to access experiences during in-situ evaluation of a technical prototype. Insights from this case show the need for reflecting on the potential impact of adaptivity and discussing in the field how adaptivity should be practiced to add value to the work of designers in dementia care contexts.

## Keywords

Dementia · Design · Technology development · Methodology · Retrospective reporting

## 1 Introduction

The increasing number of people with dementia worldwide creates a growing need for meaningful support in their independent living and overall well-being. People with dementia may experience changes in memory, attention, reasoning, and communication abilities that eventually require an increasing need for care by family members and care professionals [44]. Research in the field of supportive technology development shows the potential of technology [9] to facilitate people with dementia and their close family members in their social contacts, daily activities, and feelings of safety (such as Ref. [19]). A great variety of contemporary Human–Computer Interaction (HCI) work also demonstrates the engaging possibilities of technology and design for people with dementia, such as multimedia systems [4] and virtual reality

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environments [16]. Not only to empower them to engage with their own care but also to use technology design practice in challenging the prevailing societal views on dementia [23]. Researchers highlight the importance of designing technology that is tailored to every individual's personal experience, desires, and abilities [2, 18, 38]. To this effect, earlier work shows the importance of involving people with dementia in the development of technologies [37]. Numerous research methods are used in these development processes to involve possible end-users, such as interviews, participant observations, and group sessions. In addition, the ethnographic approach is an acknowledged practice to work more intensively together with people with dementia to co-design technologies [1, 12, 27, 42] and make use of additional forms of participatory research practice, including observing bodily movements instead of prioritizing verbal expressions [23, 26]. All these efforts are intended to exchange information and access the experiences of people with dementia to inform design considerations and steer technology development accordingly.

Within the process of designing and developing technology *with* instead of just *for* people with dementia, a certain amount of sensitivity and responsiveness to the participant's reactions is needed [19], which goes beyond the mere choice of a particular research method. It may require designers and researchers to practice 'adaptivity': being flexible when utilizing design methods, (e.g., [1]) to the complex, ever-changing and individualized needs of people with dementia [25]. This 'adaptivity' does not only refer to the method and material in a research-setting but might be even more crucial in the construction of a supportive research-relationship. A designer or researcher needs to create a relationship that enables a positive atmosphere where participants open up and invite the researcher into their experienced world [28, 36]. This researcher-participant relationship is especially important when a prolonged engagement of participants is desired [11], which usually is the case when designing technology. Knowing the participants will increase the sensitivity to their needs and wishes when being involved in research. Yet, given the diversity within groups of people living with dementia, the most appropriate way to establish this relationship may differ among participants.

Design researchers have reported difficulties in practicing adaptivity in involving people with dementia, for instance pertaining to how they should take the participants' needs and the limits of their engagement into account respectfully [41] as well as how to communicate these 'adaptive' efforts [14] to genuinely involve people with dementia in the process of designing technology. Furthermore, limited research is available how designers access the experience of people with dementia, establish a good relationship with participants, and practice adaptivity within the boundaries of an actual technology development project including other stakeholders such as IT-specialists, care providers, researchers, and business developers. Reflections on how designers pursue this, and how it might impact the design process and outcome, is therefore needed. Several scholars in the field have been sharing such reflections and rendered thoughtful suggestions and new perspectives. These were often based on retrospection on their own first-hand experiences in one or more codesign projects (e.g., [1, 24, 35, 41]), or on interviews with experienced designers who had performed such projects (e.g., [17]). In this paper, we take a slightly different approach and performed an in-depth analysis of the reflections of one single designer, in one single project, throughout the process of engaging with the participants in her study. Via extensive interviews, repeated several times over the course of her research, she was invited to reflect on her recent efforts in adapting to the different participants, respecting to what extent they wish to and can be part of a research and development project.

## 2 Methodology

In this research we use a qualitative in-depth case study methodology to gain further understanding of how the context of research affects the sensitivity and adaptivity of a designer to the personal needs and abilities of people with dementia. In addition, we explored how this 'adaptivity' might have affected research and design outcomes.

## 2.1 Participant, Materials, and Procedure

The designer (second author) was invited to take part in this study by a researcher (first author) who was not affiliated with the designer's project. The designer (female, 30 year of age) was selected because of her experience in designing with people with dementia, both within her PhD research as well as in her position as a design researcher at a Dutch care organization. In total, the designer had approximately four years of extensive experience of designing with and for people with dementia at the time of the retrospective interviews.

The three-year project she was involved in followed an inclusive and engaging co-design approach, in line with earlier important work in this field [17, 24]. The project aimed at creating new technologies supporting social connectedness for people living with dementia at home. Together with different stakeholders, including people with dementia and family members, a social technology intervention was designed [21]. This intervention was referred to as 'Warm technology' [18]; technology as a means to emphasize inclusivity, uniqueness and focusing on what people are still able to do.

To dive into specific adaptive efforts of the designer, it was decided to choose one phase of the project in which new research-relationships had to be established over time. Within the project, people with dementia and family members who were new to the project were invited to evaluate the abovementioned technology intervention for four to six weeks at their own homes between October 2020 and May 2021. This evaluation phase, with a high-fidelity prototype, included different research activities from recruitment to exit interview [39]. For the current study, it was interesting to understand how the designer practiced adaptivity over the course of these different activities in the direct interaction with participants during the meetings, as well as on a distance when the prototype was being used without her presence. The retrospective reporting interviews with the designer were held while this evaluation phase was ongoing, so that there was a short amount of time between the interactions with the participants and the retrospective interviews for this study, thus optimizing recall from the designer's perspective.

Over six narrative interviews (total time was 6 h and 25 min), the designer reflected in-depth on her interaction with eight participants living with dementia and their family members. An online post-it wall [45] was used to capture and retain the different experiences per participant and visually guide the conversation (Fig. 1). The process started with discussing the set-up (aim of the design project, aim of the evaluation study within this project). Then the planned approach and methods were described in detail, including the reasoning behind these choices before the actual research took place. This was done per activity (recruitment, registering, first contact, initial interview, the four to six weeks of testing and the exit interview). In the following interviews, the interactions per participant, per activity, were extensively discussed to understand how the designer adapted her research to these specific people and contexts. These reflections included her positive and negative expectations preceding each research activity and her positive and negative experiences during each research activity. Adaptations to approaches and materials were shared and evaluated. All six interviews were carried out online via Microsoft Teams, audio-recorded with permission, and transcribed in full.

## 2.2 Data Analysis

Results from the reflective interviews were analyzed thematically [3] by two researchers, including the first author and another researcher who was not present during the interviews. To develop the coding scheme, the researchers independently engaged in a process of immersion in and familiarization with the transcripts. Both

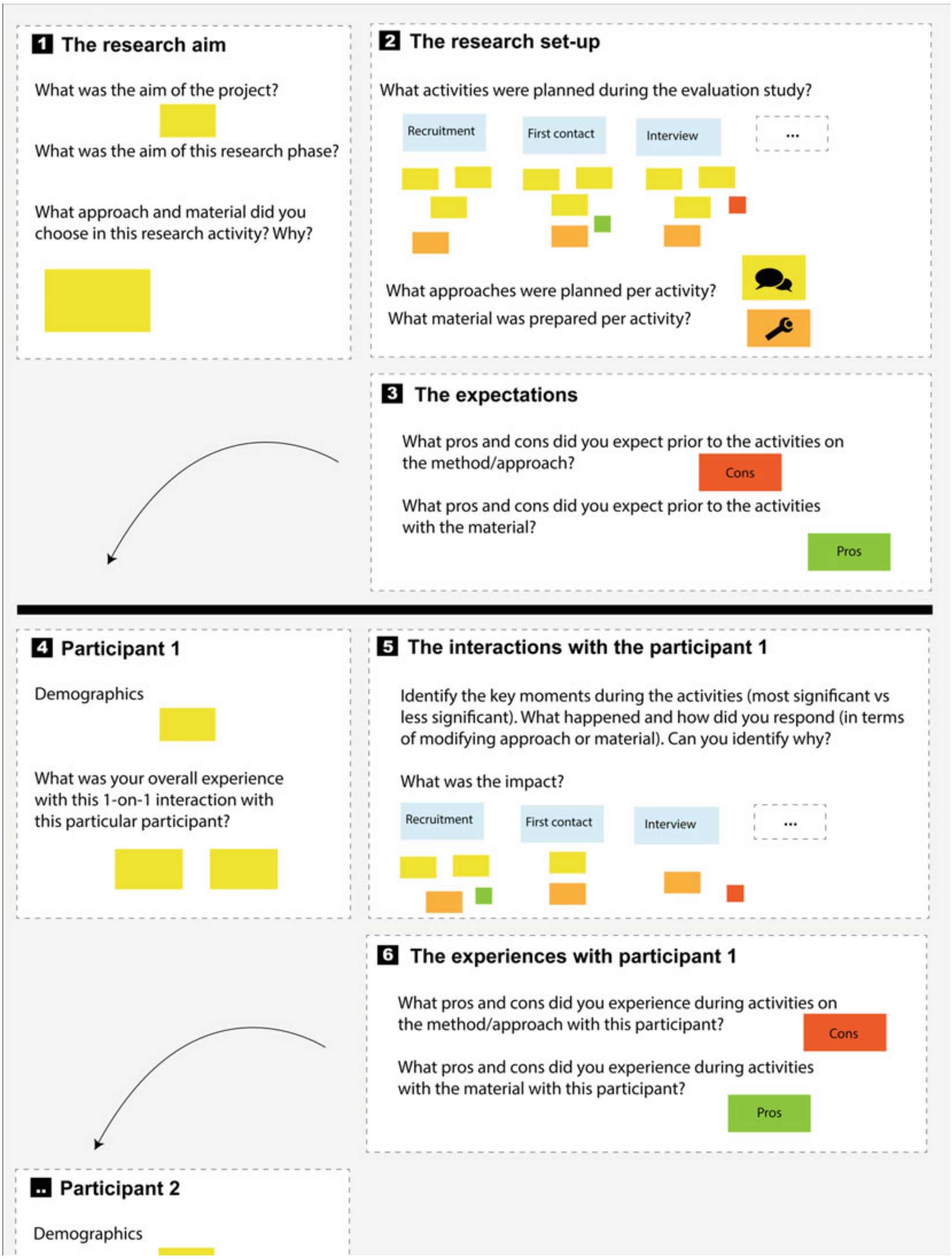

**Fig. 1** The online post-it wall including reflections of the designer on her interactions per participant, per activity

**Table 1** Categories of the codes with the most relevant adaptations highlighted (duration, explanations and accessing experiences). Other adaptations included changes in in- and exclusion and informed consent

| Preparations | During the research activity | | |
|---|---|---|---|
| | Adaptations | Reasons for these adaptations given by the designer | Impact of these adaptations identified by the designer |
| Assumptions from experience<br>Needs and wishes from research team<br>COVID-19 measures | In- and exclusion<br>**Duration**<br>**Explanations**<br>Informed consent<br>**Accessing experiences**<br>Other adaptations | Difficulties in recruiting<br>Discontinuation of participation<br>Characteristics of participant<br>Characteristics of other people present<br>Influence of technology<br>Atmosphere considerations<br>Other reasons | Positive interactions<br>Other positive outcomes<br>Negative interactions<br>Other negative outcomes |

researchers open coded two interviews in MaxQDA2020 and discussed the level of detail of their coding afterwards. This was used to further code two new interviews independently. Eventually the researchers grouped the concepts into categories. To increase the reliability, a third researcher (third author) was involved throughout the process to discuss these categories and subsequent themes. All interviews were then coded with the final coding scheme by the first author. As the interviews followed a chronological timeline, these final codes were categorized accordingly (Table 1). For this paper, it was decided to present three adaptations that were considered most relevant by the designer as they might have impacted the design outcomes the most: differences in the duration of testing, the variety of explanations addressed to the person with dementia, and the different forms accessing experiences of the participants. In the findings we present these 'adaptive' efforts of the designer, if reported, with related preparations, assumptions, the identified reasons, and the impact on the specific participants (as identified by the designer). Some explanatory quotes, presented in a *cursive font,* were selected to support the results further. In the last phase of the analysis, the findings were shared and cross-checked by the designer. She reflected on the insights from her perspective, and these results are presented at the end of the Findings-section.

## 3 Findings

In the reflective interviews, the designer explained that the aim of the evaluation phase of the project was to further understand how new technologies could support social connectedness for people living with dementia at home. The designer reported that a prototype was developed to be tested for four to six weeks. The designer described her experience during the evaluation study with eight persons with dementia (PwD) and their family members or formal carers (Table 2). The findings from the interviews with the designer are structured according to the adaptations made by the designer during the research on the duration of the research activity, explanations, and accessing the experiences of her participants with the technology.

**Table 2** Summary of the eight different participants in the evaluation study of the designer and which adaptations were made

| Nr | Stage of dementia | Others involved | Duration | Explanation | Accessing experiences |
|---|---|---|---|---|---|
| #1 | Mid | Spouse | Shortened | – | Mostly by observation |
| #2 | Mid | Spouse & formal carer | Extended | With help of others | Mostly by observation |
| #3 | Early | Spouse | Shortened | – | Mostly verbal |
| #4 | Mid-to-late | Spouse | – | – | Mostly by observation<br>With help of others<br>Perspective of others prominent |
| #5 | Early | Spouse, children, & grandchildren | Extended | Mostly verbal | Mostly verbal |
| #6 | Mid | Spouse & formal carer | Shortened | – | Mostly verbal<br>Perspective of others prominent |
| #7 | Mid | Spouse (with memory problems) & children | Extended | More extensive | With help of others |
| #8 | N.A | Daughter | Shortened | – | Perspective of others prominent |

## 3.1 Adaptations in the Duration of the Research Activity

A first important aspect that was discussed in the reflective interviews with the designer pertained to the duration of the prototype testing at the homes of her participants. Eventually, in almost all cases the duration of the testing was either shortened or extended.

**Duration of testing was shortened**

During the research activity of the designer, four of the participants (#1, #3, #6 and #8) withdrew from the research early. According to the designer, reasons for the withdrawing were serious illness or deterioration of the dementia symptoms. When recollecting the prototypes, the designer therefore had to interact with various participants and family members who experienced deep distress in their situation. This also impacted the designer emotionally. She reported to feel that she was not—and could not have been—prepared for this type of interaction. The designer expressed that she acted on her personal intuition on how to act in these circumstances ("*I just thought about how I would want to be treated if I was in their situation*"). During two of these meetings, she had an extensive conversation with the family member about the grief as well as the experiences with the prototype ("*Of course, I asked them whether it was OK to ask a few questions for the research*"). The designer reported that she felt that these illnesses or deteriorations greatly impacted the experiences with the prototype in a negative manner and that therefore she decided to leave out some of these insights in her evaluation study ("*When I recollected the prototype, they were very negative about the use. That was totally different from their first experience. […] If someone is very sick, it obviously impacts research. It was a shame, though*").

**Duration of testing was extended**

The designer reported that she fulfilled the wish of three other participant couples (#2, #5, and #7) in her study to extend the test with the prototype (up until 5 months). The designer reflected that when the duration of the test was extended, she had more time to build a deeper connection with the participants. By knowing the participants more personally, the designer explained that she felt more able to tune her behavior further and create a more positive atmosphere during the meetings. For example, in the interaction with one of these participating couples (#5), the designer reported to have shared information about having a dog ("*It was not that I talked about my dog without a reason, but it was more as a response to them having dogs as well*") to connect directly with the person with dementia who showed a special interest in dogs. This eventually led to the couple sharing books about dogs and special dog-brushes with the designer ("*I was not only giving to them, but I got something in return as well*"). To the designer it felt that the extended duration, and with that the closer connection with these participants, resulted in richer insights into the experiences with the technology. On the other hand, a possible drawback of these types of intimate interactions was also mentioned by the designer and illustrated in an example of one family member (#7) having difficulties in criticizing the prototype. She ensured this participant that she would use all input from the evaluation, so that he could be honest while filling a questionnaire about usability. From her perspective, she also reported to feel somewhat awkward when recollecting the prototype as she experienced that the participants had enjoyed the technology and would perhaps be reluctant to let it go. In these cases, the participants, in turn, ensured the designer that they were prepared to end the research.

## 3.2 Adaptations in Explanations

Another significant topic that emerged from the reflective interviews with the designer was the importance to adjust and fine-tune the explanations. She reported about the extensive preparations to fully inform her participants about the procedure and prototype as she believed this would support her accessing their actual experiences with the technology. In the interviews, the designer reported about the challenge to share complete but concise information with people with dementia in her research. Indeed, one of the persons with dementia, who was able to verbalize his experiences well (#5), reflected that the information that was shared was substantial and diverse. The level of detail that the designer chose to use during the verbal explanations was, initially tuned to the level that participants already appeared to have (based on written information or via their caregivers). When she thought to recognize signs that participants were already informed and seemed to have a good understanding during the meeting, this would typically be shortened. Then in one instance a family member (#7) explained that they did not inform their parents about the visit of the designer to avoid confusion prior to the meeting (*"he said that they forgot everything he says"*). The designer regarded this as a reason to be more extensive in her introduction. Reflecting on this situation in the interviews, she acknowledged that she then felt that she could have been keener on the extensive introduction with other participants as well.

A different approach in explaining the study was chosen in another case, in which the family member opted to be the person to explain the research during the meeting. This strategy was chosen by one family member (#2) to ease the person with dementia into the research activity. The designer explained the research to the family member first while the person with dementia was in a separate room. Afterwards, the family member introduced the research to the person with dementia himself. The designer expressed mixed feelings about this situation. On the one hand she felt that the person with dementia was literally left out of the conversation, but on the other hand she experienced that the person seemed less overwhelmed than other participants with dementia by all the information given. The designer reported that she saw this participant fully focusing on interacting with the prototype during this first meeting. Because of these mixed feelings of excluding someone but also seeing the benefits of limiting the information flow, the designer did not repeat this approach in first meetings with other participants. In general, the designer did stress that the presence of others considerably impacted to what extent she had to adapt her explanations. It varied between being the main communicator and being extensive in explanations herself and acting more as a support system in creating an understandable, suitable explanation for the person with dementia in collaboration with others present *("I noticed that I do not know the person as well as the family members do, they know best how to involve them in the conversations.")*.

## 3.3 Adaptations in Accessing Experiences

Eventually, the main purpose of the research of the designer was to access the experience of people with dementia and their family members in social experiences by means of her prototype. In her reflections, she discussed how she tried to accomplish this with verbal interactions and observations, both during the first meeting with the participants as well as during the multiple weeks of testing (*"Of course, I would have wanted to observe all behavior myself but that is not possible when researching over a longer period of time in a home context")*.

**Differences in engaging in verbal interactions**

The designer indicated in the reflective interviews that she made several adjustments to her strategy when interacting with her participants verbally. To the designer, her research felt more *"inclusive"* if the people with dementia actively participated verbally in the conversation. However, differences between participants were apparent. Despite the preparation on interview questions specifically designed for the person with dementia, the designer explained that she was only able to establish in-depth verbal interactions with three participants with dementia (#3, #5, and #6). She explained that in other cases she adapted her questions on-the-spot (*"With some of the participants I started with asking open questions, but if no answer was given, I tried closed questions.")*. This was based on the level of elaboration in the responses given by the person when the designer tried to ask them to reflect on their experiences (*"With one participant, when I asked how it went, they only briefly said 'Yes, it went well.")*. Another difficulty in verbal interactions she reported pertained to some participants' hearing problems (#4 and #7). In these instances, the designer had to rely on the caregiver repeating every question or remark, which resulted in a somewhat unnatural flow of conversating *("Their son had to repeat everything I said… That was a bit awkward. […] There were quite some silences during the meeting.")*. In other cases, some of the family member used the diary that the designer provided to prepare the interviews thoroughly beforehand, so that the person with dementia was prepared in voicing their experiences and to contribute to the evaluation. Next to the supporting initiatives of family members to engage the people with dementia in verbal interactions, the designer described that in a few other instances, family members were more in control and may have overruled the experiences of the persons with dementia (#4, #6, and #8). When asked about her role in possibly adapting these dynamics, the designer experienced these roles as part of a long-lasting relationship between family members and the people with dementia. She therefore did not see an active role for herself to interfere.

**The role of observations**

The designer adapted the methodology in accessing the experiences whenever the verbal interactions were more difficult. In these instances, she chose to rely more on the observations during the first visit when people interacted with the prototype. The tangibility of the prototype served to focus the interview on this 'trying-out'. For one of the participants with dementia (#1) this resulted, according to the designer, in a feeling of proudness (*"This was something especially for him."*). The meeting got a different, positive, vibe when changing the situation from mostly verbal interactions, to engaging with a prototype. In two other instances the designer reported a less positive effect, as the persons with dementia seemed reluctant to be in the center of attention (#2 and #4) although the designer did not report to change her approach when this happened.

Next to the adaptation to rely more on the observed interaction with the prototype, the designer reported that the comments given by the caregiver during these observations were an additional way to understand the experiences of the persons with dementia. For example, family member #7 shared his perspective by briefly confirming questions directed to the person with dementia. *(“He explained what happened and often asked the person with dementia to either confirm or affirm his remarks. […] So, it was about the person with dementia ánd together with him.”).*

### 3.4 The Reflection of the Designer on the Reflective Interviews

The designer was positive about the reflective interviews. According to her, the interviews challenged her to reflect in detail on the way she is doing research.

> Participating in these reflective interviews was an interesting exercise, because it challenged me to really reflect on my way of doing research in this field. I know that I try to move along with participants; for one participant a certain approach works and for another one it doesn’t, so, then I do it differently. But these reflective interviews also highlighted my doubts on this. Is it still a valid way of doing research or must it really be the same for everyone? Am I a good researcher? To me, this ‘practicing adaptivity’, supports people in feeling at ease during a research activity. In hindsight, I might have wanted to be more conscious about adapting my approaches to the individual needs and wishes. From the reflective interviews, I see more clearly the different approaches, but it also creates additional questions on what the impact was on my evaluation study.

## 4 Discussion

In this paper, we provided an in-depth reflection of the evaluation phase in a technology development project. In our case-study the designer had different experiences among her participants which shows the importance of the responsiveness and adaptivity of a designer in this field of research. From the interviews we learn that different elements had an impact on the necessary level of adaptivity of the designer and the possibilities of practicing this adaptivity in duration, explanations, and approach to access experiences of participants. We discuss below the potential impact of adaptivity and the value of further practicing adaptivity in this field of design with people with dementia.

### 4.1 The Potential Impact of Adaptivity

The analysis of the adaptations by the designer in her evaluation study brought into foreground the interplay of the different people, relationships, and approaches. From our study we gain additional insights on what design research processes and outcomes these differences might have had an impact. The potential impact of adaptivity in duration, explanations, and approach to access experiences of participants relate to the possible relationship building with participants (both the people with dementia and their family members), and the level of information gathered and shared.

When, for example, the duration of the study was extended, a certain degree of rapport and reciprocity [20, 33] between the designer and her participants unfolded. Designers in this field have both a ‘researcher-role’ and a ‘relational role’ to fulfil which can exist next to each other [13]. Adapting the duration of a research activity, such as an evaluation study, can support a designer in refining these roles in the different interactions with participants. Without working towards an instrumental application of rapport building, more reflective accounts could help understanding the supporting role of different specific responses such as self-disclosure [8], the appropriate use of humour [15], and how these impact decisions in designing technology.

However, having a close relationship with participants may also increase the pressure for social desirability and make it more difficult to be explicit in comments or criticisms about the designed technology. This was reported by the designer in the current study and was also found in previous work [24]. In addition, it can be debated whether displays of empathy are always conceived by participants as a means of establishing a conversational space of rapport. Especially since empathizing with people with dementia and their family members can, in generally, be challenging for designers [34]. Hence, maintaining sufficient distance can also be a sign of respect for the participant and their deeply personal stories [10].

The designer in the current study also described her challenges in giving thorough explanations to the people with dementia, yet, at the same time staying concise in exchanging information. This might have resulted in the various participants having a different understanding of the research and the functionalities of the technology. Scholars have highlighted the need for a form of 'ongoing-consent' in dementia research [7, 11, 17], although the attention is mostly on the consent part instead of the level of being informed. From our study, we learn that it is difficult for a designer to understand to what extent the person with dementia is aware of the role of the designer and what participating in research means. In line with earlier work [31, 32, 40, 43], the supporting or interfering role of the family members was further illustrated in our findings. The '*move-along-with-participants*'-approach of the designer from the current study, also created room for the family members to be creative in their ways of involving the people with dementia. Collecting these best practices, including their potential impact, may also be helpful for designers to support caregivers in their role as co-researcher [22].

## 4.2 The Value of Practicing 'Adaptivity'

The duration of research activities with people with dementia have been discussed in earlier work, in particular lengthy interviews that should rather be split up into multiple meetings [5]. In the current study we highlighted that the duration of an evaluation study of multiple weeks with people with dementia possibly needs either shortening or extending as well. Shortening the duration of research by the designer, mostly due to health-related issues, indicated the vulnerability of this user group. This might not be a surprisingly novel insight to researchers in this field, but how researchers or designers respond to these situations is not often described in existing literature. It is important to acknowledge the difficulties in handling changing experiences with prototypes when participants are dealing with additional stressors in their lives. Not the adaptation to shorten the duration of the evaluation study itself, but the reasons behind this adaptation created situations in which the designer interacted with grieving family members for which she was not fully prepared. As earlier work implied that designers in the field of Experienced-Based Design, should be trained in deliberate use of their own humanness [27], we propose to highlight these skills in the broader domain of design research in dementia care context as well. Reflecting and learning about how designers can canalize their emotions professionally could contribute to the development of design strategies in which designers respectfully adapt their way of addressing to different emotions of others. With these strategies, designers can be supported in empathizing with others to support the atmosphere during the design process. Not only when designing for and with people in later stages of dementia, in which this might be more profound, but also when entering the lives of people with dementia living at home.

Furthermore, the reflections of the designer show that it is difficult to adapt consciously to situations that occur. In the tradition of science, with a researcher being neutral and objective, a designer might feel uneasy when navigating towards the appropriate level of integrating in a person's social, physical, and emotional context and still adhere to the demands of research ethics committees and principles of standardization and objectivity [17]. For future studies, it could be helpful for designers to identify what challenges to expect prior to the research, ranging from people having hearing problems to the absence of active family members, and plan different routes together with the research team on how to respond to these challenges accordingly. This may provide designers with additional tools or strategies, helping them go beyond responding intuitively in the variety of possible situations.

### 4.3 Conclusion

Researchers and designers have reflected on their roles in the field of dementia care through reflexivity [6, 27]. It can be argued that we might benefit from more uncomfortable reflective practices [30] to further understand the complexities of doing engaged research in designing with people with dementia. The retrospective reporting in the current study, with an external researcher, supported the designer in structurally laying out her experiences and therefore possibly enriched self-reflexivity [29]. With this study we illustrated how different elements in research impact the sensitivity and adaptivity needed in engaging with people with dementia to design and evaluate meaningful technologies.

No study comes without limitations. The current analysis was limited to one designer, approach, design phase, and technology. The designer's style cannot be disentangled from her perceived interactions. In future studies it would be insightful to include other designers, or researchers from a different field, and technologies to gain a broader understanding in how different designers and researchers make choices in their interactions with people with dementia. With the focus on one field study, however, the complexity of practicing adaptivity was already apparent and made us able to dive into these adaptations instead of generalizing findings across studies.

In a future study we would like to incorporate more detailed, and structured evaluations of actual interaction data (e.g., transcripts or direct observations) for further in-depth understanding of adaptive interactions in participatory activities in technology development. Furthermore, we suggest that in these types of projects a multidisciplinary research team should reserve appropriate time, tools, and people to discuss the ethical inconsistencies and imperfect responses to practical problems despite careful efforts to make the right choices. Designers need to be upfront about their behavior and role to be able to use this as an additional lens when analyzing the data. Discussing ethical considerations and reflecting on choices and efforts together will further support and appreciate the work of designers in this field in creating a positive and fruitful research atmosphere.

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# Impact of Care Home Design on Wellbeing and Social Connections of People with Dementia During the COVID-19 Pandemic

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## Abstract

The functionality, well-being, and quality of life of people living with dementia can be positively impacted by careful environmental design. As a consequence of the COVID-19 outbreak, sudden rearrangements were made in the social and physical environment of dementia care residents. The present study aimed to explore the lessons learned regarding the design and use of the built environment during the COVID-19 lockdown and to find how the built environment might contribute positively to improved well-being, and social and physical connection of dementia care residents in the future. In a mixed-method explorative study, social-physical aspects of the built environment that influence quality of life during the COVID-19 pandemic were explored. In general, buildings with a spacious layout and flexible use of spaces contribute to a higher quality of life and level of resident well-being, improved infection control, greater resilience, and enhances social and physical contact. Currently, the buildings of many care facilities are not designed to accommodate a severely infectious disease outbreak. Additionally, nursing staff have learned the importance of attending to the number of stimuli in the social and built environment and attuning these to individual, instead of group needs. Our findings indicate there is a need for designing and building spacious long-term dementia care facilities that allow for flexible, social and personalized appropriation of spaces.

## Keywords

Built environment · Dementia · Quality of life · Well-being · COVID-19 pandemic · Social contact · Affective touch · Care home

## 1 Introduction

Architectural design of long-term dementia care facilities plays an important role in the life of people with dementia [1]. When done well, design is a non-pharmacological intervention, reducing agitation, anxiety, conflict, confusion, and depression, while improving familiarity, orientation, pleasure, mobility, and all activities of daily living [2]. Thoughtful design of the environment can improve dementia residents' social wellbeing [3], positive social interactions [3, 4], affect [5], and behavioral health [6], as such impacting their well-being and quality of life positively [7, 8].

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The outbreak of a new and deadly virus, however, has meant that all care facilities had to adjust fast. To prevent and control the spread of the COVID-19 virus, many care facilities implemented restrictive measures, including severely limited visiting policies, mandatory social distancing, and a rearrangement of living and social activity spaces. In this paper, we want to draw lessons from the COVID-19 pandemic and its associated measures in the context of Dutch intramural care facilities [9–11] to help us better understand how environmental design can contribute positively to improved infection control, and prevent negative side effects on the health and well-being of dementia care residents [9, 12]. It is evident from literature that the built environment has a significant impact on the functioning and well-being of dementia care residents [2, 3, 6, 9, 13–24]. In addition, the social distancing, mobility restrictions, and restrictive visiting policies had a pronounced effect on the opportunities for interpersonal social contact, and particularly interpersonal touch. Providing interpersonal social touch is of significant importance for persons with dementia and crucial for feelings of belongingness, happiness, and communication while suffering from impaired reasoning and responsiveness [25].

With the dramatic reconfigurations in the design and use of physical and social spaces, the pandemic has become a de facto challenging "natural experiment" that gives us the opportunity to rethink the role of the built environment and the importance of social contact for the person with dementia living in it. The pandemic and its related measures therefore probes awareness around issues of quality of life in dementia care facilities and the impact of trade-offs in choices made focusing on safety and physical health versus choices made focusing on quality of life and feelings of well-being [26]. The design of buildings, however, is unlikely to be the single solution to improve quality of life of residents of dementia care facilities; we are aware of the need to facilitate and explore warm technology solutions to support the caring and social environment of the person with dementia living in these buildings [12, 26].

## 2 Methods

### 2.1 Design

In this study, social-physical aspects of the built environment were explored that influence well-being, social interaction, affective experiences, and quality of life of residents in dementia care facilities after the onset of the COVID-19 pandemic in March 2020. We used a mixed method approach, combining an online survey of staff working in a variety of dementia care facilities in the Netherlands, randomly selected throughout the Netherlands, with complementary observations of dementia care residents. While the online survey probed a representative sample of staff on a broad range of issues, including social contact, the (changes in) use of various spaces, and the impact of social distancing measures, our participatory observations allowed us to gather more in-depth, richer information on the behavior, changes in the layout, social interactions, and use of spaces in dementia care facilities that were a consequence of implementing safety or distancing measures during the COVID-19 lockdown.

### 2.2 Online Survey

**Participants.** The online survey was completed by a total of forty-six dementia care professionals. With the selection criteria *"nursing home" & "care home", "Dementia", & "Alzheimer's disease"* 60 regular Dutch dementia care facilities were randomly selected and contacted from 620 results on the website Zorgkaartnederland.nl, a Dutch website with a database for all dementia care facilities in the Netherlands. Additionally, 40 private Dutch dementia care facilities were randomly selected and contacted from 449 results that were found with the selection criteria *"privately funded", & "privately funded residential care center".*

**Setting and Materials.** The online survey was administered through LimeSurvey with open and closed questions structured in several categories, including: general questions on the period after March 2020, demographic questions, questions about the people residing in the living room or department of the care facility, about the residents and their well-being during the covid-period, the visits from family and friends, the care professional, personal experiences with the governmental restrictions regarding visits and social distancing, and finally some questions on the built environment.

**Procedure.** The randomly selected regular and private dementia care homes were each contacted by phone, after which the head nurse of each care facility was invited to participate in the online survey through a personalized email.

## 2.3 Participatory Observations

**Participants.** Seventy-six dementia care residents were observed across four dementia care facilities located in the South of the Netherlands. In total, 19 males were observed as well as 57 females. For the observation one researcher visited 4 dementia care facilities, either one location per observation was picked as the subject of the observations, or one resident per observation was selected as participant if the resident was mobile and moved around.

**Setting.** At each care facility, either the living room, an alcove, a communal room, or a terrace outside was chosen as location for the observations. Residents using the room were observed or individually discretely tracked across the facility/department, depending on the movements of the residents within the care facility. The majority of observations were made of residents (socially) interacting within the described locations of the care facility.

**Materials.** The observations were partially structured with an observational scheme. To create the observational scheme, the MEDLO tool (the Maastricht Electronic Daily Life Observation Tool) [27–29], the observational scheme previously used by one of the researchers during her undergraduate degree for observing people with dementia in a care home facility [30], and Zeisel's [31] chapters on observing physical traces and observing environmental behavior were used as a basis. For detailed specifications of the observational schemes used during the observations see Coppelmans [32].

**Procedure.** Residents of the four dementia care facilities were observed during their entire day. Using the observational scheme, partially structured notes were taken on the (social) interactions within the room, the use of the space, levels of engagement, facial expressions, gazing behavior, and atmosphere. Furthermore, a sketch of the floorplan was made with the location of furniture, doors, and windows, which was used to indicate where the interactions took place and to indicate the lines of sight and walking trajectories of persons using the room.

## 2.4 Data Analysis

Thematic analyses were used for analyzing the open questions of the online survey and observation data, using a combination of Boeije's approach [33] and Braun and Clarke's approach [34]. The thematic analyses were carried out by two researchers independently, and later combined and reviewed in discussions within the research team.

## 2.5 Ethical Considerations

The online survey and observations were both approved by the ethical board of the Human-Technology Interaction group in Eindhoven. Informed consent was provided by care professionals for the online survey as well as the observations. Both studies were performed on a voluntary basis and there was no compensation.

# 3 Results

The responses to the questions in the online survey covered a broad range of opinions and observations, within the topics. The responses were individually inspected per question which led to several insights that fit within the themes.

## 3.1 Thematic Analysis

The thematic analysis of the responses to the online survey and the observations of residents with dementia in long-term care facilities yielded seven overarching themes, which will be discussed next.

**Theme 1: Nurturing a Balance Between a Serene Versus a Lively Atmosphere in the Living Room.** Nursing staff reported to experience more calm residents during the Covid-19 lockdown, during which visitors were not allowed in the dementia care facility, group activities were no longer provided, and residents could not go outside. This calm atmosphere among the residents seemed, to their mind, to be beneficial for the residents and has made nursing staff more aware of the number of stimuli the residents are exposed to and attune the number of stimuli to the needs of individual residents.

> For some residents the absence of (for them) strangers in the living room caused a more calm atmosphere (Online survey)

Those care facilities that are no longer welcoming visitors in the living room of the care facility have seen an increase in the use of the bedrooms and the garden. The function of these spaces has therefore changed. As a result, some care facilities have made adjustments to the garden during the Covid-19 lockdown to welcome guests. Other care facilities have adjusted the built environment such that residents have a choice to go to a calm space or a more lively space when seeking social contact.

Overall, nursing staff of dementia care facilities have become more aware of the sensory and social stimulation residents are exposed to, where they originate, and how they may be balanced according to the needs of individual residents.

**Theme 2: The Built, Natural & Social Environment Facilitates and Sets the Mood.** Nursing staff report on a range of experiences related to the relative confinement to the built environment during the Covid-19 lockdown. As residents were not allowed to go outside, and sometimes even had to stay in their bedrooms as much as possible, it became obvious that for some care facilities the built environment facilitates the needs of residents and staff, whereas in other care facilities residents and staff experienced difficulties and found that the built environment is lacking. Nursing staff reported a renewed appreciation of the importance of a good spatial layout and a spacious design of the built environment, both for its functional flexibility as well as its atmosphere. Having a spacious design facilitated flexible use of spaces in times of need, making infection prevention easier, and was said to be enjoyable for residents as it can stimulate and foster social contact and affective connections. Some nurses experienced that the living rooms were in fact too small, a fact that care professionals became (more) aware of during the COVID-19 pandemic. Indeed, during the observations nursing staff were seen to be struggling to move around in the living room of the care facility, maneuvering themselves around wheelchairs, walkers, and furniture in the room. Also, easy, ground floor access to a secluded garden is much appreciated by nursing staff. Frequently, the garden was upgraded to be able to seat more guests and in some care facilities the garden was made weather-proof. Some care facilities created seating in the hallway so that residents could choose to sit somewhere quietly or partake in an individual activity if they wish to. Others created a separate visitors' room. Finally, private nursing homes (often) have a more spacious layout allowing them to make changes within a room more easily as compared to regular nursing homes, and also more often have access to a garden.

**Theme 3: Shift in Focus from the Best Interest of the Group to the Best Interest of the Individual.** In the absence of otherwise organized activities, and outside visits, nursing staff could pay more attention to the residents and their individual needs. As a result, a shift arose in focus from the best interest of the group to the best interest of the individual, with nursing staff being able to give residents more individual attention. Nursing homes reported to have realized that there is room for improvement in providing person-oriented care, taking a more personal approach in caregiving, and better attuning to the needs of individual residents, with the realization that they unintentionally had not been attentive enough to the needs of individual residents before the lockdown.

> We should learn from the lessons learned during COVID-19, how can we welcome visitors while considering the needs of the resident and the other residents of the group. We should customize for every resident, making agreements with family, about their visit, where, when, and how long. We should explain, make clear why we chose something in the best interest of their loved ones. Person-oriented care is very important, including personal histories, we should document personalities (Online survey)

Moreover, with fewer distractions, nursing staff have become more aware of the care needs of residents with dementia, especially regarding their personal needs in the regulation of the number of stimuli in the environment and their needs in physical and social touch.

> Residents always longed for social contact, socially and physically, touching remains important (online survey)

**Theme 4: Awareness of the Importance of Social Touch and Closeness to Loved Ones.** Having to be socially isolated to prevent infection with the COVID-19 virus, nursing staff, family, and residents have all realized, more than before, that social contact is necessary and that people should not be restricted from it. As nursing staff were advised against giving hugs or holding hands with residents, many of the residents were deprived of social touch and residents were reported to experience touch cravings [“huidhonger”]. Respondents of the online survey shared that social touch is a basic need that is very much needed in times of distress, like during a pandemic.

> Residents are touch starved. They miss receiving a hug (Online survey)

During the observations, furthermore, residents often initiated affection, social touch, holding hands and hugging, and so did the nursing staff.

> She walks to the woman in a wheelchair, talks to her, brings her head close to hers and holds her hand. She chats with the woman, both smile, she stands up straight and chats some more, both are smiling again, she walks away (Observations)

There is considerable individual variation in how the lockdown was experienced, and the relationships between residents and their loved ones has been impacted variously. Some residents have experienced a great loss in the absence of visitors and otherwise organized activities. They have experienced feelings of loneliness, boredom, under-stimulation, alienation, and incomprehension in missing their loved ones and daily activities. Some further deteriorated in their disease of dementia due to the changes that have been made for infection prevention, especially those with more advanced stages of dementia who no longer recognize their relatives. In contrast, some residents with dementia flourished during the lockdown. With the lack of visitors and activities, nursing staff saw a revival of these individuals and they even seemed to be doing better than prior to the pandemic. Accordingly, for some residents their social bonds have strengthened, whereas for others they were weakened or remained unaffected. A number of relatives reportedly lost some of their affective connection with the person with dementia, leading to personal distress. Social touch and closeness to loved ones are very important for people with dementia. The visits themselves have changed as well, now being experienced more consciously. There is more attention for the resident during the visit (not being able to sit in the living room with other residents and family) and this has sometimes led to the development of new activities and stronger family ties.

> I think that visitors are now more involved with their individual loved one, that sometimes new activities have developed, like walking. When the conversation is sometimes difficult, this is a nice activity that does not require much talking, but sometimes it is more difficult, if it is difficult to make contact. Then visitors can no longer contact us in the living room or connect with another resident (Online survey)

All in all, the restrictive measures of the Covid-19 lockdown have led to the realization of the importance of social touch and closeness to loved ones and they have impacted the life of residents and their family dramatically differently.

**Theme 5: Compensating the Restrictive Measures and the Consequences of Covid-19 Lockdown.** Nursing staff have tried hard to accommodate the absence of visits and activities in various ways. Respondents reportedly engaged in more social contact, giving extra individual attention, offered warm care, hosting more activities in the living room, and offering alternatives to facilitate contact with relatives.

> It was a tough period of time, but overall there was much understanding. Video calling, contact through the window, contact in a tent with a microphone, contact across a hedge in the garden. We have tried many things to still allow some contact. However, real, physical contact, a quick hug or a social touch, which is very important, was very much missed (Online survey)

Families valued being kept informed about the well-being of their loved ones and worried that their loved ones would no longer recognize them. Many residents, on the other hand, did not understand the alternative visit and became more agitated and frustrated by the lack of intimacy and touch. Other residents, however, did enjoy the alternative means of social contact.

> We tried everything to establish warm contact, but real physical contact, like a hug, the inability to touch, was a great loss (online survey)

**Theme 6: Resilience of the Nursing Staff After Experiencing a More Complex and Diverse Role During Covid-19 Lockdown.** The Covid-19 pandemic was clearly challenging for nursing staff. In addition to the long hours, and the specter of the disease taking its toll on the most vulnerable, the outbreak of COVID-19 also meant that everything in the care facility suddenly changed—physical structures, work processes, and social interaction norms. Residents with dementia did not recognize care staff wearing masks, face shields, gowns and aprons, and communication was impaired as it was difficult for residents to hear the care staff and emotions were hard to convey through the personal protective equipment (PPE). Nursing staff had to invest more time in cleaning, guiding alternative visits, and arranging activities for residents in the living room. On top of that, there was fear of infection with a serious yet unknown virus and nursing staff had to sometimes deal with frustrated family members, which made them feel like having to be a police officer.

Finally, the passing away of residents during the lockdown was intense and heartbreaking. The role of the nursing staff was therefore more complex and diverse with a higher workload, more emotional ups and downs, and extra non-medical responsibilities during the global pandemic.

> My work has not changed, and I enjoy to keep going. I am glad that family is allowed to come visit again and that restrictions are starting to lift. What personally really hit hard was the process of passing away of residents (Online survey)

Nevertheless, many respondents also look back on this difficult period with positive feelings, such as feelings of strong collegiality, accomplishment and collective pride. They feel they managed to get through this period together as a team and have a positive view of their future in caregiving.

**Theme 7: Clashing Values in Caregiving: Safe Care Versus Warm Care.** Inherent to many of the experiences that were reported was a fundamental tension between on the one hand wanting to keep residents safe and prevent infections with COVID-19, while on the other hand providing warm care, to show affection, and give warmth through social and physical touch, especially when their relatives could not. This tradeoff became especially salient in the social distancing regulations, including keeping physical distance, separating groups of residents, sometimes putting residents in isolation, continuously wearing PPE, and taking extra hygiene precautions.

> For some residents a chat is not enough or not possible. They clearly have a need for physical touch in the form of holding hands, cuddling. This was discouraged as much as possible, so it felt like you were not doing right by the resident (Online survey)

These clashing values are not only reflected in caregiving itself, through human interaction, they are also reflected in the built environment. Many care facilities have made adjustments to the built environment to minimize the risk of infection by seating residents further apart, creating a separate room for nursing staff to change into PPE, or a separate entrance for visitors.

> Social distancing was not always possible, our residents need a lot of physical care, you have to stand close. We tried to touch and hug less, but when the residents asked for it we couldn't resist to hold hands or offer a hug.

Throughout the responses of the online survey, the observations and informal chat with the care staff, it is clear that nursing homes have struggled with providing safe care and warm care simultaneously during the Covid-19 lockdown.

## 4 Discussion

Research to date has demonstrated that the design of one's living environment is extremely important in maintaining good health, social contact, and wellbeing [3–5, 35]. In this paper, we investigate the effects of the COVID-19 pandemic and its associated measures on changes in the built environments of dementia care facilities, and their impact on the experiences and wellbeing of residents and professional carers. We combined an online survey of care personnel with participatory observations at various care locations, in order to draw lessons on how the social and physical environment might contribute positively to improved resident well-being, now and in the future.

First, in the absence of visitors and group activities during the Covid-19 lockdown, nursing staff have learned the importance of being attentive to the level of sensory and social stimulation in the social and built environment of residents with dementia in order to balance and attune these to individual, instead of group, needs. Our insights underline the importance of personalized care for the person with dementia [3, 36]. Secondly, the restrictive measures of the Covid-19 lockdown have led to the realization that social touch, physical contact, and physical closeness to loved ones are really necessary for the well-being of people with dementia. From this, the third insight of the Covid-19 pandemic follows, which is that the built environment facilitates residents and nursing staff in flexible use of spaces in times of need, easier infection prevention, enjoyment for residents, and resilience of the nursing staff. In many care facilities, however, the built environment is not optimal which has provided struggles with infection prevention and overall atmosphere among the residents. The clash in values in caregiving—especially between a focus on safety and task oriented care versus a focus on social and physical connection and interaction—has become more salient, as reflected by the reported struggles of nursing staff and residents. A spacious and flexible layout with easy access to private and green areas, supports more personal autonomy and freedom to allow for optimal solutions along the warm care vs. safe care tradeoff. Moreover, a spacious layout of the care facility allows for the creation of both private and social spaces, the creation of a two-persons couples room, and space for private items to create a sense of home and familiarity for residents with dementia [3, 17, 20, 37–39]. This is beneficial for the well-being of residents, easier infection prevention, and better working conditions for the nursing staff.

These findings match the already existing literature on the facilitating role of the built environment in the functioning, positive social interactions, and well-being of people with dementia in long-term care facilities [1, 3–5, 7, 8, 13, 18, 23, 35], however, the COVID-19 pandemic has revealed, now more than ever, that residents and nursing staff of many care facilities have to cope with poor physical building design [40]. One reason for this state of affairs is that surface area is costly and financial cuts in nursing home care have led to the optimization of floor plans in the premises [39]. However, confining residents to their rooms, for fear of infection with COVID-19, made dementia care residents vulnerable to the risks of social isolation and loneliness [41]. It has been advocated to spend money on better environmental design, even before the COVID-19 pandemic, [39], and now it even seems vital; to save lives in the next pandemic, and to reduce stress of residents and nursing staff of nursing homes [40].

A spacious and flexible layout of the care facility is key to provide residents with the option to take a seat in a lively versus a serene environment; the personal autonomy to adjust the environment to their needs. Additionally, the findings of this research support Torrington's [42] claim that quality of life is related to building design. Residents of buildings that prioritize safety and health over social interactions, empowerment and freedom of movement typically report poorer quality of life. Indeed, our results indicate that those care facilities that have prioritized safety and health have endured greater struggles, 'more difficult to handle' residents, and limited endurance of nursing staff. In addition to environmental design being key to improved well-being of dementia care residents, there is a larger on-going movement towards person-centered care and dementia emancipation, where the focus is more on human rights, personal autonomy, meaning and dignity, rather than a pure medical focus on dementia as a disease. Specifically, the built environment can be viewed as a specific opportunity for applying the principles of warm technology in environmental and building design [26, 29, 36, 43]. The lessons learned through the COVID-19 pandemic underline the importance of such a person-centered approach. Future research should investigate the changing care needs of people with dementia in the coming years. As a new generation of more diverse, more empowered and tech-savvy elderly arises, the design of nursing homes and other care facilities should reflect their changing requirements.

## 5 Conclusion

The aim of this explorative research was to find out what has been learned with regards to the built environment during COVID-19 lockdown in long-term dementia care facilities and how the built environment might contribute positively to improved well-being in the future. The findings of this research reveal that the built environment facilitates and sets the mood, that the building is not always suited to the current care demands of people with dementia, and that buildings are generally not designed to accommodate a pandemic or any other outbreak of a severely infectious disease. This is why more research should be directed towards the design of the built and social environment of long-term care facilities. We all have realized, more than ever before, that social contact is necessary and that people with dementia should not be restricted from it. Indeed, the absence of social interactions has deeply affected this vulnerable group, whose opportunities to express these needs and take action to meet their unmet needs are limited. Our research highlights the fact that social relationships and physical contact are key to personal wellbeing and underlines the importance of the entangled role of touch in dementia care, not only the task-related touch but especially the benefits of affect-related touch interventions [25, 44–46]. In all, the person with dementia should be put more at the center of attention, should receive person-centered care, attuned to individual needs, and should be able to express and experience physical as well as social touch and closeness to loved ones. In the design of future living residences, people with dementia as well as care staff should be involved. Here too, the adagio of person-centered care—*"nothing about me, without me"*—is a valuable guideline. Only collaboration with people with dementia will ensure future residential design that promotes quality of life, well-being, social and physical interaction, and engagement, while fostering choice and ensuring person-centered care [26, 47, 48].

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# The Role of Interior Design Materialities in Dementia Care: Mundane Elements from the Past

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## Abstract

Apathy, defined as an affective state characterized by loss of interest and indifference towards the surrounding world, has been widely identified as an important behavioural syndrome in Alzheimer's Disease (AD). The aim of this paper is to inquire the existing relationship between materialities, meant as tangible elements of an interior, including various spatial elements, objects and bodies, and their role in enabling people with dementia to engage in spontaneous interactions with the surrounding environment, diminishing apathy. In particular, the authors extend the definition of "materialities of care", including the visual representation of mundane elements typical of past decades, defined as "mundane elements from the past" including them in thematic collections of visual posters presented in an on-going pilot study. The placement of these collections in the spaces of a day care centre enhanced recognition and sense of belonging, enacting meaningful interactions and reminiscence conversations among people with dementia and caregivers.

## Keywords

Dementia · Materialities of care · Mundane elements from the past

## 1 Introduction

Population aging is usually defined as "the percentage of a given population aged 65 or older" [1]. More than 19% of Italy's population is age 65 or older, turning this nation into one of the world's "oldest" countries. Population aging bring forward an increase in the incidence of degenerative diseases, such as dementia. Dementia is a clinical syndrome characterised by a loss of memory and cognitive functions of such a magnitude as to interfere with the individual's usual social and work activities [2]. One of the most common forms of dementia is Alzheimer's Disease (AD). AD may be identified as the "four A's disease": significant memory loss (amnesia), inability to formulate and understand verbal messages (aphasia), inability to correctly identify stimuli, recognize people, things, and places (agnosia) and inability to perform certain voluntary movements correctly even using objects, for example, dressing (apraxia) [3]. Loss of memory characterizes AD

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[2]. In addition, there are also non-cognitive symptoms, which concern the sphere of personality, affectivity, ideation, perception, vegetative functions and behaviour [4]. Furthermore, AD encompasses different behavioural symptoms, including apathy. Apathy is commonly defined as an affective state characterised by loss of interest and indifference to the world around us [5]. More broadly, "it is conceptualized as the absence of responsiveness to stimuli as demonstrated by a lack of self-initiated action, lack of concern, and emotional indifference" [6].

The environment, meant in this paper as the interior features of care environments, plays an important role in engaging people with AD in spontaneous meaningful activities, reducing apathy [7]. In particular, the on-going study presented in this paper inquiries the existing relationship between materialities, meant as tangible elements of an interior, including various spatial elements, objects and bodies [8], and their role in enabling elderly with AD to engage in spontaneous interactions with the surrounding environment, diminishing apathy. Within this wide group, the authors focus their attention on visual elements, such as photographs, images, collages and graphics. Thus, this paper presents the project of thematic collections of visual posters, composed by "mundane elements from the past" aimed at diminishing apathy in people with AD attending a day care centre.

## 2 Apathy in Dementia

Apathy, defined as an affective state characterized by loss of interest and indifference towards the surrounding world, has been widely identified as an important behavioural syndrome in AD [5]. It is widely recognized that apathy commonly affects many individuals with dementia, and in particular AD, as well as people with other neuropsychiatric disorders as Parkinson's disease and stroke [9].

Apathy usually occurs in the early stages of AD, but it persists with its progression. It can be defined as a loss of motivation compared to the individual's previous level of functioning [10]. In particular, it includes lack of emotion, lack of initiation, lack of enthusiasm, lack of self-initiated actions, which may encompass "social apathy", lack of sense or purpose, sluggishness/low energy levels and passiveness, detachment from life and personal events and lack of intellectual curiosity [11, 12]. Moreover, it manifests itself in a decrease in cognitive and behavioural goals [12].

According to literature, there is still no clear advantage of a particular drug therapy in the treatment of apathy. Thus, part of the attention has been directed to non-pharmacological therapies, which have shown some effectiveness in reducing behavioural, psychotic symptoms and improving cognitive symptoms, well-being and quality of life of people with AD [10, 13–15].

### 2.1 Long-Term Care and Day Care for Dementia

Long-term care for elderly with AD represents a key issue in many countries worldwide as it involves a range of services such as nursing, various forms of community care and day care, residential care, trained staff, and long-stay hospitals and clinics [1]. In western countries, aging policies are moving towards the promotion of home care, small-living groups, and daily care, instead of residential long-term care, unless specific medical treatments need to be administered only by medical personnel. In this framework, day care centres represent an important support for families and people living with AD. Day care is a semi-residential service where older adults are welcomed during the day, supporting them in all their needs, engaging them in meaningful activities to stimulate communicative, relational and cognitive skills. In the daily care for elderly with AD, environment plays an important role, as it should be recognized as familiar, welcoming, and engaging, supporting residual capabilities, and stimulating the impaired ones [16, 17]. Through appropriate stimulations, the environment could represent a successful tool to engage older adults with AD in spontaneous meaningful activities, reducing apathy [16, 18].

## 3 Materialities of Care

According to different studies in the field of social sciences and humanities, many aspects of the material world we live in have a causal efficacy on our minds [19, 20]. In this paper the authors adopt the term “materialities” to identify tangible elements of the environment, including objects, spatial elements, bodies and visual elements [8]. Respectively, researchers have begun to investigate the role of materialities in dementia care, paving the way for further research [21]. As argued by Buse et al. [22] “Materialities of care is outlined as a heuristic device for making visible the mundane and often unnoticed aspects of material culture within health and social care contexts and exploring interrelations between materials and care in practice”. Moreover, “Seemingly mundane materialities are intertwined with important, but often neglected, care interactions. It has been argued that if healthcare professionals paid more attention to the roles materialities can have, everyday routines could become important occasions for care” [23] (p. 126). Among the existing studies, some develop frameworks focused on the description of meaningful interactions of elderly with dementia with specific objects and on their characteristics to stimulate people with dementia’s senses [24, 25]; others explore the role of materialities in facilitating collective activities, support relations, interactions, and self-recognition [26–28].

Moreover, these materialities are daily involved into everyday practices, mostly passing unnoticed through the course of dementia [19] but representing key elements into personal habits which enhance a sense of belonging and recognition into an environment [29]. As Miller et al. [30] argue, “objects are important not because they are evident and physically constrain or enable, but precisely because we do not ‘see’ them” (p. 5). They have effects in ‘setting the scene’, creating a certain mood and shaping behaviours in part because “we are unconscious of their capacity to do so” [30] (p. 5). Accordingly, Buse et al. [22] argue that materialities may make “visible the ordinary, tacit and non-verbal aspects of care practices” (p. 245).

As reported by different studies, materialities of care does also consider mundane objects of care, as they act as triggers in embodied routines and habits and consequential actions that usually take place through and between bodies, objects and surrounding spaces [22, 23]. Furthermore, mundane elements may include coffee cups, newspapers, toys, clothings, napkins, cutleries, packagings, etc. as everyday things become part of personal invisible relations because our engagements with them rely on culturally and historically grounded habits. Often, certain objects remind us of past events, happy times or specific moments or moods. These habits, moods, and past memories remain clear and untouched even with the onset of AD.

In fact, previous studies found that the memory of persons living with AD can be classified into 2 differing systems: explicit memory and implicit memory systems [31]. Explicit memory is conscious, directed effort to recollect prior experience and facts. Implicit memory is described as an unconscious memory system that is unavailable to direct recall and demonstrates the effects of previous experiences on subsequent task performance, without any conscious recollection of specific episodes [32]. In different studies, this way of acting is referred to as “habits”. A growing body of evidence demonstrates that older adults living with AD have preserved implicit memories even in the severe stage despite obvious explicit memory losses. So, we can believe that people living with AD can keep their “habits” until the end of their life.

Hence, mundane elements often participate in specific enactments of care and of daily life in dementia care units or daily care centres [23]. Accordingly, particularly interesting is the concept introduced by Cleeve [21] in her research: mundane mattering [21]. Mundane mattering denotes instances where informal practices of residents, patients, family members, and staff members involving seemingly mundane materialities offer possibilities for shaping daily life, identities, and agencies [21]. This aspect underlines how some of these mundane materialities may represent a trigger for reminiscence and spontaneous engagement. In fact, Cleeve [21], and, previously, other researchers as Buse and Twigg [26], Majlesi and Ekström [27] and Moser [28], highlighted the role of everyday and mundane materialities in enhancing people living with AD's participation in everyday activities, emphasizing how the adjustment and the look of objects may enable spontaneous interactions in everyday activities. Moreover, they argue that it is possible for healthcare professionals to learn how to utilise materialities so that older adults with AD can be involved as collaborators in everyday activities [33].

## 3.1 Mundane Elements from the Past

In the study presented in this paper, the authors explore how mundane materials of care may shape relations and may have consequences in terms of enhancing recognition and sense of belonging, enacting meaningful interactions and reminiscence conversations for people living with AD experiencing apathy, in a care environment.

In particular, in this study the authors extend the definition of "materialities of care" given by Buse et al. [22], including the visual representation of mundane elements typical of past decades, defined as "mundane elements from the past".

The authors, as furtherly explained in the methodology section, supported by family caregivers, identified a group of mundane elements, popular and well known by the elderly involved in the study. Those mundane elements symbolize "everyday products" such as objects, sweets, snacks, beverages, toys, beauty tools, etc. commonly used by the majority of the Italian older population, during 1950s, 1960s and 1970s, as the study was undertaken in Italy. Those decades coincide with adulthood of people living with AD involved in the study. Furthermore, those "mundane elements from the past" represent for older adults clear and nostalgic old memories, shared among individuals living in the same daily care environment (same age, nationality and cultural sphere).

Thus, the aim of this study is to explore the potential of popular material objects to evoke narratives and elicit memories in people with dementia due to AD, and their capability to engage in spontaneous meaningful activities and conversations, diminishing apathy.

In the study discussed here, the authors introduce reminiscence factors to the concept of "materialities of care" aforementioned [19, 21–23]. Prior to the study, the authors hypothesized that the photographic representation of "mundane elements from the past" could represent a valid visual stimulus for people living with AD. Photographic representation allowed them to intervene graphically, to enhance their recognition and identification in the built environment, their peculiar characteristics, and finally, the introduction of a proper set of background colours able to valorise and make more evident the identification of those objects by the elderly involved in the study.

# 4 Methods

This is a qualitative research project that uses a research through design approach. The term "research through design" refers to a method of scientific inquiry that takes advantage of unique insights gained during design practice [34]. The pilot-study is structured as follows:

- phase 1, March–June 2021, semi-structured interviews with family caregivers
- phase 2, early September 2021, workshop with family caregivers
- phase 3, early October–mid November 2021, mini-ethnographic case study observation and informal interviews with older adults with AD and day care staff.

In the first instance, it was necessary to identify a group of "mundane elements of the past" relevant for the elderly with dementia involved in phase 3 of the pilot-study. Data were collected by conducting semi-structured interviews [35] to caregivers of people living with AD attending the daily care centre GRACE, in Milano. In qualitative research methods, semi-structured interviews are one of the most used tools, as they extensively demonstrated to be useful tools to obtain efficient qualitative data collection, to explore emergent and pragmatic issues, to check and balance on differing opinions, and to direct validate concepts [36]. In particular, 20 family caregivers were involved in this phase of the pilot-study. They are daughters, sons, spouses and husbands of the older adults attending the day care centre. Their age ranges from 47 to 71 years. The authors, in agreement with the medical staff of the day care centre, decided to explore the perspective of family caregivers to find the widest, cross-sectional perspective on the personal stories and habits of the elderly with AD involved in phase 3 of the pilot-study. The aim was to identify as many relevant experiences, objects, habits, experiences as possible from which to identify a set of objects for the following phases.

Accordingly, the authors conducted 2 semi-structured interviews, during the period March–June 2021, with the group of caregivers of people living with AD attending the daily care centre. At the beginning of the semi-structured interviews, informed consent was given and signed by participants. Then, participants were asked to focus on their knowledge of their relatives with dementia, their childhood memories involving their parents, spouse or husband. In particular, participants were asked to recollect pleasant meaningful memories of everyday life with their relatives. The semi-structured interviews consisted of an open discussion following a list of topics to be explored, and they were focused on two main aspects: daily life habits and familiar rituals. For each category, participants were asked first to reminisce and describe daily routines and habits, and later to list related meaningful objects which were considered popular both for the society and in their familiar context. The interviews lasted on average 1.5 h and were transcribed verbatim. Thematic content analysis was used to analyse semi-structured interviews. The analyses were performed in accordance with a thematic 4-step analysis: (1) familiarization with the data through repeated readings of the transcripts; (2) systematically generating initial codes across the entire dataset; (3) searching for themes among the generated codes; (4) identifying and naming themes. Authors used NVivo software for data management. Accordingly, the authors were able to identify a group of “mundane elements of the past” which were recurrently citated by participants and organize into 3 categories: popular foods and snacks, everyday mean of transportation, beauty and hygiene products.

In early September 2021 participants were invited for a workshop with the purpose to thank them for their participation, and to present and reflect on intermediary results. During the workshop, the authors presented to participants the different graphic solutions for the images previously selected. Graphic characteristics such as colour contrasts, positioning, and background colour scheme were discussed. After this intermediate phase, the authors realized 3 different collections of visual posters, following the aforementioned categories, and the graphic solutions identified.

During the period early October–mid November 2021 the visual posters were hanged in the main corridor of the daily care centre involved in the study. Each visual poster collection was continuously hung for 2 weeks. This space is not simply a junction between the different rooms, but a real space of daily life, experienced by the residents at different times of the day, thanks to its large size. For the last phase, the authors used a mini-ethnographic case study approach, to understand the culture and study everyday behaviours [37]. A mini-ethnographic case study uses ethnographic methods such as semi-interviews and observations. This project was approved by the ethical committee of Politecnico di Milano, and the internal ethical committee of EQUA Cooperativa sociale, the organization managing the day care centre. The study was conducted in a day care centre in Milan, which welcomes 30 older adults living with AD. This site is a three-story building. The ground floor includes the day care centre, which offers common areas, activity rooms, a dining room, and a corridor connecting all the aforementioned spaces. This study adopts triangulation approach to collect the data. Triangulation refers to the use of multiple methods or data sources in qualitative research to develop a comprehensive understanding of phenomena [38]. Triangulation also has been viewed as a qualitative research strategy to test validity through the convergence of information from different sources [39]. People with AD and day care staff are included in this phase of the pilot-study. The inclusion criteria for this research were as follows: (1) The participant is willing and able to give informed consent to participate in the study; (2) If the person living with dementia is not able to give informed consent, relatives were asked to give informed consent to participate in the study; (3) Dementia due to AD has been diagnosed; (4) Regularly attending the day care centre; (5) Day care staff is regularly involved in the day care centre activities, more than 3 days a week.

Over the course of 1.5 months, the authors conducted participants observations throughout the day, 4 days a week, from 9 AM, until 4 PM. They observed day care staff and people with AD in their everyday activities, and collected data on interactions with the visual posters, conversations, and occasional spontaneous interactions. Comments and gestures (in the form of body positions, non-verbal gestures and communications, movements) made by participants were collected to understand the overall reactions.

As people with dementia are a vulnerable group, the influence of the authors' presence was continuously considered. Any indication of distress or negative influence on the attendees would have resulted in the authors interrupting the observation and leaving the area. If the participants expressed interest and asked the authors questions during the observation, these were answered in a friendly manner. Otherwise, the authors tried not to attract attention.

Field notes (including drawings) and photographs are examples of the data collected through participant observation. The purpose was to observe if and how older adults attending the centre noticed the visual posters, the kind of interactions, and if those interactions generated reminisce conversations. Specifically, the observations conducted, involved a group of 5 older adults attending the day care centre. Participants ranged in age from 75 to 82 years, involving 3 women and 2 men. Moreover, participants were experiencing apathy (apathic symptoms were identified by the MD of the day care centre) and lack of social interactions and interest in social interactions with other older adults attending the day care centre. The MMSE was used to provide an overall picture of cognitive status and dementia severity and produced a range from 9 to 17 where lower scores correspond to greater dementia severity [40]. Data were collected through participant observation and informal conversations with day care centre staff involved, following mini-ethnography methods [37, 41]. The number of staff participating in the informal interviews was determined by the number of staff members present at the day care, and hence, the total number of participants was 7. The group size varied from 2 to 5 participants. The participants were all female, and their professional backgrounds were as follows: occupational therapist (3), and assistant occupational therapist (4). In particular, informal conversations were recorded throughout the study period, mainly at the end of the day, in the day care centre, to note any particular interaction or mood change, retraceable in the older adults involved in the observation phase. Audio recordings of these informal conversations were partially transcribed, and the field notes partially digitized.

## 5 Outcomes

The phase 1 of the pilot-study encompassed semi-structured interviews with family caregivers of people living with AD attending the daily care centre GRACE, in Milano. The main outcome from this initial phase has been the identification of 3 meaningful categories of "mundane elements of the past", relevant for elderly with AD participating in the study: popular food and snacks, everyday means of transportation, beauty and hygiene products.

Accordingly, the authors organised the visual posters, which represent the main final tool for this pilot-study, into 3 collections of 8 posters, each depicting an object, with a contrasting background, to facilitate viewing by older people with dementia, avoiding any misrecognition or visual impairment (Figs. 1 and 2).

During phase 2, the authors presented to the family caregivers involved in the study, a large collection of images related to the 3 identified categories, with different graphic solutions for their visualization. The following needs and guidelines emerged from the workshop:

- use of sharp images of the objects, background evidence, with strong contrasts that clearly delineate edges and contours;
- creation of a contrasting monochrome background on which to place an object for a visual poster;
- the possibility of using a small image from advertisements of the time, telling the story of the use of the object, or depicting an everyday action or habitual action involving the object, in order to clearly and simply display its use (and facilitate its recognition);
- use logos if they are iconic and clearly recognizable;
- use of a maximum of 2 visual elements per poster.

Cultural factors were clearly represented in this phase of the research: history of local national products, habits, popular culture and popular representations were strictly linked to the national history, and so the national context in which elderly participating in the study were grown up.

The mini-ethnographic case study observation (phase 3) highlighted different reactions in the 5 older adults with AD involved in the study:

- Maria (fictional name), woman, uses to spend her time in the day care centre mostly seated in an armchair. Staff usually asks her questions, trying to involve her into the activities.

**Fig. 1** Visual posters from the thematic collection: food and snacks

**Fig. 2** Visual posters from the thematic collection: beauty

They take care of her personal needs, accompanying her to the toilet, helping her to feed herself. She doesn't interact verbally with the other residents, but merely observes the various activities. During the observations, the authors noticed that on several occasions, while being accompanied to the bathroom, Maria slowed down her steps, stopping to look at the visual posters on the walls. On two occasions the images (the collection on beauty and hygiene products) spontaneously attracted her attention, although she was unable to verbalize her comments. Following these 2 episodes, the staff voluntarily approached Maria at the posters, asking her questions, moving the posters on the wall, trying to strike up a conversation. Maria did not respond verbally, but waved her arms and smiled to express pleasure, recognising some of the objects and expressing joy in looking at them.

- Carla (fictional name), woman, uses to refuse any active involvement in group activities, preferring to remain seated in one of the armchairs. When questioned, she usually replies with low interest, without engaging in spontaneous conversations with other elderlies. She usually never engages in spontaneous interactions with the environment, or with any everyday object found in the daily care centre. Carla initially showed no interest in the visual posters. The staff introduced them to her, taking her around for a walk and passing by the visual posters. The food and snacks collection was the one that caught her eye: while taking a walk with a staff member, she noticed one of the products visualized. She walked by and started to reminisce. She described an old memory related to breakfast using words like "I know that", "I like it" and "I was drinking in the morning". After that episode, while taking a short walk in the corridor, the staff was able to attract her attention using the visual posters and start a simple conversation.
- Luca (fictional name), man, and Giorgio (fictional name), man, both experienced a great passion for cars in the past years. Luca worked was a former mechanic, and became

very fond of his work. Giorgio, on the other hand, was very fascinated by cars in the past, as a mechanical engineer. On days spent at the day care centre, they are usually accompanied by their wives, without expressing any interest in their surroundings. They sit quietly in one of the armchairs and follow the various activities as observers, usually expressing no involvement. Often, Luca's gaze is fixed on a point in the floor, lacking any motivation in engaging in activities or conversations. When the collection "everyday means of transportation" was hung up, Giorgio noticed one of the posters one morning as he entered the day care centre. He stopped and looked at it, holding his wife's arm. He exclaimed "Fiat!", (car's manufacturer). He stared at it for a long time, very interested. Over the next few days, in the mornings Giorgio expressed a willingness to take a walk in the corridor, to "see the cars", to quote him. He expressed great interest, willingness to move and walk around to admire the pictures, expressing phrases such as "beautiful! Very nice!", "I had that one", "I remember this one." Often these comments were associated with facial expressions indicating enjoyment and astonishment, hand gestures and non-verbal expressions indicating positive amazement. Luca instead showed great interest in the visual posters, recognising the logos depicted inside them. On 2 occasions he told to the staff an anecdote about his job. The staff pleasantly noticed that Luca took pleasure in trying to describe little details about his life as a mechanic, some small memories, short sentences. He often tried to touch the visual posters, as if he wanted to caress the objects.

- Gina (fictional name), woman, does not usually express any interest in group activities, preferring to remain aloof. If not stimulated, she does not interact with the environment or other people, sitting silently next to the other guests. Compared to many other residents, she does not participate in the small actions of preparing the table for lunch, or in conversations with other seniors. In the afternoons, she usually sits in the chairs placed at the large windows of the corridor. Following the installation of the visual poster collections, she immediately showed interest in the posters of 2 collections: beauty and hygiene elements, food and snacks. On 3 occasions, while sitting in the corridor, she looked up incuriously, walked towards the posters and looked at them with interest. A member of the staff walked up to her, and asked her if she recognized the pictures, remembered them or liked them. Gina nodded her head, answered with phrases like "I remember it", "I had it", "my daughter likes it", "beautiful, beautiful!" The same scene was repeated several times in the following afternoons. On one occasion, another guest followed Gina as she walked to get closer to the visual posters. After looking at one of them, Gina turned to the other guest and took her hand, trying to indicate the poster and attract her attention. A member of the staff approached them, and started a conversation, successfully engaging both of them.

Lastly, informal conversations with care staff highlighted that for some of the participants, spontaneous interactions represented a new and pleasant action. According to the staff, after the interactions with the visual posters, all the older adults with AD involved in the study showed a good mood throughout the day, and a greater involvement in the following activities. When stimulated, the seniors involved recognized the objects, or their use. Moreover, the staff noticed that the visual posters were also a source of curiosity, interaction, and conversation also for the other guests of the centre, who were interested in them and often started to reminisce while looking at them.

## 6 Discussion and Conclusions

The pilot study was conducted with a small sample of participants due to the limited number of elderlies with AD attending the day care centre, presenting apathic symptoms. Considering this limitation, the results are promising. Accordingly, future studies with larger sample sizes have the potential to show results even more significant.

Previous research supports the role of materialities in facilitating collective activities, support relations, interactions, and self-recognition [19–23]. Moreover, in designing for people with dementia, a frequent strategy consists in the use of cultural references from the past, to engage them and elicit reminiscence conversations [42]. In this framework, mundane materialities for care, in the form of mundane objects, act as triggers in embodied routines and habits and consequential actions that usually take place through and between bodies, objects and surrounding spaces [23, 25–27, 33]. Accordingly, from the on-going pilot study presented in this paper it is possible to deduct that "mundane elements from the past" may shape relations and may have consequences in terms of enhancing recognition and sense of belonging, enacting meaningful interactions and reminiscence conversations for people with AD (experiencing apathy) in a care environment.

Cultural factors were clearly represented in this phase of the research: local national products, habits, popular culture, and popular representations were strictly linked to the national history, and so the national context in which elderly participating in the study were grown up. Accordingly, to generate reminiscence conversations, the poster content has to be culturally relevant and recognised by older adults in the care environment. "Mundane elements from the past" are strictly linked to everyday habits, culture, and cultural sphere. Those parameters should be extensively investigated in further research.

Pleasurable comments, interest, conversations between participants and staff observed while the different collections of visual posters hung in the day care centre underline the positive outcomes and promising results. Key findings from the pilot study are that the graphic design guidelines defined during the initial phase, resulted effectively in the creation of visual representations of mundane objects which could be, in most of the cases, clearly recognized by people living with AD, and which represents meaningful mundane objects capable of triggering reminiscence memories. The spontaneous interactions that occurred to some participants represent a promising result towards reducing apathy by using nostalgic memories in the form of visual elements in the interiors. Further research may explore and evaluate the relationship between the spatial location of the visual posters, angles of sight and their enacting role.

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# Humanizing Information About Meaningful Activities for People with Dementia

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## Abstract

Stigma and discrimination regarding dementia are still very impactful on the experience of having dementia and of being a carer. To tackle this issue and uplift the quality of life of people with dementia and their carers, efforts are being made to push forward a change in the societal perception of dementia. These include raising awareness and promoting inclusive initiatives that conjointly involve people with dementia and their carers, such as engaging in meaningful activities. Meaningful activities have a crucial role in enhancing the well-being of people with dementia as a means for participation, connection with others, self-expression, and control. This position paper calls attention to the need for improving the design of information so that it is tailored to people with dementia and supports their self-determination, individuality and autonomy, and the feeling of living a meaningful life. Although there is plenty of information about dementia, often this is not targeted to people with dementia, nor designed in a way that facilitates their access and understanding. This is an opportunity for design practice and research to contribute. This position is driven by person-centred, rights-based and participatory design approaches and is anchored in the authors' previous research on co-designing with people with dementia and their families to support their engagement in meaningful activities.

## Keywords

Communication design · Participatory design · Dementia · Information · Meaningful activities

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# 1 Introduction

As dementia evolves, people diagnosed and those who care for them face several challenges related to the gradual worsening of symptoms and the subsequent need for more support. The experience of having a diagnosis of dementia and of being a carer can be very demanding, not only due to the disease's symptoms and progression but also due to the stigma and discrimination surrounding dementia. Both aspects notably contribute to making dementia a highly feared condition [1].

This position paper advocates for design practice and research to have a prominent role in the development of information for and with people with dementia and informal carers, which is particularly relevant when the information focuses on strategies to make their lives more meaningful. This position paper is grounded in person-centred values [2, 3], as well as rights-based [4] and participatory design [5] approaches. In addition, it emerged from previous research [6] by the authors, where family carers of persons with dementia have shown a need for information on how to communicate and support the person with dementia to take part in activities. The aforementioned design-led study, conducted in Portugal, aimed to contribute to the maintenance of social relationships and the preservation of personhood. This was explored through designing opportunities for communication and meaningful engagement, by involving people with dementia and family members in co-designing artefacts according to their preferences, interests, and abilities [6]. Nonetheless, even when using the artefacts that were personalised for the person with dementia, family carers mentioned that engaging their relatives in activities was demanding due to a perceived lack of knowledge and information resources [7]. Subsequently, these conclusions led to a recently started ongoing research project that aims to fill the abovementioned gaps by exploring and improving information regarding strategies to engage people with dementia in activities, targeting both family carers, and people with dementia.

To substantiate the conviction that the design of information directed to people with dementia should be improved to support their independence and pursuit of a meaningful life, the paper is structured as follows. First, it presents a brief account of the theoretical framework that underlies this position, including (a) the importance of dementia awareness and literacy as a means to encourage a dementia-friendly society, and (b) the relevance of providing information on keeping active to people with dementia, as a means to support their self-determination and engagement in meaningful activities. Second, the paper introduces a preliminary web search about available information resources on meaningful activities in the Portuguese language and its findings. Third, the paper closes with considerations for future developments in designing information for persons with dementia.

# 2 Theoretical Framework

## 2.1 Importance of Dementia Awareness and Literacy

Raising public awareness and dementia literacy is fundamental to reducing stigma and contributing to a more inclusive society [1]. This is stated in the World Health Organization's (WHO) *Global Action Plan on the Public Response to Dementia 2017–2025* [8] and throughout the national dementia plans of several European countries [9]. Concurrently with other work fronts related to care services for people with dementia and their carers, these political documents and guidelines have prioritised the need for increasing public cognizance and friendliness of dementia based on person-centred and rights-based approaches [8, 9]. The recently published *WHO Toolkit for Dementia-friendly Initiatives* [10] is an example of the efforts that are being made to encourage a shift of attitudes towards dementia and to empower people with dementia to live according to their preferences and values. van Corven and colleagues [11] point out four domains that are crucial for the empowerment of people with dementia: “having a sense of personal identity, having a sense of choice and control, having a sense of usefulness and being needed, and retaining a sense of worth” (p. 2). As part of this change of attitudes towards dementia, people must be understood beyond their diagnosis and the dysfunctions associated with it. Sabat [12] explains how fundamental aspects of humanity are maintained, despite the diagnosis. The same author advocates the importance of supporting the relevant remaining cognitive capacities and strengths in order to maintain independence and meaning in life, through raising public awareness, education and psychosocial approaches.

Kimzey and colleagues [13] call for the promotion of health literacy through health education and information suited to the needs of people with dementia and their carers since the diagnosis. Health literacy is understood as “the combination of personal competencies and situational resources needed for people to access, understand, appraise and use information and services to make decisions about health” [14, p. 6]. Furthermore, health literacy interventions contribute to a person- and community-centred process of empowerment that enables people to make informed choices to improve their health [14]. Prior studies [15–17] indicate that although there is a considerable amount of information about dementia, particularly web-based, people with dementia and informal carers reported that they often felt overwhelmed and unable to find the specific information they needed. This difficulty is mainly associated with a lack of adequacy of information and, in some cases, with how information is presented, in a way that makes it hard to navigate and understand [16].

This constitutes an opportunity for design to intervene, due to its ability to mediate and adapt information to different audiences, and to contribute to the well-being of people with dementia [18]. Aligned with the movement to encourage friendliness, inclusiveness, and the empowerment of people with dementia [8, 10], this paper calls for attention to designing information that is (more) accessible, adequate, and tailored to encourage the self-determination of people with dementia. In particular, and as a starting point, this research focuses on information that supports people with dementia to keep active in ways that are meaningful for them.

## 2.2 Importance of Information Regarding Meaningful Activities for People with Dementia

In a recent review that included the perspectives of both people with dementia, informal and formal carers, Strick and colleagues [19, p. 5] found that “the fundamental purpose of occupation is to support the person living with dementia to feel they were living a meaningful and fulfilling life”. Prior studies that looked for the perspectives of people with dementia regarding their engagement in activities identified that activities are meaningful when they constitute opportunities for pleasurable and enjoyable moments that reflect individual interests, values, and motivations, as well as when they nurture a sense of belonging and connection to the self, to others and the environment [20, 21]. The value and meaningfulness of occupation should be perceived by the person with dementia, which is affected by their worldview and that of their carers, and the social and physical environment where the activities occur [19].

Meaningful activities are considered crucial for the well-being of people with dementia, to address their psychological needs [2]. Their paucity has been associated with more social isolation, challenging behaviour, and decreased quality of life [22]. Engagement in meaningful activities and leisure has been linked with several interrelated benefits: as a way to maintain a positive attitude, a sense of hope, and to feel they are fighting against and coping with symptoms through being proactive, hence in control [23, 24]; as a source of enjoyment, stimulation, self-expression and choice [24, 25]; as a chance for participation and communication with others, contributing to the maintenance of social relationships [25, 26]. Meaningful activities were also found to be pertinent for the informal carers of people with dementia as a means to engage in social interaction with their loved one, and as opportunities for respite [25].

In a study on the perspectives of people with dementia about activities, Han and colleagues [21] concluded that people with dementia "want to engage in personally meaningful activities to be connected with self, with others, and with the environment" (p. 121). Nevertheless, often people with dementia do not have opportunities to engage in activities on their own terms, reported as one of their most frequent unmet needs [24]. For occupations to be meaningful, a supportive environment is required where the person with dementia feels valued and finds security and freedom [19]. However, despite being mostly emphasized as beneficial, family carers also associated activities with difficulty, resistance, uninterest and frustration, particularly due to the progression of dementia symptoms, difficulties in planning and finding activities that their relatives with dementia value, and lack of resources and support [21, 25]. This might explain why learning skills and strategies to communicate effectively and support capacities, as well as to stimulate and provide activities for the person with dementia are among the training and information needs conveyed by informal caregivers of people with dementia [27–29].

The awareness and perception of carers and persons with dementia about the importance of keeping active, influences its meaning and conditions the accessibility of people with dementia to occupational opportunities [19]. Information and support should be provided to people with dementia, and their informal carers, to recognise motivations, desires and needs for engagement in activities, which is crucial to suit and adjust such activities to each individual and ensure satisfaction [21].

## 3 Preliminary Search

A preliminary web search was undertaken to understand what information on promoting independence and meaningful activities is readily available for people with dementia and their carers in Portugal, the context of research. The country has a percentage of older people above the European average and ranks fourth among OECD countries on the prevalence of dementia [30, 31].

In a systematic review, Soong and colleagues [16], refer the Internet as the primary source of information for people with dementia and informal carers, as well as the most preferred one. In a study undertaken with family carers, Allen and colleagues [15] found that the most valued characteristics of information sources were trustworthiness, accessibility, and the ability to answer specific questions. Although participants in that research revealed a preference for obtaining information from a relational source, such as a well-informed healthcare professional, the Internet was favoured and predominantly used due to its accessibility [15]. Likewise, informal carers in Portugal also value web resources for their convenience (the possibility to access at any time and from any location), despite some discomfort or lack of experience when using the Internet [32].

A preliminary web search was performed on Google, deliberately as if a person with dementia or an informal carer located in Portugal would search for information on activities for people with dementia. The search was done in Portuguese, using the keywords: people with dementia/dementia and activities, occupation or stimulation. The 10 most frequent websites from the emerging results were analysed. All pages with contents in Portuguese were eligible for analysis, irrespective of the nationality of the organisation producing the contents (e.g., the pages could either be in European or Brazilian Portuguese). Although there might be cultural differences in the contents, for instance, from Brazil versus Portugal, the search aimed at mimicking a natural search from a user, who

**Table 1** Most frequent websites with information on activities for people with dementia[a]

| | Website organisation | URL | Country | Activities-related content | Target |
|---|---|---|---|---|---|
| 1 | NeuroSer<br>Private healthcare clinic (neurological conditions) | www.Neuroser.pt | Portugal | Information articles with tips and suggestions. Information about the clinic's services | Informal carers |
| 2 | Alzheimer Portugal<br>Not-for-profit dementia association | www.Alzheimerportugal.org | Portugal | Information on past training events. Information articles with tips and suggestions. Information about activity products and resources | Formal and informal carers<br>People with dementia<br>General public |
| 3 | Projecto Eu Consigo<br>Private healthcare clinic (occupational therapy) | www.projectoeuconsigo.pt | Portugal | Information on past and current training offers. Information articles on the importance of occupation and strategies to support it. Information about the clinic's services | Mostly formal carers (OT)<br>Informal carers |
| 4 | Joaquim Chaves Saúde<br>Private healthcare clinic (miscellaneous of specialities and clinical analysis lab) | www.jcs.pt | Portugal | Information articles on the importance of occupation and cognitive stimulation | Informal carers |
| 5 | Fundação AFID<br>Not-for-profit association on disabilities | www.afid.pt<br>www.afidsenior.pt | Portugal | Information and news about their services within their facilities, in particular, a neurostimulation unit | General public |
| 7 | Alzheimer 360<br>Information and training platform (including both free and paid content) | www.alzheimer360.com | Brazil | Information articles with tips and suggestions | Formal and informal carers |
| 9 | Saudebemestar.pt<br>Information website on health (miscellaneous issues) | www.saudebemestar.pt | Portugal | Information article on approaches to cognitive interventions for people with dementia | General public |
| 10 | Reab<br>Information and training website (occupational therapy) | www.reab.me | Brazil | Information articles with practical tips for specific activities | Formal and informal carers |

[a] The 6th most frequent website was the Federación Iberoamericana de Asociaciones de Personas Adultas Mayores (FIAPAM), due to an article on Cognitive Stimulation Activities in the routine of a person with Alzheimer's (Available at: https://fiapam.org/atividades-de-estimulacao-cognitiva-na-rotina-da-pessoa-com-alzheimer-aspectos-praticos/). However, with the exception of this article which was translated to Portuguese, most website's contents are in Spanish. Therefore, this website was excluded from the analysis

most likely does not filter the results by country. Since the research targeted information resources directed at persons with dementia and informal carers, academic papers, thesis and dissertations were excluded. Social media results (facebook and pinterest) were also excluded due to their volatility. In total, eight websites and two PDF publications from Portugal and Brazil, were

**Table 2** Frequent PDF publications with information on activities for people with dementia

| | Publication title[a] | Coordination | Publication date and country | Description and activities-related content | Target | URL |
|---|---|---|---|---|---|---|
| 6 | Care manual for caregivers of people with dementia (2nd edition) | Alzheimer Portugal (translation and adaptation to Portuguese) and Alzheimer Europe (original version) | 2006 Portugal | Comprehensive guide on how to care for someone with dementia. Sub-section dedicated to "Leisure, activities and exercise" | Formal and informal carers | https://www.saudementalpt.pt/backoffice/pdfs/636cda5370.pdf |
| 8 | Dementia: good practices handbook | União das Misericórdias Portuguesas (not-for-profit organization) | n.d Portugal | Manual on what dementia is, and how it affects people; on different intervention approaches; and on supportive arquitecture and environments. Sub-section on "Neurostimulation: cognitive, behavioural and functional intervention" | Formal (and informal) carers | https://cdn.ump.pt/files/files/Manual_Boas_Praticas_Demencia.pdf |

[a] The titles were freely translated from the Portuguese, by the author

analysed. Tables 1 (websites) and 2 (PDF publications) show the findings.

Despite the high prevalence of dementia in Portugal, the information available on the web to support the engagement of people with dementia in activities is sparse. Among the ten most frequent results, three of them were not produced by Portuguese organisations. Available information is mostly provided by private healthcare clinics, generalist or specific to neurological conditions and occupational therapy (3 in 8 websites); health information websites, generalist or specific to dementia and occupational therapy (3); and by not-for-profit associations (2), including the Portuguese dementia association, Alzheimer Portugal, and an association for people with disabilities. The two PDF publications were available through a mental health information website and the website of a not-for-profit care organisation. Worth mentioning that none of the ten most frequent websites displayed through the google search was a governmental website, which are frequently regarded as reliable and trustworthy sources of information [15]. Within the analysed websites, the content related to activities for people with dementia consisted of: informative articles (in 7 websites, out of 8), some broadly referring to the importance and approaches of different therapeutic interventions related to keeping active, mostly occupation therapy and cognitive stimulation (4), and others with more practical tips and suggestions on what to do and how to conduct the activities (5); about or related to the services offered by the clinics, organisations or training websites (5); training events on the subject (2) and activities-related resources or products (1).

From a person-centred and rights-based perspective, a striking aspect was that most of the information was exclusively directed to (formal or informal) carers of people with dementia. Only the Alzheimer Portugal's website had some articles targeted to people with dementia, including one about activities, found through navigating on the website (and not displayed in the google search results). The lack of information in Portuguese specifically targeting people with dementia was confirmed by the authors in consultation with Alzheimer Portugal.

When analysing the 8 websites and 2 PDF publications from a visual communication design perspective, several issues were identified in the way information is presented and organised. Such concerns might make it harder for someone with dementia to navigate, read and comprehend. The analysis of the websites from a design perspective took into account the design requirements and recommendations identified in previous international research [33–35]: 4 out of 8 websites had poor colour contrast between the text and the background, or in specific elements (e.g. headings, highlights, links); 6 out of 8 websites had inconsistent, inadequate or very subtle text hierarchy; 7 out of 8 websites had issues with spacing—4 had inadequate line spacing (too wide or too tight), 3 had inconsistent or inadequate spacing between paragraphs, 1 had inconsistent spacing between words and another 1 had inadequate spacing between website elements (e.g. main content and sidebar); all 8 websites do not make the best use of images: the choice of images is often irrelevant, redundant or inadequate (culturally, or because it presented the person with dementia as withdrawn) and, in some websites, they are too small (3), stretched (1) or with low resolution (1); in all 8 websites, it was hard to find specific information, due to the lack of organisation of information articles in a way that facilitates finding them (e.g. no apparent organisation; organised by date rather than by content, or due to being more generic health-related websites); in 3 websites the text size was too small, and in 2, the text column was too wide; 2 websites were found to use inadequate typefaces (too ornamental, or not adequate for reading long texts on screen); 4 out of 8 websites were found to have a dense overall appearance (too many elements, lack of white space), and 2 were found to use elements that might be confusing (such as sliders or dense sidebars). Regarding the 2 PDFs, both were very long, dense and text-heavy publications and one of them had issues with the typeface choice (inadequate for lenghty text reading), tight line spacing, and inadequate choice of images (infantilising, naive, poor-quality illustrations).

## 4 An Opportunity for Design

The UN Convention on the Rights of Persons with Disabilities [36] recognises the importance and need to ensure that persons with disabilities, such as persons with dementia, have better and equal access to information, namely about available resources to support them. Moreover, the Convention highlights the pressing need of designing inclusively, for everyone to use (inclusive design) [36]. There are international examples of web resources targeting information on dementia and for people with dementia, designed in a dementia-friendly way. For instance, the Alzheimer's Society UK provides information on how they improved their website's accessibility and usability for people with dementia [37] and compiled guidelines to design dementia-friendly websites [35]. Even though good examples exist, only a few studies address the information needs and preferences of people with dementia [16]. In addition, dementia-friendly information is still not a generalised practice. This assumption is supported by the preliminary search presented in this manuscript, which demonstrated that, from a dementia-friendly (design) perspective, there are significant gaps for web resources available in Portuguese. Just one of the 10 analysed websites and publications had information directed to people with dementia, but only to their carers. All these resources had design issues that might make it harder for people with dementia (and even their carers) to find, read and understand the information provided, regarding the choice of colours, the use of images, the website layout and text formatting, and navigation. Another concern is the observed need for improving the visibility of relevant information and websites on the web. The content of many of the web search results did not specifically provide information about keeping active and meaningful activities (but rather on related training events and available health and therapy services). However in some cases, more relevent content was found on the same websites when further exploring them. Most of the results come from private healthcare clinics and informational websites, which are sources that do not match what people with dementia and informal carers perceive as trustworthy [15], which also correspond to their information source preferences [16]. Moreover, many of the information articles addressed the topic of activities for people with dementia broadly and generically, which might make it more difficult to relate to individual needs and situations.

The differences between the international dementia-friendly examples and those found in the preliminary search might also relate to how different cultures view and represent dementia. Comparative studies that analyse the relationship between cultural portrayals of dementia and how information is presented is an interesting and necessary topic for future research.

The existing knowledge and guidelines can still be further investigated from a design perspective. Design—as a research approach, practice and way of thinking—deals with mediation between (i) artefacts and the characteristics, needs and desires of future users; as well as (ii) utility, usability, symbolic construction and aesthetics [38, 39]. Moreover, through the designed artefacts, design can play a role in mediating, encouraging and supporting happiness-enhancing activities [40] and social interaction [41, 42]. Visual communication aspects can be explored to make information resources more dementia-friendly, i.e., more accessible, adequate, usable and appealing. Furthermore, prior research has suggested that information resources should match individual needs, and that ways to make them relational should be sought [16]. In addition, drawing on the idea that artefacts can support the promotion of positive experiences for people with dementia [43], it might be possible to design information resources in a more humanized way. Thus, design might deliberately contribute to encouraging the self-determination of persons with dementia, as well as their autonomy and individuality. In this sense, and regarding information content, the focus on meaningful activities is instrumental. Especially in the early stages of dementia, and for as long as possible, people should be supported and incentivised to have control and find ways to make their lives more meaningful [39]. Strick and colleagues [19] affirm that a catalytic environment is required for meaningful occupation. This paper aims to put forward the hypothesis that if information on meaningful activities is carefully designed and tailored to people with dementia and their carers, it might promote this supportive environment and augment their occupational opportunities.

Aligned with a rights-based perspective that people should have a say about what might impact their lives, information resources must be designed in participatory processes, collaborating with people with dementia and informal carers as experts by experience, to share control and inspire change [44]. The guidelines and other initiatives advocating for making information and websites more accessible, such as The UK Network of Dementia Voices, also claim the importance of involving people with dementia in producing of websites and information resources [34, 35, 45]. In a study on promoting health literacy in people with dementia and informal carers, Kimzey and colleagues [13] also emphasize the need for their inclusion in the development of information materials, which would additionally contribute to the literature in this field. An interesting example of information co-created with people with dementia is the self-help guide My Life, My Goals [46].

Even though guidelines on dementia-friendly websites and information are available [33–35], the preliminary search work presented in this manuscript identifies several gaps in information websites concerning how dementia-friendly their design is. However, this preliminary search was exploratory. More in-depth, systematic and comprehensive research work will be conducted by the authors, who will not lose sight of the importance of disseminating the findings to people with dementia, their relatives, and those who design content targeted at them. The importance of public dissemination and communication of research results has been increasingly recognised and reinforced. Effective strategies should be sought to raise awareness about the knowledge of how to produce and design dementia-friendly information, and its implementation should be supported and pushed forward. This knowledge would be particularly relevant to dementia and healthcare information providers to ensure that dementia information materials and resources are dementia-friendly. It would also be essential for design practitioners, so that these dementia-friendly concerns can be taken into consideration in all kinds of information and web resources, as part of the desired shift toward a dementia-inclusive society proposed by WHO [8, 10].

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# House of Memories: A Tangible and Multisensory Museum Installation Focused on Daily Life with Dementia

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## Abstract

One of the major global challenges of the twenty-first century is the aging population. This is reflected by the growing group of people living with dementia. Even though awareness of dementia is growing, the gap between awareness and understanding still causes stigmatization. This stigma pervades discourse regarding dementia and threatens wellbeing. In this project, an interactive museum installation is built to create awareness and educate people about daily life with dementia. This study investigates how an interactive museum installation contributes to awareness of dementia of the public. During this study, Personal Meaning Maps, field notes, and semi-structured interviews are used to gather data which is analyzed through a thematic analysis. Overall, the exhibition was found to be recognizable from different perspectives, and it was an appropriate form to convey daily life with dementia in a meaningful manner. Each separate aspect of the exhibition contributed differently and evoked emotional responses in participants. The results indicate that the visitor's awareness is increased.

**Keywords**

Design for dementia · Tangible interaction · Multisensory museum installation

## 1 Introduction

Currently, there is a lack of public awareness and understanding of dementia and the consequences of dementia on people's capacity, ability, and well-being [1]. Individuals dealing with dementia can experience a set of negative and often discriminatory beliefs that society may have about their condition [2]. "*Stigma is a social construct based on perceptions of visible or invisible marks or traits that discredit or devalue individuals*" [3]. Stigma regarding dementia can result in stereotyping, prejudice, and discrimination against people living with dementia that create major barriers withholding people from seeking information, advice, and support [4–6].

Stigmatization can unfold in two ways. In the case of *self-stigma*, people internalize certain prejudices that negatively influence psychological well-being, self-esteem, and quality of life [1]. *Public.* and *courtesy stigma.* are, often negative, behaviors directed towards a person with dementia or people close to them such as

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relatives [1, 4]. These behaviors come from false beliefs that people with dementia lose their dignity and self-hood. As a result, the quality of social interactions, social roles, and relationships can decrease and experiences of empathy are hindered [1, 4].

To overcome the mentioned consequences, public awareness and understanding should be raised [1]. Hence, it is important to slow down the perception process and the judgment of what it means to live with dementia [4]. However, people with limited experience with dementia often do not know what to do [7]. Designers and developers that work with user-centered approaches recognize the need to engage with the psycho-social aspect of dementia. They build an understanding of the lived experience of people living with dementia to apply in their design processes [8]. By increasing under-standing from different perspectives, feelings of empathy towards the lived experiences may increase [4]. Eventually, the stigma may be reduced and hopefully taken away by cultivating empathy and increasing awareness of various aspects of dementia to the public.

Until now, (educational) initiatives to decrease the stigma are aimed at family, caregivers, or professionals who work with people with dementia and are often delivered via the internet [3, 9, 10]. However, physical alternatives aimed at the wider public are hardly present, demonstrating an opportunity for designers to explore.

The project started with a collaboration between care organization Pleyade and the Dutch open-air museum to build a museum experience to increase awareness around dementia. This project is called "house of memories". The house will consist of an interactive museum installation to share everyday perspectives on the daily life of people living with dementia. Museums are meaningful institutions that have two major roles in society: serving public education and contributing to cultural preservation and conservation [11]. Geerte and de Bruijn [12] argue that "*exhibitions and heritage sites can facilitate an embodied learning experience that, in using all senses, can more easily elicit an effective response and stimulate empathy*". As heritage museums can elicit an effective response, they offer unique opportunities for challenging views. In addition, museums can hold up a mirror to society, provide a safe space for contemplation, create experiential learning opportunities, and can challenge public perceptions of disability and difference [13, 14]. Therefore, the museum environment is an interesting opportunity to design an engaging (and interactive) story to convey the experiences of dementia to museum visitors.

The exhibition, designed and built by the first author, presented in this paper serves as an explorative study to inspire the final "house of memories" scheduled for 2025. In this paper, a tangible and multisensory interactive museum installation of a kitchen set is presented, where visitors encounter engaging personal stories from different perspectives (i.e., from care professionals and informal caregivers). The stories used in the exhibition were gathered through user studies in prior research and translated into tangible experiences in a home setting to create awareness of daily life with dementia for a general audience.

This design research project contributes by exploring how a custom-designed interactive experience can create awareness of daily life with dementia for a general audience. In addition, this paper aims to find out how the designed installation contributes to people's views on daily life with dementia.

## 2 Design

From literature, we understand that tangible interaction is "*a broad range of different systems and interfaces relying on embodied interaction, tangible manipulation, and physical representation (of data), embeddedness in real space and digitally augmenting physical spaces*" [15]. The designed kitchen contains a vintage interior and different objects that are scattered throughout the space. These objects can be typical for people living with dementia (e.g., small notes and misplaced objects). To create a home-like ambiance, several objects, such as paintings, a mirror, a clock, side tables, a cabin, a fridge, a kitchen counter, some kitchen devices (e.g., a stove and a coffee machine), and some plants were moved into the shed. As can be seen on the floor map in Fig. 1, different tangible interactive aspects are present in the exhibition. Through a T65 PTT phone, visitors can experience an everyday conversation, the CD player contains three CDs with stories about music, and the cupboards contain pictures and a projector. On top of this, a smart object (i.e., a cuddly toy) is used to present a separate layer of information: location-specific, personal stories that are linked to different objects in the kitchen. For example, objects such as foreign money, wine glasses filled with silicone replicas of wine, and small post-it notes that accompanied the stories were scattered throughout the space (Figs. 1 and 2). Each element will be elaborated on further below.

Experience 1: For this part, a T-65 PTT phone was altered to convey a specific story and was displayed together with an agenda (Fig. 3). This agenda contained a note that said: "*call 0575 when I am home*". Participants could dial this number and hear an audio file that said it was the fifth time they called today, and they should not forget to cross the note to prevent a repetition of tasks. In addition to this interaction, when an RFID tag was presented, the phone started ringing. Participants could pick up the phone and an audio file would play. After the handset was put down, the phone immediately started ringing again. This cycle was repeated three times and illustrates a repetition of tasks.

Experience 2: As can be seen in Fig. 4, a CD player is used to play three stories regarding music. Three audio files were recorded and burned on a CD. The illustrations on the CD cases were linked to the discussed topics: Elvis Presley, 1963, and Classical music. The CD

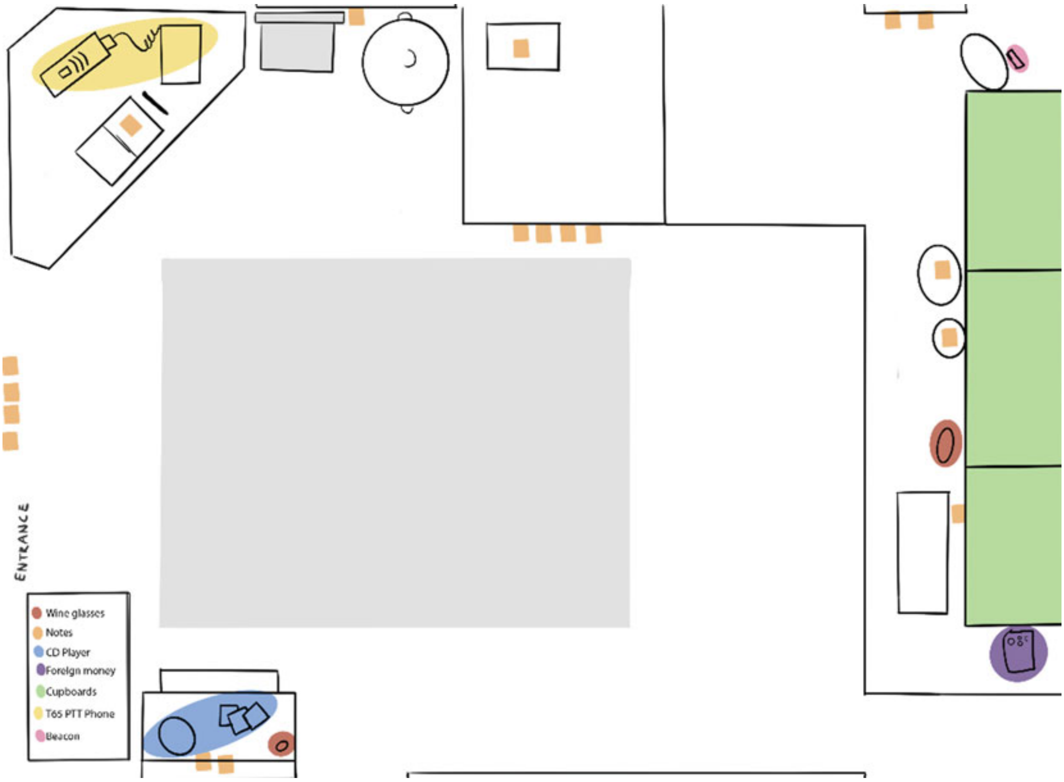


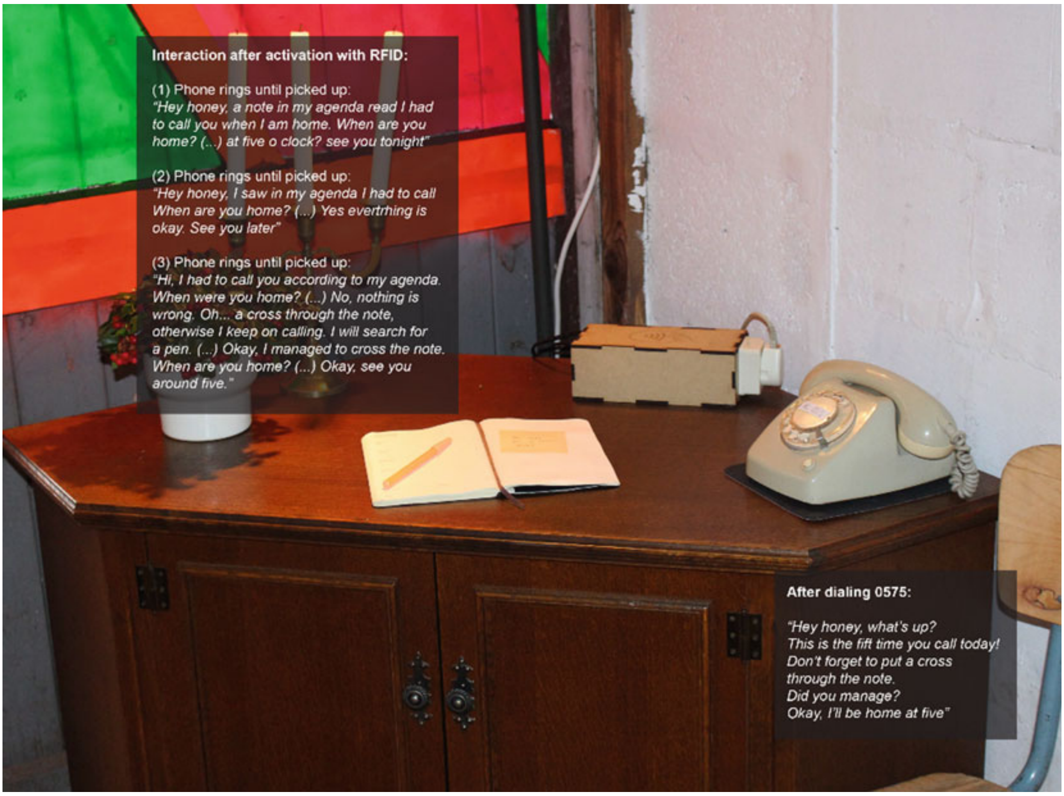
**Fig. 1** A floor map of the exhibition with its different components

**Fig. 2** The cupboards and interior of the exhibition space

player is displayed on a side table near a mirror with a wine glass. Underneath the mirror a sticker is attached that reads "*choose a CD to play*".

Experience 3: The cupboard's exterior contains two pictures of the corresponding content, and a projection (Figs. 2 and 5). The cupboards are filled with tableware and foreign products. An Optoma pico projector is used to display a PowerPoint presentation that changed pictures every ten seconds. The pictures of the content on the middle cupboard never match the actual content to illustrate confusion. The right cupboard contains products with foreign labels that are like common Dutch products and brands. These products correspond to a story about enjoying going on holiday while dealing with dementia and the inability to recognize products. Throughout the visit, people are asked to grab the jar with salt from the right cupboard.

A smart object to guide the experience: Throughout the room, different narratives were played through a cuddly cat that was carried on a person's arm and reacted to a beacon signal (Fig. 6). Smart objects are built to embed digital components to allow for their use as part of an interactive experience [15]. Through this smart object, an additional layer of content could be accessed that complements the information that is provided in the space itself. When the cuddly cat was between a range of one and three meters of the beacon, the cat would acknowledge it was near the kitchen and the first narrative played. The first story elaborates on difficulties with (opening) cupboards, and the usage of pictures to support people with dementia. After each story, the cat gave participants an assignment, for example opening the cupboards. After accomplishing the assignment, the cat had to be stroked to continue to the next story. In total four narratives could be heard according to this interaction pattern before closing the audio tour. This smart object is developed by the company GoWonder [16]. The narratives had four different perspectives: (1) a daughter, (2) both a male and female partner of someone with dementia, (3) a person living with dementia, and (4) a formal caregiver.



**Interaction after activation with RFID:**

(1) Phone rings until picked up:
*"Hey honey, a note in my agenda read I had to call you when I am home. When are you home? (...) at five o clock? see you tonight"*

(2) Phone rings until picked up:
*"Hey honey, I saw in my agenda I had to call When are you home? (...) Yes evertrhing is okay. See you later"*

(3) Phone rings until picked up:
*"Hi, I had to call you according to my agenda. When were you home? (...) No, nothing is wrong. Oh... a cross through the note, otherwise I keep on calling. I will search for a pen. (...) Okay, I managed to cross the note. When are you home? (...) Okay, see you around five."*

**After dialing 0575:**

*"Hey honey, what's up?
This is the fift time you call today!
Don't forget to put a cross
through the note.
Did you manage?
Okay, I'll be home at five"*

**Fig. 3** The two interactions of the T-65 PTT phone and the agenda

## 3 Method

In this study, we investigated how the different aspects of the exhibition contributed to the overall experience and awareness of visitors. The pop-up museum was available for two weeks in Eindhoven, The Netherlands.

### 3.1 Participants and Sampling

In total, 29 participants between the ages of 22 and 65 participated. Participants were found by convenience sampling. Even though the exhibition was open to the public, all participants were invited as partners or acquaintances of the researcher for the study. Participants had different experiences with dementia, as can be seen in Table 1. These differed from experiences such as primary family members (parents), secondary family members (grandparents), experiences through work or school, to almost no experience with dementia. Participants that had little experience received their knowledge mainly from reading books, watching television programs, or from the news.

For the observations, a floor map of the exhibition was used as a template to make field notes of participants' behavior while visiting the exhibition. This floor map was like Fig. 1. Specific interactions were focused on, such as the cuddly toy, CD player, analog phone, and cupboards. In addition, general notes about comments, activities, and strategies were collected. After the visit, and the second time filling in the Personal Meaning Map (PMM) [17], the semi-structured interviews were conducted about the general experience, clarity, specific feelings afterward, and representativeness of this exhibition for daily life with dementia. After discussing the general experience, all components (i.e., the

**Fig. 4** The CD player and the corresponding CDs with illustrations of the topic of the narratives

cat, cupboards, phone, and general space) were separately discussed. As for the PMM, participants were individually asked to explain their writing and thoughts pre- and post-visit. They were asked whether this was newly obtained knowledge and what was the most meaningful or impressive story (Fig. 7).

### 3.2 Procedure

Participants were welcomed outside the exhibition space to prevent distraction and therefore (additional) biases. They were asked to fill in a consent form and a PMM before being guided into the exhibition space. Of the 22 visits, seven visits were in duos. Inside the space, the researcher briefly explained the space and context of the cuddly toy. Participants were explicitly told they were allowed to touch everything. Before the researcher left the exhibition space to take field notes, participants received the cuddly cat around their arms, and the RFID tag to activate the phone, after which they could start exploring. When finished (which took about 20 min), participants were asked to complement the PMM post-visit and subsequently were interviewed. These interview sessions were recorded and there was an opportunity for questions and feedback.

**Fig. 5** The cupboard's interior and exterior

**Fig. 6** The cuddly toy and beacon were developed by GoWonder

**Table 1** Participant demographics: age, gender, occupation, and experience with dementia

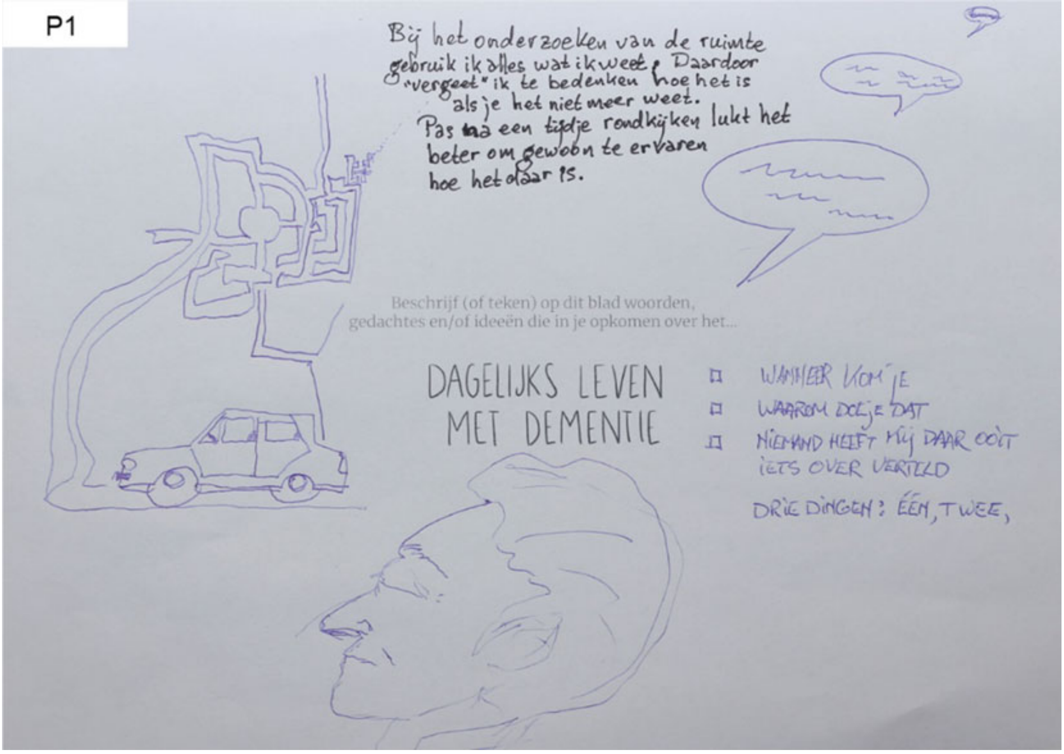
| Participant | Gender | Age | Occupation | Experience |
|---|---|---|---|---|
| P1 | M | 64 | Active member of political party | Primary family |
| P2 | M | 56 | Manager industrial automation | Primary family |
| P3 | M | 58 | Architect | Primary family |
| P4 | V | 24 | Hospitality employee | Secondary family |
| P5 | V | 24 | Student Industrial Design | Secondary family |
| P6 | V | 24 | Student Industrial Design | Secondary family |
| P7 | M | 28 | Mechatronic architect | Secondary family |
| P8 | M | 29 | Urban planner | Secondary family |
| P9 | V | 29 | Physics teacher | Secondary family and neighbor |
| P10 | M | 28 | Self-employed IT manager | Secondary family |
| P11 | V | 30 | Advisor in the healthcare sector for quality inspections and development of medical guidelines | Secondary family and medical experience |
| P12 | V | 65 | Municipality | Work |
| P13 | V | 23 | Student Industrial Design | Study projects |
| P14 | V | 25 | * | Study projects |
| P15 | V | 26 | Service designer | Work and study projects |
| P16 | M | 29 | Social therapist | Internship psychopathology (study) |

(continued)

**Table 1** (continued)

| Participant | Gender | Age | Occupation | Experience |
|---|---|---|---|---|
| P17 | V | 61 | Hospitality in nursing home | Work |
| P18 | V | 23 | Student Industrial Design | Study |
| P19 | M | 34 | Hospitality employee and formal caregiver | Work |
| P20 | V | 24 | Student Industrial Design | Little experience |
| P21 | M | 24 | Student Mechanical Engineering | Little experience |
| P22 | V | 24 | Student Industrial Design | Little experience |
| P23 | V | 24 | Student Biomedical Engineering | Little experience |
| P24 | M | 27 | Data analyst | Little experience |
| P25 | V | 27 | Designer | Little experience |
| P26 | M | 28 | IOT engineer | Little experience |
| P27 | M | 34 | Expedition employee | Little experience |
| P28 | V | 24 | Student | Little experience |
| P29 | V | 22 | Student hospitality | Little experience |

*Due to noise on the audio file, this occupation was unidentifiable



Bij het onderzoeken van de ruimte gebruik ik alles wat ik weet. Daardoor "vergeet" ik te bedenken hoe het is als je het niet meer weet.
Pas na een tijdje rondkijken lukt het beter om gewoon te ervaren hoe het daar is.

Beschrijf (of teken) op dit blad woorden, gedachtes en/of ideeën die in je opkomen over het...

☐ WANNEER KOM JE
☐ WAAROM DOE JE DAT
☐ NIEMAND HEEFT MIJ DAAR OOIT IETS OVER VERTELD

DRIE DINGEN: ÉÉN, TWEE,

**Fig. 7** The template of the PMM was filled in by participant one. The blue ink is pre-visit, and the black ink is post-visit. This PMM shows memories of the participant. His mother with dementia is drawn, and the text balloons become smaller as she has less to talk about over time. The car illustrates that the mother would get lost while driving. The addition post-visit (black ink) is the realization that people make sense of situations relying on prior knowledge. While being in the exhibition space, he tried to simply experience the space and realizes that someone with dementia might not have the prior knowledge to understand a situation anymore

### 3.3 Data Collection and Analysis

The interviews were processed through six phases of thematic analysis as described by Braun and Clarke [18]. The observations were analyzed on two different levels: (1) on the general space and remarks, and (2) per component of the exhibition space (e.g., the cat, phone, CD player, cupboards). Throughout the analysis, the focus lay on how participants would react to each of the separate components.

After, each PMM was reviewed, and the most striking and remarkable comments were used to amplify the thematic analysis. From the PMMs, no new themes emerged. In addition, the general observations, and remarkable findings in PMMs were extracted and linked to the themes.

## 4 Results

In the next section, the three main themes are described: (1) what was experienced, (2) what was recognizable, and (3) what messages were taken from the visit. All themes are related to experiences during the exhibition.

### 4.1 Theme 1: How Did People Experience the Visit?

#### (I) Realizing its impact on daily life

Three participants realized that even though dementia is severe, there can be room for warmth and positivity. This sense of positivity came forward in the PMMs as well. For example: "*I realize that when I am asked to write something down, I immediately think about all the negative aspects of dementia. However, I forget to think about the positive aspects. These positive aspects were mainly present when I listened to the story about going on a holiday, and that people with dementia can enjoy things in a relationship or situation*" (P19). The exhibition made people realize that it represents only a snapshot of someone's life with dementia (P11, 23). In addition, some participants realized that the concept of time changes: life becomes momentary (P10, 25). "*You sometimes hear that people do not realize they have dementia. At that point in life, you live from moment to moment. I think this is strange, shocking, or sad for the environment. But for that person, it might not be that bad*" (P10). Other participants understood the severe consequences of living with dementia (P5, 25, 26).

Three participants realized during the visit that people with dementia lose the ability to rely on prior knowledge. Searching for the salt contributed to this realization. "*I was quite surprised by the assignment with the salt. I immediately tended to grab the jar with the bigger grains because they are like the salt at home. Then I realized, however, that my parents have fine salt that looks a lot like sugar. So, to know, you must taste it. At that point, I noticed how difficult it is to recognize something. We immediately rely on what we read, or what is recognizable from our own experience. I assumed that even though someone with dementia is not entirely sure, they would recognize something but that appears not to be the case*" (P11). Four participants did not expect that people living with dementia may be unable to recognize products or lose an object's meaning. People got that being unable to recognize products can lead to severe consequences such as consuming products that are not meant for consumption.

The observations showed that the T-65 PTT Phone was troublesome for seventeen participants. Twelve mentioned, or showed, behavior that indicated confusion on how a T-65 PTT Phone works. For one participant, the inability to use the T-65 PTT Phone was crucial for understanding dementia: it illustrates how difficult it is when someone is unable to operate a machine even though it appears familiar (P24). Being unable to recognize a device as such was found to be intense.

Nevertheless, the phone showed meaningful and different perspectives, for example how someone with dementia could feel: "*I think it is intense to realize that you forgot something. The moment someone claims that you call for the fifth time, but you experience it as the first time, you will think that they are crazy. Everyone can fool* *you into thinking that the air is green even though you are convinced it is blue. It is awful to question yourself into being crazy*" (P6). In addition, eight participants realized the intensity and daily requirements for informal caregivers that live together with their loved ones with dementia. For example, very specific instructions need to be given, such as crossing a note to prevent a repetition of calling (P4, 11). "*The phone gives the impression of how it is to live with someone. That was something that got me. When I would visit my grandmother, and I found something strange in the fridge, I would just put it back. This did not bother me so much. But being called hundred times, and then explaining to cross through a note every single time… If you take that feeling, and multiply it by a hundred, it starts to reflect how it is to live with someone*" (P9). Next to this, participants realized how difficult continuously thinking for two could be (P3), and how hard and annoying this could be for family members (P15, 24, 28, 29).

The notes illustrate how people with dementia try to help themselves and how much support they require (P16, 18, 29). Participants found the notes an obvious solution, but at the same time chaotic. "*Those post-its were intense. I thought that tranquillity was brought by structure and planning, but the notes become too chaotic*" (P5). For one participant it "*illustrates that, with small things, life can still be livable*" (P2). However, eight participants were not sure whether the notes would remain functional or would even become dangerous (P25). "*I saw a note that said to clean the bed. But there was no date whatsoever, so when was this task done?*" (P4). Furthermore, participants found that keeping track of many notes was ineffective and overwhelming. They found that at a certain point one would lose track of whether a task was performed at all.

### (II) Emotional responses to the experience

Participants felt sorry for the deterioration of small aspects of life: "*Especially the moment that someone realizes they forget. I think that point is horrible. When you are not aware, it is no problem, but the moment you are… I think that is difficult*" (P14). Furthermore, participants imagined how horrible being afraid that something is happening to the mind would feel (P22). In addition, participants did not realize that aspects of one's identity (i.e., address, things someone loves), and meaningful events (i.e., the birth of a grandchild), could fade away (P9). This could feel vulnerable (P5), and heartbreaking (P20). Being ashamed of deterioration was touched upon by another participant. "*It was intense to see that someone is ashamed. I mean, a person with dementia has no control over the situation and is not at fault. As a result, they live in fear, and try to hide things. Sadly, someone feels too ashamed to show this, even to the people closest to them*" (P6). This made the participants imagine how it would feel if you cannot rely on your mind (i.e., common sense) anymore (P22).

The stories of music were found to be beautiful and positive. Participants were moved by the illustration of positive, shared memories (P11, 22). Other participants were moved by hearing about a nursing home resident that becomes more energetic and active while listening to Elvis Presley (P14), the realization that the core values of a human being become evident when hearing music (P5), and that music can be a strong motive for action (P21). Nevertheless, it was found to be intense that the presence of memories is not a given (P23).

Five participants mentioned that the smart object (i.e., a cuddly cat) was preferred over other alternatives, such as a button, or headphones (P3, 19). The smart object was clear and instructive. Fourteen participants were positive about the guidance throughout the room, however, some freedom to explore was an important requirement. "*When you start stroking the cat, it was a set point. It tells you what to do, and everything will be okay. Without the cat, I would have to search a bit because I learned to be cautious to grab stuff in someone else's house. This felt strange*" (P11). Furthermore, the smart object helped to imagine the severity of dementia. For some participants, the cat helped keep the situation rather light as the topic of dementia can evoke sad emotions (P15, 16, 25). Three participants thought the cat to be soothing because it gave feelings of control over the situation (P20), it is stable and loves you unconditionally (P18) and creates a moment of rest in the chaos of the notes (P22).

## 4.2 Theme 2: Recognizing the Experiences in Their Own Life

Interestingly, people recognized different aspects of the exhibition from two perspectives. The first perspective is the link of activities to the participant's personal activities such as using small reminders (i.e., notes) to prevent forgetting a task (P9, 27), medicine (P4), meetings (P16) or to create structure (P25, 28). In addition, two participants mentioned that they experienced memory loss while being stressed, and that this might be the closest a 'healthy' person comes to experiencing dementia (P10, 28).

The second perspective is that participants linked aspects to their experience with dementia. For example, concerning the CDs, three participants experienced someone being able to play the piano even though other aspects appeared lost. In addition, two participants mentioned that their relatives revived when they recognized places (P2) or saw pictures (P7). Others experienced this in nursing homes while performing music at a special event (P8) or at work (P19). Keeping the situation light was experienced as well (P13). For example, one participant experienced a lot of positivity in the family surrounding their grandfather (P6). On the contrary, another participant experienced a more severe and sad situation (P5).

The repetition of actions was seen by parents (P2), or other relatives (P10, 28). This was also seen in repeating stories (P15). Hiding dementia was recognized in secondary family members (P9, 28). Feelings of shame while forgetting, or how to cope was recognized by parents (P2), or grandparents (P8). One participant experienced how specific notes need to be through her education: "*When one forgets to put 'open the water bin' on a note on the coffee machine, a person with dementia will pour water over the coffee machine. You must be very specific and that is hard to imagine because most steps are intuitive for us*" (P14). Others recognized the notes, pictures from work experience (P19), or stories (P12).

To forget how a machine works had been experienced through study projects (P18), stories (P22), or from relatives (P9). This holds for old patterns as well, such as eating a hot meal in the evening instead of bread (P2). In addition, the shoes on the projection and sunglasses in the fridge evoked recognition from personal experience with primary and secondary family members (P2, 9), or stories (P22).

## 4.3 Theme 3: Lessons Learned Regarding Dementia

Five people mentioned a positive shift in their view of dementia post-visit. "*The CDs were my favorite part. We tend to focus on how bad and sad it is, which makes it even more severe or sad in my opinion. Our society is not built on forgetting. There were many examples in the exhibition that illustrate how much a person needs to remember. The CDs showed that you need to turn this view of sadness around. There are still pretty sides. I mean, it will be horrible but when I left the room, I felt lighter*" (P6). For one participant, mainly sad memories were recalled pre-visit. They realized that families search for ways to make it manageable, which they found beautiful and inspiring to see (P11). Another participant expected daily life to be gloomy: "*I thought people with dementia live in a rut and experience no fun. I mainly had negative thoughts, but I see now that there are also beautiful, connective moments*" (P29). The exhibition illustrated how, depending on the situation, positivity can be built around dementia (P21).

The exhibition increased knowledge about dementia and expanded views after the visit (P21, 29). It showed how tiny the aspects can be that one forgets (P4, 24), and how someone's sense of time changes when dementia progresses (P11). Additionally, four participants realized they underestimated how difficult dementia can be: "*I think we underestimate how difficult life* *with dementia is. Of course, we know the general things such as forgetting things, but not knowing just how specific these can be, that was intense*" (P4). One participant imagined how strange it would be if one could only be happy with music from the past (P3).

Other learned lessons were more practical. For example, a perspective outside one's own (P8, 13), and how it is to live together with someone diagnosed with dementia (P10). It was said that the story of going on a holiday can be used to explain how dementia can feel (P13, 20), and might prove useful in the future (P27).

Others found new inspiration to apply at work (P15) such as the usage of person-specific music, and new ways to accept dementia (P13). In addition, people would search for creative solutions (P11), such as pictures on the cupboards (25) or how to improve the usage of notes (P23).

## 5 Discussion

The purpose of this study was to find out how different aspects of the exhibition contributed to the entire experience, and whether visitor awareness regarding dementia was increased. Results from this research support future designers aiming to design interactive installations to convey sensitive content. The insights can be considered when designing interventions that aim to challenge a certain stigma.

### 5.1 Interpretations of the Results

As can be seen in the themes, the exhibition illustrates daily life with dementia and makes dementia tangible. People realized how intense living with someone with dementia can be, and what kind of emotions are present. This supports the claim that the overall experience brought forward in the pop-up museum was appropriate to illustrate daily life with dementia in an insightful manner. More specifically, each of the separate elements contributed to the overall experience in its way.

The distributed notes made people feel overwhelmed, frustrated, and overstimulated. This illustrates how difficult it is when tiny aspects of life get lost such as operating devices, loss of important emotional events (e.g., birth or a grandchild), and aspects of one's identity (e.g., one's address). These findings indicate that the interior contributes to the influence of dementia on space and environment.

In addition, the cat contributed to retaining a sense of positivity for the participants. The cat's interaction was favored over other alternatives and was found to be soothing in the sometimes-overwhelming chaos of the exhibition space. Moreover, the cuddly toy was relevant in the context of dementia as a smart object, that creates an experience that is fully integrated into an exhibition. This is in line with the found literature [15].

Regarding the CD player, we did not expect it to stand out as an experience. The device was placed to complete the room. Nevertheless, the CDs increased knowledge about the implementation of music when living with dementia: it can help retrieve emotions or memories. Also, this contributed to feelings of empathy and positivity while leaving the room, since it stood near the exit, and might have contributed to a slightly more positive attitude.

Next, the cupboards made participants realize that people with dementia may be unable to recognize products, which can lead to severe consequences. Through interaction with the cupboards, people realized that human behavior mainly depends on previously acquired knowledge and intuition. As well as realizing how difficult it is when this is not present anymore. Another thing was that participants empathized with how frustrating it would feel when automatic behavior fades while living with dementia.

For the T-65 PTT Phone, it was unexpected that many participants experienced difficulties operating the analog phone. Nevertheless, it still made them realize that previously learned actions could be forgotten, and what kind of methods can be used to remember these actions (e.g., putting a cross through a note). People liked that the phone shows different perspectives, and this enabled them to imagine what the situation would feel like. Especially the burden that lies on informal caregivers and the negative emotions that can be felt through that experience (e.g., frustration).

Overall, the results show that the exhibition is a relatable presentation of daily life with dementia because many participants recognized aspects from both their personal perspectives and experiences. Participants, both with and without experience with dementia, were able to empathize with the presented narratives and learned from them. People with a primary or secondary family member mainly knew aspects of the exhibition from relatives. People with a background in healthcare recognized aspects they encounter at the workplace. And people with little experience with dementia could imagine it when going through the installation.

Overall, the results show that the exhibition increased visitor awareness in different ways and levels. The separate aspects of the exhibition (i.e., phone, cupboards, cat, etc.) contributed to unique perspectives and various emotional responses from the participants. In addition, the overall experience contributed to a coherent story with many different experiences and related insights. Conveying these different stories to the visitors contributes to their constructive understanding of what it means to live with dementia. Based on the themes found in our analysis we found that visitor awareness is increased for those that participated in this study. How the exhibition in general could contribute to stigma is subject for further research. However, we can state that the exhibition, and its separate aspects of it, are suitable stories and interactions to convey experiences in dementia and increase awareness of daily life with dementia.

### 5.2 Limitations and Recommendations

People take different lessons and emotions with them after the visit, which are mostly reflected by a more positive view. In addition, the exhibition contributed to an increase in knowledge about dementia and a broader image from multiple perspectives. Some views were widened on how severe dementia could be, especially while living together. Others gained tips and tricks they can use in their daily lives. For example, using person-specific music to create a nice moment, going on a holiday to relax, and new ways to accept the situation. However, the extent to which these experiences and insights gained in the exhibition influence people over the long term is unknown.

Preferably participants should represent the public as much as possible. Even though different experiences with dementia were present, this research represents only a small group of society. Most participants were well-educated and had a Dutch nationality. For further research, it would be interesting to include people of different nationalities, and different levels of education.

Also, during the interviews, two participants explicitly mentioned that they felt the pressure of being observed by the researcher. This could lead to different behavior as they were aware that they were being observed. To decrease the urge to achieve, video recordings can be used as a method to observe behavior in the space that is analyzed afterward. Additionally, to find out whether people would visit the exhibition out of personal interest, instead of through invitation of the researcher, it would be interesting to test in a public environment to see whether people's interest is sparked.

## 6 Conclusion

This study investigated how an exhibition with several separate elements contributed to the overall perspective on dementia, and whether the awareness of the visitor's mindset regarding dementia could be increased. This study presents a first exploration of how applications can be made within the context of dementia, and how stories could be brought forward through interactive objects. Each aspect of the exhibition contributed to different realizations and evoked different emotional responses. The exhibition increased the awareness of visitors and achieved that the dementia experience was recognizable from different perspectives and appropriate to illustrate daily life with dementia in an insightful manner. The results successfully indicate that these interactive exhibitions are a suitable manner to clarify and increase awareness of daily life with dementia.

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# One Step at a Time: Evaluation of a Step-By-Step Recipe Tool Designed for People with Dementia

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and Rens Brankaert

## Abstract

Due to dementia, people lose the ability to deal with complex tasks such as cooking. We can support this group by designing new tools to keep them active and enhance their feeling of self-worth. Previous studies have focused on step-by-step guidance for people with dementia using innovative technology, which is often too complicated to learn and set up for the users. In this paper, we designed and evaluated an intuitive, non-intimidating, step-by-step recipe tool for people living with dementia. The tool is designed for collaboration to stimulate socialisation between people with dementia or with a caregiver. The design was evaluated in situ, with 36 individuals at varying stages of dementia. Participants were instructed to cook a dish using the recipe tool and reflect on its usability. The step-by-step approach of the tool appeared highly suitable for people with dementia, and added visuals helped with understanding the recipe. The level of initiative shown by the participants with dementia seemed to depend on the amount of trust shown by the caregiver. We found that collaboration between participants during cooking as facilitated by the tool was enjoyable and highly suited for both at-home and meeting centre settings. We offer several suggestions for designing step-by-step tools and encourage facilitating more collaborative, non-intimidating activities for people with dementia and their caregivers.

## Keywords

Dementia · Cooking · Step-by-step

## 1 Introduction

Dementia is a syndrome in which a person's cognitive abilities deteriorate beyond what is expected to be caused by normal ageing [1]. Sixty per cent of risk factors for developing dementia are still unknown [2], only a few dementia cases can likely be prevented [3], and no cure is currently available [1]. Since we cannot cure or prevent dementia soon, we must find

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alternative strategies to support people living with dementia. This paper guides you through designing and evaluating a cooking aid tool specifically designed for people with dementia, also referred to as clients. Thereby we aim to add quality of life and a sense of agency to the years people with dementia still have ahead.

### 1.1 Complex Activities

As dementia progresses, people usually experience behavioural changes, difficulties recognising relatives and friends, difficulties walking and being unaware of time and place [4, 5]. However, dementia often starts with minor forgetfulness and struggling with more complex activities [5], such as driving a car, managing finances, and planning meals [6, 7]. Although these tasks used to be performed with ease because they are routine and familiar [8], Chevignard et al. found that errors occur more frequently as a person with dementia's cognition changes over time [9]. The tasks become too complex because they require coordinating multiple cognitive processes such as object selection, sequencing numerous steps, and perceptual-motor operations [9–11]. Therefore, people with dementia's changes in cognition prevent them from successfully executing their daily tasks [9].

This reduction in abilities is also known as *everyday action impairment* and is a severe challenge for persons with dementia. Clients require more help with daily tasks, which increases the caregiver burden [7]. Furthermore, their autonomy and self-esteem could be lowered, causing a feeling of helplessness [7] or even depression [12]. In turn, depression can increase the development of functional disabilities [13]. We can potentially address some of these adverse outcomes by designing to support people with complex activities and contribute to their self-reliance and independence.

### 1.2 Cooking Challenges

One of the most challenging complex activities of daily living is cooking, as it requires planning, multitasking, and problem-solving [14]. As dementia progresses, people often stop cooking because it is experienced as tiring or frustrating. Furthermore, cooking may no longer be safe as people with dementia might get distracted easily [15], will not recognise particular objects [16], or are not aware of their limitations [17]. Nevertheless, it is essential that cooking is maintained as long as possible and desired by people with dementia themselves since it contributes to their autonomy, sense of purpose, and cognitive and motoric skills [15, 18].

### 1.3 Guidance Through Activities

Several researchers [11, 19, 20] have previously investigated how step-by-step technology can guide people with dementia through daily tasks.

Although these solutions present promising results, they all use technologies, such as VR glasses, tablets, and computer screens, that often feel unintuitive for people over the age of 65 [21] and are difficult to set up for family caregivers [22]. Moreover, as people with dementia often experience a reduced learning capacity [6, 17], it becomes extra challenging to learn how to use the technology. Thus, users may feel intimidated and hesitant to use it.

Furthermore, the studies [11, 19, 20] focused on increasing people with dementia's independence by letting them execute tasks by themselves. Although this increases autonomy and decreases caregiver burden, it does not contribute to the desire for social interaction by people with dementia [23]. People with dementia often withdraw from social interactions as they fear others will recognise their memory deficits [23, 24], leaving them feeling lonely and increasing their chances of further developing dementia [25]. As Fitzsimmons et al. suggest cooking is the most social of all activities of daily living [18], this task is highly suitable for socialisation purposes.

Therefore, this study aims to design an intuitive and unintimidating step-by-step cooking tool that offers guidance for people with dementia in collaboration with other people with dementia or their caregivers.

## 1.4 Happje—A Step-By-Step Recipe Tool

We developed a new paper recipe tool called "*Happje*" ("bite" in Dutch) through an iterative design process. We completed thirteen cycles of building a prototype, evaluating it with the target group, and creating a redesign. At each iteration, the target group of people with dementia and caregivers was consulted to ensure the designed tool addressed the participants' needs, values, abilities, and everyday context [26].

People with dementia struggle with planning and figuring out the order of the cooking steps, not necessarily with executing them [27]. Yamaguchi et al. [21] found step-by-step guidance beneficial for improving the performance of people with dementia as it takes the challenges of the planning and order of steps out of their hands. Happje implements this approach by offering step-by-step instructions for recipes (Fig. 1). Each step only mentions a single task, as direct and short instructions are found to be most effective [28, 29]. Furthermore, as some people with dementia find it difficult to remember the details of the step they are working on [19], each step mentions the number of ingredients and where they should be added. Lastly, since the linguistic reading capabilities of people with dementia tend to decline over time [30], comprehending written instructions becomes challenging. For this reason, we developed an iconographic language to add visual instructions to the textual ones. These icons are a visual representation of each step's tools, actions, and ingredients.

We found that the elderly participants were often reluctant to use digital interfaces during our iterative design process, which could be because people over sixty-five often lack information technology skills [21]. All iterative paper prototypes were easy to use and non-intimidating for the participants; thus, Happje is presented on paper (Fig. 2). When participants of previous studies were only shown one step at a time, they often lost track of the overall cooking process. Therefore, Happje presents multiple steps on one page to ensure users can keep an overview of the entire sequence of tasks. Because seeing all the steps at once can be overwhelming, the steps are visually organised in coloured sub-groups. All pages show the recipe's title and photo to help users with faulty memory remember what they are cooking.

Due to the decline in short-term memory [31], people with dementia may also forget the actions

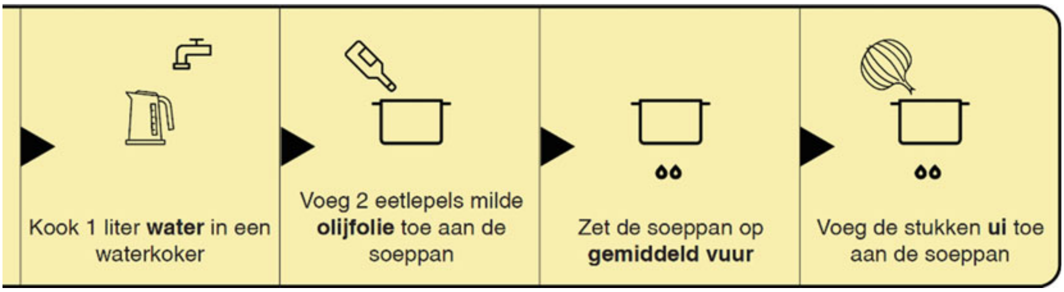


**Fig. 1** Happje presents step-by-step cooking instructions with additional icons. Translated, the steps say: Cook 1 L of water in a boiler, Add 2 spoons of mild olive oil to the soup pan, Put the soup pan on medium heat, Add the pieces of onion to the soup pan

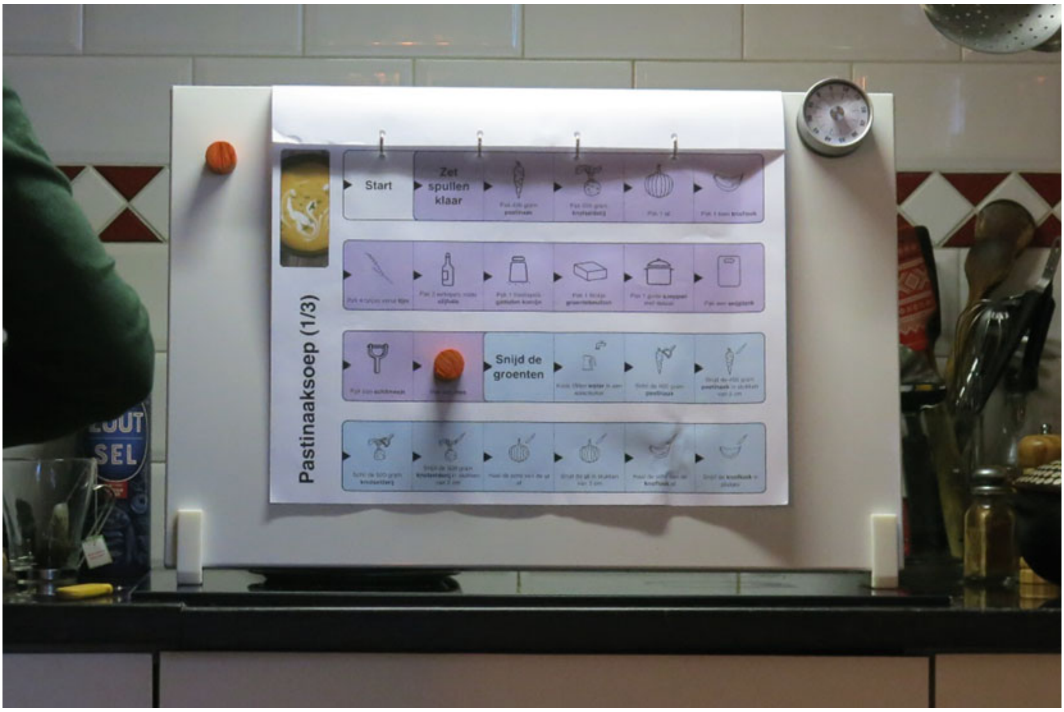


**Fig. 2** Happje is presented on paper and shows multiple steps at once

they have just executed or why they have set a timer. For this reason, Happje includes a magnetic pawn (Fig. 3), which users use to mark the step they are currently working on and remember which actions they have completed. Caregivers can also look at the pawn to keep track of the progress. Additionally, for timed activities, a magnetic timer is placed on top of an allocated 'timer' step on the recipe to help users remember the reason for setting the timer.

### 1.5 Study Aim

This study evaluates whether Happje achieves its goal of guiding people with mild dementia through a cooking activity in collaboration with other persons with dementia or caregivers. Four research questions have been set up to guide the evaluation. (1) Does the design help people with dementia and their caregivers *understand* the cooking steps? (2) Does the design help people with dementia and their caregivers *navigate* the cooking steps? (3) How do people with dementia and their caregivers *collaborate* during the cooking process while using the design? (4) Does collaborative cooking with Happje generate a *desirable experience* for people with dementia and their caregivers?

## 2 Method

### 2.1 Participants and Environment

We conducted one pilot and eight evaluations with 36 Dutch participants (Table 1). The stages of dementia of the participants ranged from mild to moderate. The evaluation took place in two contexts (Fig. 4), which both reflected the intended contexts and were familiar to the participants to create a pleasant experience [26]. In the at-home context, one person with dementia cooked together with an informal caregiver. In the meeting centres, groups of clients collaborated under the supervision of an informal caregiver.

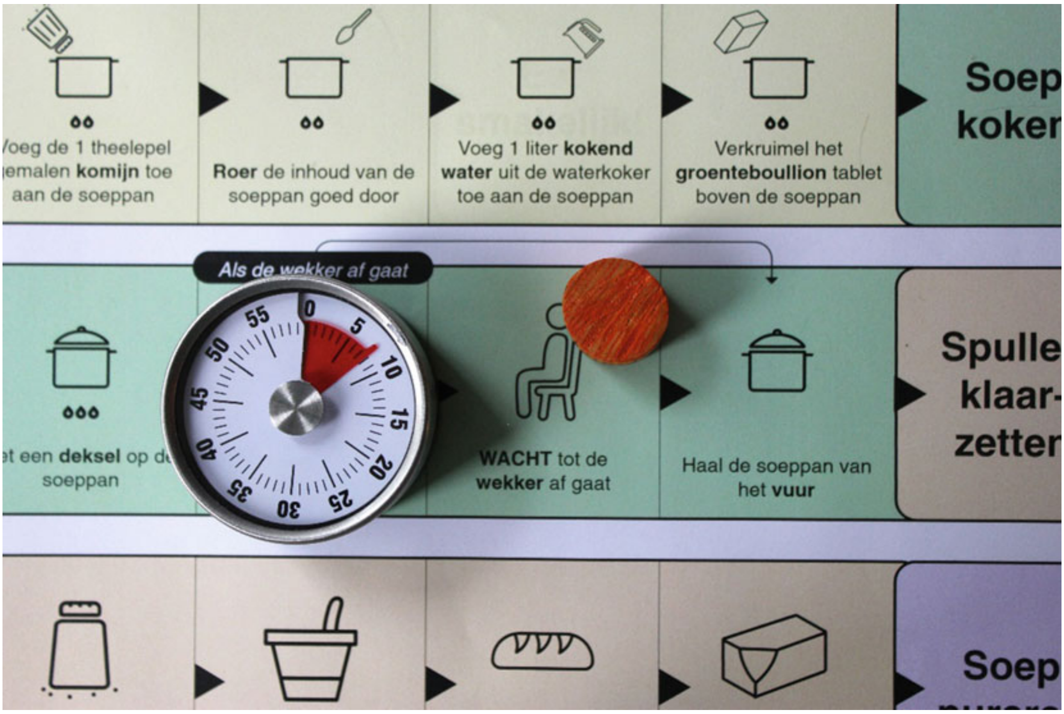


**Fig. 3** A magnetic timer and pawn are placed on top of the recipe to help with navigating through the steps. Translated, the steps say: Put the lid on the soup pan, If the timer rings, Wait until the timer rings, Remove the soup pan from the heat

**Table 1** Participants of evaluation

| Group* | Location | Clients (persons with dementia) | Caregivers | Volunteers | Participated in previous studies? |
|---|---|---|---|---|---|
| P1 | At home | 1 | 1 | | Yes |
| H1 | At home | 1 | 1 | | No |
| H2 | At home | 1 | 1 | | No |
| H3 | At home | 1 | 1 | | Yes |
| H4 | At home | 1 | 1 | | Yes |
| M1 | Meeting centre | 4 | 2 | | Yes |
| M2 | Meeting centre | 6 | 3 | | No |
| M3 | Meeting centre | 2 | 1 | 2 | Yes |
| M4 | Meeting centre | 2 | 1 | 3 | No |

*P = Pilot, H = Home, M = Meeting centre

**Fig. 4** One client and one caregiver are cooking at home (left). Multiple clients are cooking together at a meeting centre (right)

## 2.2 Prototype

A physical prototype with the same functionality and appearance as Happje was created for the evaluation. In most cases, the prototype was presented standing up against a whiteboard (Fig. 5). Five different recipes were designed to cater to the dietary preferences of the participants and ensure we tested the tool and not one specific recipe.

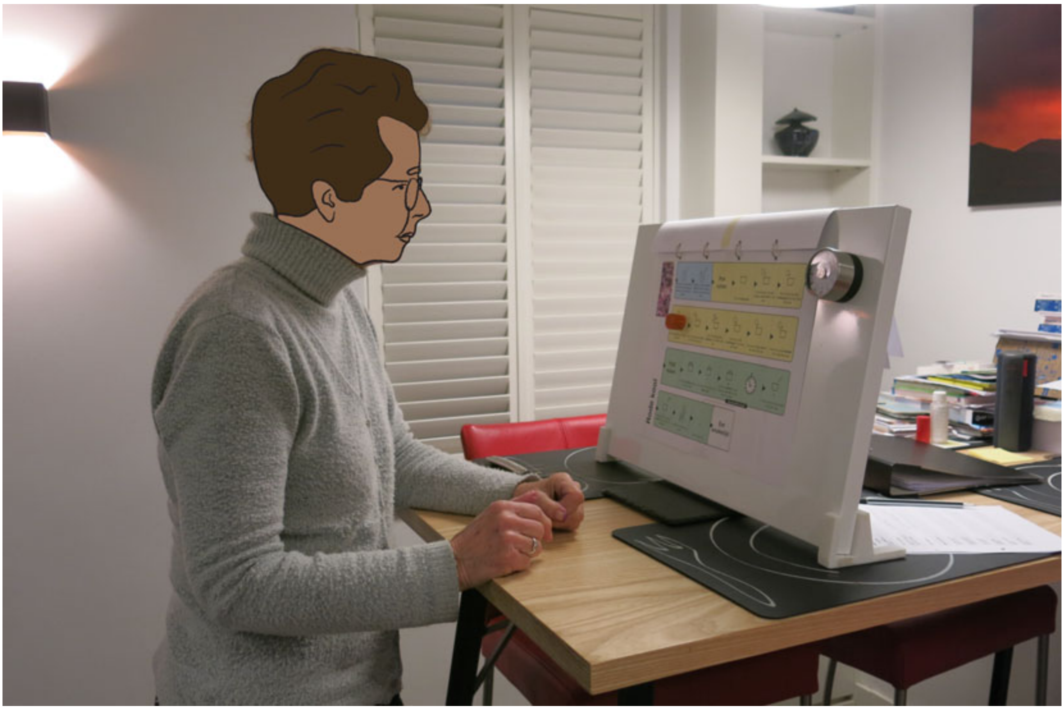


**Fig. 5** The recipe presented on the whiteboard in the kitchen of one of the participants

## 2.3 Ethical Considerations

Ethical approval for the study was obtained from the Human Research Ethics Committee of the Delft University of Technology. All caregivers gave written consent. Clients were also asked for verbal or written consent [32] and observed for non-verbal cues during the study indicating they did not want to participate [33].

## 2.4 Procedure

Figure 6 presents the three phases of the session. The study was introduced in the first twenty minutes, and the participants gave informed consent. Furthermore, time was spent on small talk about a topic of the participants' desire to establish a relationship in which the participants felt comfortable expressing their opinions [34].

Next, the participants were presented with the prototype and given the following instructions "*Please use this recipe for cooking the specified meal together. Each block in the recipe explains one step. Use the pawn to move through the steps.*" The researcher observed the interaction with the prototype and filled in the 'Researcher observation sheet' (Table 2). The sheet consisted of eleven usability elements and was rated on a three-point scale, ranging from always, sometimes, and never working as intended. Additional notes were taken to explain the rationale behind the observation.

The participants used the 'Participant self-report sheet' (Table 2) to state whether they agreed or disagreed on a five-point scale on thirteen statements concerning their experience of using the prototype. All statements were written in positive statements to reduce the cognitive load of the participants. This section was audio-recorded, and the researcher asked participants additional questions to clarify why they agreed or disagreed.

## 2.5 Analysis

The quantitative data of the observation and self-report sheets were digitised in a spreadsheet in Excel. All recordings of conversations with participants were transcribed. Quotes and observational notes related to the observation and self-report elements were interpreted and linked to said data (Table 3). Interpretations were then clustered into themes concerning the usability and experience of the prototype.

# 3 Results

The results are presented in the order of the study's four research questions. Group M4 did not fill in the self-report sheet; thus, we offer eight observations and seven self-reports.

## 3.1 Understanding the Cooking Steps

We observed that the clients from six out of eight groups perfectly understood the steps in the recipe and knew what to do after reading them (Fig. 7). One client (M4) did not look at the recipe, probably because she could no longer

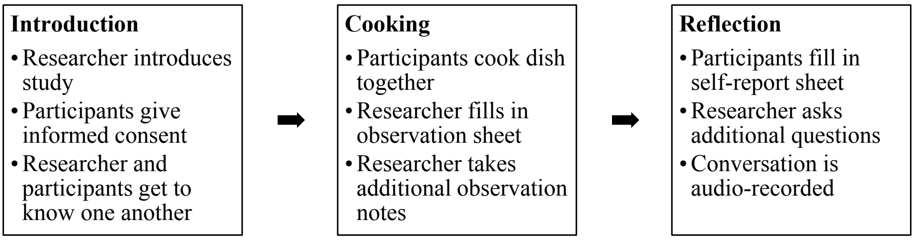


**Fig. 6** The three phases of the evaluation sessions

**Table 2** The two parts of data collection. The researcher filled in the observation sheet, and the participants the self-report sheet. The elements of the sheets were based on the four research questions posed in the introduction

| Research question | Researcher observation sheet (Always, Sometimes, Never) | Participants self-report sheet (Completely agree, Agree, Neutral, Disagree, Completely disagree) |
|---|---|---|
| (1) Does the design help people with dementia and their caregivers *understand* the cooking steps? | Clients understand the steps and know what to do after reading them | "Every step was clearly formulated"<br>"The icons helped with understanding the recipe" |
| (2) Does the design help people with dementia and their caregivers *navigate* the cooking steps? | Clients move through the steps in chronological order<br>Clients move the pawn<br>Clients look at the pawn to remember their progress<br>Clients properly use the kitchen timer | "The recipe was easy to follow"<br>"It was always clear what the next step was"<br>"The pawn made it easy to remember where we left off"<br>"Cooking in this way is easier than cooking with a normal recipe" |
| (3) How do people with dementia and their caregivers *collaborate* during the cooking process while using the design? | Clients initiate the steps themselves<br>Participants trust each other to execute the tasks properly<br>Collaboration between participants feels equal<br>Clients execute actions safely | "We trusted each other to execute the steps correctly"<br>"We felt safe while cooking" |
| (4) Does collaborative cooking with Happje generate a *desirable experience* for people with dementia and their caregivers? | Participants have a social experience<br>Participants stay interested | "We enjoyed collaborating while cooking"<br>"When we saw the recipe, we immediately felt like starting"<br>"We all stayed interested while cooking"<br>"We felt proud after cooking"<br>"We would like to cook this way again" |

read it. When asked what the next step was, she would guess instead of looking at the recipe.

Five out of seven groups completely agreed that every step was clearly formulated, and most clients were observed to be able to execute the tasks before forgetting them. One group (M2) felt it was sometimes unclear where each ingredient should go and felt some steps could be combined.

All groups agreed that the icons helped them understand the recipe. Participants did not solely look at the icons to understand the steps but glancing over them while reading the textual instructions helped provide context. "*The weird thing is that if you left out the icons, you would miss them. But if they are there, you look at them more fleetingly.*"—client (M4). Furthermore, the icons made the recipe look calmer as participants

**Table 3** Examples of two researcher observation- and two participant self-report responses. Additional quotes and observations were interpreted and linked to the corresponding responses data to add meaning to the quantitative data

| Data type | Statement | Group | Response | Quote/observation | Interpretation |
|---|---|---|---|---|---|
| Researcher observation | "Client navigates through the steps in chronological order." | H3 | Always | [10 min after the client sliced the apple.] Client: "*The finely chopped apple, have we already cut those?*" | Client followed the steps in the intended order but sometimes forgot which steps she had already completed |
| | | H4 | Sometimes | Client first chopped the parsley and then the mushroom, while the recipe stated these steps the other way around | The client moved around the order of some steps but did complete all steps in the end |
| Participant self-report | "It was always clear what the next step was" | H3 | Neutral | Client: "*If you looked properly, then yes. But sometimes, I would look at it and not immediately find what I was looking for.*" Partner: "*She also sees badly lately, so at a certain moment, I saw her standing there and not being able to read what it said.*" | The client could not always find the next step quickly because she could not see them correctly |
| | | H4 | Completely agree | Client: "*Also, because you can move [the pawn] one square every time and push it forward, I always know where I left off.*" | The client feels the pawn helped her remember where she left off |

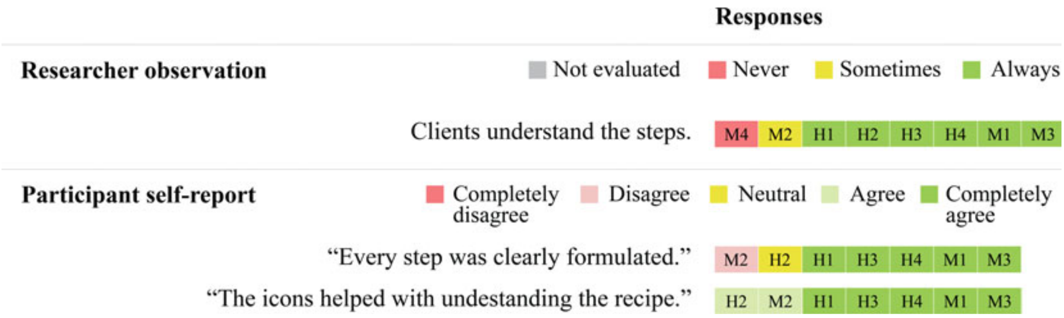


**Fig. 7** Results understanding cooking steps

could get a feel for the recipe without reading all the text. "*I notice that this recipe looks very calm, which is nice. It is clear because all the icons are added, so you can see what it [the step] should actually be.*"—client (H4).

## 3.2 Navigating the Cooking Steps

All participants stated the recipe was easy to follow (Fig. 8). Participants mentioned they enjoyed the step-by-step approach, as it helped

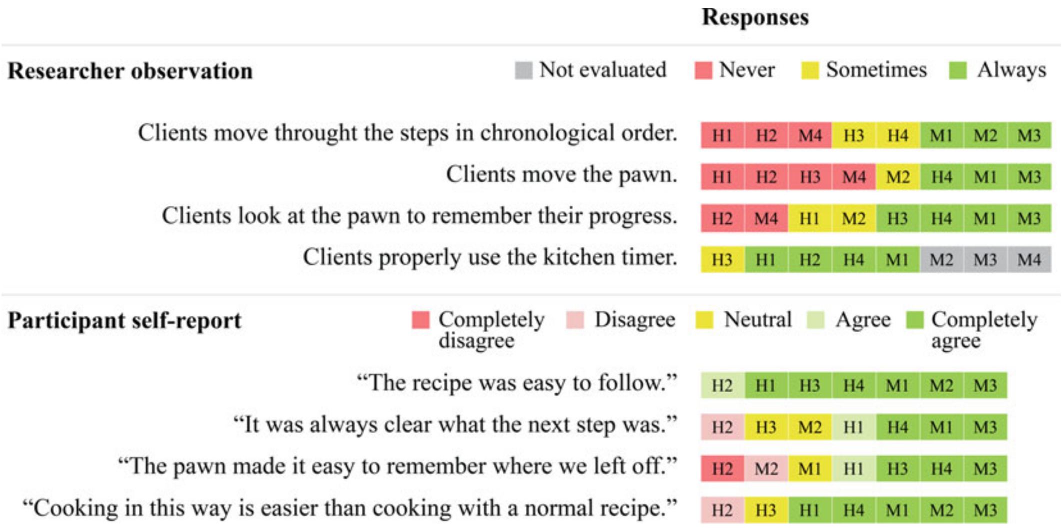


**Fig. 8** Results navigating cooking steps

guide them through the process and made them feel calmer. "*The fact that it is made step by step, image for image, may seem unnecessary for some. But it is not unnecessary for me.*"—client (H4). "*It is indeed very simple and very much step, step, step, which prevents you from feeling nervous. That is the thing with cooking; it makes you super nervous. And we are not getting nervous from this.*"—client (M2).

However, only four out of seven groups felt it was always clear what the next step was, and only three out of eight groups were observed to move through the steps chronologically. Some clients (H3, H4) could not remember whether an action had been completed. For instance, a client (H3) asked, "*Thin slices of apple, have we already cut those?*" only a few minutes after slicing the apple. Furthermore, some clients could not immediately find the step they were looking for on the large paper recipe. One client (H3) would stare at the recipe for a few seconds before finding the step she was looking for. "*If you looked properly [it was always clear what the next step was]. Sometimes I would look and not immediately find the thing I was looking for. Then I would just wait and see for a little bit.*"—client (H3). Also, some participants (H1, H2, H4) would stray off the recipe, start improvising, and then find it difficult to find their way back to the steps. They found it difficult to follow the step-by-step plan as it did not allow for any improvisation. *"I've noticed that you always, also with other recipes, want to fall back on the routines you already know. On the one hand, you want to follow the steps, but on the other hand, you think you know it better yourself."*—daughter (H3).

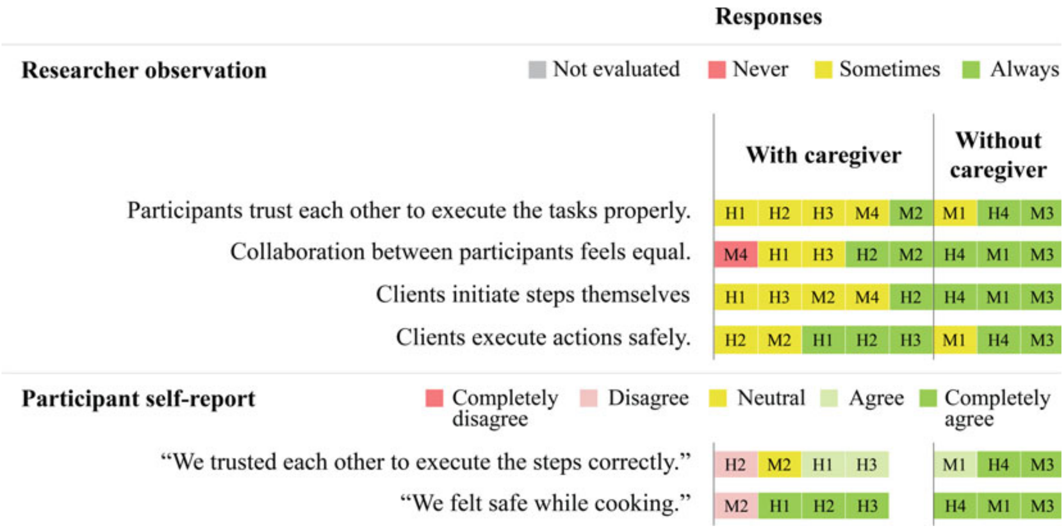
The orange pawn was designed to help participants keep track of the steps they had completed and quickly find the next step on the paper recipe. Four out of seven groups found the pawn helped them remember where they left off. "*Especially also because you can move the magnet [pawn] one square and push it forward every time. I always know where I left off. Because of that magnet, it is clear to me at which step I am. That makes it very easy.*"—client (H4). The other three groups did not feel the pawn was beneficial in remembering the current step. Clients of five out of eight groups did not move the pawn after every step. Two clients (H3, M1) felt they would have to practice more to get used to using the pawn. "*Yes, I think [with practising, I can remember moving the pawn]. I think it will simply become a habit.*"—client (H3). Clients also seemed to overlook the pawn as four groups did not refer to the pawn to remember their progress in the recipe. Although not all groups consistently used the pawn, several participants still felt something to keep track of the current step would be valuable. "*The pawn is there to help indicate at which step you are. And that would be valuable because sometimes you [mother] completely lose track of where you are. But for some reason, you do not [use the pawn].*"—daughter (H2).

In three cases (M2, M3, M4), participants did not use the magnetic timer because the researcher took care of it. One group (H3) required help to figure out how to set the timer. The others showed a perfect understanding of setting the timer and remembered what to do after the timer rung.

Even though the navigation was challenging, five out of eight groups completely agreed that cooking this way (with this prototype) was easier than cooking with a standard recipe. The two who disagreed (H2, H3) felt they could still easily use their standard recipes. "*If I have those little books from Blue Band, that is also really easy. If I just have one of those little booklets, and it is not too complicated, then it goes fine.*"—client (H3).

## 3.3 Collaboration While Cooking

The nature of the collaboration seemed to differ based on whether a caregiver (either the partner or formal caregiver) was present. Caregivers appeared to be less trusting towards the perception and execution of tasks of the client. All groups without caregivers (M1, H4, M3) agreed they trusted each other to execute the steps correctly (Fig. 9). Only half of the groups with a caregiver stated the same. We also observed less trust in groups with caregivers than in groups without. Formal caregivers or partners would continuously check whether the client executed the steps correctly. "*Yes, I was indeed checking a little bit […] whether she was doing it according to the steps.*"—daughter (H2). "*I often walked towards the board [recipe] to check how far she was.*"—partner (H3). Or sometimes, when the caregiver disagreed with the actions, they would take over the task without being asked. For instance, when a client (H1) was cutting a vegetable, her partner took over to show her how to do it. "*If you cut it this way… yes, no, like this.*"—partner (H1).



Responses

**Researcher observation**

⬜ Not evaluated 🟥 Never 🟨 Sometimes 🟩 Always

| | With caregiver | | | | | Without caregiver | | |
|---|---|---|---|---|---|---|---|---|
| Participants trust each other to execute the tasks properly. | H1 | H2 | H3 | M4 | M2 | M1 | H4 | M3 |
| Collaboration between participants feels equal. | M4 | H1 | H3 | H2 | M2 | H4 | M1 | M3 |
| Clients initiate steps themselves | H1 | H3 | M2 | M4 | H2 | H4 | M1 | M3 |
| Clients execute actions safely. | H2 | M2 | H1 | H2 | H3 | M1 | H4 | M3 |

**Participant self-report**

🟥 Completely disagree ▨ Disagree 🟨 Neutral ▨ Agree 🟩 Completely agree

| | With caregiver | | | | Without caregiver | | |
|---|---|---|---|---|---|---|---|
| "We trusted each other to execute the steps correctly." | H2 | M2 | H1 | H3 | M1 | H4 | M3 |
| "We felt safe while cooking." | M2 | H1 | H2 | H3 | H4 | M1 | M3 |

**Fig. 9** Results collaboration while cooking

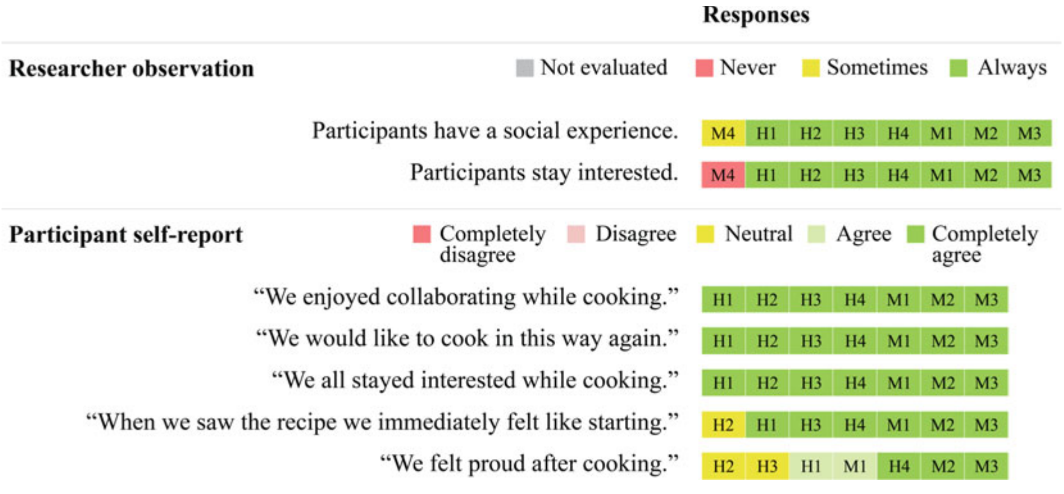
We observed much autonomy in groups without a caregiver present. Here, all clients initiated the steps themselves. In two of these groups (M1, M2), a client took charge and handed out the tasks to other clients. In four out of five groups with caregivers, the clients only sometimes initiated steps themselves. These clients would wait for instructions from the caregiver and only take the initiative when prompted by the caregiver. Clients would also often look at the caregiver for insights on whether they were doing it correctly. However, over time, two caregivers showed an increasing trust in the clients and encouraged them to figure out the steps themselves. "*I thought it was great [that the client was handing out the tasks instead of me], better even. It is good to be aware of that because it sometimes sneaks in to take over things [as a caregiver] while [the visitors] can do a lot themselves.*"—formal caregiver (M1).

## 3.4 Experience While Cooking

All participants stated they enjoyed collaborating while cooking and would like to cook this way again (Fig. 10). Seven out of eight groups were also observed to have a pleasant social experience. Participants thought the collaborative cooking with the prototype was an enjoyable social experience (H2, H3, M1), an excellent way to keep everyone engaged (M1), and an easy way to cook (M2). *"I do [want to cook this way again]. I simply want a cookbook like this."*—client (M2).

All participants, except M4, who could not read, stayed interested and involved throughout the entire activity. Furthermore, six out of seven groups stated they immediately wanted to start when they saw the prototype, indicating that the prototype felt inviting and non-intimidating to use.

Lastly, five out of seven groups felt proud after cooking. "*Well, I definitely do [feel proud]! Because I have had so many times that I just could not get [the cooking] done. And then I thought, why can I no longer get it done? Why can I no longer do it? And if it does work, wow!*"—client (H4). However, one caregiver said cooking is too much of a daily routine to say he was feeling proud about it. "*Proud, well, I think that is a heavy word. I would say it is just such a daily routine.*"—partner (H3).



Responses

**Researcher observation** ⬜ Not evaluated 🟥 Never 🟨 Sometimes 🟩 Always

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| Participants have a social experience. | 🟨 M4 | 🟩 H1 | 🟩 H2 | 🟩 H3 | 🟩 H4 | 🟩 M1 | 🟩 M2 | 🟩 M3 |
| Participants stay interested. | 🟥 M4 | 🟩 H1 | 🟩 H2 | 🟩 H3 | 🟩 H4 | 🟩 M1 | 🟩 M2 | 🟩 M3 |

**Participant self-report** 🟥 Completely disagree ▨ Disagree 🟨 Neutral ▧ Agree 🟩 Completely agree

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| "We enjoyed collaborating while cooking." | 🟩 H1 | 🟩 H2 | 🟩 H3 | 🟩 H4 | 🟩 M1 | 🟩 M2 | 🟩 M3 |
| "We would like to cook in this way again." | 🟩 H1 | 🟩 H2 | 🟩 H3 | 🟩 H4 | 🟩 M1 | 🟩 M2 | 🟩 M3 |
| "We all stayed interested while cooking." | 🟩 H1 | 🟩 H2 | 🟩 H3 | 🟩 H4 | 🟩 M1 | 🟩 M2 | 🟩 M3 |
| "When we saw the recipe we immediately felt like starting." | 🟨 H2 | 🟩 H1 | 🟩 H3 | 🟩 H4 | 🟩 M1 | 🟩 M2 | 🟩 M3 |
| "We felt proud after cooking." | 🟨 H2 | 🟨 H3 | ▧ H1 | ▧ M1 | 🟩 H4 | 🟩 M2 | 🟩 M3 |

**Fig. 10** Results experience while cooking

## 4 Discussion

This evaluation investigated whether people with dementia could be supported in cooking using a specifically designed recipe concept, which includes a step-by-step guide.

First, we conclude that breaking up the cooking process into step-by-step increments makes recipes easier to understand and follow for people with dementia. The size of the steps can be adjusted to suit the cognition level of the client. As the text per instruction is short, the tasks are easier to understand and remember. Furthermore, the additional icons make the recipe look less overwhelming and help people with dementia with linguistic difficulties [31] comprehend the steps more easily. As the icons were only shown in combination with textual descriptions, further research could investigate the understanding of people with dementia of standalone icons.

A minor downside to the step-by-step approach is that it does not allow much for improvisation. Like Wolf et al. [20], we found some participants tended to change the order of the steps and improvise steps as they saw fit and then struggled to find their way back to the fixed order of the recipe. Therefore, we suggest investigating how a step-by-step guide can clearly describe a process while allowing for improvisation.

A pawn was introduced to the prototype so users could keep track of their current place in the recipe. The pawn helped half of the participants quickly find the next step in the recipe. However, as the learning ability of people with dementia tends to decline [6], not everyone seems to be able to learn to move or look for the pawn. Without it, due to their decline in short-term memory [31], clients could not always remember which steps they had already completed or quickly find the current step on the page with multiple steps. People with dementia are still able to (re)learn [6, 11], so future research could assess if the person with dementia's pawn use can be improved through practice. Another approach could be using an automated interface that only shows one step at a time [11, 19, 20] but making it highly intuitive for people with dementia and integrating a way to see the overview of the entire process.

We found that caregivers and partners significantly influence conveying agency and trust to people with dementia. Like Wijngaarden et al. [23], we found that caregivers and partners often lacked trust in the perception of the person with dementia and would check or take over tasks without being asked to. This behaviour influenced the behaviour of the people with dementia, as those in groups with a caregiver or partner took less initiative. However, the results of our study do suggest that the caregiver and partner's trust can improve with practice. We recommend conducting further research in which people with dementia and caregivers collaborate, for example, with this cooking tool to understand and enhance trust.

We also found that collaborative cooking is an enjoyable and suitable activity for people with dementia and their caregivers, both at home and at meeting centres. Although many people with dementia often stop doing activities they are still capable of to avoid challenging situations [28], all participants of this study were excited to start cooking. Stanyon et al. and Fitzsimmons et al. suggest giving direct short instructions [29] and introducing collaborative cooking activities [18] can increase the involvement and initiative of people with dementia. Thus, we recommend using intuitive and inviting tools such as Happje to counter the apathy [35] often seen in people with dementia.

Like Fitzsimmons et al. [18], we found that participants with dementia highly enjoyed collaboratively cooking with other people with the same condition. Brataas et al. and Wijngaarden et al. [23, 24] suggest this is because people with dementia feel more like 'equals' when interacting with one another and feel they do not have to hide their symptoms. Therefore, we suggest introducing more activities to the lives of people with dementia where they can create together.

### 4.1 Limitations

The evaluation's context, participants, tasks, and prototype are representative of the intended context, users, tasks, and design. Furthermore, as the evaluation contained eight cases with 36 participants, we believe the study gives valid insights into various users and contexts.

However, the data may have been biased as the caregivers and clients collaboratively filled in the self-reporting questionnaire. The caregivers could have overpowered the conversation, clients may have had a too optimistic view of the situation, and both parties may have felt reluctant to be critical of each other's performance. Furthermore, the self-reporting questionnaire only consisted of positive statements to suit the participants' cognitive abilities, which perhaps made participants look less critically at each statement and feel inclined to agree with all of them. Also, the analysis mainly focused on what was said by participants, which is challenging for those with linguistic difficulties [34]. Lastly, the observation and analysis were done by one researcher, meaning some observations may have been missed or the analysis was biased.

## 5 Conclusion

This paper presents a novel cooking tool called Happje to support people with dementia in cooking activities in collaboration with other people with dementia or caregivers. Our recipe tool uses a step-by-step approach, which helped people with dementia understand the steps more easily. A pawn was introduced to help users remember their place in the recipe. However, navigating through the steps still proved challenging as half of the clients struggled with learning to move and look for the pawn. The caregiver's trust significantly impacts the clients' agency and confidence in their perception and capabilities. Collaborative cooking with the cooking tool is an excellent activity to introduce at homes and meeting centres for people with dementia as it is not intimidating and stimulates socialisation.

The pawn should be further iterated on to become so intuitive that users no longer need to learn how to use it. Furthermore, a more extended study using the recipe tool could evaluate whether the caregiver's trust in the client can increase over time. We also suggest designing more intuitive and collaborative activities such as facilitated by Happje for people with dementia to reduce apathy and loneliness. Future studies around the experience of people with dementia should not just focus on what people write and say but also on how they behave during the experience. Moreover, clients and caregivers should be interviewed separately to ensure they both get to express their opinions.

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# Supporting Intergenerational Dialogue Through Memories: A Case Study of Hilde Kramer's Picturebook for Dementia

Serpil Karaoğlu and Ilgım Veryeri Alaca

## Abstract

This paper examines the potential of picturebooks to stimulate communication, interaction, and recall in individuals with dementia together with their caregivers. Focusing on a picturebook created by Hilde Kramer specifically for older people with dementia, this study analyzes the production process having people with dementia in mind as we examine the utilization of the visual and verbal devices to enhance the reading experience. Insights from an interview with the author stressed the role of research and the importance of artistic and sensory considerations while creating a literary tool as an intervention for people with dementia. Investigating multisensorial experiences that stem out of the picturebook content both for the wellbeing of people with dementia and as an aid for their caregivers, we pinpoint how these strategies may be furthered in the future. As such, shared reading was found not only to foster a dialogue and trigger memories but build intergenerational relationships and cross-cultural sharing for the empowerment of both parties and beyond, bearing the potential to attract a wide range of audience.

## Keywords

Picturebook · Dementia · Multisensory · Shared reading · Intergenerational relationships · Empowering aging · Care · Reminiscence · Crossover

## 1 Introduction

With an aging population tends to come an increase in cases of dementia, an umbrella term for the progressive loss of cognitive abilities. Dementia encompasses a range of symptoms including loss of memory, concentration, the ability to plan or organize, visuospatial skills (e.g., assessing depth or distances), and orientation (confusion about location or time) [1]. The degradation of memory, as well as cognitive and emotional abilities, adversely affects the daily experiences of people with dementia [2] and hence decreases their quality of life [3]. In the absence of a cure, some studies have been dedicated to discovering ways to manage the challenges of cognitive degeneration that would support people with dementia and their caregivers. In addition to pharmacological interventions, non-pharmacological interventions have been developed. Some interventions have been found to even slow the progress of condition's

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effects [4]. These include social, physical, or intellectual programs and activities [5–7] as well as tailor-made tangible multisensorial artifacts [8, 9] meant to enhance the wellbeing and quality of life of people with dementia [10, 11]. Other dementia-related studies have mainly focused on research into reminiscence therapy that have been observed to positively impact the cognition, mood, and behavior of people with dementia via triggering their memory [12].

Tailor-made engagements such as Life Story Books (LSBs) have been widely used as a reminiscence tool for people with dementia [13, 14]. LSBs can be used interchangeably with "life story album", "story book", "memory book/album", "life album", reminiscence book/album, auto-biography book, and life history book. LSBs are primarily in hard copy formats, although there are digital versions also, that consist of diverse materials such as photographs, music, narratives, news stories and etc. [7]. The applications of LSBs are wide-ranging in that they have been found to benefit children, people with learning difficulties and older adults without dementia as well as those with dementia [14]. Beyond supporting the well-being of the care-receiver, the personal life stories documented in the LSBs give caregivers insights into the care-receivers' lives that have the potential to build a rapport between them [12]. When creating a LSB as part of a person-centered care approach [15], that book should not only be tailored to the individual but include their input as much as possible. By including mementoes, keepsakes, photos, and experiences specific to the person, this crafts a personal LSB that would better support the individual's □ autobiographical memory system. LSBs may also help prolong an individual's language skills and memory through reading. As such, reading is regarded as instrumental to mental well-being [16], and in the case of people with dementia, books have also been found to have a positive influence on their emotional status [17]. Shared reading activities especially benefit social and cognitive abilities of older people with dementia [18].

One study points out the intellectual aid to the cognitive functions of older adults while reading picturebooks to children [6]. The related research shows that older adults improve strategies to memorize the story and create interactivity during the dual route of reading aloud to children. While the dual-route model for reading picturebooks is discussed mainly in terms of its benefits for children with an emphasis on the children-adults relation [19–23], this paper shifts the focus from children to adults. We argue that picturebooks for adults should be viewed no differently than when children gravitate towards books geared for adult audiences (ex. Alice in Wonderland) that have over time come to be considered children's literature [24]. Thus, at this time we seek to examine the further possibilities and benefits of the shared reading of picturebooks for older adults and their caregivers in the context of dementia. To explore picturebooks as a medium that supports the well-being of people with dementia, our paper specifically examines Hilde Kramer's recent picturebook, *Minner i Bilder* (Memories in Pictures). This book is a project Kramer developed for the older generations of Norwegians with dementia.

In the paper, while we analyze Kramer's picturebook designed for people with dementia in detail as an adapted book production case, we also unpack and discuss the possible usages of picturebooks' artistic and meaning-making affordances for people with dementia. To gain better insights for our analysis, we share the results of our structured interview with Kramer, the creator of the picturebook. We draw on the findings that have implications for the designs of picturebooks for older people with dementia specifically, that emphasize multisensorial experiences in the context of shared intergenerational reading.

## 2 Making a Picturebook for Dementia

In this section, we analyze Hilde Kramer's *Minner i Bilder* (Memories in Pictures) (2014), focusing on the book's visual, verbal, and interactive aspects. In addition to our own analysis, we benefit from the interview conducted with Hilde Kramer, discussing her process in completing the final product. Kramer is a Professor of Illustration at the University of Bergen, Norway, interested in incorporating the new approaches in illustration and communication into picturebook design to form rich narratives. She often adopts artistic research methodologies that involve the viewer in the development process. Kramer's motivation for creating this picturebook was based on her personal experience with dementia as an acquaintance was diagnosed with the affliction before reaching her fifties. Witnessing the devastating decline of her colleague and friend, Kramer decided to create a work that would trigger some good moments by initiating dialogues between people with dementia and their caregivers. Kramer [25] explains that "To give relief, even if only for some minutes, is helping people with dementia." It is just as likely that these precious moments would give relief to their caregivers as well. Though this picturebook does not offer a cure, it does offer respite through the recollection of good memories and experiences with the support of caregivers' assistance.

Kramer's picturebook is originally designed for older people with dementia but it also takes into account the participation of their caregivers. In that manner, the picturebook can be regarded as an instructional one with informative parts designed for the best possible shared reading experience. Kramer gathered a rich array of visual and verbal instruments with an artistic approach in her picturebook, but the content is a reflection of a particular era of Norway, including real objects, experiences, and people, which can be defined as non-fiction and informative. The reader is not expected to come up with abstract associations but to reminisce about past experiences belonging to a specific geography. Moreover, the nostalgic content of a particular era and region in Kramer's work might appeal to the general public so this might also be considered a crossover picturebook [26] with its inclusive features.

## 2.1 Production Process: From Idea to Publishing, and Its Reception

Kramer's project was funded by Leser Soker Bok (Books for Everyone) Association, which is "working to give everyone access to good books aiming for a real cultural democracy", and that develops adapted books for the ones who are facing varied reading difficulties [27]. After an undertaking of five years from inception to production, Kramer's picturebook was published in 2014 by Aldring og Helse (Aging and Health). Kramer [25] explained that they worked on a variety of different formats, but the final version was created within the bounds of a standard format including images and texts related to popular contents. Kramer mentioned that she had proposed a format that would integrate her research into the olfactory influence on memory (ex. the smell of coffee, orange, flowers, soap) into the picturebook but had difficulty finding publishers due to the lack of commercial interest. Kramer explained that the first idea was inspired mostly by the tactile books and books with smell for children accompanied by studying peer reviewed articles about dementia. Hence, the final picturebook did not incorporate either tactile or olfactory affordances due to concerns relating to the technical complexities and cost effectiveness. Publishers were concerned about the risk to potential sales especially considering that books printed in Norwegian already have a limited market. Despite these concessions, Kramer's project was well-received and presented positive outcomes among the targeted audiences. Thus, we outline the research and creation process in the next section to present the development phase.

### 2.1.1 Research and Design Process

The publishing house Aldring og Helse (Aging and Health) that accepted Kramer's book introduced her to consultants with an expertise in dementia, and health personnel to expand her knowledge on dementia. Based on our interview

[25], Kramer mapped out her artistic research and production process as follows;

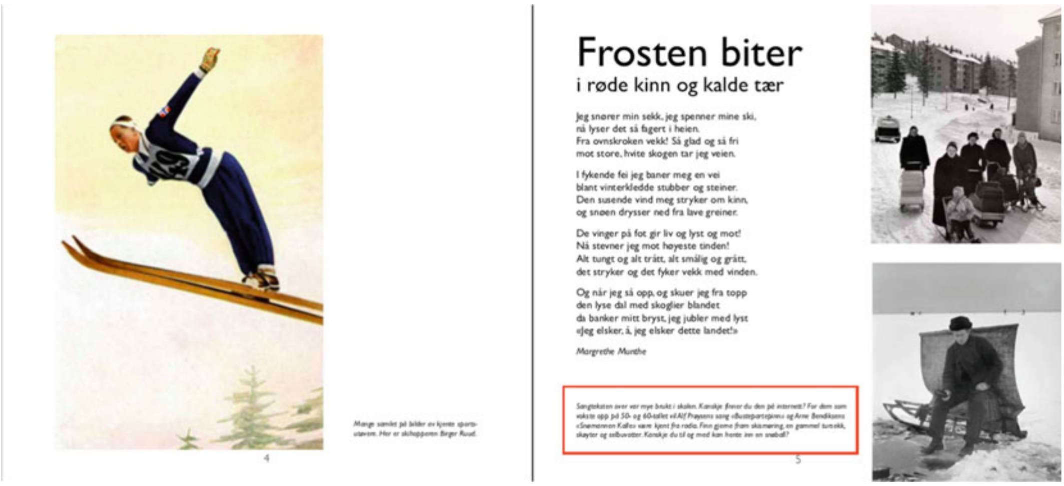
- Worked with tests of design ideas; nostalgia/romantic/playful/fact-oriented
- Ordered smell samples from specialists in printing
- Tested tactile options and their correlations with certain feelings
- Tested experience of the physical aspects: different physical formats of the book (size, weight, matte paper versus shiny paper, ease of book handling by the user and the caregiver)
- Tested different typefaces, font sizes and placement (for this phase, Kramer also contacted a typography expert in relation to people with dementia)
- Tested out image placement and compositions in the page
- Worked with color as a reflection of sensation in the photos: warmth, the sour taste of some berries, the feeling of freedom when children are playing etc.

During the research and testing phases, Kramer regularly met (8–10 meetings within 2 years) with a dementia healthcare personnel provided by the publisher to discuss design iterations. As the core audience for this project is older adults living with dementia, Kramer accompanied by a staff nurse was given permission by one of her publisher's contacts to consult with people with dementia in healthcare home located in Oslo. Kramer's visits to the healthcare home for people with dementia provided the opportunity to conduct and observe the results for the tests mentioned above. Participants were categorized into three different groups (4–5 people in each) based on the different stages of dementia: early onset dementia, people who had had dementia for a few years, and those with advanced dementia who had lost their verbal skills. Kramer observed that even a moment of happiness had a positive impact for people with dementia, especially for those in late stages and experiencing anxiety. After she completed the tests at the healthcare facility, consulted with healthcare personnel and held expert meetings, it was decided the book would include songs, film references, and photos that the people with dementia would hopefully recognize from their childhood and youth.

### 2.1.2 Target Audiences

The main target audience of Kramer's book was defined as Norwegian people with dementia born before the 1950s. The visuals were collected in a strategy to evoke the targeted audiences' memories. For instance, the picturebook starts with a photo (see Fig. 1) of Birger Ruud, one of Norway's top ski jumpers in the 1930s. While it is unlikely that the younger generations will remember or that older adults from different countries will emotionally engage with this visual, it is an image that the target group could both recognize and relate to. Despite an image relevant to a specific time and place, the picturebook nonetheless aims to engage people from different age groups and cultures by presenting the content in a manner akin to a guidebook or an instructional book on reminiscing. As mentioned in the preface of the book, co-readers from other cultures, for instance formal caregivers, are encouraged to support the reading by singing along with the music or talking about different objects, possibly making references to their own cultural background to add depth and interest to the topic being discussed. As authors of this article, we also found the picturebook to be intriguing on many levels as the content unveiled the cultural heritage of a certain era to us from another country through eloquent layouts. Not only did the content arouse our interest in the Norwegian way of life in a bygone time, it also inspired us to draw parallels and make comparisons to traditions and practices from our own backgrounds for the same era. Evidence of at least one outcome of the book that surpassed the initial design strategy. Thus, the book designed for a niche market but still manages to offer its international readers enough material from which to draw parallels between different geographies and initiate dialogue.

Since the co-reader of Kramer's picturebook is most likely the one purchasing the product, his/her mindset should also be taken into consideration.



# Frosten biter
i røde kinn og kalde tær

Jeg snører min sekk, jeg spenner mine ski,
nå lyser det så fagert i heien.
Fra ovnskroken vekk! Så glad og så fri
mot store, hvite skogen tar jeg veien.

I fykende fei jeg baner meg en vei
blant vinterkledde stubber og steiner.
Den susende vind meg stryker om kinn,
og snøen drysser ned fra lave greiner.

De vinger på fot gir liv og lyst og mot!
Nå stevner jeg mot høyeste tinden!
Alt tungt og alt trått, alt smålig og grått,
det stryker og det fyker vekk med vinden.

Og når jeg så opp, og skuer jeg fra topp
den lyse dal med skoglier blandet
då banker mitt bryst, jeg jubler med lyst
«Jeg elsker, å, jeg elsker dette landet!»

*Margrethe Munthe*

**Fig. 1** Screenshot of the spread from the picturebook (p. 4 Photo rights: Ullstein Bild; p. 5 Top: Unknown photographer, Oslo Museum; p. 5 Bottom: Photographer Anders Beer Wilse, Oslo Museum)

The main targeted readers can also buy and interact with the book by themselves -depending the level of dementia- but for the best practice of Kramer's picturebook, the target reader will be made aware of the images together with text (poetry, songs, rhymes, etc.) by the co-reader. The co-reader will be also conscious of the context by the annotation containing extra information usually located at the bottom of the page in smaller fonts. The translation below is of an instructive text (we framed in a red rectangle) under the lyrics of a song (see Fig. 1) [28] that gives a brief information and advises introducing other songs and items from the relevant decades to evoke more memories via a multisensorial experience.

> The lyrics above were widely used in school. Maybe you can find it on the internet? For those who grew up in the '50s and '60s, Alf Prøysen's song "Bustepartepinn" and Arne Bendiksen's "Snømannen Kalle" will have played on the radio. Feel free to find ski wax, an old backpack, skates, and seal mittens. Maybe you can even bring in a snowball?

These annotations are directed at the co-reader, encouraging props and additional aids to introduce multisensory experiences that Kramer believed would benefit the target audience. As the theme is winter, and text proposes presenting a snowball to trigger some interactivity and foster conversations on winter-related memories. The sensation of grabbing the icy snowball could evoke embodied memories [29] to emerge of playful games in snow. By offering these recommendations for reciprocal interaction with physical and sensory engagements, Kramer's picturebook supports the co-reader in their care of the audience in a way that enriches the shared reading experience.

When we examined the intertextuality of Kramer's picturebook, there has been a strategic selection of historical events, celebrations, pictures, customs, and texts for famous poems/songs related to the past times of the older generations being directly targeted. Moreover, the informative and directive texts create a familiarity with the content that helps the co-reader to make meaningful connections that they might otherwise not know to make. Consequently, and despite the colorful format rich with visuals, Kramer's picturebook can be easily categorized under adult reading (more specifically older adult). However, as it can be argued that this book's intertextuality can engage readers and co-readers alike, and since the co-readers can include young grandchildren, this book could fall under a "crossover" category. The definition of the crossover that differentiates it from books solely in the adult category [30] is that the content is relevant for both children and adults. Since the content in this book is directed primarily at older adults, it can be challenging to understand the content in its entirety without previous knowledge [31]. In addition to intertextual and interpictoral references, the subjects addressed in this picturebook are oriented mainly to grown-ups, definitively categorizing this picturebook for adults [32]. However, when the picturebook is regarded from the perspective of subject matter and its content, incorporating the cultural heritage of materials, performances and memories, this may expand the target group and situate this work alongside picturebooks presenting historic content. This implies that there are indeed aspects to Kramer's picturebook that put it in the crossover category after all. Marie Ommundsen believes that the distinction between crossover picturebooks and picturebooks for adults is too vague for there are to be strict boundaries, and that divisions should be based on literacy, experience, and knowledge rather than age [31]. Though it may not be homogenous among differing audiences, how visual and verbal language are utilized will be studied in the next section.

## 2.2 Design via Visual and Verbal Language: Images and Texts

In this section, we analyze Kramer's picturebook's visual and verbal content and configure how it relates to the reading experience. Each double spread generally follows a pattern of the left side (verso) with images and text and the right side (recto) with full-width images printed to the bleed. There are some variations of image and text arrangements, such as different backgrounds, to break the monotony. Kramer was consulted as people with dementia might have difficulty differentiating between images and used clear borders to separate them [25]. Thus, on those rare occasions two or three images can be seen on the same page. Kramer emphasizes images in her picturebook since images tend to have a greater success at eliciting memory than words do [33], so they might lead the selected audience to make those associations with the lived memories. The text complements the images; for instance, if the picture is of spring flowers, then the text could be a poem about spring. The informative text (located at the bottom of a page) might suggest presenting real spring flowers or gardening implements to trigger spring-related memories and start a dialogue. While each two-page spread initiates a new experience and a new topic to discuss, the content is generalized rather than personalized as it is in LSBs. Despite this difference, Kramer's picturebook and LSBs have both been carefully composed to trigger memories of the user. In Kramer's picturebook, the target audience is meant to be reminded of their own special occasions and everyday childhood experiences through photos from the past. As research on children literature shows, where picturebooks incorporate photographs or photo-based illustrations and include varied subjects, documentary value comes forth choreographed by the artist [34]. Since reality of a certain era is critical to Kramer's book, this might account for her preference for photography over illustration.

### 2.2.1 Using Photography as a Narrative

The term "photobook" applies to all types of books involving photography, even picturebooks [34], and for this reason, Kramer's picturebook can also be viewed as a "photobook." Hilde Kramer, although a picturebook illustrator, has created a narrative via photographs, sourcing them from museums, city archives. She also took staged photos herself specially for this picturebook to re-create past time periods. The placement of photos establishes meaningful connections among the images in each spread's context. The photos taken by Kramer are colorful and usually feature nature, such as flowers, fruits, animals and objects, akin to those images in a concept book. In this regard, the strategy of concept books [35] to convey their images simply and in isolation seems to be utilized here as well. Using vividly colored photos of the subject matter that accurately represents the item might support people with dementia in making the correct association. When the readers or viewers see the flower, fruit, or fruit peeler as they would appear in real life, the photo's non-verbal message might raise a memory. In one of her photos, Kramer stages and photographs flowers on the pillow (See Fig. 2) in an attempt to reenact a tradition associated with a Norwegian midsummer's eve ritual. As such, young girls place varieties of wildflowers under their pillow to dream of their future. The photo is paired with a famous Norwegian painter's work depicting a midsummer celebration and text explaining the customs associated with a typical midsummer's eve, such as lighting a fire, cooking special soups or deserts.

In each spread, visual and verbal content presents a different activity pertinent to the season as the months of year pass from January to December through the picturebook. The activities are not repetitive but quite varied and rich, conveying a palimpsest of experiences to delve into. The images include people swimming in summer, skiing in the winter, gathering for special occasions, dining, or dancing; activities that invite comparison and discussion. The varied content has the advantage of offering something for everyone since there is still enough diversity for almost anyone to find something of interest.

Kramer wanted the audience to focus on the positive memories of the past, such as camaraderie, friendships, and family rather than traumatic events such as World War II and the difficult years recovering from the war's devastation which actually coincides the targeted audience past periods. To that end, the picturebook attempts to create an overall upbeat atmosphere with bright colors, smiling people, familiar objects and nature scenes to evoke happy memories. Kramer arranged images sequentially to reflect the changing months, starting with the winter-related images of January, continuing with spring, summer, and fall to finish with Christmas and the bells ringing in a new year. This gives a natural structure to the flow of pages mimicking the months of the year and at the same time supporting an easy understanding of the page sequence of the book. Furthermore, holidays are emphasized in the picturebook, such as Easter, midsummer celebrations, and Christmas, as memories around special occasions and gatherings might have made a lasting impression. In each spread, the images and texts are selected to complement each other and the subject. For instance, (See Fig. 3) when the theme is childhood and play, the selected images are children biking and swinging together in fond moments that reflect joy and motion. The accompanying text is a Norwegian nursery rhyme often used to decide the child who would be "it" in a game such as hide-and-seek.

Midtsommers-
feiring

Midtsommernatta ble feiret forskjellig vis.

Dagen markerte at sommeren var i gang og det var lov å gå barbeint i gresset.
På kvelden var det vanlig å tenne bål.
Mange hjalp til med slåtten.

Suppe av brennesle eller karvekål var både næringsrikt og godt.

Server gjerne rabarbragrøt med fløte eller en nystekt vaffel med rømme.

23

**Fig. 2** Screenshot of the spread from the picturebook (p. 22 Painting by Nikolai Astrup (Midsummer Eve Bonfire, 1904–1917). Rights: O. Værings Eftf.; p. 23 Photographer Hilde Kramer)

Vil du bli med ut og leke?

GAMLE REGLER

Akka bakka
bonka rakka
etla metla
sjong dong
filli fong
issa bissa topp.

En gul knapp
virre virre vapp
du slapp!

Ole Dole Doff
Kinkliane koff
Koffliane birkebane
Ole Dole Doff.

14

**Fig. 3** Screenshot of the spread from the picturebook (p. 14 Photographer unknown, Oslo Museum; p. 15 Photographer unknown, Oslo Museum)

The rhyme consisted of nonsensical but entertaining words, "Akka bakka bonka rakka," that the reader might still remember. Rhymes have long been used in children's literature to foster learning and memory, and when we look at rhymes in different eras, we often find that they were used to facilitate easy recall and memorization [36, 37]. The photographic narrative combined with the childhood rhyme in this spread (see Fig. 3) is meant to evoke a reminiscence of childhood that hopefully elicits happy memories for the readers.

### 2.2.2 Format

As mentioned in the section on process (Sect. 2.1), Kramer assessed the efficacy of various formats and stimuli on test groups of older adults with dementia, her core audience. Kramer observed that each individual's personal experiences and their degree of dementia would determine how much they would benefit from the picturebook. Even some of those with advanced dementia reacted positively to the stimuli, which convinced Kramer to pursue her project. A variety of the most popular songs, poems, and rhymes that would best suit the images and serve the various preferences of the readers and create diverse reflections in their minds were selected. Different-sized sanserif fonts are used to demarcate the main text areas from the informative text areas where smaller font sizes are used, while the titles are in large, bold font.

Though the text contributes to the overall message, the visuals are expected to draw more attention from the targeted audience. Studies on human memory have found that pictures are more easily remembered than words as the visual materials employ various representations and evocations that require detailed encoding during the memory process [33, 38–40]. Although the mechanism of processing words and pictures is found to be similar, the levels of activity in the related regions of the brain while processing differ [33]. The reason why words are being recalled inferior to pictures could be related to the qualitative differences in encoding pictures managed by the more efficient engagement of areas that are important for visual memory [33]. Thus, positioning the visuals as focal points of the page would better serve the targeted audiences for recalling memories. Yet, the capacity of these visuals to trigger memory could be furthered with interactive exchanges and multisensorial experiences during shared reading.

## 2.3 Tapping into Interactive and Multisensory Exchanges

It can be argued that Kramer's work, with its verbal and visual elements, suggests an interactive and multisensorial experience that its picturebook format cannot deliver as a fait accompli. Instead, the informative texts are offered as instruments that explain how to set these interactions in motion using senses such as audio, taste, smell, and haptic experiences. For instance, (See Fig. 4), the left-side page has a photo of food and an accompanying text dedicated to the importance of being grateful and praying for food. The right-side page has a full-color image of hands peeling an apple that might remind readers of the motions in this action. In the sense-oriented images such as peeling an apple, Kramer's photo is cropped to focus on the hands and object, purposely omitting the face so the reader can focus on the situation and not become distracted or confused by an unfamiliar face [25]. To simulate the photo of an apple being peeled, it is recommended in the informative text area that the co-reader/ caregiver provide kitchen utensil for people with dementia as holding the familiar objects can stimulate memories in conjunction with reading. In fact, activity reminiscence therapy often encourages people with dementia to use old-style tools that they are familiar with from their past experiences [41]. Related study have pointed the importance of galvanizing people with dementia through activities that they formerly engaged in that give them a sense of empowerment that increases their confidence [41]. Here, interacting with the given object might also support the audience's recall of those memories associated with taste. Besides, the informative text suggests laying a table with hard cheese, sour milk, lefse (a traditional soft Norwegian flatbread), foods that would likely be familiar to older Norwegian generations to trigger related memories. The relation between taste and autobiographical memory (together with smell-memory, touch-memory, sound-memory) was primarily pointed out by Marcel Proust in his literary work "In Search of Lost Time" [42], which then the scientific explorations verified the concept as the "Proust Effect" [43], commonly associated with smell- memory relations. Yet, many studies have been working on the correlation between smell and memory [44–47], which was also Kramer's initial concept: integrating olfactory in her picturebook. Instead, Kramer arrived at the concept of offering tips (bringing flowers, preparing foods, interacting with objects, etc..) to the co-reader to mediate interactivity and support a reader's recollections that may be supported by

Takk for maten!

Gud signe maten på vårt bord,
og mette kvar ein munn på jord.
Gud signe oss med Faderhand.
Gud signe heim og folk og land.

Gledens Herre, vær vår gjest
ved vårt bord i dag!
Gjør vårt måltid til en fest
etter ditt behag.

30

**Fig. 4** Screenshot of the spread (page 30–31) from the picturebook (p. 30 Photographer Thorleif Wardenær, Oslo Museum; p. 31 Photographer Hilde Kramer) multisensorial experiences. So, while the picturebook itself lacks the smells, sounds, and tactility to initiate multisensorial occasions, it is a vehicle for different sensory interactions via embodiment of instructional texts and set dialogues.

It has been found that integrated multisensorial features for tangible interactions such as combining pictures with sound or touch with digital system tend to increase engagement of people with dementia [8]. A parallel study which integrates sound with pictures in a tangible multimedia book format shares similar result [9]. Besides, it highlights the importance of familiarity as the used technology for sensorial interactions should be obscured [9]. This way, people with dementia (especially older ones) can easily interact with the familiar forms they used to know. Though the interactivity in Kramer's picturebook is not tangible or visible, the verbal instructions/suggestions of activities support the co-reader to set up multiple interactive sensory experiences. From this regard, Kramer's strategy has the potential of serving for better outcomes in relation to familiarity and being more tailored to people with dementia if the co-reader assists as presumed. For this, we will look into the importance of co-reader's (ex. caregiver or a friend) encouraging attitude during reading in the next section.

## 2.4 Empowering Intergenerational Relationships via Shared Reading

While Kramer's proposed instructions in this picturebook provide interactivity through suggested multisensorial elements and conversation, a secondary effect has emerged: a bridge between generations and cultures. As discussed in previous sections, co-readers of Kramer's picturebook may be from significantly younger generations or other cultures. Hilde Kramer explained that in Norway, taking care of elders has been privatized, and since many caregivers are from different cultures, the possibility of sharing the same memories decreases. Kramer hoped that this picturebook could help create connections and build "bridges" between different parties that would support intergenerational relationships and cross-cultural experiences, empowering people with dementia and co-readers alike. Since the contents of Kramer's picturebook is tailored to older adults, the idea is that they can expand on the topics related in the photos and verbal narratives and share their knowledge with their co-readers. In doing so, older adults' active participation in aforementioned communicative incidents builds their self-confidence which improves their well-being [41]. At the same time, the co-reader might enjoy learning about older adults' memories of past experiences, celebrations and customs. Thus, Kramer's picturebook adding layers of information into the content supports both parties by providing an opportunity for learning together.

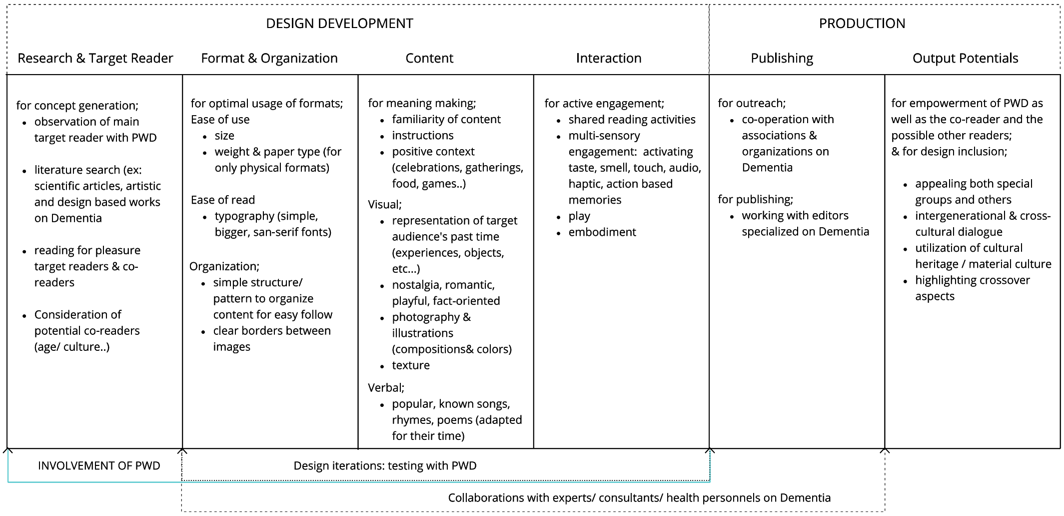
Picturebooks have rich multi-layered semiotic (verbal and visual) content that help readers of any age approach the subject matter in their own way [48]. For instance, targeted readers or co-readers might view the photos and texts in Kramer's picturebook from different perspectives and contribute new knowledge or experiences to the other. While the photos represent a particular time, the conversations they initiate differ depending on the reader groups. In one study, photographs which are composed depending on old age participant's narratives, have been found to successfully initiate dialogue with younger students while simultaneously fostering intergenerational understanding [49]. Following this line of reasoning, it can be inferred that the photos in Kramer's picturebook have the potential to create a playground for intergenerational dialogues. In this regard, this picturebook keeps a valuable record of a certain time and place reflecting a disappearing generation's experiences and history. Kramer's picturebook is a compilation of historical experiences, objects, verbal expressions creating a nostalgia for a bygone era and cultural heritage. According to Jane Wattenberg, “Photobooks are time capsules” [34], and Kramer’s picturebook with many photos of Norwegian life in the past can evoke a sense of time travel by encapsulating memories. A picturebook can successfully serve as an object of cultural heritage and in sum an “artefact of culture that contains visual images and often words” [50].

## 2.5 Design Considerations for Picturebooks in the Context of Dementia

In this section, we summarize the steps and design strategies while designing a picturebook created as a shared reading and viewing experience for people with dementia which can both work for physical and digital formats. The considerations suggested are mainly based upon Kramer’s non-fiction picturebook developed for older people with dementia, but also might be applicable for other age groups with dementia.

Design considerations of making a picturebook for older people with dementia are listed in the table (see Fig. 5) and are briefly explained below.

- Research should involve the main target reader and consider shared reading (children-adult or adult-adult), the generation gap, and culturally different backgrounds. The content should be adapted to the main target audience (adjusted for readability and familiarity) and take account of the potential co-readers.
- Guiding the co-reader to trigger dialogue and interactivity will extract a deeper meaning from the content and enjoyment for everyone involved.
- Integrating multisensorial interactions can increase engagement, embodied by the co-reader or embedded in the output.
- Content should be selected according to the main target readers’ date of birth in order to refresh certain memories, reflecting experiences, materials, etc. Nurturing positive emotions, organized in a simple way while not losing the artistic value may be prioritized.



| DESIGN DEVELOPMENT | | | | PRODUCTION | |
|---|---|---|---|---|---|
| Research & Target Reader | Format & Organization | Content | Interaction | Publishing | Output Potentials |
| for concept generation;<br>• observation of main target reader with PWD<br>• literature search (ex: scientific articles, artistic and design based works on Dementia<br>• reading for pleasure target readers & co-readers<br>• Consideration of potential co-readers (age/ culture..) | for optimal usage of formats;<br>Ease of use<br>• size<br>• weight & paper type (for only physical formats)<br>Ease of read<br>• typography (simple, bigger, san-serif fonts)<br>Organization;<br>• simple structure/ pattern to organize content for easy follow<br>• clear borders between images | for meaning making;<br>• familiarity of content<br>• instructions<br>• positive context (celebrations, gatherings, food, games..)<br>Visual;<br>• representation of target audience's past time (experiences, objects, etc...)<br>• nostalgia, romantic, playful, fact-oriented<br>• photography & illustrations (compositions& colors)<br>• texture<br>Verbal;<br>• popular, known songs, rhymes, poems (adapted for their time) | for active engagement;<br>• shared reading activities<br>• multi-sensory engagement: activating taste, smell, touch, audio, haptic, action based memories<br>• play<br>• embodiment | for outreach;<br>• co-operation with associations & organizations on Dementia<br>for publishing;<br>• working with editors specialized on Dementia | for empowerment of PWD as well as the co-reader and the possible other readers;<br>& for design inclusion;<br>• appealing both special groups and others<br>• intergenerational & cross-cultural dialogue<br>• utilization of cultural heritage / material culture<br>• highlighting crossover aspects |

**Fig. 5** Considerations of Picturebook design for older people with dementia

- Design iterations and collaborations with related partners are important. Designs should be tested with the target audience, and design decisions should be reached in consultation with health care personnel and experts in dementia for a better outcome.

## 3 Conclusion

In this study of Hilde Kramer's picturebook, *Minner i Bilder* (Memories in Pictures), we presented an example of how images of a certain time period with an emphasis on daily lived experiences might trigger memories in people experiencing dementia. We examined the visual, verbal and interactivity aspects of Kramer's work as well as her design approach to evaluate the potential benefits of tailormade picturebooks for older adults with dementia and discussed the implications of shared reading for intergenerational co-operation and cross-cultural understanding. Based on our case study, works produced in the future coupled with multisensory considerations, may have the potential to bridge the cross-cultural and intergenerational gap and reach even broader audiences through shared reading experiences of cultural heritage and materialities. Our findings in this study synthesized with research highlight how tailor-made picturebooks for people with dementia can cultivate opportunities for shared reading for both sides, foster intergenerational relations, and advance cross-cultural communications. Through their artistic and informative affordances, picturebooks might heighten pleasurable and sustainable engagement through sensorial interactions for the well-being of people with dementia and caregivers while empowering both parties via exchanging knowledge and joy. The study also highlights the importance of designing in collaboration with related partners and users to create an appealing book, meeting the needs of a special targeted reader group as well as embracing wider audiences.

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# Designing for People with Dementia: A Portuguese Case Study

Cláudia Raquel Lima and Eliana Penedos-Santiago

## Abstract

This article reports design practices for People with Dementia carried out within a curricular context between September 2021 and January 2022. The project was developed from a collaboration between Alzheimer Portugal, and the Lusófona University, Porto, through the Communication Design BA. Based on the case study of the Memória de Mim Day Care Centre (a service from Alzheimer Portugal), it aimed to create signage and cognitive stimulation materials inspired by Portuguese culture and biographical components of the Centre's users. Research has shown the need for design intervention in the creation of artefacts aimed at People with Dementia, given the scarcity of materials in this area in Portugal. This project is a starting point to fill this gap in the Portuguese market, while aiming to introduce contents in the field of Social Design to design students, an area less addressed in current courses. The materials developed benefited the Centre's community, contributing to cognitive stimulation activities and moments of sociability among users with dementia. The project also benefited the students by providing a real work context and highlighting the importance of their role in society as designers. A larger project is now under study, integrating various Alzheimer Portugal services and university contexts, aiming to research and create further cognitive stimulation artefacts targeted at People with Dementia in Portugal. We believe that a more focused study on biographical components and vernacular culture of these people will contribute significantly to improve their health and well-being.

## Keywords

Alzheimer Portugal · Design for People with Dementia · Social design · Cognitive stimulation materials

## 1 Introduction

Since 2018, design projects oriented towards social issues have been developed within the scope of the Design Lab curricular unit, a subject of the 3rd (and last) year of the Communication Design degree of the Lusófona University, Porto,

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Portugal. The Program of this degree is mostly oriented to the market context, with no subject oriented towards Social Design, which indeed is common to most design BAs in Portugal [1]. This may be due to the fact that the concept of design emerged in a market context, leading courses to be more oriented towards practices in this field. As referred by Margolin [2], this concept is different from what is understood as Social Design "exercised towards the satisfaction of human needs" arising from situations such as population ageing, social inequalities, disability, environmental issues, among others. Indeed, and in line with theories by authors such as Morris [3], Papanek [4] and Margolin [2], it is our belief that design can play a key role in creating solutions to social problems, and as a contribution to achieving the Sustainable Development Goals adopted by the United Nations in 2015 [5].

Therefore, it was decided to dedicate this subject to practical projects for local social needs. Along with a Program that envisages training students for the workforce, it is our aim to highlight the importance of social innovation as a fundamental field of application for the area of design while educating attentive, participatory, and responsible designers regarding the planet's sustainability and human needs.

Prior projects within Design Lab subject were developed in partnership with Portuguese Red Cross, through the local Delegations of Vila Nova de Gaia and Matosinhos, and with Eu Sou Eu—Associação para a Inclusão Social de Crianças e Jovens (Association for the Social Inclusion of Children and Young People), an institution that aims at the inclusion of children with trisomy 21 and other disabilities, as well as children and young people who are experiencing problems. The outcomes of these projects included campaigns to raise awareness of the social role of these institutions and their areas of intervention, campaigns to promote the engagement of society in their actions through volunteering and membership, campaigns to raise funds, and promotional materials to disseminate activities and actions developed by these institutions [1, 6]. Although these projects made a very positive contribution to the partner institutions and their users [6], they focused primarily on the needs of the institutions themselves.

In the 2021–22 academic year, we have decided on a different approach by targeting projects towards the needs of People with Dementia. A partnership was established with Alzheimer Portugal association to carry out a project focused on the users of one of its services: the Memória de Mim Day Centre. The option to act for People with Dementia was essentially due to two factors: (1) the high percentage of People with Dementia in Portugal, a problem that is expected to worsen significantly in the coming decades; (2) the fact that there are few materials and artefacts in Portugal oriented for this audience.

Portugal is the 4th OECD country with the highest rate of People with Dementia, with more than 20 cases per 1000 inhabitants [7]. In 2018, dementia cases in Portugal exceeded 193,000. Given the increase in life expectancy in the country, the number of People with Dementia is estimated to exceed 340,000 by 2050 [8]. The most prevalent symptoms of dementia include "memory loss; difficulty performing familiar tasks; problems with language; disorientation in time and place; poor or decreased judgement; problems with concentration, planning or organising; misplacing things; changes in mood or behaviour; trouble with images or spatial relationships; withdrawal from work or social activities" [9].

Recent research has shown that non-pharmacological treatments are effective in improving cognitive function and quality of life with positive outcomes among people with mild to moderate dementia [10, 11], namely the Cognitive Stimulation and the Sensory Stimulation Therapies [12, 13]. Still, according to Pereira, Sousa, and Nunes [14], "in Portugal, there are no widely used non-pharmacological effective interventions to ameliorate the symptoms of dementia and improve quality of life, as the ones available frequently require special equipment or user licences".

Several authors have argued that a determining factor of these therapies, is the implementation of activities focused on people, their personhood and remaining abilities, their life experiences and, therefore, on their culture and vernacular traditions [14–16].

Alzheimer Portugal is the only organisation in the country created specifically to promote the quality of life of People with Dementia and their relatives and carers. Its vision is a society that integrates People with Dementia and their carers and the recognition of their rights. It acts according to the principle of the person-centred approach and the absolute respect for the right to self-determination. Its mission includes informing, supporting, and empowering those living with the disease and those providing care and guiding them to the answers that exist in the community. Moreover, it offers a set of responses that include a residential home for the elderly, day care centres, home support, a helpline; and services such as psychological counselling, cognitive stimulation sessions, occupational therapy, physiotherapy, among others [17].

Memória de Mim Day Centre is a service from the North Delegation of Alzheimer Portugal specialized for people with Alzheimer's disease and other types of dementia, providing a range of therapeutic activities, with the aim of stimulating the remaining cognitive, psychomotor, and sensory skills. As reported by the Director of the Centre, the materials they use in these activities, when purchased from specialized companies, are expensive and do not reflect biographical and cultural aspects of the users (they are often imported) and therefore it is common for the professionals themselves to develop materials in amateur fashion in software such as PowerPoint.

## 2 Methodological Approach

Between September 2021 and January 2022, 9 students from the 3rd year of the Communication Design degree at the Lusófona University, Porto, participated in the project carried out for Memória de Mim Day Care Centre. The students were in their early 20s and included 2 male and 7 female students. 6 students worked in groups (2 students per group) and the other 3 held individual projects. The project extended over 15 3-hour sessions, one per week, with a two-week break over the Christmas period.

The sessions were all in person, with the exception of the first session, dedicated to the presentation of the project by the Technical Director of Memória de Mim Day Centre, which had to be held online due to restrictions arising from Covid-19. This session included a contextualization of dementia, statistical data on the incidence of this disease in Portugal, an overview of the most prevalent symptoms of dementia, the role and mission of Alzheimer Portugal and main services provided to People with Dementia, their carers and families. This was followed by a brief presentation about Memória de Mim Day Care Centre, the services it provides and activities it develops with its users, as well as the main characteristics and prevalent symptoms of those who attend this Centre. The session ended with the presentation of the project proposal, which was configured in two possibilities:

- Study of signage materials for the Day Care Centre
- Study of cognitive stimulation materials based on biographical and cultural characteristics of the Centre's users

The focus on biographical components and Portuguese culture was highlighted given the recognised importance of these elements in cognitive stimulation activities and the scarcity of materials in this field in Portugal.

In the following weeks, a seminar was organised with Rita Maldonado Branco, a researcher from ID+—Research Institute for Design Media and Culture (University of Aveiro), specialised in design studies for People with Dementia: her research explored communication design contributions to dementia including design practices to support the maintenance of social relationships and communication between People with Dementia and their families, and their involvement as participants in co-design processes [18]. Branco's PhD and MA research were focused on these subjects which were taken forward in subsequent research at ID+—Research Institute for Design Media and Culture, and on the research group Health +

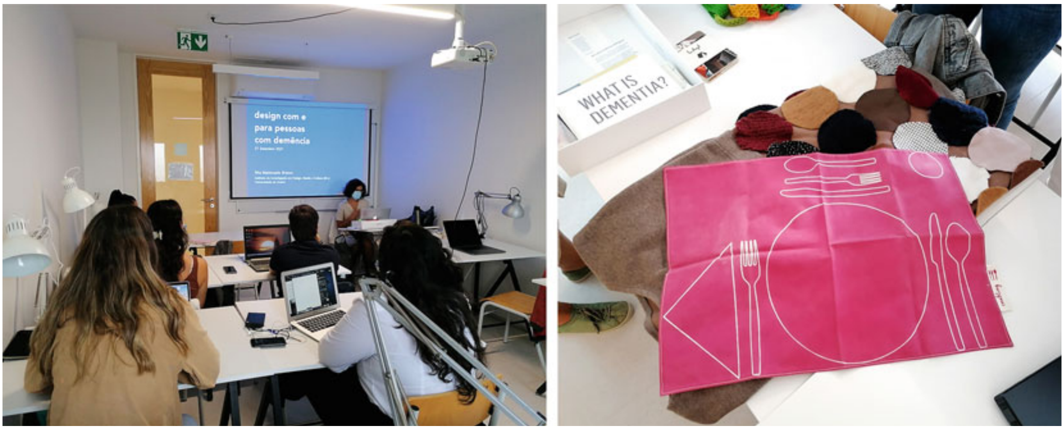

**Fig. 1** Presentation by Rita Maldonado Branco at the seminar held on 27 September 2021 at Lusófona University, Porto, and materials developed with and for People with Dementia during her Master and PhD research

Design Lab (HEAD). Her presentation to students was based on methodologies applied in her research, difficulties experienced in the research process, considering the particularities of the audience under study, successful aspects, and outcomes, namely a set of artefacts created for and with People with Dementia (Fig. 1). Moreover, a set of bibliographical references of her work were suggested including Branco [18, 19], and Branco, Quental, and Ribeiro [20–22].

The following sessions were devoted to further research on this subject and searching for existing cognitive stimulation materials and signage materials. Due to the lack of Portuguese websites and companies dedicated to materials for People with Dementia, much of the research resorted to foreign websites. Hence, the search included websites such as Relish[1]; projects by Association France Alzheimer (such as Memorama); the Fátima Muñoz Einerun project, with a set of cognitive stimulation exercises; the MA research of Maria Millan Escasany [23], *Hem estimat la vida: una història sobre l'Alzheimer*, an editorial project aimed at the preservation of memories focused on the life story of an Alzheimer's patient; among others.

Moreover, some students conducted informal interviews on their own initiative with professionals working with People with Dementia; and further information was collected about the users of the Memória de Mim Day Care Centre, namely, data on where they were born or where they live, their former occupation, favourite hobbies, favourite dishes, particular interests.

In these sessions, which extended over a month, the findings of the research process and possible ways to approach the project were continuously discussed in group between students and teacher. It was important to share and discuss findings between peers, difficulties experienced in the research process and possible ways to overcome them.

By the end of October, the first ideas were outlined, and different design approaches were experimented. In this phase, oral interim presentations were held every three weeks, requiring students to reflect on the work process and results obtained so far to better communicate the project. In these sessions, each project was carefully analysed by the teacher and students, and issues related to usability, accessibility, safety, and project viability were raised.

In November prototypes of signage and cognitive stimulation materials were produced. As these prototypes were being developed by the students, they were presented to the Centre's Technical Director to assess the suitability of the projects to the characteristics of People with Dementia (and to the Centre's users), as well as issues related to usability, accessibility, and

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[1] https://relish-life.com/.

safety. By the end of this month, a session was also held with the researcher Rita Maldonado Branco for project analysis and discussion. In this session, Branco met with the authors of each project and analysed in detail their work, with particular focus on functional issues. The input of the Centre's Technical Director and Rita Maldonado Branco were both of great importance for the project: the first due to her professional knowledge and experience as a therapist and Technical Director of Memória de Mim Day Care Centre; the second due to her expertise as a researcher and designer who has been working for and with People with Dementia over the last decade.

In January, the project was concluded with an oral presentation of the outcomes to the Centre's Technical Director which included a set of prototypes of the materials produced, later made available for use at the Centre. Not all projects were physically prototyped due to financial constraints. Certain projects were only virtually simulated through mock-ups.

The work process and outcomes, achievements, and weaknesses, were later discussed between teacher and students. It was important to understand the students' perception of working with a real client on the one hand and contributing to a response to a social issue on the other. In addition, as neither the teacher nor the students had worked for People with Dementia before (and looking forward to continuing this project in subsequent semesters), it was of utmost importance to draw conclusions from the work process and outcomes.

These issues, along with the impact that the developed projects had on the users of the Memória de Mim Day Care Centre were also discussed with the Centre's Technical Director and the researcher Rita Maldonado Branco in individual sessions led by the project's teacher. These sessions were crucial for the project's conclusions and to determine which aspects should be improved in future projects, as it is intended to continue this partnership between academia and the Alzheimer Portugal association.

## 3 Project Outcomes

From the research carried out with students, it was evident the absence of materials (especially cognitive stimulation materials) specifically targeted at Portuguese People with Dementia. There is one specific online platform in Portugal—Replicar[2]—dedicated to the training of technicians working with the elderly population and mental health which offers a limited range of cognitive stimulation products, hardly focused on characteristics of Portuguese culture. There is also an online service—COGWEB[3]—which provides remote cognitive training for a wide audience (from children to senior citizens), including People with Dementia, which is a paid service that, despite allowing personalised plans, does not consider user's life experiences, vernacular culture, or traditions.

Occasionally, other initiatives were found, such as the ReSense project which, together with the Associação Tempos Brilhantes, develops workshops with the community of the Almeirim and Chamusca municipalities[4] aimed at creating kits of artefacts for sensory and cognitive stimulation from recycled materials; Humanamente[5] with cognitive and sensory stimulation products, part of them imported and in a foreign language, others produced by themselves in an artisanal fashion; or Gerontologicamente Activo[6] with cognitive stimulation materials produced by their therapists with an apparent absence of intervention from design experts.

Indeed, it is clear in most of the materials from these initiatives, especially those focused on Portuguese culture, the lack of design intervention resulting in a poor image and frequent problems related to usability and accessibility. This was in fact confirmed by the Technical Director of the Memória de Mim Day Care Centre who revealed that, given the scarcity of materials in this field for Portuguese People with

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[2] https://www.replicar.pt.

[3] www.cogweb.pt.

[4] Municipalities located in the centre of Portugal.

[5] https://humana-mente.pt.

[6] https://www.facebook.com/gerontologicamenteativos.

**Fig. 2** Seasonal illustrations to be placed in the center's kitchen by Alexandra Sayenko (Bolo Rei, a typical Christmas cake; Pão de Ló, a typical Portuguese sponge cake for Easter or Christmas; Chestnuts, fruit of the Autumn), 2022

Dementia, and the lack of human resources specialised in design, many of the cognitive stimulation materials used at the Centre were created by the therapists themselves with software such as PowerPoint.

Hence, this became the great challenge to students: the creation of cognitive stimulation materials based on biographical and cultural characteristics of the Centre's users and signage materials for the Day Care Centre, also considering biographical and cultural features of the users. Considering the results of the research process, interviews and information gathered, namely about the Centre's users, students developed a set of proposals focusing on aspects such as personhood, life experiences and vernacular culture of the target audience.

One of the signage projects was the creation of a system to identify the users' lockers, based on biographical aspects identified in the interviews. Each locker was decorated with a set of illustrations allusive to its owner's personal interests and favourite activities. These illustrations not only reinforced the user's self-identification (complementary to his/her name, also displayed in the locker), but also encouraged the sharing of stories about the content and meaning (for the user) of each illustration displayed.

Other two signage projects were also based on sets of illustrations. One of them was developed to identify the different spaces of the Centre (e.g., kitchen, rest room, lounge area). The other project consisted of several illustrations alluding to year seasons to be displayed in frames around the Centre on a rotating basis, according to the season of the year in which we are (Fig. 2). These illustrations included seasonal fruits common in Portugal (such as kiwi, figs, strawberries, or chestnuts) and traditional elements alluding to festive seasons (such as Bolo Rei, a typical Christmas cake, or Manjerico, a potted plant symbolising Saint John's Day). Therefore, this signage project was not limited to the identification of spaces/areas (the reinforcement of orientation in space), but also sought to reinforce orientation in time (year seasons) and memory stimulus (which element is associated to which season).

Other projects have been developed within the framework of cognitive stimulation materials based on Portuguese culture and users' life experiences. These included a puzzle with simplified illustrations of two iconic places in the city of Porto meaningful for the users: the Clérigos Tower, at the historical centre of Porto, and the Dom Luís I Bridge, a double-deck iron arch bridge that crosses the Douro River connecting the cities of Porto and Vila Nova de Gaia. Considering the different remaining abilities of the Centre's users, 3 versions of each puzzle were created, varying in the number of pieces: 6, 12 and 18 pieces.

A Goose Game[7] was designed specifically for Portuguese People with Dementia. This game includes a board with a spiral shape divided into 43 numbered spaces distinguished by a palette of 6 colours and corresponding sets of cards (Fig. 3). These colours indicate the activities to do each time a player reaches one of these coloured spaces: for example, on reaching the yellow space, the player collects a yellow card, reads the activity proposed on that card and tries to do it. The yellow spaces and cards relate to life experiences (childhood stories, holiday memories, professional experiences, memories of friends and relatives); the red ones address food-related topics (food they like or dislike, favourite dessert, mealtime schedule, local traditional dishes); the blue ones propose players to complete popular sayings; the green ones are focused on music subjects (encouraging the singing of certain traditional songs or questions such as favourite music, singers liked/disliked, music styles); the white spaces and cards only give an indication of the number of spaces to move forward or backward (no specific activity related); and the black ones suggest the player to choose himself/herself a theme to address. Hence, this Goose Game was designed to encourage greater interaction and socialisation between users through the sharing of personal life stories and memories and resorting to cultural subjects and vernacular traditions. Moreover, the game includes one die and 4 pawns larger than those in the original game, to facilitate its use by users, considering their limitations due to dementia.

Based on similar premises, a Bingo Game was adapted to People with Dementia while including cultural themes (Fig. 4). The numbers of the traditional game were replaced by illustrations addressing 4 categories related to Portuguese culture and biographical components: local heritage, through monuments, objects and symbols such as the Rooster of Barcelos, Portuguese tiles or Portuguese Guitar; traditional festivities, represented through objects or symbols typically associated to them, such as Manjerico for Saint John's Day, Pão de Ló for Easter or Christmas, or 12 sultanas for New Year's Eve; occupational activities, focusing on traditional Portuguese occupations, such as the fisherman, a Fado singer or a varina[8]; seasons of the year through objects and foods that in Portugal are usually associated with each season, such as figs for Summer, chestnuts or marmalade for Autumn.

The game consists of scorecards with combinations of illustrations and calling cards, each with one of these illustrations. Two versions of this game were designed to provide two distinct levels of difficulty for a more inclusive activity: one with scorecards with combinations of 4 illustrations, the other with scorecards with combinations of 8 illustrations. The calling cards are inserted into a cloth bag at the beginning of the game and drawn one by one during the course of the activity (as in the traditional Bingo Game). Additionally, neutral colour cards were created with the size of each scorecard illustration to fully cover the ones already drawn and found on the player's scorecard. These cards were developed as an alternative to the traditional pieces (or beans, in the case of Portugal) that are used to mark illustrations/numbers already drawn, considering the particularities of People with Dementia. By fully covering each illustration, they enhance the perception of the elements that are still to be drawn.

Although the main objective of this game is to stimulate memory through a cognitive recreational activity, by focusing on aspects so characteristic of Portuguese culture and traditions (some of them ancestral), it will inevitably act as an activity that promotes the sharing of stories and memories, fostering interaction and socialisation among users.

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[7] Goose Game is the English name used for the game in Portugal called Jogo da Glória. It is a game widely used by Portuguese children and is deeply rooted in our culture.

[8] Varina is a Portuguese female fish peddler, usually associated with the regions between Aveiro and Porto.

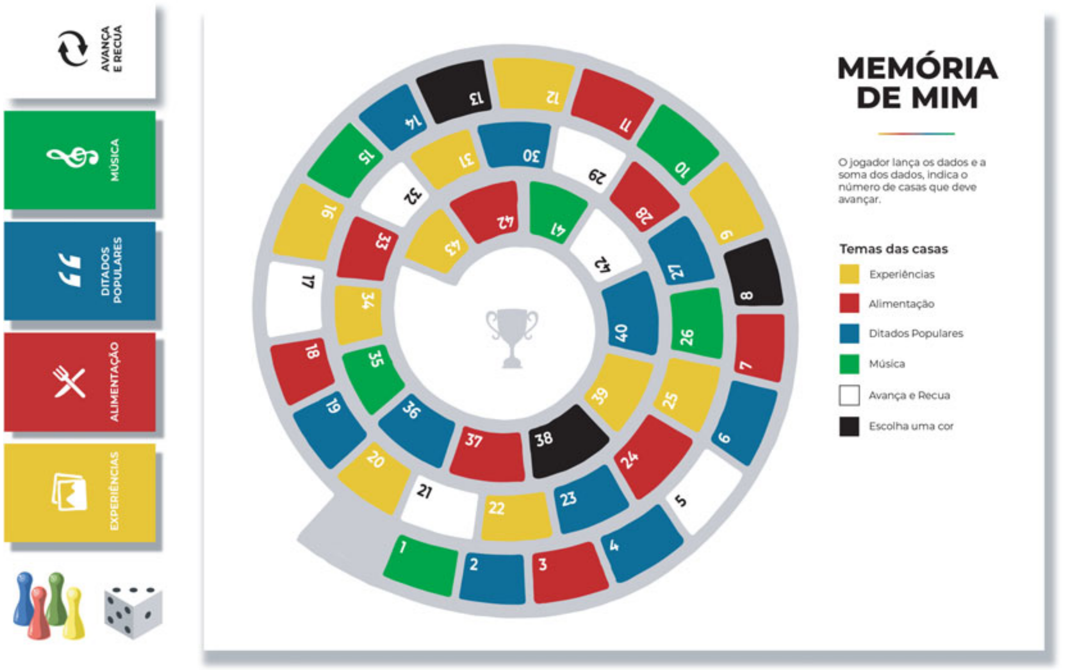

**Fig. 3** Goose game by Anabela Thomé and Diana Cruz, 2022

**Fig. 4** Bingo game by Mafalda Marinho, 2022

Finally, an editorial project was also developed: a colouring book addressing biographical and cultural aspects of the Centre's users (Fig. 5). Each spread of this book had an illustration to be coloured of a monument or site related to the user's life experiences, such as Serralves Museum, Crystal Palace Gardens, Clérigos Tower, the Dom Luis I Bridge, Douro

**Fig. 5** Colouring book by Anna Le Floch and Lara Guivarch, 2022

Vineyards, or Bom Jesus do Monte Sanctuary (in Braga city). For each illustration, an area was created for users to write/share the stories lived in that place, and to identify the colours, sounds, smells, tastes, and textures that they associate with it. Moreover, the book is complemented by a set of sounds for each illustration (supplied on a flash drive), recorded at each location aiming for a greater immersion of the user in the place depicted and subsequent stimulation of his/her memory. Hence, this book provides moments of relaxation through the colouring of the illustrations, memory stimulation through activities proposed and resorting to the 5 senses, and sensory stimulation through the sounds of each place. Furthermore, by recognizing the places portrayed, users may feel encouraged to share stories experienced there.

## 4 Discussion

The projects developed were presented in January 2022 to the Technical Director of Memória de Mim Day Centre and were highly appreciated. According to her, all the projects corresponded to the proposal initially made, and there were cases in which a greater concern became evident in targeting the materials to the specific characteristics of the Centre's users and not only to the characteristics of Portuguese People with Dementia.

It also became clear the students' concern with issues of usability and accessibility through their options in the selection and scale of materials, the fonts used and letter sizes, or through the simplification of shapes in illustrations, particularly those intended for colouring. However, it was noted that some illustrations in the colouring book may still be complex for certain users with greater limitations.

There was a strong interest by students in including information about people's life stories and personal interests, resorting to the data collected in the interviews with professionals from the Centre. Furthermore, students became aware of the different abilities of the users providing distinct levels of participation in the materials created, i.e., there was a great concern that the experience should not eventually become something that people felt assessed and questioned about their abilities. Additionally, part of the cognitive activities could be played individually or in groups aiming at greater inclusiveness.

Some of these materials have already been tested with the Centre's users. This testing phase was not done in the presence of the students since visits to the Centre are still very limited due to the pandemic. Therefore, the tests were carried out by the Centre's professionals during their daily activities and later communicated to the project teacher.

According to the Centre's Technical Director (personal communication, February 7, 2022), the Bingo Game has been much appreciated and has provided moments of engagement and sociability among users. The illustrations were praised by them, the game dynamics were well understood, and its operationalization proved to be functional and practical considering the characteristics of People with Dementia. Emphasis was placed on the provision of neutral-coloured cards to cover the illustrations of the drawn boards, an element which worked considerably better than the solutions offered by similar games available at the Centre.

The seasonal illustrations have already been applied to the frames of the Centre. At the time of its application, the therapists questioned the users on the identification of the elements represented. The elements were correctly identified with the exception of the asparagus illustration. When users were asked what it was, most of them answered that it was a plant. According to the Centre's Technical Director, this could be justified by the fact that asparagus is better known nowadays than in past generations, more striking to the Centre's users. This issue highlights the importance of direct contact between designers and users in the research phase of the project (the phase that will lead to the development of ideas) but also the need for usability tests with users. Indeed, the projects were discussed with the Centre's professionals, but they were not tested with the users during their development given the short time for project development and the difficulty in accessing the Centre's users due to the restrictions arising from Covid 19. Apart from this issue, it was reported that the illustrations were much appreciated and praised by the users.

The other projects have not been tested by users as it has not yet been possible to create prototypes that meet the necessary safety and quality requirements. Indeed, possible forms of project funding are now under study, either through patronage for the production of the materials developed by the students, or through government funding that allows the continuation of this research for the creation of other cognitive stimulation materials.

## 5 Conclusion

The partnership created between Alzheimer Portugal, through the Memória de Mim Day Care Centre, and Lusófona University, Porto, through the Communication Design BA, had a very positive impact, both for students and for the Centre.

For the students it provided an experience in a real context through a social project that confronted them with a reality very little known to them. This required extensive research for an assertive response. They all showed a deep interest and commitment to the project, extending the research process far beyond the tools provided in class. On their own initiative, they deepened their research about the disease, searched for materials on the market (national and international), interviewed professionals in the field, and kept in close contact with the Centre's Technical

Director to discuss project options. In the end, it became clear to the students the importance and relevance design (and the designer) has in creating solutions to social problems, and for People with Dementia in particular.

For the Centre, materials were studied through design practices specifically targeted to its users, considering their biographical components, life experiences, culture, and vernacular traditions. Two of the projects, the Bingo Game and the seasonal illustrations, have already been experimented by the Centre's users and were well received by them. The Bingo Game, in particular, had a very positive impact, both for the moments of amusement and conviviality that it brought to the Centre's users and professionals, and for its accessibility and usability, since the pieces were carefully thought out considering the characteristics of this public and different levels of difficulty were provided for a more inclusive experience.

According to the Centre's Technical Director, all the projects were surprising and likely to be used by the Centre, although some were more in line with the characteristics of the users and the characteristics of dementia—there are works where a more in-depth study of what is dementia can be perceived. She also stressed the importance of materials being flexible, allowing for different levels of user participation (as users are at different stages of dementia), as well as the suitability of the scale of the materials and the font size used, which the students took into account in their projects.

This study highlighted a gap in the market—the scarcity of cognitive stimulation materials adapted (and affordable) for Portuguese People with Dementia—and the urgent need to work in this area through multidisciplinary teams that include health professionals, therapists, designers, and People with Dementia for whom the materials are intended.

The projects developed by the students also faced financial limitations. It was possible to produce a prototype in certain projects, such as the Bingo Game or the seasonal illustrations, but in other cases it was not financially feasible to produce a prototype of sufficient quality to make it available to the Centre, as occurred with the Goose Game. Hence, although this curricular project has allowed the creation of cognitive stimulation materials appropriate for Portuguese People with Dementia, filling a gap in the current market, it was limited by financial issues, not being possible to test and put into practice all the materials developed.

One possible way to minimise these financial issues, as suggested by the Centre's Technical Director, could be through digital media, considering that the activities are mediated by therapists and therefore the potential digital illiteracy of the users can easily be overcome.

Based on the results of this study and fieldwork subsequently carried out with the Centre's Technical Director and other professionals from Alzheimer Portugal, a larger project is now under study involving various services of this institution and several Portuguese Universities. It is expected to create a multidisciplinary network of professionals for a more assertive response, designed on a national scale, although contemplating the vernacular culture of each region of the country. In this context, possible funding solutions are also under study, to support the research process, usability tests and the production of cognitive stimulation materials aimed at Portuguese People with Dementia.

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# Correction to: Designing for People with Dementia: A Portuguese Case Study

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**Correction to:**
**Chapter "Designing for People with Dementia: A PortugueseCase Study"**
**in: M. Houben et al. (eds.), *Dementia Lab 2022: The Residue of Design*,**
**Design For Inclusion 3, https://doi.org/10.1007/978-3-031-14466-0_9**

In the original version of the book following belated correction has been incorporated: An acknowledgement has been added in Chapter "Designing for People with Dementia: A Portuguese Case Study".

The correction chapter and the book has been updated with the changes.

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The updated version of this chapter can be found at
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