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Unique Experiences

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UNIQUE EXPERIENCES

DESIGNING WARM TECHNOLOGY TO SUPPORT PERSONAL DYNAMICS IN DEMENTIA

MYRTE THOOLEN

UNIQUE EXPERIENCES

DESIGNING WARM TECHNOLOGY TO SUPPORT PERSONAL DYNAMICS IN DEMENTIA

Doctoral Dissertation by Myrte Elise Thoolen

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Unique Experiences

Designing Warm Technology to Support Personal Dynamics in Dementia

PROEFSCHRIFT

ter verkrijging van de graad van doctor aan de Technische Universiteit Eindhoven, op gezag van de rector magnificus prof.dr. S.K. Lenaerts, voor een commissie aangewezen door het College voor Promoties, in het openbaar te verdedigen op woensdag 21 juni 2023 om 11:00 uur

door

Myrte Elise Thoolen

geboren te Breda

Dit proefschrift is goedgekeurd door de promotoren en de samenstelling van de promotiecommissie is als volgt:

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Adviseur:	dr. G. Kenning (University of New South Wales)

Het onderzoek of ontwerp dat in dit proefschrift wordt beschreven is uitgevoerd in overeenstemming met de TU/e Gedragscode Wetenschapsbeoefening.

To the men and women

living with dementia

without whom this work would not have been possible

PREFACE

'Unique experiences: designing warm technology to support personal dynamics in dementia' is the culmination of years of dedicated study and research. I am honored to present it as my *dissertation*.

It all started eighteen months prior to beginning my PhD journey when I enrolled in my final master's program in the Faculty of Industrial Design. I was passionate about understanding the lived experiences of people with dementia, and therefore, I dedicated my graduation project to this pursuit. As a designer and researcher, I have always been intrigued by how design can be used to create products and systems that promote appropriate and sustainable human experiences, particularly for the most vulnerable members of our society. Design plays a crucial role in creating artifacts and systems that these individuals can enjoy using, as well as in enhancing the living standards and quality of life of vulnerable individuals and providing equal opportunities for them to participate in society fully.

It can be noted that the world is becoming more complex. Technology is playing an increasingly significant role in changing the world in which we live, as well as the way we live. Also, for the ever-growing group of people with dementia, new technology offers promising opportunities. They can provide support in daily activities, offer enriching leisure experiences, and facilitate connections with loved ones. These are just a few examples of what is possible with technology, which I will explain in more detail in the introduction of this dissertation.

During my master's program, I recognized a significant gap between existing technology and the needs of individuals with dementia. To address this issue, I initiated collaborative efforts with people living with dementia as part of my degree. By actively engaging them in the design and research process, I sought to understand their experiences with current technology and involve them in shaping future solutions. Through workshops and discussions, participants had the opportunity to share their experiences regarding existing technologies and newly developed prototypes. These sessions provided valuable input for designing technology that considers their specific needs and abilities, integrating them into the design process.

From the first moment I entered a dementia care facility, I noticed that people with dementia are just like any other person and can retain a sense of self and have a positive quality of life. Having dementia does not define a person per se. When talking about

dementia, people often consider those with dementia no longer as a whole person, while they are like other people who can experience life fully. Even though the very nature of dementia signals the loss of cognitive, sensory, and motor abilities, instead, and more importantly, people with dementia have a rich, lived experience. As I walked through the residential care facility, I observed that each person's experience is unique and needs to be considered at that moment. While some may find pleasure in looking at photos, others may prefer to have a conversation. One may suddenly no longer enjoy looking at photos and would rather listen to music. Every individual has their own needs and preferences, and care facilities must understand and accommodate these differences to provide personalized support and enhance the quality of life for individuals with dementia.

My curiosity led me to wonder what actually differentiates people with dementia from those without dementia. Although they have changed, they still share the same humor and stories. All they need is a certain amount of support to continue doing things they love or discover new talents. Therefore, it is imperative not to worry about what was possible in the past, nor will we worry about what can be done in the future. Instead, we must focus on what is feasible now and push for it. Hence, I saw the opportunity to use design and technology to enhance the present and provide opportunities to empower those with dementia. How helpful would it be if design researchers and technology experts could empower people with dementia in the here and now? Since the time I met individuals with dementia who resided in a residential care facility, I have constantly asked myself this question. Is it about experiencing fun moments with loved ones and significant others or being assisted with everyday activities such as getting dressed, drinking coffee, or doing the laundry? In my graduation project, called ***Sentic***, described in *Chapter 4*, I discovered that listening to music had all the facets that people with dementia wanted- autonomy, control, and adaptation – leading to moments of joy, familiarity, and empowerment. This chapter focuses on the application of music in particular; however, people with dementia are likely to experience moments of happiness not only when they listen to music but also when they view photographs and videos. The lack of use of these media applications in the care of people with dementia made me wonder why so little is being done with them.

With this rationale as a guide, my dissertation objective is to provide opportunities for people with dementia to be empowered and have agency by providing them with autonomy and control, as well as access to interactive systems that provide enjoyable and meaningful experiences through the use of (multi)media. It is important to note that the goal is not to make a system that gives people control but to make sure they feel like they have control. This means that the focus of the design is to provide opportunities for them to be empowered and have agency. This subtle shift in perspective changes the design focus from us as designers being the agents of empowerment to creating a system that

supports individuals in having agency themselves. During my acquaintance with people with dementia, I discovered that complexity only raises more questions and confusion in people with dementia. Therefore, interactive systems should be as simple as possible to use in order to be accessible to people with dementia. Then the question arose: ***How should we design technology to give people with dementia access to enjoyable and meaningful experiences?*** People with dementia are all unique and different. Every person has their own abilities, preferences, and needs. ***How can we consider these differences when designing technology for people with dementia?***

Therefore, I present this dissertation with sincere pride and excitement. This dissertation is the result of my passion for understanding the needs, experiences and abilities of people with dementia and how design can be tailored accordingly. It takes the reader on a journey through an in-depth examination of how design can be catered to the unique needs and abilities of people with dementia. Through three extensive field studies, my colleagues and I explore how design can be used to account for each person's unique care pathway, as well as how interaction design and the aesthetics of interactive systems can enhance personalized media experiences for people with dementia and facilitate their access to these experiences.

The ultimate goal of this research is to design technology that can adjust to personal dynamics, so that it can better suit the various needs and capabilities of people with dementia. The goal is to facilitate more personally meaningful and enjoyable moments in their everyday lives through the use of interactive media systems. In this dissertation, I aim to improve the lives of people with dementia by utilizing design approaches and strategies to gain a deeper understanding of how to design interactive (media) systems that are appropriate for them. This involves working with people with dementia to create technology that enables them to engage with warm and meaningful technologies, supporting their well-being while living with dementia. My dissertation is not only an exploration of user-friendly design for dementia but also a call to action for designers, developers, and researchers to create accessible technology that truly serves and enhances the lives of individuals with dementia. I believe this research will significantly impact the design field for dementia, and I am confident that it will make a meaningful difference in the lives of people with dementia.

I invite you to embark on this journey with me as we explore the unique experiences of designing warm technology to support personal dynamics in dementia.

SUMMARY

Globally, an estimated 57.4 million people are living with dementia. This number is estimated to rise to 152.8 million by 2050. Without effective pharmaceutical treatment to prevent, treat or cure dementia, this number will grow further and impact individuals, families, caregivers, health systems and governments globally.

Dementia is a collective term for a chronic and progressive neurogenerative brain disorder that affects an individuals' cognitive, sensory and motor abilities that interferes with everyday life. Dementia is a complex and ever-changing condition affecting the brain such that researchers do not fully understand it yet. Therefore, in addition to efforts in the medical domain, alternative initiatives are being launched worldwide to enable living well with dementia and improve quality of life. One such initiative involves the utilization of technology and interactive systems that harness (multi)media to deliver non-pharmacological care. These systems can help stimulate engagement and support the social and emotional needs of people with dementia. Despite the potential of these interactive systems, there are still many challenges regarding the design and adoption of these systems.

Existing interactive systems devised for people with dementia are often conceived and designed from a technology-focused approach, whereby the personal needs, wishes and abilities of people with dementia are overlooked. Given the diverse nature of dementia, it is crucial to consider diversity when designing these systems.

Human-Computer Interaction (HCI) researchers have recently shifted towards a person-centered and inclusive approach, creating more meaningful and warm technologies. This approach acknowledges the rich diversity among people with dementia, supports their social and emotional needs, fosters positive and empathetic user experiences, and strives to make technology more inclusive. Despite these advancements, further research is needed to determine how interactive (multi)media systems, in particular, should be designed to accommodate the unique interests, abilities, and needs of each individual. For these systems to help people with dementia maintain a quality of life, it is necessary to explore how they can be designed to complement the remaining skills and experiences they may still have.

This dissertation expands on the field of HCI and design for dementia by exploring the design of interactive systems that provide engaging and stimulating experiences and aid the personal abilities and related needs of people with dementia in accessing and utilizing them. This dissertation, therefore, addresses the following research questions:

RQ1: How can we design technology to cater for the diverse abilities and needs of people with dementia?

RQ2: How can we empower people with dementia to directly engage with interactive systems?

This dissertation adopts an inclusive *research through design* (RTD) approach, which involves the development and evaluation of design artifacts and the use of other tools such as stimulating materials to gain qualitative and quantitative insights into the subjective experiences, diverse abilities and related needs of people with dementia and their caregivers (e.g., their partner, family or professional caregivers). This dissertation aims to investigate to what extent and how the design of interactive systems should be personalized or customized to meet the diverse abilities, desires and needs of people with dementia. To achieve this objective, each of the presented studies adopts a different RtD process that explores a specific aspect of designing for individuals with dementia and relevant stakeholders. A "*Warm Technology*" approach is utilized in technology development and design to provide enjoyable and stimulating experiences for people with dementia

Section 1 introduces an exploration of the barriers and facilitating factors of current technology that both hinders and enables the social participation of individuals with dementia and their partners. The study presented in ***Chapter 3*** reports the outcomes of four co-creation sessions in which we placed people living at home with dementia and their partners at the center of the process. It provides a first insight into the key limitations and challenges experienced by our participants in the context of social interactions and technology use and explores which skills and adaptation strategies can help overcome these barriers, which can then be used for the design of new systems.

Section 2 builds upon these insights by exploring how technology can effectively be designed to support meaningful activities and social engagement through the use of multimedia. To gain a better understanding of the different timelines and pathways of dementia, we conducted three exploratory field studies with three designed artifacts. To determine the validity of these artifacts, we evaluated them in different contexts: with individuals with dementia living at home and with individuals living

in assisted living facilities. ***Chapter 4*** presents a research through design process that involved a series of engagement workshops, which provided valuable insights into the individual experiences, familiarity, and understanding of people with dementia towards various existing music systems. This led to the creation and evaluation of the *Sentic* system with a customizable interface that caters to the abilities and needs of individuals with dementia. ***Chapter 5*** reports the results of a field study with *AmbientEcho*, an interactive system for individuals with dementia living in a care home that provides bespoke and curated media through different interaction modes. The study provides insight into how an interactive system can cater to the individual variability of residents in a care facility. Building upon the insights from *Chapter 3,* ***Chapter 6*** presents the results of a field study conducted with *LivingMoments*, a communication system that integrates digital and physical interactions. The study aimed to address the varying and changing abilities of individuals with dementia and reduce barriers to communication and social engagement, as identified in *Section 1.*

Section 3 reflects on the significance of designing interactive systems that cater to the abilities and related needs of individuals with dementia, in order to foster meaningful experiences and promote access to them. Through an inclusive RTD methodology, which involved the development and evaluation of artifacts with the active participation of individuals with dementia and their caregivers, we were able to gain insights into how to design interactive systems from a "*warm technology*" perspective, so as to cater to the unique needs and abilities of individuals with dementia in their individual care journeys. ***Chapter 7*** summarizes the key research conclusions, which address the two research questions posed. Subsequently, it discusses the main contribution in the field of design research and emphasizes the importance of 1) adaptability in the interaction design to address abilities, 2) appropriate calibration of multimedia content, 3) importance of aesthetics for adopting technology, and 4) involving multiple perspectives in design for dementia. Additionally, *Chapter 7* explores the practical and societal implications of this dissertation for the care of individuals with dementia, and how it contributes to the advancement of innovative care practices. Collaborating with a multidisciplinary innovation team with professionals connected to practical field contributes to the creation and adoption of appropriate technology in care practices. Finally, this chapter concludes by acknowledging the limitations of this dissertation and offering recommendations for future research.

This dissertation highlights the untapped potential of adapting and tailoring interactive systems for people with dementia, thereby filling an important gap in the field.

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“

Als de dooi invalt
smelt het ijs aan de takken
de druppels vallen en
verdwijnen voor eeuwig in het groene mos
maar blijven eeuwig bestaan
in diepte der aarde
zo gaat het met onze herinneringen
van gisteren en eergisteren zo langzamerhand
tot jaren terug en blijven voor altijd een geheim

Het leven blijft een mysterie en ook een wonder
De toekomst is nog altijd een vraag
waar niemand zekerheid over heeft

Maar de klok tikt door
en het geheim van de herinnering vergaat
wat er gisteren was is er vandaag niet meer

Zo leven wij al sinds jaren
en het hiernamaals is nog het grootste raadsel

Maar ik geloof erin!

When the thaw sets in
the ice melts on the branches
the drops fall and
disappear forever in the green moss
but last forever
in the depths of the earth
that is what happens with our memories
from yesterday and the day before yesterday gradually
to years ago and will remain a secret forever

Life remains a mystery and also a miracle
The future is still a question
where no one has certainty about it

But the clock is ticking...
and the secret of the memory perishes
what was yesterday is no longer there today

We have been living this way for years
and the hereafter is the greatest mystery

But I believe in it!

”

This poem has been written by a participant with dementia that participated in the ***LivingMoments*** study, as described in *Chapter 6*. He shared his poem with us during a home visit to express his feelings about having dementia. These people's lives change profoundly, and their future remains uncertain, while memories last forever.

Dementia, HCI and design

An individual's life can be greatly affected by receiving a diagnosis of dementia. While living with dementia can be a life-changing experience, it is crucial to recognize that the person remains the same individual with a wealth of personal history and significant relationships. As demonstrated by one participant in this research, uncertainty is a common feeling that can accompany dementia. This sentiment was expressed through a poem that highlights how memories can endure for a lifetime.

Dementia affects various types of memory, including episodic memory, which refers to the ability to recall specific events or experiences from the past. As dementia progresses, episodic memory becomes increasingly impaired. However, significant memories can endure when prompted well, helping individuals with dementia maintain their sense of identity and connection to their past. Despite the challenges posed by memory decline, individuals with dementia can still access aspects of their past. To ensure a high quality of life for individuals with dementia, it is important to provide them with resources and support to make the most of life's moments. This dissertation aims to contribute to providing individuals with dementia with meanginful experiences by examining what is needed in the design of interactive systems to provide access to these moments.

In this introduction chapter, we provide an overview of the topic of dementia, including its economic and societal impact, the shift towards a socially just perspective on dementia, the importance of non-pharmacological care to support social and emotional needs, and the role of design and technology in addressing these issues. Lastly, we introduce our inclusive research through design approach, formulate our research questions, and outline the structure of our dissertation. This background information sets the stage for the academic focus of this dissertation.

Chapter 1

1.1 Dementia and society

1.1.1 Dementia

Dementia is a collective term for various progressive and chronic neurogenerative brain conditions. Dementia does not refer to one specific disease but to a collection of similar symptoms. The symptoms go beyond what might be expected from the usual effects of normal, biological aging. Dementia can be classified into over 200 subtypes [100]. However, *Alzheimer's disease*, the most common type of dementia, accounts for 60%-70% of all dementia cases [82]. In Alzheimer's disease, beta-amyloid and tau proteins accumulate in the brain to the point that they interfere with normal cognitive functions, leading to symptoms such as forgetting how to engage socially with others, anxiety over forgetting the right words or names [115], getting lost in familiar places, and an inability to schedule appointments with relatives [117]. However, people with Alzheimer's disease often retain memories of the past [349]. On average, people with Alzheimer's disease live between three and ten years after diagnosis [48]. The second most common form of dementia is *Vascular dementia*. According to estimates, it accounts for 15 to 20 percent of dementia cases in North America and Europe and approximately 30 percent of dementia cases in Asia and developing nations [347]. It occurs when the brain is not getting vital nutrients and oxygen from the blood flowing through it. This can happen after a stroke in a strategic brain region or a series of small strokes. The decline in Vascular dementia is not as gradual as in Alzheimer's disease. The course of Vascular dementia can be erratic, with periods of increased deterioration alternated with periods of partial improvement. *Dementia with Lewy bodies* and *frontotemporal dementia* are other major forms and underlying causes of dementia. It is also linked to *Huntington's disease* and *Parkinson's disease* [82,91]. Since Alzheimer's disease and Vascular dementia are the most common forms of dementia, we refer to these forms when we use the term dementia. It is, however, important to recognize the different ways in which dementia can manifest itself in individuals. For example, some individuals may experience changes in behavior such as agitation or aggression, while others may have difficulty with speech and communication. By acknowledging the diverse ways in which dementia can affect individuals, we can better understand and humanize the experiences of those living with this condition.

The diagnosis of dementia can have a significant impact on a person's everyday life. Dementia manifests itself via cognitive, sensory, and motor ability changes

that impact memory, orientation, learning capacity, and language, which reduces people with dementia's ability to perform daily tasks and activities [93,143]. The condition has a neurodegenerative nature, which means the disease begins in one part of the brain and spreads to other parts, affecting more functions in the body. It is a progressive disorder characterized by three stages: *mild* (early-stage), *moderate* (middle-stage), and *severe* (late-stage) [250]. In the *early stages* of dementia, people encounter problems with forgetfulness and struggle with feelings of depression and frustration as they have to cope with the deterioration of their abilities [67]. The majority of people are capable of functioning independently in many areas, but they may require assistance with certain activities to maximize their independence and ensure their safety [314]. As dementia progresses to the *middle stage*, symptoms become more pronounced, including behavioral issues, difficulties with speech, incontinence, and a need for assistance with *activities of daily living* (ADLs) [93]. Those with dementia in the late, *severe stage* will be completely dependent on others due to the impairment of their communication skills as well as their sensory and motor skills [314]. About 90 percent of people with severe stages of dementia will experience *behavioral and psychological symptoms* (BSPD) as part of their condition [65]. These include agitation, aggression (verbal and physical), apathy, delusions, and depression. These symptoms may affect the ability to perform activities of daily living [98,105] and the ability to remain socially active and maintain social autonomy [258,324]. Often, a decline in these abilities is accompanied by a greater degree of functional dependence in activities of daily living, which is associated with lower quality of life [157].

Aside from these indicators of dementia, it is a complex and dynamic condition that is multifaceted. For this reason, the division into stages are mere general indicators of dementia. Even within the same disease, there is a considerable phenotypic heterogeneity with varying symptoms and disease trajectories [278]. For each underlying disease, and each individual affected, the symptoms can come forward in different ways [170]. Every person with the same type of dementia will not necessarily exhibit the same set of symptoms and will vary greatly in what they experience, according to their personality, unique abilities, biography, and coping strategy [168]. This makes it a personal condition in which everyone has their individual care pathway. At each stage of the care pathway, the care setting (for example, at home with a partner or by themselves, or living in a residential care facility) is determined by the needs and abilities of the person with dementia.

Therefore, in this dissertation, we are attempting to highlight the unique abilities and experiences of those with dementia so that they may be empowered and have a meaningful quality of life appropriate to their individual care pathway.

1.1.2 Societal and economic impact of dementia

Over the past century, people have been living longer and healthier lives as medical care, and hygiene has improved significantly worldwide [50]. As a result, life expectancy is increasing, with a prediction that the number of people affected by dementia will grow in the near future [314]. It is inevitable that the brain changes with aging, but dementia should not be considered a normal part of aging [257]. According to the World Health Organization, dementia is the leading cause of disability among older adults [350], and it is the seventh leading cause of death among all diseases worldwide [100]. Recent reviews estimate that globally the amount of people with dementia is approximately 55 million, with 10 million new cases every year [351]. A number that is projected to grow to 155 million by 2050 [351]. In the Netherlands, dementia already affects 290,000 people and is projected to increase to 620,000 by 2050 [360]. With these high numbers, dementia constitutes one of the most pressing challenges of the 21st century, impacting individuals, families, communities, and governments. A considerable body of evidence shows that dementia has a significant economic impact, resulting in increased costs for individuals, families, communities, and governments. It is estimated that global dementia costs will reach US$1 trillion by 2030, with projections of these costs doubling in the following decades [249]. Approximately 9.3 billion euros were spent on dementia care in the Netherlands in 2017 [219,360]. As a percentage of the total expenditures in the Dutch healthcare system, this represents 10.5%. As a result, health and social care services worldwide have devised a variety of strategies to address this phenomenon. Researchers around the world are working to develop effective treatment for dementia, but they have not yet succeeded in curing dementia. In the development of a drug to cure dementia, there is a high rate of failure [70]. Currently, two types of drugs are available, which both target some dementia-related symptoms [249]. Therefore, we cannot trust that a cure or treatment will offer solace in the near future.

In the absence of effective pharmaceutical treatment to cure dementia, care for people with dementia remains highly needed. The care available for people with dementia depends on the healthcare system in each country. Many variables can influence the path a person with dementia may take, as it varies greatly between cultures and countries [266]. In one culture, care relies more on the social environment, while in another, it is built more on residential care [134]. For example, in the Netherlands, the public sector is primarily responsible for caring for persons in need, which can be termed the *Scandinavian model of care* [227]. Greece is an example of the *Mediterranean model*, where the extended family is responsible for providing care. Efforts should be made to ensure that the care provided matches each individual's care pathway, which may vary between home care and care in a residential facility, as well as cultural considerations.

Home care

In general, people with dementia prefer to age in place, which means living at home and in the community with at least some degree of independence and comfort rather than in a facility for residential care [317]. For people with dementia, however, this is not a self-evident fact. Given the progressive nature of dementia and related behavioral and psychological changes, individuals with dementia need increasingly more assistance with daily activities [286]. These activities include bathing, dressing, using the toilet, walking, and even eating in the later stages of dementia [256]. As it becomes more challenging for people with dementia to perform these activities independently, the responsibility will increasingly shift to the individual's relatives, which are usually next of kin (e.g., spouses, children, or other relatives) who provide informal care [46]. The annual global number of informal care is estimated at about 82 billion hours, of which 71% are supplied by women [245,249]. The role of these informal caregivers can range from emotional support and discrete assistance with the activities of daily living (e.g., bathing, dressing, and household tasks) to more complex responsibilities such as home medical care and even serving as decision-makers [318]. In some instances, informal caregivers must resign from their employment to fulfill their responsibilities as caregivers for someone with dementia [304]. However, this is not the only change that can turn the lives of informal caregivers upside down, as they must also deal with the cognitive decline and behavioral changes accompanying dementia [318]. As a result of these many challenges, the relationship between people with dementia and their informal caregiver changes to a formal caregiver-recipient relationship [19,84]. As such, taking care of someone with dementia can be a significant burden and can lead to physical and psychological strain [4]. At a given time, individuals with dementia may have to relocate to a residential care facility, usually due to a lack of resources, including a lack of social support and the ability to manage daily activities [334].

Residential care home

As dementia progresses, it may become more challenging for someone to live safely at home. Relatives may no longer be able to care for their loved ones with dementia, leading to a move to a long-term care facility [334]. Many individuals with dementia spend several years in care homes [220], where they often experience distressing behavioral and psychological symptoms of dementia (BPSDs) such as agitation, depression, and anxiety [287]. Living in a care home is not typically viewed as a pleasant experience and can be described as depressive and lonely [220,315]. This is partly due to a lack of qualified care professionals and a high demand for care worldwide [33,314], resulting in little time for social interactions and activities. As a result, people with dementia spend their day primarily inactive in a lying or sitting position [247]. Therefore, a change in care provision for individuals with dementia in residential care homes is needed, emphasizing emotional and meaningful social interactions [315]. An increasing number of non-pharmacological activities are being employed to reduce the effects of related BPSD, strengthen interpersonal relationships, and increase positive emotions among those with dementia to mitigate these effects [221]. The objective of this dissertation is to contribute to the growing field of research and practice of non-pharmacological approaches to dementia care that prioritizes the overall well-being of persons with dementia, which fits with the humane perspective on dementia outlined in the following section.

1.2 Towards a social approach in dementia care

1.2.1 Reframing dementia: towards a humane and social view on dementia

In the 1980s and 1990s, people with dementia were primarily seen as '*sufferers*' and '*passive recipients of care*' defined by reduced abilities and dependency [206]. In this dominant biomedical view of dementia, people were approached as having little agency, autonomy, and empowerment. As a result, people with dementia no longer felt like full-fledged people but like dehumanized individuals with fewer abilities [201]. The experience of people with dementia was attributed to a disease process with its expected symptoms and challenges. However, this perspective changed from 1992, since Kitwood and Bredin (1992) no longer looked only at the objective symptomatology of dementia but rather took the subjective experiences of dementia into account [170]. The focus in care shifted to how to support and care for people with dementia to achieve the best quality of life possible. In this more humane and social view on dementia, people with dementia were seen as unique persons that feel, have a sense of self, have desires, and a life story. In this for that time novel perspective on dementia, people with dementia are not defined exclusively by the condition. A person's abilities are shaped by health, individual psychology and especially the environment, with a particular emphasis on the social context. Kitwood and Bredin's (1992) approach aims to understand and support the interpersonal care that affirms the '*personhood*' of people with dementia [170]. People, in general, are dependent on each other's recognition, respect, and trust. These needs do not disappear when a person is diagnosed with dementia. He believes that personhood is dependent on other people. This view on dementia has been fundamental to the development of a conceptual approach to care, referred to as *person-centered care* (PCC) in the context of dementia [47], which is currently regarded as the primary, dominant approach in good dementia care practice [87].

Person-centered care is a philosophy of care that is built around the psychosocial needs of people with dementia and focus on the lived experience of the condition [169]. In person-centered care, needs such as comfort, attachment, inclusion, occupation, and identity are given priority in addition to medical or physical needs [47,169]. Central to this approach is the creation of an environment in which the person is treated as an individual, can give voice to personhood, and experience a positive social environment [47]. From this point of view, person-centered care can be an effective way of preventing and providing care for people with dementia and providing support for the unmet needs of individuals with dementia [167]. Given the effectiveness and success of person-centered care in dementia care, this approach in care is essential to provide meaningful care for people with dementia. It opens new possibilities in the delivery of care. Building further on this more

holistic view of health, in 2011, Huber and her co-writers [145] proposed a reformulation of the WHO *(World Health Organization)* definition of health in which health is no longer seen as the absence of disease, but as the ability of people to deal with (changing) physical, emotional, and social life challenges and to take control as much as possible of their own health. Having such a positive view on health builds further on person-centered care because it emphasizes the importance of knowing the person, recognizing the person's reality, supporting opportunities for meaningful engagements, and maintaining meaningful and caring relationships as ways of enriching the experience of dementia [47,80,87]. In fact, people with dementia possess the ability to experience happiness, joy, and humor [251]. It is, therefore, essential to treat people with dementia as unique individuals, each with their own subjective experience of dementia [168].

In this dissertation, we focus on this humane and socially inclusive approach that specifically addresses the *lived experiences* of people with dementia. We focus on providing opportunities for people with dementia to be empowered and feel strenghtened in their personal abilities by making their voices heard in research. Therefore, to align with this view, we place great emphasis on treating individuals with dementia with the utmost respect, which begins with effective communication. Therefore, we refer to the term *people with dementia* and do not use abbreviations in this dissertation. In some cases, we refer to *people living with dementia*, by which we mean those diagnosed with dementia and the relatives who support them.

1.2.2 Non-pharmacological care to add life to years

The literature refers to *non-pharmacological and psychosocial care* as being effective in providing meaningful care to people with dementia as well as cost-effective care that contributes to the quality of their lives [198,242]. Non-pharmacological interventions can be defined as any intervention that does not directly involve medication, although they can be used in conjunction with medication [78,99]. It refers to a set of approaches for engaging individuals in physical, cognitive, or social activities that improves functioning, interpersonal relationships, and well-being in people with dementia [221]. Participating in these activities can help alleviate the feeling of boredom and reduce sensory deprivation [308].

Initially, non-pharmacological interventions are developed as first-line strategies to alleviate *Behavioral and Psychological Symptoms of dementia* (BPSDs), such as aggression, agitation, and wandering [99]. These interventions were viewed from a staff-oriented approach in which the challenging behavior had to be resolved as

quickly as possible without antipsychotic drugs. However, since the emergence of person-centered care in practice, non-pharmacological interventions are more seen as strategies to address the psychosocial needs of people with dementia [61], and improve cognitive, emotional and social functioning [90,307,325]. Non-pharmacological interventions have been demonstrated to be effective in promoting engagement in activities [269], which in turn may delay disability, address people's unmet psychosocial needs [335], and even slow the progression of dementia [214]. An increasing number of non-pharmacological interventions have been developed for people with dementia. These interventions can be broadly classified into three categories: standard therapies, alternative therapies, and brief psychotherapies. Standard therapies include behavioral therapy and reminiscence therapy, while alternative therapies include music therapy, art therapy, aromatherapy, and multisensory approaches. Brief psychotherapies include cognitive-behavioral therapy and interpersonal therapy [78].

In this dissertation, we do not view these interventions solely as conventional *"therapy"*. Instead, we recognize their potential to have therapeutic effects and serve as valuable tools in enhancing the quality of life for people with dementia. The goal of these interventions is to enhance different aspects of well-being, such as cognitive function, emotional well-being, and social engagement.

Psychosocial needs

Psychosocial needs are fundamental human needs for social interaction, emotional well-being, and a sense of purpose and fulfillment, as described in *Maslow's hierarchy of needs* [208]. In people with dementia, their psychosocial needs may differ from those in the general population due to the cognitive and physical changes that occur as the condition progresses. For example, people with dementia may have difficulty communicating their needs and may experience social isolation [73,324]. Neglecting these psychosocial needs can result in negative outcomes such as behavioral and psychological symptoms of dementia, reduced quality of life, and increased caregiver burden [53,340]. Creative and expressive interventions, such as art and music, have been found to be effective in meeting the psychosocial needs of people with dementia [285]. Additionally, a multisensory approach that includes music, tactile stimulation, and visual cues has been shown to reduce anxiety and depression in individuals with dementia [202] These interventions offer opportunities for self-expression, social interaction, and emotional expression, which can enhance a sense of purpose and fulfillment according to Maslow's hierarchy of needs [208]. By supporting psychosocial needs, these interventions may contribute to self-actualization, the highest level of human needs in Maslow's hierarchy.

Reminiscence care

Reminiscence care, in particular, has been identified as a particularly popular non-pharmacological, psychosocial intervention for individuals living with dementia [349]. This approach involves utilizing tangible props such as photograph albums, artifacts, objects, or other familiar items from the past to facilitate the discussion of past activities or experiences. More recently, digital presentations of photos, music, sound recordings, and video clips have also been utilized in reminiscence care, further expanding the potential of this intervention [222]. It is worth noting that people with dementia often exhibit an increased ability to recall events from the distant past rather than from the more recent past, making reminiscence an ideal approach for this population [349]. Reminiscence care is based on memories from early life. It aims to evoke them, stimulate mental activity, promote positive interactions and communication, and improve the well-being of people with dementia in all stages [2]. When a connection is found with the person's cognitive strengths and abilities, the person with dementia feels comfortable enough to talk about earlier life experiences and share memories [349]. Activities based on reminiscence are effective in reducing emotional disturbances and enhancing cognitive and functional capacity in individuals with dementia [2,55,216]. Reminiscing can be accomplished by listening to personal music [325]. Music as part of reminiscence therapy shows a decrease in a range of behavioral and psychological symptoms [302], apathy [180], as well as an increase in memory recall, levels of engagement [292] and quality of life [332]. The creation of a *Life Story Book* is also a common approach in reminiscence therapy [81]. Life Story Books are tangible books made together with people with dementia to store and bring back memories and simultaneously provide useful information to caregivers. These books typically include a combination of written narratives, photographs, illustrations, and mementos that portray various phases and facets of an individual's life.

Reminiscence activities that are in line with person-centered care require knowledge about the person's biography, interests, and personality in order to create a valuable experience for the person with dementia [17,348], making it time-consuming and reliant on the availability of knowledgeable care professionals, and is therefore costly to implement in care [198]. This is also the reason why reminiscence activities have not been widely implemented in residential care homes where people with severe dementia reside [64,83] nor in home care where people with mild to moderate dementia reside [210]. People with dementia living in a residential care home even report a lack of access to non-pharmacological interventions [247]. Research shows challenges in implementing reminiscence activities in practice and for non-pharmacological interventions in general. Many barriers have been identified to implementing non-pharmacological interventions in practice, which include issues such as time constraints [83], a lack of understanding of dementia, a lack of autonomy and empowerment towards people with dementia [161], and a lack of knowledge among care professionals about the different non-pharmacological interventions [83]. Consequently, these challenges call for an urgent need for technological solutions to improve the facilitation of non-pharmacological interventions in dementia care.

As a means of contributing to the care of both those living at home and those in residential care homes, this dissertation, therefore, focuses on exploring the opportunities of technology-based interventions, whether in residential or home settings, as a way to contribute to their quality of life.

1.3 Design and technology for dementia

Before diving into the topic of technology-empowered non-pharmacological support, we first illustrate technology trends until recently. We then delve deeper into the change in perspective among designers and researchers, shifting the focus from designing technology to support for deficits towards technology for supporting the richness of human potential.

1.3.1 Assistive technology to support dementia

Technology-based interventions have only recently become an area of interest Technology is an effective tool that facilitates support and makes it easily accessible for people with dementia [288]. Until recently, the primary scope on technology development in dementia care was limited to overcoming deficits and deterioration in cognitive and physical abilities caused by dementia through assistive technologies [24]. Assistive technologies include any product, service, or system that aims to enable people and compensate for the difficulties in performing everyday activities or tasks they would otherwise be unable to do. More specifically, assistive technology developed for people in the early stages of dementia focuses primarily on cognitive and memory support, while technology for people with severe dementia focuses on safety and security [77,163,199,339]. Technologies that are developed for this can, for example, detect fall accidents or enable safe walking via a GPS-tracking device [44], remind people of their medicines [272], support in the day and night rhythm via lighting systems [57], assist in physiological measurements (e.g., blood pressure) [122], support in remembering appointments through a digital agenda [10] or a HoloLens [119], promote independent living through memory aids [272], safety devices [85] or conversational agents [359], and support in cooking via augmented reality [346]. In addition to these applications, assistive technologies are developed for functional purposes and used for therapeutic purposes. For example, *Socially Assistive Robots* (SAR) are increasingly being used for non-pharmacological therapeutic purposes in dementia care [1,192]. A *SAR* is a form of assistive technology that aids the user on different levels. It can support users in their cognition or functional abilities (e.g., task reminders). However, it can also support enhancing social participation and psychological well-being (e.g., companionship) [262]. *Paro* is an example of a *SAR* that is currently used for therapeutic purposes in care organizations [293]. *Paro* is a therapeutic animal-like robot in the form of a baby seal mainly employed for encouraging social behavior and alleviating stress. *AIBO* [313] and *Huggable* [306] are other examples of robot companion pets. There is evidence, however, that social robots are not widely adopted due to users' unmet needs, given the lack of understanding of the experience of people with dementia [149].

In contrast, ICT-based interventions, including telephone, video, and computer-

based interventions, have also been applied in recent years to support people with dementia. For example, in order to provide support for those with dementia and their caregivers, a smartphone interface was developed [43]. This interface provides simplified and personalized functionalities to allow people with dementia to communicate with family or caregivers, offer personal navigation, and send out an emergency signal when lost. Additionally, the use of ICT-based interventions is increasingly being used to relieve the behavioral and psychological symptoms of people with dementia without the need for medication [8,246]. However, a recent study shows that most ICT-based non-pharmacological interventions do not match the needs of people with dementia and are, therefore, difficult to use [288]. One reason for this is that many of these technologies are primarily technology-driven, whereby the social and emotional needs of people with dementia have been less central to the development of the technology [49,149,153]. This type of technology places particular emphasis on disabilities and identifies people with dementia by their symptoms [11], which disempowers them [153]. Moreover, it is interesting to note that people with dementia indicate that they have a desire to experience meaningful, personal moments surrounded by family members [343]. These moments can be stimulated by technology. These findings are reflected in the ongoing developments in the field of HCI and dementia in recent years, which are described in the next section.

1.3.2 Paradigm shift from assistive to warm technology in HCI

For many years, assistive technologies were primarily used to overcome cognitive or physical disabilities [24]. Recently, there has been an increased focus on developing more social, person-centered technologies for the care of those with dementia, complementing the social and person-centered approach to dementia care [186]. An emerging body of work in HCI has changed the way designers and researchers look at technology for people with dementia. They approach technology from a more holistic perspective, addressing individual's potential and supporting personal experiences and abilities rather than disabilities to live well with dementia [40,131,186,225,338]. Designers and researchers are increasingly looking for ways to add life to the years of people with dementia instead of adding years to lives [22], and focus on individual possibilities rather than the loss of skills or abilities [11,182]. This focus has also been adopted in the inclusive framing called – *warm technology* – which emphasizes the importance of looking at potential skills and experiences people with dementia have or may develop and support the richness of human potential in a broader sense through technology [153]. They propose five principles regarding warm technology: (1) A focus on the possible wealth of skills and experiences older individuals possess or may wish to develop; (2) Support for social and emotional needs, enhancing feel-good moments; (3) Technology that is familiar, personally empowering, non-intimidating, and highly

user-friendly, thus increasing self-reliance and self-efficacy; (4) Aesthetically pleasing, non-stigmatizing design solutions, acknowledging the rich diversity in older age; (5) Personalized designs, utilizing and supporting the richness of natural human sensory and motor system, and acknowledging personal context and history. Warm technology aims to improve the quality of life by supporting the social and emotional needs of people with dementia and contributing to humane and enjoyable moments. Technology in this approach does not seek to replace assistive-oriented technology. Instead, it offers a novel perspective on the design of technology for people with dementia, one that emphasizes the lived experience of individuals rather than simply assisting them [225]. This framing of technology has been explored in the HCI literature in recent years through *Experience-Centered Design* (ECD). As part of this approach, the perceptions and realities of the individual with dementia are highly valued in the design process. Design helps uncover personal experiences and understand the person as a whole rather than just their deficits [96,133,226]. Continuing this movement that focuses on the personal experiences of people with dementia, this dissertation explores the design of interactive systems using the principles of warm technology. We treat the technology not as assistive but personally empowering by focusing on the preserved wealth of experiences and abilities of people with dementia to promote self-reliance and self-efficacy. Warm technology does not necessarily mean that it excludes assistive technology but offers a different, warmer perspective on technology.

1.3.3 HCI and design for people with dementia

In a recent overview of technology and dementia, researchers identified leisure and activities, such as listening to music or participating in social activities, as one of the main domains of technology development within dementia care for now and in the future [13]. More researchers are beginning to recognize the benefits of utilizing technology to provide meaningful activities. For example, researchers identified that one of the three directions in the global need for technology is to support meaningful and pleasurable activities such as cognitive stimulation and physical activity [215]. In addition, technology is needed to improve social participation, contact, and support. Noteworthy is that in the literature, there is no single term used for non-pharmacological interventions provided by technology, but it appears in many names. It is called technology-enabled leisure activities [13], technology-mediated recreational activities [188], design for playful activities [328], design for meaningful and social activities [140,225], or design for sensory engagements [76]. According to previous work, four areas of technology-empowered design solutions address the psychosocial needs of people with dementia, namely 1) sensory-based design, 2) design for reminiscence, communication, and connection, 3) augmented environment designs, 4) others,

such as Virtual Reality or exergames [87]. The literature reveals that these categories are difficult to distinguish from each other and are overlapping. However, regardless of the naming and categories, it follows from this that an emerging body of work in HCI is exploring the role of design in contributing to the well-being of people with dementia and supporting them to engage in meaningful experiences [185,222]. In this dissertation, we address the design of interactive media systems to support the delivery of non-pharmacological activities and engage people with dementia in meaningful and enjoyable experiences.

> In the context of this dissertation, *'meaningful'* refers to activities that have personal significance to people with dementia, are tailored to the individual's interests and abilities, and that promote social interaction, cognitive stimulation, and emotional well-being. In particular, we aim to do so by designing interactive systems that utilize (multi)media to stimulate reminiscence and establish social connections.

Reminiscence refers to sharing life experiences, memories, and stories from the past [349]. People with dementia tend to be better at recalling events that happened a long time ago than recent events; therefore, reminiscence relies upon this characteristic. Using a skill that people with dementia still possess, such as reminiscence, can provide a sense of self-worth, identity, and individuality to those with dementia [72]. Therefore, reminiscence is a popular and growing area for technology design. Researchers have considered technology-aided reminiscence activities as an opportunity to engage people with dementia in social interactions and offer a meaningful experience throughout the dementia process [15,147,171,199]. Research shows, for example, that sensory-based designs that make use of auditive [139,226] or visual cues [14,133,284] can support the delivery of non-pharmacological activities, such as reminiscence therapy [189]. The advantage of using technology for reminiscence purposes is that it can provide easy access to rich and engaging multimedia reminiscence material (e.g., music, photos and videos), it can reduce the preparation time for caregivers, it can make the delivery of the therapy remotely accessible, and the intervention can be tailored to individual interests [189]. With these benefits in mind, there has been a growing interest in the HCI community in finding ways to stimulate reminiscence using interactive systems that integrate multimedia and sensory-based designs as a prompt for supporting conversations [101,342], providing opportunities for them to be empowered and have agency [96,284], and providing enriching experiences in the moment [133]. *CIRCA* is one of the first interactive systems for reminiscence designed that uses multimedia as a resource for engaging people with dementia. CIRCA is an interactive, multimedia touch screen system that contains a wide

range of stimuli (e.g., photographs, music, and, video clips) to provide an engaging reminiscence experience and prompt conversations by evoking long-term memories [15]. Following CIRCA, encouraging reminiscence as a resource for engaging people with dementia is also at the heart of the design of the *VITA* pillow. This pillow combines personal and general sound content to facilitating meaningful conversation, playfulness, and connection between residents and caregivers of a care facility [139]. Another example also shows the importance of personally relevant content [172]. A *Virtual Reality binocular* with haptic input was designed to enable people with dementia to scroll through vivid memories from their past [172]. Based on the findings, the researchers of this study point, among other things, to the need for adaptation to the motor abilities and mental models of people with dementia as a requirement for future technology-aided reminiscence activities. This conclusion was endorsed by other researchers following the study of a tangible interactive multimedia book developed by them to provide people with dementia with the opportunity to interact with images and hear accompanying sounds. The authors concluded that it is crucial to provide content that people with dementia can easily relate to [148]. Other scientists expanded on this work by developing tangible objects that use multimedia content (i.e., music and photographs) to provide reminiscence [146]. The developers found that their newly developed tangible objects could enhance the reminiscence experience by adding novel aspects to the interaction design, making them recognizable and intuitive to use.

In line with this subject matter, research in the HCI community in the context of dementia has investigated the design of interactive systems to support people with dementia in participating in conversations and preventing loneliness. Multimedia engagements are utilized to build strong connections between people with dementia and their social circle (i.e., family, friends, or neighbors). Media is used not merely to engage people with dementia but also to invite family members to collate content to aid them in finding topics to discuss with their loved one with dementia. For example, researchers designed *Ticket to Talk* [342], a mobile application that enables young people to collect media relevant to individuals with dementia and use it to support having personalized topics for conversations. A project that also supports communication is *Printer Pals* [96], a receipt-based design in which questions, riddles, images, and audio can be uploaded to facilitate storytelling between residents of a care facility and younger people. Residents could participate in the social activity, whether it was through listening, smiling, singing, or dancing, and in doing so, support the agentic abilities of the person with advanced dementia. Other researchers developed the *"A Better Visit"* app that focused on the interests of the residents of a care facility (e.g., hobbies). They used music as an incentive to foster social interactions [229]. All these examples show

the benefits of tangible interactions and personally relevant media content in interactive systems to enhance the reminiscence experience and support social connections with relatives. Personalization is critical in this regard, as it also appears that people with dementia show a reduction in challenging behavior when senses are stimulated in a format that the person with dementia can understand [18]. However, this is still a challenge in technology-aided reminiscence systems, and further research is needed on how these systems can best be personalized to provide an appropriate and accessible experience for each individual with dementia.

1.4 Involving people with dementia in design

Throughout the history of HCI, *human-centered design* has been used to understand people's experiences and needs and how design can address them [16]. The human-centered design approach places the end user's needs and requirements at the center of the design and development process [234]. *Research through design (RtD)* is one of many methods employed in this human-centered process for producing an outcome in the form of a design that is applied for research purposes [300,301]. An aspect of research through design involves the creation of a prototype as part of the research activity and using stimulating materials that can foster a collaborative process [300]. In most cases, the findings of the research are applied to the design outcome as a way of guiding its development. This is known as an iterative process consisting of several phases. The way these phases are accomplished depends on the approach being applied. Human-centered design encompasses various approaches to exploring people's experiences, including *participatory design, ethnography, empathic design,* and *co-design* [303].

Until recently, the voices and experiences of people with dementia were not sufficiently heard in designing and developing novel technologies. Insights were mainly collected from caregivers or family members who are around the person with dementia [244]. In addition, their involvement usually takes place in the evaluation phase of technology development, where the focus is on understanding the effectiveness, usability, and acceptability of the technology [135,215,311,323]. Moreover, the significant diversity within and between people with dementia makes it a yet greater challenge to involve people with dementia in the design and development process [311]. Recent years have seen researchers increasingly consider the experiences and perspectives of people with dementia as a guiding principle to inform design considerations and steer technology development accordingly [153,225,311]. Here, design decisions in technology development are made *with* instead of just *for* people with dementia. In this human-centered process of designing and developing novel technologies for people with dementia,

a certain degree of sensitivity is required [160]. *Participatory action research* methods are applied as part of human-centered design to find out the users' needs and experiences [123. Hence, traditional participatory methods cannot be used to investigate the experiences and needs of people with dementia. This is because these rely heavily on the communicative and cognitive abilities of the users involved, which, however, is a challenge for people with dementia [125]. As a result, participatory action research approaches require modification when being applied with people with dementia [311]. Consequently, many researchers in the field of HCI and dementia have explored tools and methods to overcome the challenges of involving people with dementia as equal partners in design research [124–126,205,310,326]. This holistic approach to design research enables inclusivity, irrespective of disability, gender, vulnerability, or age. Design is applied here to allow researchers and designers to explore the reactions, actions, and personalities of people with dementia that would not be visible in other circumstances [124]. The use of props, design probes, artifacts, and other stimulating material in real-life settings can help uncover the personal opinions, thoughts, experiences, and reflections of individuals with dementia as well as other vital stakeholders [38,270], as shown in work described by [96,138,226,338]. As shown in these examples, people with dementia are involved in an inclusive and participative way. This provides a richer understanding of the experience of personhood in dementia [338]. In addition, it informs the development of sensitive and meaningful designs [141]. Throughout this research process, these design proposals serve both as a tool for design as well as a tool for exploration or empathic understanding [336,345], which would not be evident in other situations [124].

Therefore, throughout this dissertation, we use ***design proposals*** and ***stimulating materials*** as mediators in the interaction with people with dementia to extract and identify their subjective experiences and abilities, intending to design interactive systems to suit the individual more closely. It should be noted that, in this dissertation, the interactive media systems are being designed ***with*** and ***for*** people with dementia, rather than simply being imposed upon them. The goal is to involve people with dementia in the design process, creating systems that are tailored to their needs. This dissertation seeks to provide opportunities for people with dementia to take an active role in their own care, and to support them in engaging in meaningful activities that have personal significance to them.

02

Research gap and design direction

In this chapter, we intend to examine the research gap in the field of interactive systems for individuals living with dementia based on the *Warm Technology* perspective. By analyzing the literature comprehensively, we identify why interactive systems are not widely used in the care of people with dementia. Subsequently, we present an overview of our two research questions arising from this research gap. We additionally outline our inclusive design research approach and the context in which we design warm technology for individuals living with dementia. To conclude, we present a concise outline of the dissertation structure by which we address these research questions.

Chapter 2

2.1 Research gap

Dementia encompasses not only a pathological condition but also a multifaceted psychosocial experience that profoundly affects one's identity, social interactions, and living circumstances. This experience is highly unique and influenced by factors such as personality, life history, interests [168], as well as changes in cognitive, sensory, and motor abilities. These factors impact both the progression of the disease and the effectiveness of interventions designed to enhance quality of life [102,196]. Recognizing the complexity of this impact is crucial as it can further complicate the experience of dementia and influence the effectiveness of interventions aimed at improving quality of life. Not only do symptoms and experiences change over time, but dementia affects each person in a different way. Partly, this has to do with the underlying causes of dementia, other health conditions, the person's cognitive functioning before diagnosis, and the ability to cope with the condition [199]. This makes dementia an even more complex and multifaceted condition. In this regard, there is no doubt that dementia has an adverse effect on the use of interactive systems and technology in general as a result of its impact. The ability to use technology can vary greatly depending on the time, day, and the mood of a person with dementia [76]. There may be occasions when a particular technology fails to meet the current needs or skills of a person with dementia, as those vary from moment to moment. As a result, people with dementia may be reluctant to engage with technology [113]. The person may even become dependent upon assistance as the disease progresses into its later stages [105]. However, these stages of dementia are not as fixed as they are often presented. In practice, the stages of dementia are more fluid and unpredictable. What one person needs assistance with may differ entirely from what another need.

Past research has shed light on the needs and abilities that differ between people with dementia and how this affects the use of technology [76]. Although a growing number of researchers are adopting a user-centered approach in developing technology [42,171,268,339], further research is needed to understand how technology can be designed to meet the unique needs, abilities, and experiences of individuals with dementia.

In recent years, a number of researchers have addressed the challenging task of facilitating technology use among people with dementia. Researchers have tried to understand how people with dementia use technology and what it takes to facilitate that use. For example, research has shown that habits and familiarity alone may not provide enough support for individuals with dementia to continue using technology, and advocates for further research in this area [237]. An article published in recent years attempted to address this issue by interviewing people with dementia about how they use everyday technology daily, including smartphones, to understand their personal needs in this area better [76]. Their recommendations call for the design of more flexible systems and allow the interface to be adapted to the individual's preferred mode of interaction to contribute to the understanding of the technology. These insights from literature open up a novel topic. One that explores how the different abilities, needs, and subjective experiences of people with dementia can be considered in designing novel technologies [233]. In response to this research, other scholars argue for the need for personalized and tailored technologies to address individual variations in needs and abilities. However, the challenge remained that it was unclear how to personalize and adapt technologies to the individual and changing needs and capabilities of persons with dementia.

As a response, a growing body of research has provided an initial impetus towards the design of personalized, interactive systems to experience an enjoyable and meaningful moment and to contribute to well-being [9,131,181,241]. In one study, researchers developed a *Virtual Reality* experience that featured personalized interactive media for people with dementia [131]. The authors conducted a follow-up study to explore how they could personalize multimedia capture using smell, touch, sound, and sight to provide social contact with family [133]. These examples are a preliminary effort to gain an understanding of how technology can be personalized and become accessible to people with dementia. Especially when it comes to technology in supporting meaningful activity engagement for people with dementia, individualization of the technology is critical [108]. Hence, the question remains as to how technology, particularly interactive systems, must be designed to accommodate each person's unique interests, abilities, and related needs.

Drawing on this gap in research, it is necessary to understand people's personal experiences, abilities, and interests. This knowledge is essential for developing interactive systems that enable people to continue participating in meaningful activities despite increasing disabilities. Therefore, in this dissertation, we approach design for people with dementia in a way that strengthens an individual's realm of skills and related needs by applying a *warm technology* framing [153]. To

accomplish this, we move away from laboratory-based evaluations of technology use and enter the living environment of people with dementia [194] appropriate to the moment within their care pathway (i.e., home care or residential care). We use design proposals and stimulating material to gain insight into the use of and personal experiences with the designed technology [131,186,225,226,338], especially among people with dementia who cannot verbally share their opinion [38,147]. By adopting this design approach, we seek to understand how to design interactive systems that are accessible to people with dementia who have different abilities and needs in accessing and enjoying them. Accordingly, our research questions have been derived from the knowledge gained from the literature and the described research gap.

2.2 Research objective and questions

This section summarizes the research questions based on the research gaps addressed in this dissertation. Building further on developments in the field of HCI and design for dementia, there are opportunities to investigate how the design practice can respond to the diverse abilities and related needs of people with dementia. This dissertation, therefore, addresses the following main research question:

How can we design warm technology to support the dynamic abilities and related needs of each individual with dementia?

As the introduction discusses, dementia affects people's ability to use interactive systems. Consequently, more research is required to understand how to design interactive systems so that people with dementia can access them. The warm technology framing can contribute to this exploration and ensure that these systems are responsive to the individual care pathways of people with dementia and provide them with enjoyable and meaningful experiences. To further explore this topic, we need to enable the participation of people with dementia and their caregivers (e.g., their partner, family or professional caregivers) in design research to develop appropriate technology. Thus, in this dissertation, we aim to address the following research questions:

RQ1: How can we design technology to cater for the diverse abilities and needs of people with dementia? *(Design process & approach)*

RQ2: How can we empower people with dementia to directly engage with interactive systems? *(Interaction design or thing)*

The research questions in this dissertation seek to understand how to design interactive systems that provide meaningful experiences and support individuals with dementia in accessing and enjoying them. The ultimate goal of the research is to gain a comprehensive understanding of how to design these interactive systems in a way that enhances the personal dynamics between individuals with dementia and improves their quality of life. This dissertation is structured into *four main sections* to address these research questions. The introduction section provides an overview of the topic and sets the stage for the rest of the dissertation. The *first section* focuses on exploring the design opportunities for technology in the context of dementia care. This section aims to identify the potential for technology to enhance the lives of individuals with dementia and how it can be used to support their personal dynamics. The *second section* focuses on uncovering the experiences of individuals with dementia using design artifacts. This section utilizes various design methods to gather insights and perspectives from individuals with dementia and those involved in their care. The *closing section*, the reflection, summarizes the previous sections' findings and discusses the research's implications for the design of interactive systems for dementia care. This section also offers recommendations for future research and practice in this area. The research aims to provide a comprehensive understanding of how to design interactive systems that can support the personal dynamics between individuals with dementia and improve their quality of life.

2.3 Research approach and method

To effectively address the research questions in this dissertation, we used a *research through design* (RtD) approach in which design and data gathering methods are applied to provide insights [357,358]. We adopted a human-centered perspective and followed the principles of participatory design, involving people with dementia and relevant stakeholders (e.g., their partner, social environment, and care professionals) in our design and research activities.

To achieve this, we conducted in each of the presented studies a different RtD process that each examine a particular facet of designing for individuals with dementia and relevant stakeholders. However, *Chapters 3* and *6* are notable for being part of a larger, more comprehensive study, in which the first study (*chapter 3*) entails an exploratory field study that utilizes generative tools to identify design

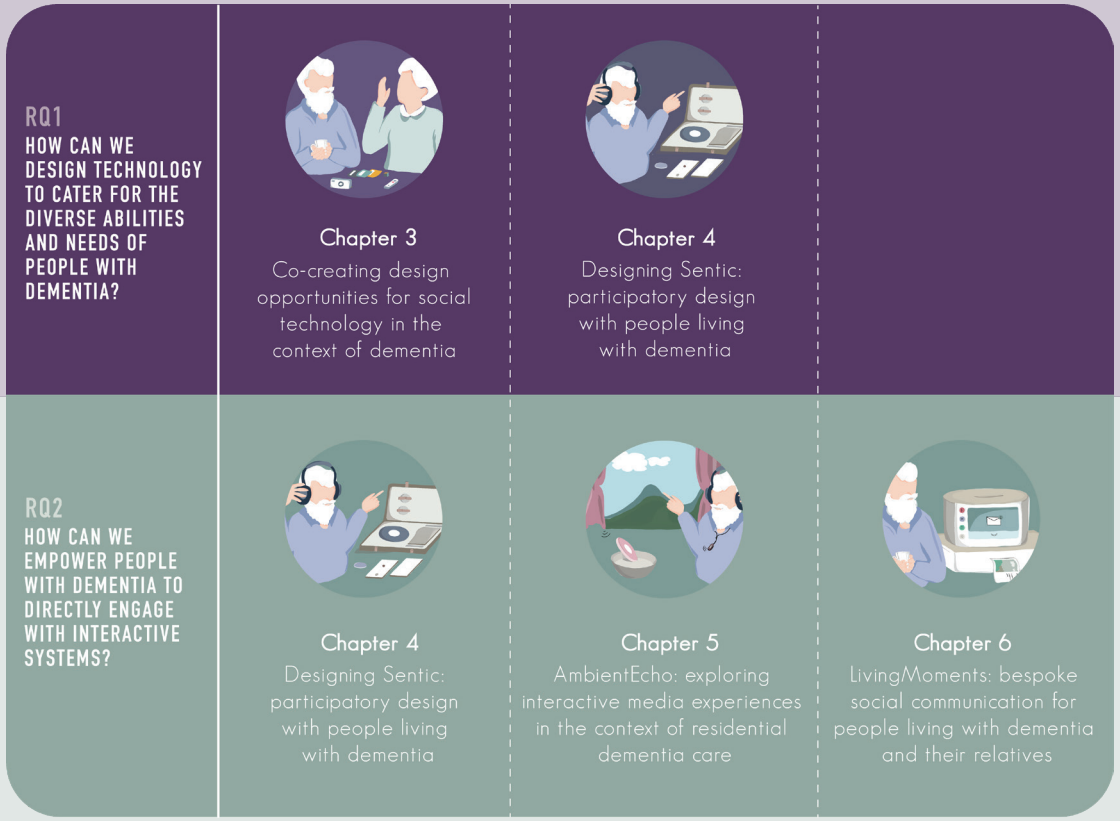

Figure 2.1. Research questions answered in the chapters.

prospects in collaboration with individuals with dementia and their partner, while *Chapter 6* details the design and evaluation of the outcomes derived from the first study. In *Chapter 4*, we conducted a process of six engagement workshops, which resulted in the creation of *Sentic*. Additionally, in *Chapter 5*, we evaluated the effectiveness of the *AmbientEcho* artifact, which was also critical to our research.

In *Chapters 4 - 6*, we designed artifacts as a physical manifestation of our inquiry, generating new knowledge in the process [86]. These artifacts supported our research efforts, facilitating a deeper exploration and understanding of effective design strategies for individuals with dementia. Our objective in designing and evaluating these artifacts was to gain insights into how best to accommodate the diverse abilities and needs of individuals with dementia. Specifically, our research sought to address two questions: Firstly, how can we effectively design for the heterogeneous abilities and needs of people with dementia (RQ1)? Secondly, how can we empower individuals with dementia to interact directly with interactive systems (RQ2)? Through this research, we aimed to ascertain the design

characteristics that would enable interactive systems to meet the varying user conditions of people with dementia and align with their diverse abilities, needs, and preferences, enabling them to access and enjoy these systems.

To answer our first research question, we conducted participatory design activities in which we aimed to explore the personal abilities, needs, and experiences of people with dementia. *Chapters 3* and *4* provide an answer to the first research question. In these chapters, we designed together with people with dementia using different stimulating materials and tools (e.g., existing products, diary study, and design probes). In *Chapter 3,* we used co-creative tools (e.g., co-creative canvases and an experience diary tool) to actively involve people with dementia and encourage them to share their needs, barriers, and facilitators in performing social interactions and using (social) technology. *LivingMoments* was developed based on insights from this study to investigate further the true engagements with people with dementia in the field, as described in *Chapter 6*. In *Chapter 4*, we applied an inclusive research through design process consisting of a series of six engagement workshops. We used existing products and mockups and specifically developed prototypes to solicit reactions from participants to various interactions, aesthetics, and functionalities in the design process. Each workshop was followed by a design iteration, which ultimately resulted in the design of *Sentic*. Eventually, *Sentic* was evaluated together with people with dementia to observe authentic engagements between them and the designed technology.

In order to address our second research question, we performed exploratory field studies with three design proposals - *Sentic, AmbientEcho,* and *LivingMoments* - as designed artifacts. These field studies, described in *Chapters 4 - 6*, were conducted in the real-life context of a home setting and a residential care facility. The design artifacts are not 'finished' products but have been developed as mediators to uncover the personal experiences of people with dementia and to enter into a dialogue with them:

- *Chapter 4* describes a participatory RtD process that resulted in the development of *Sentic*. The study included an evaluation of *Sentic* with three individuals with dementia, partially addressing the second research question. The study provided valuable insights into the unique needs of people with dementia and how they impact interaction design.
- *Chapter 5* details a study evaluating *AmbientEcho*, an interactive system that offers bespoke and curated media content through different interaction modes in a residential care facility. The study utilized *AmbientEcho* as a mediator to gain insight into the subjective experiences, residual abilities, and personal needs of residents and important actors (e.g., their partners, relatives, or professional caregivers) through interactions with the artifact. Through a three-week field study

utilizing participant observations, semi-structured interviews, and a focus group, we assess the experiences and responses of people with dementia, their families, and care staff when using *AmbientEcho*. The purpose of these insights was to better understand its utility as a tool for supporting individuals with dementia in a residential care facility.

- *Chapter 6* describes the evaluation of *LivingMoments*, a communication system that features a digital and physical interaction design considering the diverse needs and abilities of people with dementia. The study was based on insights from *Chapter 3*. It involved a real-life implementation for at least four weeks to collect qualitative and quantitative data through data logs, observations, and interviews. The goal of the study was to gain a deeper understanding of how people with dementia can be supported by exploring their personal experiences, residual abilities, and related needs.

These evaluations can help inform the development of more personalized and effective interactive systems, leading to improved support and engagement in meaningful activities for individuals with dementia.

2.4 Research contexts

In this dissertation, we conducted research in collaboration with the *Pleyade Innovation Team* (PIT) and as part of the *Dementia Dynamics in Design* (DDD) project. As part of both collaborations, multidisciplinary teams were brought together with the goal of developing innovative technology for people with dementia.

2.4.1 Pleyade Innovation Team

The research in this dissertation is partially performed at the care organization *Pleyade*. Pleyade is a care organisation based in the Netherlands and has sixteen locations in Arnhem, Elst, de Liemers, and Renkum. Pleyade offers home and rehabilitation services and has an extensive long-term care facility spread over sixteen locations. They offer care from light support to intensive guidance and treatment for people with complex care needs. The organization has a vision on healthcare where people can live the way they want, just like at home (see Figure 2.2). People are central to care and should maintain their self-reliance. Pleyade acknowledges the opportunities of technological applications in care and consciously invests in care innovation. Pleyade wants to contribute to making the lives of residents, clients, and care professionals more enjoyable by developing warm technology and deploying innovative applications in care. Eindhoven University of Technology, Industrial design, has a strategic partnership with Pleyade, and they support with design thinking and technology development to propose innovations together with and for practice. By combining these visions,

Figure 2.2. Residents have the freedom to shape their desired way of life, and *Pleyade* plays a pivotal role in transforming their aspirations into reality, bringing smiles to their faces

the collaboration was established, and the *Pleyade Innovation Team* (PIT) was set up in 2017. PIT is a multidisciplinary team of designers, researchers, technicians, and care professionals who apply design research in practice. PIT strives to create groundbreaking technologies that not only enhance the quality of life for individuals living with dementia but also streamline the caregiving process. They develop technologies within the organization as they often encounter that the innovations, they purchase end up in the storage closet. Innovations that already exist are too wide in scope and not sufficiently person-centered. In this regard, they decided to collect questions from residents, families, and caregivers, and then collaborate with internal and external experts in order to develop and implement solutions. Throughout all of their projects and activities, they utilize a design thinking methodology, which incorporates the experiences and perspectives of people living with dementia, their relatives, and their caregivers.

The studies described in *Chapters 5 (AmbientEcho)* and *6 (LivingMoments)* are examples of projects developed with PIT. In addition to these projects, PIT has created several other innovations. The *Vita* pillow is an example of a warm technology that was also developed in collaboration with PIT [140]. *Vita* is a pillow that consists of different fabrics and patterned surfaces. When these are pressed, a person's favorite music songs or sounds start to play. The pillow can recognize different residents via Bluetooth technology hidden in jewelry. The *KAS*, an intelligent wardrobe that serves as a dressing aid, is PIT's second innovation, which increases a resident's independence while saving time for caregivers. These innovations contribute to strengthening the self-reliance and well-being of people with dementia.

In *Chapters 5* and *6* in this dissertation, the designed artifacts with which the research was conducted continued to be used by the residents, family members and care professionals of Pleyade. In several cases, a new version of the designed artifact has been developed based on the insights of the research. Specifically, using the outcome of the *AmbientEcho* field study *(chapter 5),* a new 2.0 version was developed and is currently used in practice. Subsequent to the study with *LivingMoments (chapter 6)* that had been conducted in people's homes, the artifact was deployed in a communal living room at Pleyade. A pilot was conducted to explore how the device would be experienced by the residents of a care facility rather than by people living at home. These follow-up studies of both *AmbientEcho* and *LivingMoments* were conducted not for scientific purposes but for practical purposes to implement the designed artifact in the care facility. Care organization Pleyade thus contributed to scientific research and, at the same time to the development of new innovative applications that could be used in (dementia) care practice.

2.4.2 Dementia Dynamics in Design project

From January 2018 until January 2021, the three-year *Dementia Dynamics in Design (DDD)* project was carried out in parallel with the collaboration with PIT. The DDD-project was part of the Create Health program by ZonMw, which focuses on contributing to societal challenges surrounding healthy and active ageing. In the DDD-project, the aim was to design and test new technological solutions that support people with early-stage dementia to maintain social contacts. The project aimed to understand what community-dwelling people with early-stage dementia experienced in their social life and to involve them in the design of new technological solutions to support them in maintaining social health and participation. The project was a collaboration between the scientific center Tranzo (Tilburg University), Eindhoven University of Technology department of Industrial Design, healthcare institution GGzE and Cooperation Slimmer Leven. Ultimately, the partners aimed to contribute to the social health of people living at home with early-stage dementia as well as having a scientific contribution. Slimmer Leven was responsible for recruiting participants for the project and for disseminating the results and important news about the project. Tranzo, the School of Social and Behavioral Sciences, was responsible for the social and behavioral research during the project and the Eindhoven University of Technology department of Industrial Design was responsible for carrying out design-based research activities.

The DDD-project consisted of several work packages and started with a longitudinal qualitative field study to better understand the experiences and perspectives of people with dementia in their social participation. Home visits were made to 12 community-dwelling persons with mild to moderate dementia and their partners (December 2018 – February 2020). This study provided insight into the continuation of the DDD-project, specifically the execution of co-creation sessions as described in *Chapter 3* and the design of *LivingMoments* as described in *Chapter 6*.

Unfortunately, during the DDD-project, there was a COVID-19 outbreak. The co-creation sessions described in *Chapter 3* were conducted just before this pandemic outbreak. Instead of the second round of co-creation sessions, we conducted two online expert assessments (with care professionals and representatives of the scientific community) and combined the insights we gathered from these with the data collected from the first phase of the study. Based on this, we came up with the final design concept, *LivingMoments (chapter 6)*.

- More information about the innovations of Pleyade can be found on the **Pleyade Innovation Team** website.
- More information about the **Dementia Dynamics in Design** project can be found on the ZonMw website.

2.5 Dissertation outline

An outline of the dissertation serves to provide a visual representation of how the dissertation will be structured and organized into sections and chapters (Figure 2.3). The dissertation begins with an introduction, followed by **section 1** *(Explore design opportunities for technology in the context of dementia)*, **section 2** *(Uncover experiences through design)* and a reflection including a discussion and conclusion.

Section 1: Explore design opportunities for technology in the context of dementia

The first section provides a first exploration in gaining an understanding of the individual differences in the abilities and related needs of people with dementia. This section aims to answer the first research question. Therefore, the first research question seeks to determine what is needed in the design process to understand the residual needs and abilities of people with dementia in order to design for direct engagement. To answer this question, we conducted participatory design activities, in which we explored individual differences in abilities in dealing with interfaces and technology in general *(chapter 3)*.

Chapter 3. Co-creating design opportunities for social technology in dementia care

In *Chapter 3*, we employed four guided co-creation sessions together with four couples to understand the needs, barriers and facilitators people with dementia experience in performing social interactions. We explored their experienced social challenges and identified opportunities for design to improve their social participation. These focus on compensating for internal and external barriers through design, enhancing agency through the social and physical environment, and learning from previous experiences with existing social technologies. Furthermore, we identified practical implications for social technologies focusing on embracing the importance of a broader social context, sharing meaningful activities, and incorporating social contact into the everyday routines. The significance of these outcomes indicates the need for further design-research into the development of novel social technologies to enrich their interactions in a social environment. These insights led to research question 2.

Section 2: Uncover experiences through design

The second section of this dissertation focuses on answering part of the first research question and the complete second research question. Namely, *Chapter 4* answers both research questions by providing an overview of the design process and the evaluation of a designed artifact. We used a series of engagement workshops to understand what associations and aesthetics appeal to people with dementia and how interaction design can respond to these. The second research

INTRODUCTION

Chapter 1
Dementia, HCI and design

Chapter 2
Research gap and design direction

SECTION 1 EXPLORE DESIGN OPPORTUNITIES

Chapter 3 RQ1
Co-creating design opportunities for social technology in the context of dementia

SECTION 2 UNCOVER EXPERIENCES THROUGH DESIGN

Chapter 4 RQ1 & 2
Designing Sentic: participatory design with people living with dementia

Chapter 5 RQ2
AmbientEcho: exploring interactive media experiences in the context of residential dementia care

Chapter 6 RQ2
LivingMoments: bespoke social communication for people living with dementia and their relatives

SECTION 3 REFLECTION

Chapter 7
Discussion & conclusion

Figure 2.3. Detailed outline of the dissertation and distribution of the different sections of the dissertation.

question aims to answer how to enable people with dementia to directly engage with interactive systems that provide people with dementia with an enjoyable and meaningful experience (for example by offering familiar multimedia content). To address this research question, we evaluated three designed artifacts in real-life living environments of people with dementia, including a daycare facility (*chapter 4*), a residential care facility (*chapter 5*), and a home environment (*chapter 6*). We conducted field evaluations with the interactive systems (*Sentic, AmbientEcho*, and *LivingMoments*) to discover people's personal experiences and user engagements with the designed artifacts.

Chapter 4. Designing Sentic: Participatory design with people living with dementia

In this chapter, we report on an inclusive design process for creating a tangible music interface which is directly accessible to people with dementia. We performed six participatory design workshops with two groups of people living with dementia to a) explore individual differences in abilities in dealing with interfaces and technology in general, and b) understand which associations and aesthetics people with dementia relate to and how interaction design can leverage this. Using this process, we designed *Sentic*: a physical and digital music player combined to promote independence when listening to music. The realization of *Sentic* is proposed as an example of an alternative approach to design interfaces that can be tailored to the abilities of people with dementia. In this chapter, we highlight and exemplify the value of designing with people with dementia. We involved people with dementia in physical and sensorial experiences to discover their needs and abilities for accessing technology.

Chapter 5. AmbientEcho: Exploring interactive media experiences in the context of residential dementia care

Based on the insights of the previous study, we can state that embracing the differences between people with dementia in the interaction design of a system can contribute to the accessibility of technology for people with dementia. Designing a single interface was found to be inappropriate for people with dementia. A multi-user customizable interface was found to be beneficial in giving people with dementia control over their preferred appearance and interface. In *Chapter 4*, we have seen the positive effects of musical media on people with dementia. Research shows that in addition to music, other forms of media also have a positive influence on the psychological well-being of people with dementia [297,355]. This raises the question of how we can offer people with dementia personal access to a diversity of media via an interactive system. Since *Chapter 4* has shown that it is possible to design for each unique person with dementia, we wanted to further explore the opportunities of a tailor-made design approach for

people with dementia living in a care facility. Little is known about designing personalized interactive media experiences in the context of shared care spaces. People with dementia who live in a care facility can also differ greatly in their capacities and needs. This raises the question of how we can provide opportunities for people with dementia to be empowered and have agency in a shared care environment and give them an appropriate meaningful experience? To investigate this, we designed *AmbientEcho*, an interactive system that offers bespoke and curated media content through different modalities. *AmbientEcho* thereby aims to provide enriching personal experiences in residential dementia care. A prototype of this design was evaluated in a real-life care setting with three residents with mid to late-stage dementia, two of their spouses, and three care practitioners working at the residential care facility. Data on residents' responses, the design's social role, and its use in practice were gathered through participant-observations, semi-structured interviews, and a post-trial focus group. We found that a combined media approach triggered rich personal associations, facilitated revival of identity, and stimulated participation in shared experiences. Finally, we suggest designers should consider sensitive inclusion, adapted levels of interaction and variety in use when designing media interventions in dementia care.

Chapter 6. LivingMoments: Bespoke social communication for people living with dementia and their relatives

In this chapter, we present *LivingMoments*, a communication system that enables the engagement of people with dementia with their relatives. The system uses digital and physical interaction design considering people's different and changing abilities. Dementia can hinder a person's ability to engage with their relatives. Existing communication technologies do not support people with dementia in maintaining social contact since they are not designed for their different and changing abilities and needs. Over a six-week field evaluation of *LivingMoments*, involving six participants living at home with different levels of dementia, we collected qualitative and quantitative data about the experiences of them and their relatives. Based on the data analysis, this chapter reveals the need to adapt communication to individual abilities, lowering barriers through content calibration and establishing habits for continuous use. Furthermore, this chapter demonstrates a set of design considerations for technologies to support a lasting engagement of people with dementia with different and changing abilities.

Section 3: Reflect

In *Chapter 7* of this dissertation, the insights from the previous chapters are synthesized and the overall contributions of this dissertation are summarized regarding how interactive systems can be designed to provide meaningful media experiences that consider the personal dynamics of persons with dementia and

empower them to access such media experiences.

Chapter 7. Discussion and conclusion

In this chapter, the general conclusions are formulated and positioned in the literature regarding HCI in the context of dementia. The first section provides an overview of the findings regarding the design of interactive systems for people with dementia and how they address the research questions. Additionally, this dissertation discusses the contribution it makes to the field of HCI and dementia, as well as highlighting potential future research directions in the field of dementia design research. This contribution is structured around four themes: 1) adaptability in the interaction design to address abilities, 2) appropriate calibration of multimedia content, 3) importance of aesthetics for adopting technology, and 4) involving multiple perspective in design for dementia. In the context of dementia, we believe that *Artificial Intelligence* (AI) offers opportunities for personalized, adaptive, and responsive systems. Further, we expect a growing interest in data-enabled design to enable continuous mapping of the use of a system over time and take this into account when designing it. In the future, this data can be used for designing shape-changing interfaces to allow for minimal changes to the interface and allow people with dementia to interact with it. Thirdly, a reflection is made on how dementia care can contribute to society and have an impact on practice. By doing so, we emphasize the importance of design researchers having a solid foundation in care practice in order to make their studies relevant to the real world and ensure that technology is appropriate for people with dementia. In the subsequent section, the limitations of this doctoral study are discussed. These limitations include the inclusion of individuals with dementia in the research design, the duration of interventions, the sample size, and the context in which the study was conducted. The conclusion is then presented.

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03

Co-creating design opportunities for social technology in the context of dementia

As dementia progresses, it can become increasingly difficult for individuals to engage in social interactions. While technology has the potential to enhance social engagement for people with dementia, they may have difficulties using it. Therefore, it is crucial to gain a clear understanding of how current technology is used in regard to their social participation before designing novel solutions. To gain insight into these barriers and facilitating factors, we conducted co-creation sessions with four individuals with dementia and their partners as well as with experts in the field. Despite the small sample size, the in-depth nature of these sessions allowed us to obtain rich and meaningful data on how individuals experience and integrate technology in their lives. The findings from these sessions are discussed in more detail in this chapter. These results provide valuable information for the design of technology that effectively supports social engagement for people with dementia while taking into consideration their unique needs and abilities.


01
02
03

Chapter 3

3.1 Introduction

3.1.1 Social interaction within the context of dementia

Dementia, particularly Alzheimer's type of pathology, affects an increasing number of people all over the world. It is a syndrome that causes cognitive impairment characterized by progressive deterioration in abilities and behavior, affecting activities of daily living, social resilience [197] and altering former levels of functioning [97]. The challenges associated with dementia are known to negatively influence social interactions of people affected by the condition making it difficult to maintain social relationships and the sense of individual contribution to society [73]. Research shows that people with dementia tend to withdraw from social contacts, especially concerning larger groups of people [324]. Similarly, previous studies reveal that one of the most frequently experienced unmet needs of people with dementia is having other people's company [79,271]. Social context, defined not only by the size of the social network or frequency of social interactions, but most importantly by the personal experience of connection and meaning in social interactions, is crucial for promoting well-being and maintaining and (re) constructing our identities [170,279,338,341]. Kitwood and his colleagues argue that personhood is created through social participation and interactions with others [170]. It can be understood as the attributes possessed by humans that make them a person [74]. It is of particular importance within the context of person-centered care. According to Kitwood [168], a person-centered approach should emphasize communication and relationships, as opposed to medical and behavioral perspectives. Person-centered practice encourages care professionals to put the person, not the evidence-based interventions, first [209]. One of the crucial assumptions of the person-centered approach is seeing the person with dementia as an agent capable of taking control of their own life in a meaningful way [170]. *Agency* is not simply an attribute of humans. It is being generated through configurations of people and their interactions with each other and with their environment [66,185,309,316]. Therefore, we argue that the agency of people with dementia can be supported and empowered by their surrounding social and technological environment.

3.1.2 Design and HCI in dementia care

In line with the emerging person-centered paradigm in dementia care, a shift has been taking place in the field of HCI and dementia with regard to a change in perspective [186], from supporting people who are experiencing cognitive and physical impairments to addressing a persons' experience [131,138,225,321]. Given the changing nature and the complexity of the condition, research in HCI emphasizes the need to understand and support the maintenance of 'personhood' of people with dementia [38,124,226,338], by acknowledging that they are still persons that can experience life and relationships in full effect. Based on this person-centeredness, many HCI researchers have emphasized the value of inclusive design practices [96,124,131,186], enabling them to emphatically engage with people with dementia [338], to best cater to their needs and to anticipate their abilities by design [319,320]. The perception and reality of the individual is hereby highly valued, and is being investigated through *experience-centered design (ECD)* [353]. It is increasingly being applied in HCI to discover how people with dementia experience their social world [93,96,225,226], and how design and technology can enrich the interactions in this social environment [185,321,342].

Building a connection in a participatory way is fundamental for gaining a deeper understanding in the experience of people with dementia and their perspective on technology [38,124,310,326]. However, traditional participatory practice is too demanding [204,215], since it relies on the use of verbal expression, abstract thinking [186], and demands resilience and initiative [15]. Recently, new strategies have been explored to design for this space and overcome these challenges [21,38,138,326]. These works show that people with dementia are capable of being involved in research when they are treated as equal partners, adequately prepared, and feel socially connected [21]. Here, it is imperative that the method is suitably adapted [310] to pose questions in an appropriate manner through which researchers can better understand and construct the experiences of dementia [338].

3.1.3 Technology and design for social health

Social health is one of the essential components of general well-being. Needless to say, it is highly depended on communication skills, which can be compromised in the progression of dementia [35]. As a consequence, people with dementia face an increased risk of loneliness and social withdrawal. In recent years, *information and communication technologies* (ICT) have been used to facilitate independence, social inclusion, personal autonomy and to improve their quality of life [252]. Researchers have attempted to increase the communication competence of people with dementia, e.g., through the implementation of *augmentative and alternative communication* (AAC) strategies. These are designed to capitalize on the

remaining strengths of individuals and take advantage of environmental cues. Bourgeois (1990) explored the use of *"memory wallets"* assisting in the retrieval of personal information and facilitating conversation [36]. The adoption of this simple external aid was found to prompt a two-way communication. Communication issues may also arise from the lack of knowledge of caregivers and family members on how to interact with people with dementia. As a consequence, they often become reluctant to engage in conversations. This problem was addressed by Welsh et al. (2018) through the development of an application *Ticket to Talk* designed to stimulate talks between young people and older adults with dementia [342]. The application provides life context of the person with dementia by collecting photographs, videos, and sound clips related to significant events from the past. They serve as communication prompts and conversation starters. In a similar vein, *CIRCA (Computer Interactive Reminiscence and Communication Aid)* system aims at improving communication between people with Alzheimer's disease and their caregivers [12]. It comprises a multimedia database and allows the user to freely explore a variety of photographs, videos, music and textual content. The idea was built on the assumption that providing a system like CIRCA will minimize the conversational working memory load of people with dementia. Inspired by this work, Smith et al. (2009) developed a digital memory aid, called *multimedia biographies*, in which a collection of digital media assets were used to tell the story of a persons' life [297]. This carefully chosen media content provides space for reminiscence and communication.

Other work found that using technology can enable people with dementia to engage in new forms of self-expressions and connect them with others in a shared social engagement [96,133,185,186]. Even though technology is being seen as an effective vehicle for people with dementia contributing to their social health and independence, its use and applicability among this group remains scarce [29].

3.1.4 Dementia dynamics in design

Research highlights the importance of tailoring ICT interventions that promote social participation to specific individual needs and capacities [79,298]. For technology contributing to social health, it is necessary to consider the utility of it appropriately to the progression and changing needs of individuals with dementia. Thereby considering also specific requirements of the circle of care around them, made up of their important others (i.e., partner or family members) [199]. The study reported in this paper is conducted as part of a larger ongoing research project. In this project, participants with dementia are involved and being treated as equal contributors in the design of technology for improving their social participation. To this end, a *research through design* approach is adopted [357], adhering to an iterative design process covering exploration, design, and evaluation

[39] to address challenges in using social technology hardware such as mobile phones, computers, and tablets over time and enable social participation by designing new social technologies.

As the role of technology aiming to encourage and enrich social participation is still little explored [96,186,298], the aim of this paper is to build a base for a comprehensive understanding of social challenges experienced by people with dementia. The main goal of this study is to learn how their social participation can be hindered and facilitated by social technologies and find new design opportunities. This can eventually lead to increased meaningful engagement of people with dementia and enrich their social experience through technology.

3.2 Study design

This chapter reports on our exploratory field study in which we co-created design opportunities for social technology in the context of dementia. We employed a guided co-creation session to understand the needs, barriers, and facilitators people with dementia experience in performing social interactions through social technology. We conducted one co-creation session per participant, that centered around three co-creative methods.

3.2.1 Engagement in co-creation

Being aware of the challenges of including people with dementia in a participatory design process [125], a co-creation session was conducted at home to foster an empathetic relationship [195]. Following [311], we made a distinction between the person with dementia as an informant and as co-designer. To ensure that we approached participants from a collaborative design perspective, and thus involved them as co-creators, we have devised three generative, co-creative methods. The person with dementia is not seen as an 'informant' but rather as a contributor in the project [283]. This setting aimed to support the participants with dementia to take on a more active role and encourage them to share their daily experiences regarding social interactions and existing technology. Previously conducted qualitative interview study provided us with insights that were used to personalize each method and ask specific questions about identified individual patterns, experiences and needs.[1]

3.2.2 Participants and setting

This study was part of a larger ongoing project. Participants were recruited through caregivers from home care institutions in the Netherlands. In total, four participants with dementia living at home together with their informal caregiver (e.g., spouse) participated. All participants with dementia had previous experience

[1] Manuscript in preparation.

Participant *N*	Name	Age	Diagnosis
PwD1	Charles	76	Moderate, Vascular Dementia
CG1	*Joanna*		
PwD2	Frank	79	Mild, Alzheimer's disease
CG2	*Sarah*		
PwD3	Julia	87	Moderate, Alzheimer's disease
CG3	*Michael*		
PwD4	Monica	76	Moderate, Alzheimer's disease
CG4	*Sam*		

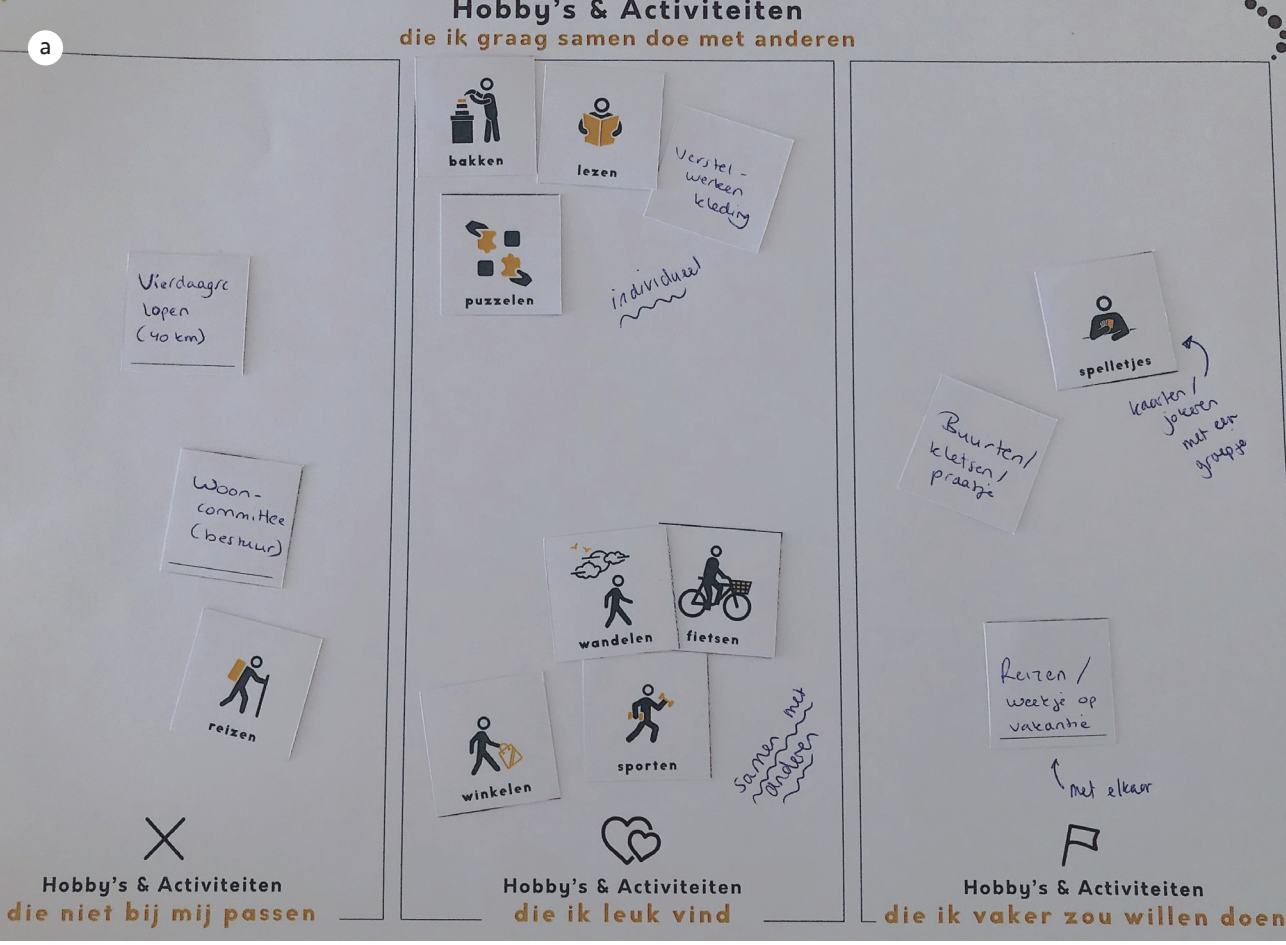
Table 3.1. Participant information; PwD – person with dementia; CG – informal caregiver

with using technology, either independently or with support. The participants shared the same socio-cultural context. Pseudonyms are used throughout for privacy purposes. We conducted four co-creation sessions, each involving a participant with dementia, accompanied by a spouse.

Prior to the co-creation session, the researchers sent a letter to potential participants and followed up with a phone call to ask for participation. The following inclusion criteria were adhered to: 1) participant is diagnosed with early-stage dementia caused by *Alzheimer's Disease* or *Vascular dementia*, indicated by a care professional; 2) participant lives at home together with an informal caregiver (e.g. spouse); 3) participant is willing to participate; 4) participant has no visual or auditory processing disorder and has sufficient physical ability to participate in the co-creation session (see Table 3.1).

The co-creation session was conducted at people's homes. Before the beginning of a session, the researcher introduced herself and engaged in a brief conversation to put participants at ease [236]. Subsequently, the researcher explained the purpose and the course of actions of the session. The participants were informed about their rights to withdraw at any time during the session. Finally, the spouse of the participant with dementia was asked to supplement the conversation only when necessary so that the participant with dementia was able to express his or her feelings and thoughts.

During the co-creation session the principal researcher guided the activities in order to go through the co-creative methods (see Figure 3.1 and 3.2). The



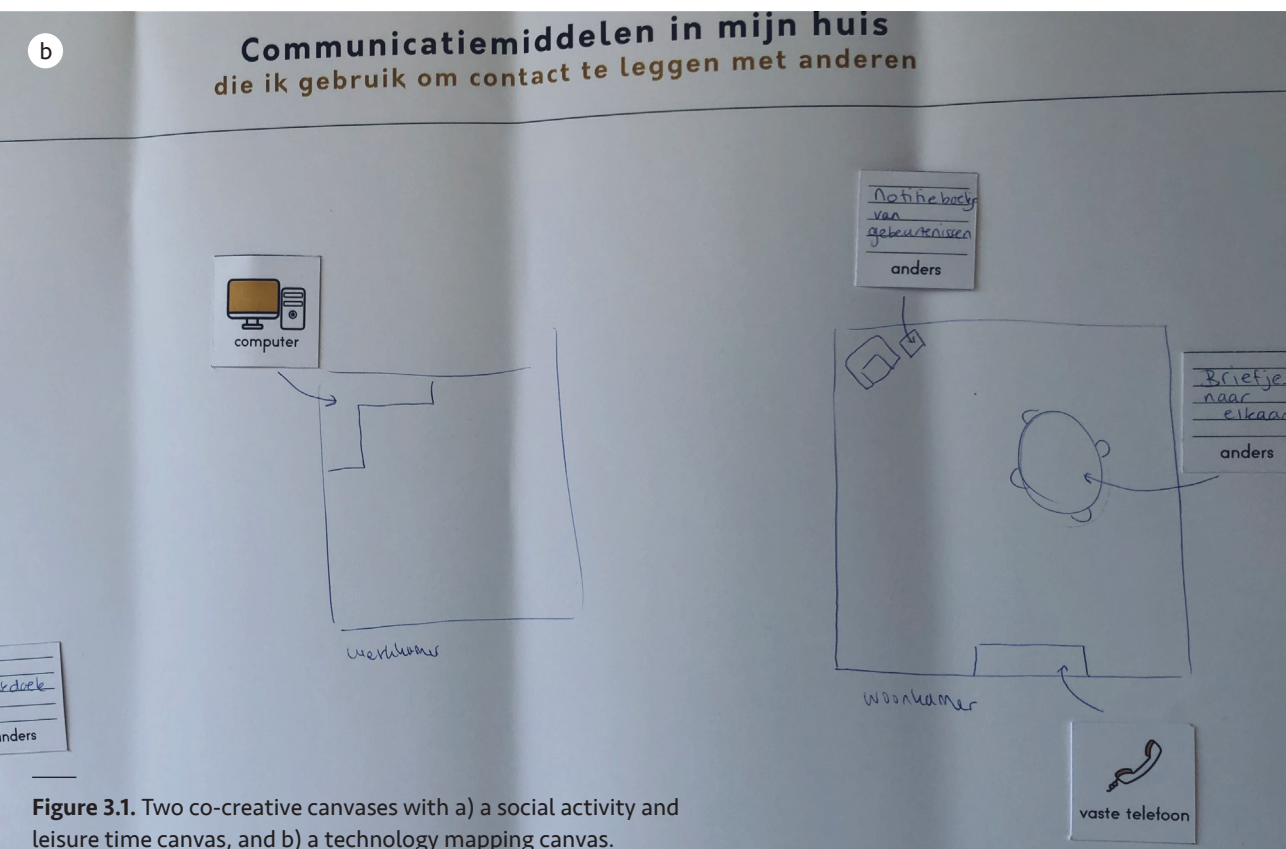


Figure 3.1. Two co-creative canvases with a) a social activity and leisure time canvas, and b) a technology mapping canvas.

generative tools were placed between the principal investigator and the couple to stimulate dialogue. By using these tools as building blocks, we aimed to encourage the participants with dementia to steer the conversation. As follows, it allows the researcher to get a better understanding of the role of the context in hindering or facilitating the use of social technology, and to extract their experiences and perspectives to steer the design agenda for social technologies.

1. Social activity and leisure time canvas

To facilitate a meaningful conversation with people with dementia, a **social activity and leisure time canvas** was developed, inspired by [116]. In line with this research, we created a modified canvas to gain insights into solely the social and leisure time activities that the participants still pursue, would like to pursue more often, and can no longer pursue together with their significant others (see Figure 3.1a). The main objective was to allow participants to reflect on barriers and facilitators in performing social activities, and share whether social technologies were used or not. Social activities and leisure time cards were used to distribute them among the different columns and get the conversation going. These cards were personalized for each participant, based on the knowledge gathered during previous research activities with the participants. Blank cards were used to include personal activities that were not previously identified.

2. Technology mapping canvas

Secondly, we developed a **technology mapping canvas** to explore the context of use of current social technologies (such as a phone, tablet, or computer) and the social and environmental arrangements in which these are situated to fulfill their social needs (see Figure 3.1b). This empathy tool consists of a canvas on which the researcher could draw a map of placement of the technology in use. In parallel to this activity, questions were asked in a sensitive and non-intrusive way to preserve a safe atmosphere.

3. Experience diary

Finally, we developed an **experience diary** to give voice to everyday experiences and contexts of people with dementia [129], both positive and negative, regarding social interactions and the use of social technology (see Figure 3.2). After a brief introduction, it was left with the participants for two weeks. Diary studies are known to provide rich insights about personal motives and feelings, and can provide a decisive understanding into the daily lives of participants with dementia when suitably adapted [21,310]. Inspired by this literature, we developed a modified experience diary for each couple that suited our research question. The diary contained personalized question cards that were mainly directed towards the participant with dementia. These questions were based on the insights from earlier

Figure 3.2. The third co-creative tool with an experience diary consisting of three categories of personalized question cards, a dice, a camera, a voice recorder, and a notebook.

findings and divided into three categories of cards: 1) '**my daily life**' cards (e.g., *"What would you like to do today?"*), 2) '**my social life**' cards (e.g., *"What kind of activity would you like to do with others at this moment?"*), and 3) '**my device usage**' cards (e.g., *"What device did you use today to connect with others?")*. Open questions were used to stimulate a conversation between the couples. A dice was employed in the diary study to ensure randomness in card selection. Each couple was asked to roll the dice at least twice a day - which added a playful element to the research activity [310] - and thus answer at least two questions a day. They were free to choose when and where to sit together for the experience diary, and whether they preferred to answer the questions using a notebook, voice recorder or a camera [21].

3.2.3 Ethics

This research was approved by the Ethics Review Board of Tilburg School of Social and Behavioral Sciences (number EC-2018.76). Written consent was given by all participants themselves after the principal researcher went through the information letter with them. The principal researcher conducting the in-context sessions had previous experience with similar sessions with people with dementia. During the session, the participants were repeatedly asked if they would like to continue or preferred to stop. The researcher paid attention to the bodily expressions of the person with dementia that would be indicative of the need to interrupt or terminate the session [74]. A reciprocal approach was employed to lower the burden on the participants and to enable them to feel comfortable [165] in an open and safe setup with careful attention to their needs [132].

3.2.4 Data collection and analysis

Data collected in this study consisted of 1) audio recordings of the sessions, 2) photographic documentation of the completed co-creative tools, and 3) the documentation of four diaries. All audio recordings were deleted once the transcripts were made. All data were analyzed by a thematic analysis in ATLAS/ti software, which involved coding, interpretation, and generation of themes and sub-themes [45]. The transcripts, documentation and evolving theme list were discussed by four experienced qualitative researchers. We conducted a bottom-up analysis to identify participants' needs, barriers they encounter in engaging into social interactions, difficulties in using existing social technology, and strategies that are being used by the participants or their families to mitigate the influence of dementia on social interactions. The quotations used within this article are translated from Dutch to English.

3.3 Results

Our thematic analysis of data gathered from the co-creation sessions centers

around four main themes allowing us to identify design opportunities for improving social interactions of people with dementia through social technology. The main selected themes are: 1) social needs of people with dementia living self-reliant, 2) barriers in engaging in social interactions/activities, 3) strategies used by people with dementia and their families to mitigate the impact of the condition on social interactions, 4) difficulties in using existing social technological solutions. We carefully examine the themes and sub-themes in the following sections.

3.3.1 Social needs of people with dementia that live self-reliant

In order to explore the design opportunities for new social technologies that would draw on the experience of people with dementia and - subsequently - enrich that experience, we started our inquiry with discovering the most commonly expressed needs of self-reliant people with dementia involved in the study. Through the responses given by the participants and their relatives, three main themes kept recurring: the need for fulfilling relationships, agency, and shared activities.

Fulfilling relationships

Reviewing social contacts of people with dementia allowed us to identify three important components influencing the perception of individual relationships as satisfactory and fulfilling.

The need for close interactions comes before anything else. Staying in touch with family members and close friends has been indicated as an essential component of satisfactory social life by the participants. When asked about the most valuable aspect of their current social context and how it has changed recently with respect to the past, one of the couples wrote down in the diary *"Contact with children, grandchildren, direct neighbors, and good acquaintances. The quantity decreases slightly, while the quality improves."* [*Julia, Michael*]. Similarly, when asked by the researcher about the concept of an ideal social life another participating couple said:

> **Researcher:** *What is an example of an ideal social life for you right now?*
> **Joanna:** *Spending time together with our children and grandchildren. That is important to us. They are regarded as the number one.*
> **Charles:** *Yes, logically.*

In addition, a broader context of social presence has been indicated as a relevant part of social well-being. For people with dementia participation in social activities, being involved in the life of local communities and having various social ties

appears to be an important component of social health. One of the participants particularly enjoyed the home visits of her husband's business clients, as she has seen it as an opportunity to have a little chat with the visitors. Another person with dementia expressed how participating in the meetings of local community (neighborhood association) helps her to remain connected to other people, emphasizing that these social ties are the main reason why she is still a part of the group.

Apart from the nature of relationships and the proximity of social networks, the way in which a person with dementia stays connected to the social environment should be taken into consideration. According to our data, the most desirable way of connecting to others was through having mundane conversations, simple everyday chitchats. When talking about interacting with other people in a broader social context, one of the participants said cheerfully: "*I have more contact with people. I don't really have much trouble with it. It's just, you go somewhere, no matter if it's morning, afternoon or evening: good morning, everyone, how are you here? Well, and then people start talking.*" [*Monica*].

Agency

The importance of the sense of agency in dementia has been confirmed in our design inquiry. While often the assistance of family members or caregivers eventually becomes indispensable, being devoid of simple everyday choices may lead the person with dementia to the feeling of loss of control and frustration. The need for agency manifests different per person. Some of the participants were clearly expressing the need to play an instrumental role in carrying out activities. *Monica* said: *"I can still pay my bills on the computer. I know how to do it, and I do it as it should be. But my husband then says: wait until the children are with us. Then they can watch if I am doing it right. My husband does not know how to use the computer. I keep saying to myself: I can still do it. But he doesn't fully trust me.*" In other cases, the focus was not on the capacity to act, but rather on taking an active role in the decision-making process. It is particularly prominent when talking about stepping back from previous chores and responsibilities or social circles. In another example from *Monica*, being a part of a neighborhood association, the possibility to make a choice of when to resign from her membership appeared to be of great importance.

Shared activities

Lastly in this section, participants expressed the desire to stay engaged in shared activities, carry on with simple everyday tasks, chores and personal interests. When asked by a researcher what are the things that she would like to continue doing, *Monica* answered:

> **Monica:** *... what I would like to do with someone else, is to play card games and just having chit chats. As we do right now, drinking a cup of coffee and having pleasant chats. My husband is not a big fan of playing cards, but I would really like to join a group to play cards one evening.*

Another important component of well-being, falling within the category of a need of sharing activities with others, appears to be physical activity. Taking part in a variety of group sports activities, going for a walk or cycling has been identified as a relevant and enjoyable part of a daily routine of our participants.

3.3.2 Barriers in engaging in social interactions or activities

We identified two main categories of barriers in engaging in social interactions: external and internal conditions which will be explained in the following sections.

External barriers

Three main aspects of the external environment have been identified as impeding social inclusion of people with dementia: environmental conditions, location/ distance, and presence and behavior of others. The impact of environmental factors (such as weather) or the distance between person's with dementia household and a given meeting point on their participation in social activities is fairly straightforward. In addition, an important external factor influencing people's social health is not only their physical, but also social environment. The absence of family or friends, or their lack of availability and willingness to engage in interactions, may preclude the person with dementia from building meaningful connections.

Internal barriers

The most prominent message deriving from the data collected was decreasing self-confidence of the participants with dementia. We have identified two sub-themes being the most relevant internal factors leading to social withdrawal or insecurity in the social context: fear of decreasing social competence and perceived loss of technical competence.

Fear of decreasing social competence

As a result of deteriorating cognitive capacities, especially memory and attention difficulties, people with dementia experience the sense of inadequacy in the social context. Over the course of the co-creation sessions, the problem of fearing to engage or initiate social contact kept reappearing. The participants confessed to

being worried about their forgetfulness, losing track of the conversation and possible awkward behavior. It appears to be particularly difficult for people with dementia to interact with others through digital means, i.e., phone calls. Charles expressed explicitly his reluctance to communicate in this way:

> **Charles:** *She sometimes says to me, "You have to call." But I hate it to make outgoing calls, because during the conversation I cannot get the answer and then I do not know it anymore.*

Perceived loss of technical competence

Despite procedural skills being fairly well preserved in people with dementia [138,226], because of experienced deterioration of cognitive abilities, their subjective perception of technical and instrumental competency might be compromised. As a result of supposed inability, they tend to give up on the attempts to interact with new technologies and step back from various commitments and activities they used to enjoy. Oftentimes, the reluctance to use technology impedes maintaining regular contacts with others who, for example, do not live in a close proximity of the person with dementia. Abandonment of interests or giving up on previous responsibilities, on the other hand, lessens the chances of meeting new people and maintaining previous circles of friends and acquaintances. All of that together may lead to deepening the sense of social isolation of people with dementia.

3.3.3 Strategies used by people with dementia and their families to mitigate the impact of the condition on social interactions

Participants have already implemented some simple strategies to mitigate the negative impact of the condition on their everyday lives and social interactions. Identifying these means can provide valuable insights into how future social technologies should be designed. Based on the collected data, we distinguished three main strategies facilitating living with dementia and maintaining social connectedness: appropriate levels of assistance, routine, and self-management strategies.

Appropriate levels of assistance

With cognitive and functional decline following the progression of dementia, people affected by it will need assistance over time. However, in order to prompt activity among people with dementia and promote their independence for as long as possible, it is essential to offer an appropriate level of assistance, instead of

taking over tasks from them in all life domains. Based on the insights gathered from our participants, we identified three points on the support spectrum: *prompts, supported autonomy,* and i*nclusive takeover.*

The first, lowest level of assistance, aims to maintain full autonomy and independence of the person with dementia. The support takes the form of *prompts* coming from a system or device. The prompts may trigger either the execution of a particular action (e.g. answering the incoming call) or recollection of memories (e.g. exposing the person with dementia to a video that leads to recollection of old memories and prompts a conversation) leading to a start of a conversation.

The second level of assistance - *supported autonomy* - allows the person with dementia to maintain control over a given task or interaction, yet with verbal or non-verbal cues from the side of a partner or family members and under their supervision. It might be while the person with dementia tries to send a message or an email with a guidance of a significant other who, in case of necessity, suggests the next steps required to complete the action or indicates which buttons to press.

At the end of the support spectrum there is the action of *inclusive taking over* which entails the person with dementia to be indirectly involved in the execution of a given action, that is done by a family member. As an example of this dynamics, illustrated by one of the couples, it was the informal caregiver (partner) of the person with dementia who received all of the messages and pictures from the family members. Afterwards, he presented the content to his wife and sent back a response on behalf of both of them. It enabled the person with dementia to have a feeling of staying involved, without the burden of using technological solutions that might have become too demanding for her to use.

Routine

Another strategy facilitating social interactions is incorporating elements of routines. Having regular group meetings, coffee time with friends, or gym appointments helps to make social interactions an integral part of the day. For example, *Monica* combines physical activities with socializing by having a fixed appointment in a swimming pool with her friend. She explains: "*This is usually agreed, but normally if we do not call each other, the appointment will remain on Wednesday evening.*" Moreover, incorporating routines into everyday lives of people with dementia may help to circumvent the experienced memory challenges.

Self-management strategies

The third category in this section are self-management strategies. We identified three approaches within this category: *external prompts, mnemonics*, and *masking*.

A common tactic used by people with dementia and their close ones is using *external memory prompts*. Some of the involved participants used them as a communication means, for example family members leave short messages stating where they went. In another example, a participant with dementia kept a journal helping himself to find answers to frequently repeated questions or remember events of the passing days:

> **Sarah:** *If he asks me three times the same thing, he writes it down in his journal. He writes down all important things.*
> **Frank:** *Yes, I can always read it back.*

Mnemonic strategies are used as a technique aiming at memory improvement. They are based on creating connections between prior knowledge and new information through the use of various types of cues, i.e., images, key words, rhyming words, acronyms. Using mnemonic strategies is more cognitively demanding than external memory prompts and turned out to be less common among our participants with dementia. However, it appears to be helpful for some of the participants to make use of word similarities, humorous associations or acronyms in order to recall certain information, i.e., people's names.

The last strategy commonly implemented by people with dementia themselves is *masking* their cognitive difficulties. Revealing the diagnosis to one's social circle might be difficult, as the term dementia still carries a social stigma. It arose from the co-creation sessions that some of the participants try to conceal from their surroundings that they experience cognitive decline.

3.3.4 Difficulties in using existing social technologies

We learned what the most prominent barriers and difficulties were while using social technologies. The issues that have been mentioned most frequently in this part of our inquiry were: placement and level of complexity.

Placement

The placement of technological devices appears to have a very important and multidimensional role. On one hand, it can be seen as a means of facilitating habitual usage of a system. If a device is placed in a fixed, easily available location, it might serve as a prompt for the person with dementia to use it and it potentially eliminates the problem of not being able to find it. On the other hand, if a device is being stored in a hidden place, locating it becomes a challenge leading to diminished use. It has been a commonly reported problem with, for example,

mobile phones. They struggled with both finding it and charging it. This example points out to a broader problem of forgetfulness that can be amplified by a poor choice of the location of a device. If it is not placed in sight charging or bringing technology along when they leave the house might become challenging.

Complexity in existing technologies

These days there is not only a wide range of technological solutions on the market, but they also tend to keep being replaced and modified at staggering rates. It might be difficult to keep up with new technologies even for younger generations with high computer literacy, meaning this is even more demanding for older adults with lower digital literacy. In our co-creation sessions, we found evidence for three main features of new technologies that make them being perceived as too complex by people with dementia: confusing design, fast developments, and time pressure. With rapidly changing interfaces, a wide range of new functionalities and User Interfaces that are not always clear and intuitive for older adults, completing tasks that require taking prompt actions, i.e., online banking, result in being stressful and difficult.

> **Monica:** *Technology is moving rapidly. I need my husband and children for help or support.* "

3.3.5 Initiative

Ultimately, we found that the role of initiative is particularly important and complex in maintaining social interactions by people with dementia. This factor has not been described within any of the above-mentioned themes, as it appears to be in a special, two-way relationship with some of the other variables. On one hand, due to previously described internal barriers experienced by people with dementia, they less frequently take the lead or initiative to engage in social contact. They do not feel confident enough, they are afraid of their behavior being perceived as inadequate or awkward, thus they tend to avoid initiating interactions. On the other hand, the more they withdraw from their social circles, the fewer opportunities they have to challenge themselves, take the lead and recognize the abilities that remained intact. Consequently, prompting the initiative of people with dementia can be seen as an element of strategies mitigating the impact of the condition on social interactions.

3.4 Discussion

Our findings provide insights into the social abilities and limitations people with dementia experience, and the nature of interaction with existing social technology.

By using co-creative tools, opportunities for design to enrich their social experiences have been co-constructed with people with dementia and their spouses. Ultimately, we provide a list of practical implications for design.

3.4.1 Design considerations for social technology

The above findings contribute to existing research in social technology and dementia by providing an extensive insight into the social experiences and interactions of people with dementia in their daily home environment. In the following section, we will further outline the considerations for the design in this context.

Compensating for internal and external barriers experienced by people with dementia through design

The co-creation outcomes indicated that internal barriers as experienced by people with dementia cause a decrease in self-confidence in interacting with significant others. As a consequence, this may lead to social withdrawal. To enhance person's with dementia self-confidence, it is worthwhile looking at what role design can play in circumventing the internal barriers [282] and stimulating the desired social participation. One possible solution would be to design technologies that give people with dementia the feeling of being in control and reducing the distance [188]. Technology design can provide support in anchoring conversations. One possible approach is to let people with dementia interact with physical prompts as a way to indicate intentions for social sharing [185]. The involvement of the social circle (i.e., family members or significant others) is essential to trigger these intentions and to support agentic abilities of the person [96] to get the conversation started [342]. On the other hand, building on the concept of synchronous social events making it dependent on others, it is also profitable looking at a more hybrid approach, in which the technology itself could trigger social intentions asynchronously.

According to our participants, external barriers can hamper social participation. Existing social technology can help bridge, for example, the geographical distance between people. Yet, at the same time, it can create new internal barriers for individuals who lack technical expertise or necessary hardware [356]. We can contribute to the latter by creating accessible designs for people with dementia, matching the needs and capacities of the user with dementia [319]

Enhancing agency through social and physical environment

Within HCI, a strong relationship between technology and agency was reported in the literature [96,186]. Agency is created and maintained through the dynamics between individuals, those with dementia, and those without. As demonstrated in

our findings, the manifestation of agency is different for each individual with dementia. This is closely related to the facilitating strategies we found used by people with dementia to maintain their agentic abilities when interacting with existing social technology. For example, for all of our participants, it seems natural to support each other and to be there for each other within a social circle. As a result, the agency of a person with dementia is not only co-shaped but can also be strengthened by the environment. In order to improve social participation among people with dementia it is, therefore, recommended looking at the construction of everyone's agency, taking into account the social circle around it, and to enhance it through design [133,185,342].

In addition to these social dynamics, the physical environment can also provide a potential strategy. This aligns with work by [96], in which physical cues remind people with dementia to perform an action. Our findings extend current understandings and show that people with dementia adapt their environment with tangible prompts supporting them in interaction with technology. Building on these used adaptation strategies can help designers to comprehensively support people with dementia through design, specifically when it comes to interaction with social technology.

Learning from previous experiences with existing social technologies

Our findings pinpoint to the aspects that are positive and negative about existing social technologies. The properties of technology contribute to whether it is used or not. Bringing the current mechanisms of use to the center of design can better support people with dementia in performing social interactions through technology. Drawing on their preserved abilities, technology design can help to experience conversations as pleasant again. However, a certain level of flexibility and open appropriation in the design is necessary to make the technology suitable for different scenarios and contexts [321], and to foreground the social experiences of people with dementia.

3.4.2 Recommendations for future research in social technology for people with dementia

Based on the obtained results, we present possible future directions and implications for research in the area of social technology in the context of dementia.

Embracing the importance of a broader social context

Our findings point to the importance of social interactions going beyond the people closest to individuals with dementia. Even though, as one would expect,

strong social ties and close personal relationships are considered highly valuable, our participants also revealed to appreciate the presence of others, everyday chitchats with strangers and the sense of connectedness to the community. Building dementia-friendly, safe and open communities can be of a great challenge [290], yet it can be a challenge addressed by future social technology designs. Design researchers should reflect on how to engage local communities in supporting people with dementia to stay involved and active, without compromising their safety and see the role of design beyond the technology. Initiating a dialogue with the local services and communities seeking to explore and understand their perspective is vital, so as to create more inclusive social space for people with dementia.

Sharing meaningful activities

Having a fulfilling social life is composed of a variety of factors and may take different forms, depending on individual preferences and circumstances. It is easy to fall into a trap of thinking that with communication abilities being affected incrementally by the progression of dementia, meaningful interactions become out of reach. However, it is to bear in mind that communication can occur in many different shapes and forms and that meaningful interactions go beyond verbal expressions [175]. People with dementia involved in the study expressed their desire to carry on with their hobbies, physical activities and daily chores. Incorporating shared activities, promoting the concept of doing things together, and providing a safe space for expressing the wish of finding a companion for a particular activity could be a way of facilitating social engagement for people with dementia through design.

Incorporating social contact into the everyday routines

As stated in the results section, taking the initiative is an ability that decreases with the progression of dementia. Setting up a meeting or making a phone call of one's own accord happens with a diminishing frequency, yet often, while exposed to a social situation, people with dementia decide to engage in the interaction and prove to appreciate it. We have seen that, in many cases, making social experience a part of daily routines can partially compensate for the decreased initiative and prevent the exclusion of people with dementia as their condition progresses. Technology can play a facilitating role in establishing these routines. To this end, we found that external prompts can help maintain, facilitate, and create social interactions. By bringing strategies - already used by people with dementia and their families - to the center of technology design, we can promote building new routines centered around social health and connections. Future designs should take into account the necessity of embodying mitigation strategies reducing the

impact of external and internal barriers on staying socially involved over the course of dementia.

3.5 Conclusion

This chapter presents the insights arising from co-creation sessions conducted with four people with dementia and their spouses focusing on social health and communication technologies. Based on the outcomes of these participatory research activities, we were able to define the main limitations and difficulties experienced by our participants in the context of social interactions and technology usage and explore what abilities and compensating strategies may be helpful in circumventing these barriers.

Through engaging people with dementia and their partners in a participatory way, we have gathered insights into their individual experiences of the social and technological world. Building further on their needs and capacities, we identified design opportunities for improving social health through communication technology. In our design considerations, we highlight the importance of: 1) compensating for internal and external barriers experienced by people with dementia through design, 2) enhancing agency through the social and physical environment, 3) learning from previous experiences with existing social technologies.

Ultimately, we present possible design implications and future research directions. We point to the importance of reflecting not only on the role of people affected by dementia in building and maintaining their personal relationships but also on the impact of their social circles and local communities. We call for design to prompt the engagement of social networks of people with dementia and promote the sense of connectedness through shared meaningful activities. Last but not least, we encourage designers to learn from the strategies spontaneously implemented by people with dementia and their environment to compensate for the difficulties caused by the progressing cognitive decline.

3.6 Acknowledgments

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C.

Theo, neem een bijzonder moment in gedachte... Wat is voor u nu het mooiste moment om met vrienden, familie of kenissen te beleven? Waarom?

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And based off of work presented in

Myrte Thoolen, Rens Brankaert, and Yuan Lu. 2019. Sentic: A Tailored Interface Design for People with Dementia to Access Music. *In Companion Publication of the 2019 on Designing Interactive Systems Conference 2019 Companion (DIS '19 Companion).* Association for Computing Machinery, New York, NY, USA, 57–60. https://doi.org/10.1145/3301019.3325152

04

Designing Sentic: participatory design with people living with dementia

Despite a profound desire for musical experiences, individuals with dementia appear to have limited access to music in their daily lives. Due to technological advancements, music can typically only be accessed through modern systems. Furthermore, every individual's experience of living with dementia is unique, which further influences how people with dementia understand and use modern technologies. Given these challenges, we conducted an inclusive design study with ten participants to explore how people with dementia experience different existing music systems and to design an interactive music system that is more closely tailored to their preferences and abilities.

First, we examined the individual experiences, familiarity, and know-how of individuals with dementia regarding different existing music systems. Afterwards, we collaborated with these same individuals to design ***Sentic***, a novel music system. This fourth chapter presents a research through design process and approach of how interactive systems can be inclusively designed to meet the needs and abilities of people with dementia. Our approach addresses our first and second research questions on how to design interactive systems that enable people living with dementia to interact with them, while respecting their diverse abilities to use technology and their related needs.

Our study provides valuable insights into how technology can be used to enhance musical experiences for people with dementia while taking into consideration their unique needs and abilities in using interactive media systems. By closely collaborating with participants, we gained profound insights into their preferences and needs, culminating in the development of a customizable music system that caters to their specific requirements.

Chapter 4

4.1 Introduction

Over the past years, we have seen a shift in the approach toward dementia care, moving from the medical perspective focused on care-oriented processes, schedules, and staff efficiency toward a person-centered approach that elevates individual and personal experiences in care [87]. At the same time, in the field of HCI research, there is a growing interest in providing technology that follows similar philosophies and incorporates person-centered approaches, and is developed in ongoing dialog with people living with dementia and their extended care network [195,225,338]. These approaches take into account context, embodiment, sensorial experiences, and emotional experiences [186]. Using these developments, we can design for dementia care to enable participation in pleasurable activities [215], improve quality of life, and provide meaningful participation [188]. The experiences of dementia can widely vary, and different personal and social factors play a role. These differences are not always considered in design for and with people with dementia [104,238].

In this chapter, we report on an inclusive design process for creating a tangible music interface which is directly accessible to people with dementia. Using this process, we designed *Sentic*: a physical and digital music player combined to promote independence when listening to music [319]. It consists of two parts: a record player base and a mobile application (see Figure 4.1). The record player base has an interchangeable tangible interaction component that can be tailored to the user's abilities and allows users to access a range of audio files and create a playlist together with their family members and caregivers. The musical playlist is connected to a tangible token with corresponding color that acts as an interface. The mobile application allows for the creation of a personal profile by collecting personally meaningful audio files related to life events of the person with dementia (see Figure 4.2). However, the mobile application will not be discussed in detail in this chapter, which will focus mainly on the inclusive design process of the record player base.

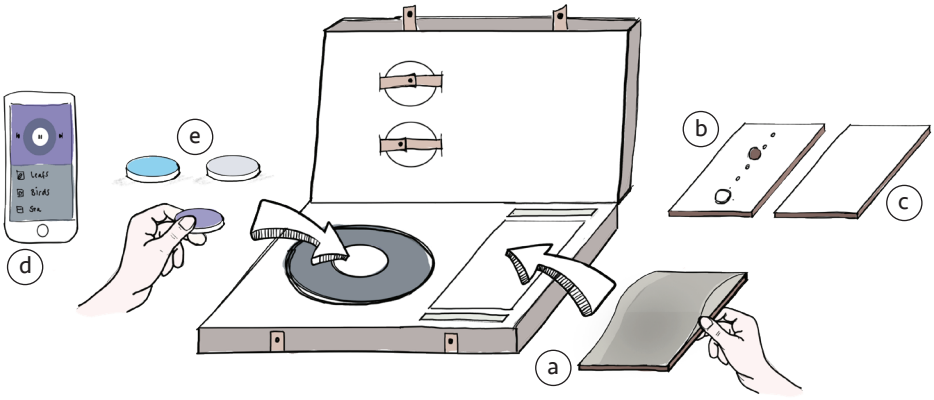

Figure 4.1. Sketch of the ***Sentic*** design concept that provides a record player base with three interchangeable interfaces: a) ***Sentic*.play** with an explorative soft interface, b) ***Sentic*.touch** with a discrete interface, or c) ***Sentic*.listen** without interface. The provided music can be tailored through: d) a mobile application that allows for the creation of musical playlists, which is connected to e) a tangible token.

We will discuss the design process of *Sentic* through a series of participatory design workshops with people living with dementia to (a) explore individual differences in abilities in dealing with interfaces and technology in general and (b) understand which associations and aesthetics people with dementia relate to and how interaction design can leverage this. This involved working with a group of ten people with dementia in smaller subsets and obtaining their reactions to existing interfaces, products, and prototypes iteratively, in order to evolve design ideas culminating in the final *Sentic* prototype. Individual differences in response due to personality and changing stages of dementia led the designers to provide multiple adaptive options for the interface.

This chapter contributes to the growing literature in HCI and the design of everyday technologies for people living with dementia. First, we outline an inclusive design process in which we highlight and exemplify the value of designing with people with dementia. In these workshops, physical and sensorial experiences were explored to provide concrete leads to enable people with dementia to reconnect both with their own personal history and with the present moment through both the music and the interface. Secondly, we show the potential of tailored tangible interaction design to support the maintenance of autonomy of people living with dementia and allow access to technology and discuss how it promotes positive wellbeing and supports their sense of self. To conclude, we reflect on the design of *Sentic* and envision future opportunities for tailored user interfaces in design for people living with dementia.

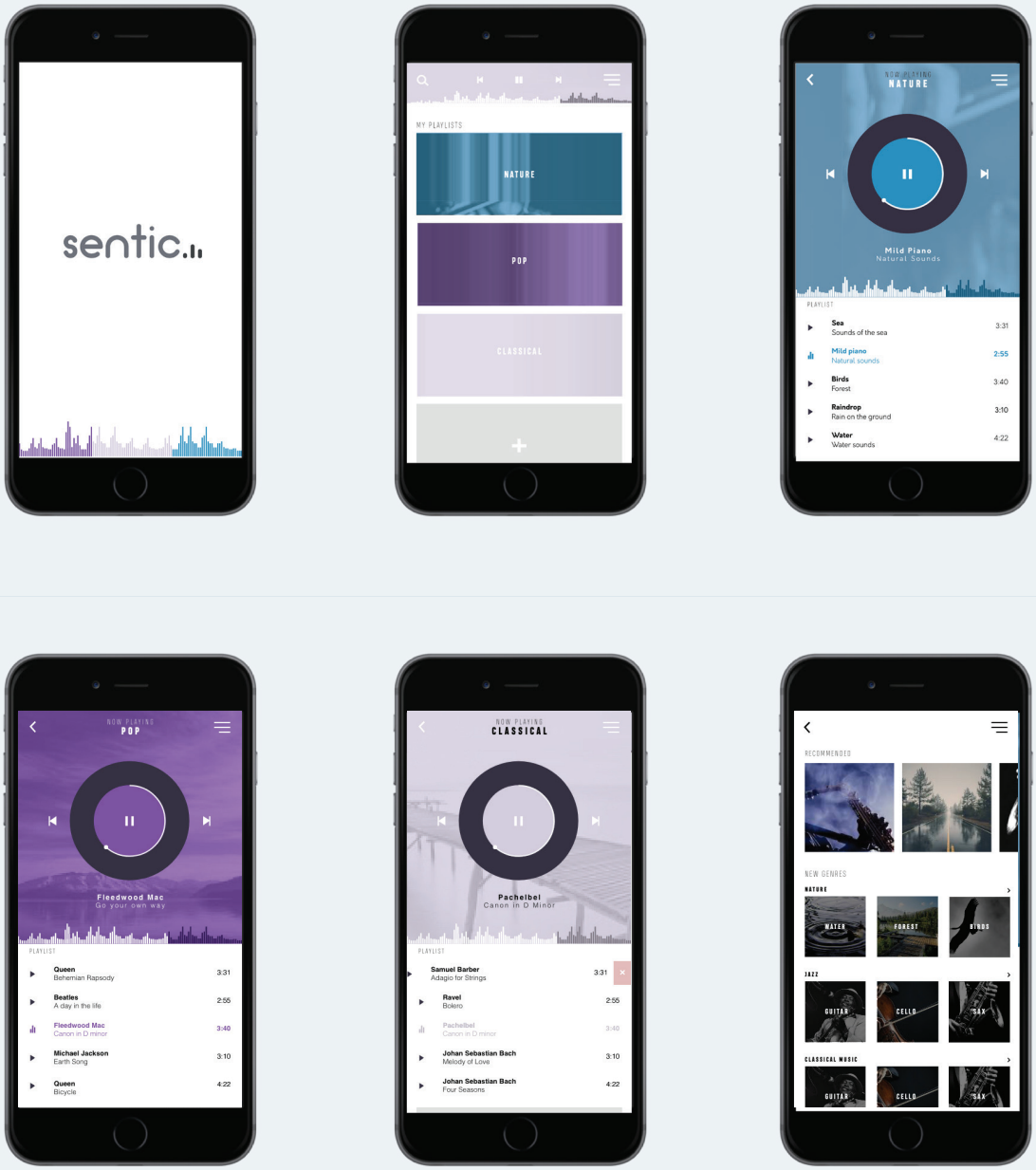

Figure 4.2. Mobile application that makes it easy to create unique playlists of personally meaningful music. The color of each playlist corresponds to the color of the physical tokens.

4.2 Related work

In this section, we introduce key considerations in designing tailored user interfaces for people living with dementia.

4.2.1 User-sensitivity in design

Technology has focused on providing support in carrying out daily activities by designing assistive technologies that address the gap that can occur in the cognition of people with dementia [38]. However, recent work in design and dementia has shifted focus to a more holistic perspective that makes use of the skills still present in the person [188,225], and focuses on what the individual can do by interpreting the contextualized meaning of these actions, rather than on focusing on deficits [186]. Every person is different, the skills and challenges people face vary and affect their ability on an individual level [168]. In dementia care, this approach is also referred to as the new care paradigm of person-centered care [38]. In parallel, there is a growing body of research in the field of HCI that incorporates this person-centered approach in the design of new technologies for people living with dementia. This research suggests that when designing for people with dementia, HCI researchers should pay attention to individual perspectives and take into account personality, uniqueness [38,338], and the changing nature of needs and characteristics of people with dementia [233]. Research highlights the importance of seeing every experience and interaction as an opportunity for engagement, even when dementia is at its most severe, each unique and complete person can experience joy and live a life with meaning and dignity [87]. With this aim, participatory design approaches are being used to involve people with dementia as co-designers in the creation of new technologies [96,125,338], as mediators in the use of artifacts [138,338], and in open approaches that focus on personalization [38,133]. This shift in HCI embraces the personal aspects of interaction with technology in everyday life [186], and is valuable for developing user-sensitive design and technologies.

4.2.2 Personal dynamics in dementia

With dementia, continuous physical, sensorial, and emotional changes affect each individual differently and can influence one's sense of self and self-reliance [59]. Changes in ability are related to decreased confidence and loss of motivation for involvement in activities [109]. Deterioration in a person's ability makes it challenging for people with dementia to understand everyday technologies, which makes it increasingly difficult to maintain access to activities of daily living [215,238], and they then require increasing support. There is a growing body of research that explores the effect of losses in both cognitive and physical skills in the technology use of people with dementia [238,264,298]. However, research has also shown that even in later stages of dementia people can interact meaningfully

and engage when prompted [111,321]. Furthermore, current research has sparked new interest in designing technologies to foster interaction, understanding, and empathy between people with diverse cognitive abilities [186]. More research is needed to determine how these different cognitive abilities can be considered in the design.

4.2.3 Music for meaningful participation

Music can enable people with dementia to participate in an activity that is enjoyable and personally meaningful [211]. Research has shown that an individual listening to music can result in a more personalized experience, which is beneficial for improving mood and relieving agitation [177]. Besides, self-selected music activates different parts of the brain and positively affects the lived experience, more effectively compared to when it is chosen by caregivers or relatives [28]. While most of the research in music has focused on the effect of music as a therapeutic intervention, the role of design in having personal access to individualized listening to music in everyday life is still unexplored [295]. One of the main problems of individualized listening to music is the person's inability to use music player interfaces. People with dementia are often dependent on caregivers to access their personal music through commercially available music players (e.g., CD player or Spotify); however, these are often too difficult to use. Additionally, research has shown that problems in accessing music go beyond the usability of the equipment and involve the importance of considerations on aesthetics and appearance [295]. Accordingly, access to music is dependent on multiple factors influencing a person's individual, social, and physical environment. Numerous commercially available music players are attempting to address this market and are sold to private parties such as the *Simple Music Player by 1958LLC*,[1] the *Memory Loss One Button Radio from GeriGuard Solutions*[2], and the *Unforgettable Music Player and Radio from LiveBetterWith*.[3] All of these systems claim to be adaptable to all individuals, although few are designed for specific cases [295] and take the changing needs of people with dementia over time into account [233]. Additionally, supporting listening to music together is often seen as an additional and less important activity by caregivers [178].

4.2.4 Tangible and customizable interactions in dementia

Tangible interactions can stimulate tactile senses and can enhance people's bodily coordination and sensorimotor skills [146]. Haptic direct manipulations, in which users can grab, move and feel the relevant elements, can invite users to interact with objects by appealing to their sense of touch, providing joy and playfulness

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1 https://www.dementiamusic.co.uk/.
2 https://designability.org.uk/projects/products/one-button-analogue-radio/.
3 https://dementia.livebetterwith.com/products/unforgettable-music-player-digital-radio.

[136]. Previous work by other researchers has shown that haptic user interfaces for therapeutic use can encourage active participation and improve the evocation of positive emotions in people with dementia [225,230]. Lazar et al. (2016) generated design recommendations for the design of recreational systems that can support activities for people living with dementia, and described the meaningfulness of integrating a personal approach as people with dementia may forget how to use the system as their condition progresses [188]. Research has suggested that looking more fundamentally at what constitutes an intuitive control related to the person themselves may help to design appropriate technology [243]. Moreover, presenting only a subset of available options in applications and content can meet diverse needs and provide a way to access recreational systems. These examples demonstrate the potential for a personally tailored approach, which can be realized through customization and adaptability in HCI and show the prospect of more suitable user interfaces for people living with dementia. In this chapter, we explore how to design systems that are customizable or can be tailored to specific needs—and investigate how aesthetics and tangible interactions enable users to maintain individual access to these systems.

4.3 Study approach

We intended for our design process to be recognizable and directly usable for those with dementia. The process was based on a three-stage, iterative design process covering: Exploration, Design, and Evaluation [39]. The study took place over the course of 11 months from early 2017 to late 2017. We investigated the associations and aesthetics that people with varying stages of dementia appreciate and relate to, and the interaction modalities that could facilitate accessibility. We conducted an iterative design process [38] using collaborative ways of designing for and with people with dementia to design an individualized recreational activity [69,233]. It explored possible interactions and functionalities with people with dementia via a series of engagement workshops [225] and investigated initial reactions to technology via group sessions [151]. We then organized a series of six engagement workshop sessions in which observations and informal interviews were conducted. To open the dialog, we used existing products, mockups, and specifically developed prototypes to solicit reactions from participants to various interactions, aesthetics, and functionalities in the design process [96,127,338]. Each workshop was followed by a design iteration conducted by the first author based on the insights gathered.

4.3.1 Participants and ethics

We collaborated with *Vitalis* care organization, in Eindhoven, the Netherlands. Care professionals selected a total of ten participants who met the following criteria: they had a formal diagnosis of dementia, varying from early- to late-stage dementia and attended a day center at least once a month (so that staff had

sufficient time to get familiar with the participant). Ethical approval was gained from the university and the care organization. Written consent was initially obtained from the participants with dementia themselves, and verbal assent was sought before and during each interview session to remind participants about the purpose of the research and their right to withdraw at any time. A family member signed the consent form in cases where participants were not able to do so.

4.3.2 Deployment in day care center

This research took place in familiar surroundings within a daycare setting, where people who live at home visit a day program during working hours, and in which a long-standing and trustworthy relationship is established between the participants and the care professionals (i.e., sharing private information). It is important that the care professional is familiar with the life history and preferences of the participant for selecting the personal music content for the study. Care professionals of the involved care organization recruited participants in early to late stages of dementia who regularly visit the day care facility. Care professionals who were familiar with the participants divided them into two smaller groups of not more than five persons per group in which the different stages of dementia were represented: a group composed of five people with early-stage dementia and a group of five people with moderate to-later stages of dementia. The majority of the participants were not in the advanced stage of dementia since they still live at home. We carried out the workshop sessions with both of the groups as part of the morning program of the daycare facility, which was allocated for brain training activities. The workshops were designed to be reciprocal and to offer participants the opportunity to engage and to experience in the moment pleasure [165], as part of a positive experience.

4.4 An inclusive design process for iterative feedback

In the workshop series a process of iterative feedback was applied which focused on trying to develop a holistic understanding of people with dementia's individual differences in abilities in dealing with interfaces and technology in general and which associations and aesthetics people with dementia relate to and how interaction design can leverage this.

4.4.1 Workshop 1 and 2: associations and aesthetics in design *(exploration phase)*

We started the process with a design activity in which two prototypes were developed to observe interactions and enabled researchers to gather insights into how the design affects behavior and their engagement. In the first workshop, the researchers introduced themselves to both groups and participated in the regular morning activity. Then two prototypes were introduced with which participants

could engage with and respond to. This was visual and tactile stimuli to prompt a response. The workshop ran for approximately one-and-a-half-hours per group. Each participant was given a prototype one after the other to explore the interaction capabilities and motor skills of the particular group, starting with the cube (see Figure 4.3). As the prototypes were unrelated to each other, transference of learning between prototypes was unlikely.

Figure 4.3. Tangible prototypes as prompts. *Left:* cube corresponding cards. *Right:* playful disc mapping.

The first prototype was based on matching the shapes [291], resulting in a simple cube probe with six different sides corresponded to six same-sized surfaces with silhouettes of the objects (see Figure 4.3, left). The second prototype was based on a playful ring interface, on which participants could map disc objects into corresponding slots (see Figure 4.3, right).

During the exploration, the participants demonstrated the ability to match shapes in both prototypes. However, the forms of interaction greatly varied per person. People within the early-stage group found the rather playful interactions childish and showed no engagement. Conversely, people within the moderate-to-later stage dementia group became enthusiastic about the playful interactions and were actively engaged in discovering the possibilities of the prototypes. All participants, clearly showed that the physical negative space on the prototype (i.e., the cutlery shape on the cube that need to be matched with the similar shape) seemed to increase the ability to understand the interaction and allowed them to interact with the prototypes individually.

From this first explorative workshop, we concluded: 1) clearly defining expectations in form and appearance provoked users to interact with an artifact across all stages, and 2) to be careful with playful interactions as these can be perceived as a

Figure 4.4. The conceptual prototype of a record player-inspired music device

negative experience and rather childish.

A second explorative workshop was organized, involving a card sort session to identify participants' know-how of audio products and understand how they related to them. The same participants as the first workshop were provided with cards depicting audio devices, such as radios, stereos, record, and players. We asked them to arrange cards in order of makes sense to does not make sense and reflect on the results.

We found that music products from the past were generally recognized. Many participants were reminded of pleasant moments, and all participants still understood some elements on how these systems worked in detail. More modern music-playing devices were not always known (i.e., *discman*, *iPod shuffle*, and *Spotify*). In these sessions, we applied the principle of error-less learning. We did not correct participants, but rather discussed their perspective to maintain or boost self-esteem and motivate people to engage in the workshop actively [67].

Based on findings the record player proved a promising metaphor for interaction suitable for people with dementia. All participants related the record player to treasured moments of their past life and stimulated recollection of personal stories. The insights from workshops 1 and 2 (*exploration phase*) were translated into a first design proposal of a new type of music player for people living with dementia (see Figure 4.4). The prototype was designed with a calm aesthetic (clean white look) and a wooden speaker. By placing colored sound discs on the white platform, sound files could be played.

4.4.2 Workshop 3: user-sensitivity in design *(design phase)*

To explore the potential of the design proposal, we evaluated the music player prototype (see Figure 4.4). Care professionals selected three participants from the first workshops, with diverse characteristics to maximize variation, who were willing to engage in a one-on-one session with the first author and were physically able and verbally articulate enough to use the prototype and create narratives. Two participants with early-stage dementia and one participant with moderate-stage dementia were asked to observe the prototype, try to use it, and play a song by placing a sound disc on the platform by themselves.

The aesthetic appearance of the prototype did not reference a music-playing device at all, they, for example, stated that the 'system was unrecognizable' for them. The chosen aesthetics and designed interaction did not match with the physical and cognitive frame of reference to allow them to make sense of and interact with the music player. The participants mentioned that the form of the artifact should not

be too 'different' in relation to music devices and should have a certain degree of 'recognition' in the audio device; therefore, it appeared that the more nuanced insights from workshop 2 were not translated well in the design proposal. However, the sound discs worked well; the participants appreciated their tactility and recognized them as CDs or records.

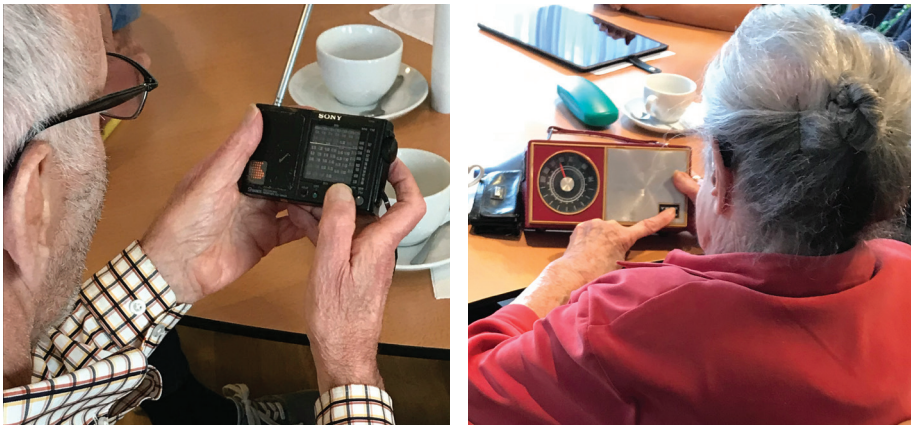

Figure 4.5. Exploring interaction with existing audio devices in a group session and discussing their personal associations with these devices.

4.4.3 Workshop 4: personal diversity in interaction *(exploration phase)*

Based on our findings in workshop 3, we stepped back from the prototype (*design phase*) and continued to discover more about the interaction and recognition preferences of the participants (*exploration phase*). In this workshop, we brought several audio devices (i.e., old-fashioned radio, *iPod shuffle*, and *Discman*) to the same participants as in workshop 1 and observed the interaction with them. We facilitated discussion on the personal associations with objects to understand how people related to the audio devices (see Figure 4.5). While exploring the audio devices, participants expressed their associations for music related to the aesthetics of a record player and shared stories from the past about listening to vinyl together with friends or their family. Interaction with the audio devices varied among the participants. Participants were not able to operate the audio devices. The first authors therefore observed the touch-related interactions with the devices to get a better understanding of appropriate interactions for the skills of different people with dementia. We concluded that the physical interaction ability of individuals varied considerably among the participants, across different stages, ages, and backgrounds; however, most devices were recognized as audio devices. Based on these observations, we found that it would be challenging to design a single interaction paradigm suitable for this group, while it would be possible to design a single recognizable aesthetic. This led to the concept of tailoring the interface to different users and their abilities.

4.4.4 Workshop 5: tailoring the interface *(design and evaluation phase)*

We developed a second design proposal with a modular interface to respond to the individual differences between people with dementia (see Figure 4.6). The proposal had: 1) a discrete interface with a volume knob and song selection, 2) a more explorative fabric interface to play music, and 3) no interface for passive listening. The prototype was designed to be reminiscent of a record player, and was evaluated with the same ten participants as in the first workshops through a *Wizard of Oz* evaluation method [162].

Figure 4.6. *Left:* a discrete interaction interface, *Right:* a more explorative soft interface. Each caters to a different type and ability of interaction with the device

The researcher observed the participant's behavior and personal preferences from which recommendations were established. The evaluation indicated the importance of a flexible interface that can be adjusted to personal abilities appropriate to individual strengths. For example, one participant with advanced dementia discovered the interface through tactile senses by touching the soft surface and became enthusiastic when a song changed to a different tune, after which he raised his thumb to fellow participants (see Figure 4.6, *left*). Another participant with mild dementia found it more pleasant to use the discrete and rotating knob (see Figure 4.6, *right*). Participants with varying stages of dementia expressed comfort and interest in using the customizable interface and indicated the potential of personalized access to audio. The findings from this evaluation session resulted in our final design proposal: ***Sentic***.

4.5 *Sentic:* A personal adaptable music player

Sentic is designed to address the issue of lack of accessibility in currently available audio devices for people with dementia experiencing condition-related changes in physical and cognitive abilities (see Figure 4.7). The aim of *Sentic* is to provide a tangible interface that can be adjusted to the individual capabilities and skills still

Figure 4.7. The final design of Sentic

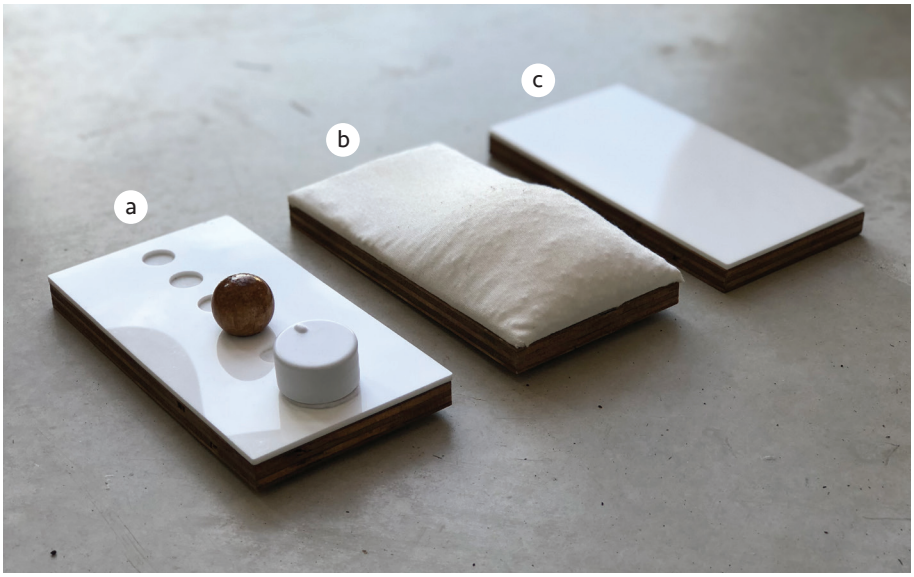

Figure 4.8. The adaptable interfaces of *Sentic* in its current implementation: a) *Sentic***.touch**, b) *Sentic***.play**, and c) *Sentic***.listen**

present within a person living with dementia. The tangible interface of the record player base can be configured by a caregiver by plugging in the module to allow people with dementia to directly engage and intuitively invite the user to interact with the controls of the system and use it. *Sentic* in its current implementation provides three interchangeable interfaces: 1) *Sentic***.touch** with a discrete interface, 2) *Sentic***.play** with an explorative soft interface, or 3) *Sentic***.listen** with no interface. The design itself is reminiscent of a record player, and sound discs (i.e., tangible tokens) can be placed on the record player to play personal music lists. The overall aesthetic is designed as a suitcase, common in record players of the fifties, with a smooth wooden finish that people appreciated and recognized. *Sentic* includes speakers to play the music and has headphones that can be connected.

*Sentic***.touch** is a discrete interface (see Figure 4.8a) that allows to select songs and adjust volume. The song can be selected by moving the ball object between five points on the interface. These reference points indicate that the music token contains five songs. At the bottom, the volume can be controlled with a volume knob.

*Sentic***.play** is an explorative soft interface (see Figure 4.8b) that is equipped with a soft fabric surface to adjust volume and go to the next song. A song can be selected by touching the soft surface, which divided into five areas vertically

Figure 4.9. Participant engaging with *Sentic*.

corresponding to the five songs. The volume can be controlled by stroking over the surface.

*Sentic***.listen** is the third interface, which removes the interaction to control the volume and switch to the next song (see Figure 4.8c). It therefore emphasizes the interaction with the sound discs and listening to the playlist that plays songs one after another.

4.5.1 Session 6: co-reflection with *Sentic*

To reflect on the final prototype of *Sentic*, we conducted a co-reflection session [322] with three participants who were selected based on their diverse characteristics and willingness to engage in a one-on-one session with the first author. All three participants were previously involved in one of the workshops; one participant was diagnosed with early-stage dementia and two participants with moderate stage of dementia. The first author did not advise the participants on how to use the interface before the evaluation. The reflection showed empowerment of all three participants through accentuation on abilities rather than limitations. After experiencing the prototype (see Figure 4.9), short interviews with the participants revealed that all participants were amazed by their own ability to control their preferred audio.

The first author, who performed the user engagements, noted a change in the interaction ability of a participant with moderate stage of dementia during this evaluation:

> He placed his hand on the *Sentic***.play** interface and made small movements over it, and the volume turned up. All of a sudden, his eyes were filled with tears. His attention was drawn and his interest to keep interacting with it was encouraged. “

While his interactions throughout the day were initially not very energetic nor independent, he markedly changed when touching the *Sentic* interface. The modularity, because of customizable interactions, helped each participant in their own way to interact independently with the system. The participants showed changes in mood and more positive emotions. As expressed by a participant with early-stage dementia:

> *Since I tried* ***Sentic*.touch**, *I can listen repeatedly to the most beautiful song on earth. Just by a simple movement with the little ball.* “

Figure 4.10. User evaluation in *Vitalis* with a participating resident listening to his favorite song

The participant expressed that *Sentic*.**touch** was his favorite interface (see Figure 4.10). This finding indicates that a simple operation that fits the individual-specific preferences and strengths is successful in supporting the ability to interact independently and contributes to the perceived usefulness of the technology. In another example, two participants began to tell stories from their past, making associations with the music played. They had not told such detailed stories in the previous sessions. For example, a participant with moderate dementia had difficulties with speaking, but when he touched *Sentic*.**play** for the first time he spoke softly:

> "*... How beautiful, and incredible ...* (repeatedly)

Engaging with the system highlighted an ease of interacting with technology and music. The participant kept touching the interface, which made the smile on his face grow bigger. It seemed as if he were becoming more comfortable with using the system independently and taking control of it. Through the evolving nature of use, it demonstrated to be an effective interface for this particular participant.

4.6 Discussion

Our case study demonstrates an inclusive design process with people living with dementia that iteratively shaped the development of *Sentic*. This work shows how we used artifacts and prototypes to engage participants with dementia and explore various forms of interaction with technology. Our major finding from the design process was that people with dementia have diverse needs, independent of the phase of dementia and age, which we cannot entirely address by a generic solution.

The *Sentic* design showcases an interface that can be tailored, which caters to diversity and personalization in people living with dementia and facilitates direct access to technology. With the possibility to select a specific user profile. This case study can open up the potential for the design of adaptable and adaptive interfaces that respond to the heterogeneity of people with dementia in terms of needs, preferences, and capabilities and address the need to include them in technology design in the HCI field [186,224,226].

This study showed the benefits of an adaptable user interface that can give users more control over the appearance and the way of interaction with the user interface. However, for some users it can be difficult to customize the interface due to, for example, lower levels of ICT literacy [114]. In order to support them, an adaptable interface with system support can be an efficient outcome for developing suitable user interfaces for people living with dementia.

In addition to this, the case study provides design researchers with insights and new perspectives on how to include people with dementia in engagement workshops and how responses could be to technology, interactions, and aesthetics. The *Sentic* design proposal is based on a familiar association with a record player, adopting its aesthetic to increase association and appreciation by people living with dementia.

4.6.1 Design considerations

Adaptable user interfaces have great potential as an approach to design for people living with dementia, to cater for diversity and change, this section presents design considerations for future design and research. The reasons for individual preference can vary and depend on the unique frame of reference, needs, or stage of dementia. Adapting and tailoring technologies for different abilities is considered challenging [131]; however, with current developments in technology, this is increasingly more feasible. Previous work emphasizes the importance of both appealing [5] and adaptive systems [191] for people with dementia; however, this is rarely realized in physical product design. Also, recommendations for the design of recreational systems are still very much in development [188]. Throughout the design process of *Sentic*, we also found that the aesthetic of *Sentic* should match with the associations of people living with dementia to invite direct engagement and facilitate improved access. We argue that associations and familiarity can be enabled through aesthetics.

In our case study, we applied the notion of tailored interface design to an audio device. This principle could also be applied in other application domains such as household products (e.g., coffee machine, washing machine, stove), recreational

systems (e.g., television, computer, mobile phone), or everyday environments (e.g., kitchen, living room, bathroom). With this approach, we can contribute to one of the pressing challenges in designing person-centered technologies and services for people living with dementia [39,69,96,133,186,337]. However, further research is required to examine suitable areas and levels of adaptability [109], both in terms of technology as well as care efforts.

Through an inclusive design process, we managed to create *Sentic*, which contributes to providing a rich interaction that stimulates tactile senses tuned to the particular needs of the person and allows for active participation. In the current design of *Sentic*, the three options of tangible interfaces are manually plugged into the system by caregivers or family members, but with more advanced prototypes we could automate this through human-aware or context-aware intelligent technologies. More research is needed to discover the possibilities of such intelligent and adaptive systems, and explore the balance between automation and manual control, desired and required in interaction design.

4.7 Conclusion

In this chapter, we covered the design process of *Sentic*, which is designed as a novel concept with a user interface that can be tailored toward people with dementia to enable personalized access to music. Our design process included multiple probes and prototypes in user engagements and showed an example of how to design with and for people with dementia and provide them with the possibility to configure their own (preferred) experience. Current technology often still requires a relatively high level of cognitive and functional ability, making it difficult for people with dementia to access. As dementia progresses, stimulating tactile senses can contribute to the maintenance of autonomy in interaction and add to a feeling of self-reliance and encourages positive health. Our final session showed how the customizable interaction modules gave participants with different stages of dementia access to their preferred music. The design of *Sentic* and the inclusive process reported in this chapter inspire new directions for interaction design for people with dementia and broaden the approach of designing with and for people with dementia. *Sentic* shows that it is possible to design for people with dementia in ways that are accessible, meaningful, and aesthetic appealing.

4.8 Acknowledgments

We thank all participants and care staff from the care organization Vitalis for participating in this study, as well as sharing their time, activity, and experiences. We gratefully acknowledge the care organization for providing a space for the workshops and the design of the *Sentic* system.

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05

AmbientEcho: Exploring interactive media experiences in the context of residential dementia care

In the previous chapter, we showed that music systems need a certain degree of adaptability to allow people with dementia to access musical experiences by themselves. Apart from providing people with dementia with access to music, we found little has been discovered regarding how to provide residents of care facilities with access to (multi)media. The purpose of this chapter is to address this research gap by examining how individual differences can be incorporated into interactive media systems in residential dementia care facilities.

To this end, we introduce a qualitative, exploratory study of the ***AmbientEcho*** installation at Pleyade, a residential dementia care facility. For this study, we recruited eight participants, which included three individuals diagnosed with dementia, two of their spouses, and three care professionals from a Pleyade care unit. The aim of this study is to gain a deeper understanding of how *AmbientEcho*, as an interactive media system, can promote a person-centered approach to care and improve the quality of life for individuals living with dementia and those who care for them. We employed a combination of observations, semi-structured interviews, and a post-trial focus group to gain a deeper understanding of the system's impact on those living with dementia and their caregivers. A smaller sample size allowed us to conduct in-depth and extensive observations and interviews with each participant, allowing us to gain a comprehensive understanding of their experiences with the *AmbientEcho* system.

Figure 5.1. *AmbientEcho* is an interactive media system with a virtual window, a photo frame, ambient music, and matching light.

Chapter 5

5.1 Introduction

With an aging population, the number of people living with dementia is increasing at an unprecedented pace [255]. Dementia has a significant impact on daily life, affecting cognitive and physical abilities progressively over time. It hinders people from participating fully in society and increases their need for care and support significantly. On top of that people living in residential dementia care are often treated as passive recipients of care that are no longer able to experience things or contribute - since their ability to express themselves, communicate and engage in activities is decreased [71,315] – and thereby are marginalized by dominant care practice. Recent studies indicated that including and engaging residents with dementia actively in the care space can support participation in social activities and thereby prevent loneliness [315] and feelings of *"loss of self"* [312], presenting opportunities to increase their quality of life.

To do so, various approaches in HCI research have been explored to facilitate and enable living well with dementia [131,133,225,331,342]. This is especially important since there is no cure available for dementia yet. In this, design and technology can play an essential role in enriching the experience of living with dementia by developing systems that contribute to enablement [253], are meaningful [337], or enhance social communication capabilities [111]. Prior work within HCI research has explored the value of meaningful activities involving media as a prompt to encourage social interaction [5,101,110,146,342]. In addition, reminiscence activities can be beneficial in providing enjoyment and positive experiences [72]. By moving toward experience-centered technologies [225], HCI researchers include people with dementia's individual preferences and context, opening up possibilities for interactive and personal media technologies in residential care [89,159]. Although others have conducted studies in this domain, the format, vehicle and methods of providing an enriched personal media experience in residential dementia care, considering individual variability [186] and support person-centered care [248] is still insufficiently explored.

Figure 5.2. *AmbientEcho* automatically displays bespoke media content when in range by means of a personal Bluetooth necklace (a), or the system displays curated media by placing a colored disc in the bowl on the table (b).

Therefore, to study this, we designed ***AmbientEcho*** as a prototype (Figure 5.1), through which residents with mid to late-stage dementia can view bespoke media (i.e., carefully selected content personalized to each individual based on their interests and history) and curated media (i.e., carefully chosen generic content that is appropriate for a wider group of people in this demographic) through different interaction means (Figure 5.2). In this paper, we report on a qualitative, exploratory study of *AmbientEcho* in residential dementia care. It was evaluated with people with dementia, their spouses, and care staff in their care facility, using observations, semi-structured interviews, and a post-trial focus group.

Findings suggest that 1) a combined media approach triggered rich personal associations, facilitated a revival of identity, and stimulated participation in shared experiences of residents, family and care practitioners when interacting with *AmbientEcho*, and that 2) diverse media contents and interactions play a role in providing suitable experiences for residents. Our findings contribute to the existing literature by a) extending our understanding of using interactive media contents in a residential dementia care space to facilitate shared interaction with other residents, family and care practitioners, and b) highlighting the value of open curation in creating a personalized and context-specific media experience for people with dementia. Derived from these findings, we offer design considerations for HCI to guide person-centered media interventions in dementia care and

beyond. Setting the stage for further explorations of user and context-specific systems to enrich intensely personal as well as shared space experiences with often excluded user groups.

5.2 Related work

In this section, we describe previous work in the field of design for dementia and recent developments within HCI, moving toward a person-centered approach that embraces user-specific needs to enrich personal experiences.

5.2.1 Dementia, design, and HCI

Dementia is a chronic neurodegenerative brain condition that affects daily functioning and loss of abilities [265]. Dementia has an unpredictable and heterogenous nature with varying symptoms, making the impact and experiences different between individuals [60]. While people with dementia report a lack of access to meaningful activities [247], researchers have found that technology can provide a means to enhance access to such meaningful activities and experiences [188]. However, for people with dementia, it is challenging to use mundane technologies (i.e., alarm clocks) as well as new technologies, since these are often cognitively demanding and require learning. This excludes them from engaging [238] and means these technologies cannot be used in a meaningful way [174]. Recent HCI work challenges this view, as the advantages of involving people with dementia actively in design and facilitating direct engagement through design leads to accessible and useful interventions [95,195,226,328]. Recently, researchers reviewed HCI in the context of dementia through a 'critical lens' [186] and promoted a view based on ability rather than disability. Looking at dementia from a more inclusive and socially just perspective opens up novel directions for technology and design research [248], showing the potential of design to support the personal experiences [138]. Such a focus on the individual makes it possible to design bespoke artifacts that are able to leverage personal characteristics [338] and correspond to people's abilities [238], which can lead to a stronger perception of self and increased emotional wellbeing [174,327]. This approach builds further on the concept of person-centered care [170], to design from the perspective and experiences of people with dementia [39,165]. This opens up a design space for continuous individual and contextual variability in meaningful activities and experiences for people living with dementia.

5.2.2 Reminiscence and a wider perspective of self

Researchers have considered reminiscence activities as an opportunity to engage people with dementia meaningfully in residential care by eliciting previous experiences with the aid of tangible prompts such as photographs [14] or life stories [81]. This has been shown to be effective in improving mood, sense of

identity [337], social inclusion [103], self-esteem [72], and cognitive function [349]. There is increasing evidence that technology-aided reminiscence by using media content can improve participation [189], provide a degree of empowerment [110], allow people to be heard and experience pride [213], and shape people's agency in a social setting [342]. This personalized approach in reminiscence positively affect people with dementia [277]; however, it does focus on the past rather than experiences and inner emotions in the 'now', and could also cause discomfort when they cannot remember the reminiscence material [110,338]. Earlier work found that generic photographs (i.e., non-personal) can trigger personal memories and elicit detailed narratives from people with dementia that are not bound to a particular place or time [14]. Generic photographs are therefore used for comparison of perceptions and values, likes and dislikes, but can provoke discussion when ambiguities and confusions occur [101]. Thus, researchers argue for a wider perspective where not only the past but also the present moment is acknowledged, in which the person with dementia is enabled to drive the experience [138,338]. For example, in the *CIRCA* project [5], the media did not target specific life events or relationships; instead, it used generic content. People with dementia and relatives could easily switch the media if it did not provide sufficient incentives to stimulate conversation. While more studies in HCI and dementia have explored the use of media interventions, more understanding is needed for widespread practical application in residential care settings [199].

5.2.3 Media experiences and dementia

Having access to rich and stimulating media can be of significant benefit for people living in residential dementia care [189]. Prior work in HCI explored the value of digital media as a prompt for supporting conversations [5,101,342], encouraging agency [95], and keeping the experience in the present moment alive [133]. Researchers found that personal media (i.e., photograph) is deemed to be vital as it is attuned to unique needs and preferences, compared to, for example, viewing TV shows [355]. Recent work brought pre-recorded nature videos into a care home and found that the media needs to provide enough context and build on existing knowledge of residents to provide a meaningful experience [200]. But they highlight that it is still necessary to generate knowledge on what media is best suited in this context. Moreover, most of the work that has been done emphasizes visual incentives for reminiscence. Recent research has found that multiple forms of media used together can be more engaging for residents [188]. Besides visual incentives, music [69], sounds [138], and colored light [155] can promote a positive experience and can enable people with dementia to connect with others [226]. To maximize access to stimulating media in residential care, the context of use and the offering of media content appropriately, need to be explored [319].

5.2.4 Interactive public displays & interaction

Research in HCI has studied interactive public displays for engaging and stimulating people in long-term care environments [159]. These platforms are initially designed to present digital photos, videos, and text, but have evolved from systems that only display screen-based information towards alternative ways of displaying information through light, projection, and soundscapes [254]. Although there are some examples of interactive public displays designed for dementia care [89,200,344], few of them use a broad range of displaying media. Many of these systems seem to fail to address specific user needs and preferences due to inadequate design and poor facilitation resulting in limited use of such interventions [155]. Researchers found that enabling residents in care facilities to experience competence and being able to make their own decision can evoke self-esteem and a sense of autonomy [188]. The physical and social environment of residents can help maintain aspects of self by enabling choice, recognizing the person's reality, providing autonomy, and supporting meaningful engagement [87]. Therefore, a growing body of research suggests shifting the focus from cognition toward embodiment in designing technologies for dementia care [225]. People with dementia can meaningfully interact with their environment using their bodies through, for example, movement, gestures, and singing [186,226]. They can feel engaged when the body is embraced as a medium for interaction [174]. As many authors note earlier, research calls for tangible units in design that embraces the body in the user interface and provide autonomy in interaction [336].

5.3 AmbientEcho design

AmbientEcho was designed by a group of design practitioners and care professionals in co-design [42] to engage people with dementia meaningfully through media. The system is placed in a half-open 'room' with cozy features to provide media in a non-intrusive way. To further enhance this, the primary media vehicle in *AmbientEcho* is a virtual window, to facilitate the calm experience of looking outside [200].

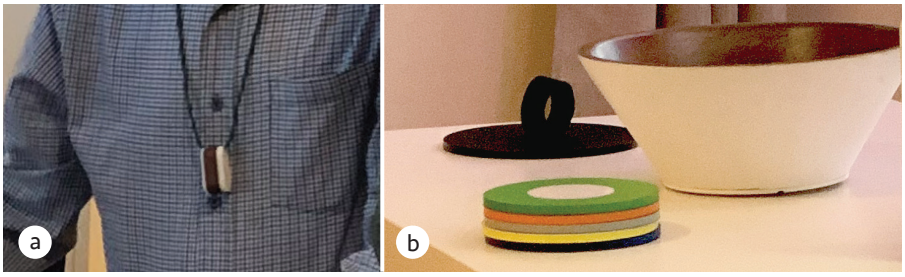

Figure 5.3. Necklace with Bluetooth technology as an input mechanism to adapt *AmbientEcho* remotely to bespoke media (a), and RFID discs as a manual input for curated media (b).

Source/ theme	Window	Photo frame	Light	Sound
Beach	Ocean waves	People on the beach	Blue, yellow	Ocean waves
Nature	*Flowing water stream*	*Forest, animal, landscapes*	*Green, blue*	*Water flow*
Relax	Fireplace	Sunset, candles	Dark blue, red-orange	Crackling wood
Floral	*Floral garden*	*Flowers, bouquet*	*Pink, green*	*Scott McKenzie, San Francisco*
Food	Orange tree	Meals, tea, coffee table	Orange, yellow	Marconi Union, Weightless
Active	*Shopping street*	*Outdoor games, board games*	*Blue, white*	*Ben E. King, Stand by me*

Table 5.4. *AmbientEcho* includes six colored discs to activate curated media. One video, four photos and a sound per theme.

Additionally, the photo frame in *AmbientEcho* displays content for a more intimate experience [101], and shows four pictures in a slideshow per theme. Finally, the sound and light support a coherent and immersive experience in the system. The name of the design reflects ambient media, as being integrated in the environment, that is 'echoed' when the presence or input of residents is detected.

Based on reminiscence literature and experience, two types of media were found to be used in dementia care: very personal often autobiographic media and more generic widely available media. Given the dementia care context, the system was designed for easy access to the media. To access the personally preferred media, residents wear a personal necklace with Bluetooth technology. When residents are within range with this necklace, the media content shifts to their personally preferred media, referred to as bespoke media in this paper onwards (see Figure 5.3a). To access generic media, an RFID enabled bowl is placed on the table with a set of colored discs next to it. When the residents place one disc in the RFID bowl, the system will overwrite the bespoke media and present the selection of generic media, referred to as curated media in this paper onwards (see Figure 5.3b). Both interactions are separate. As such, the system provides both bespoke media that is personal for people to relate to emotionally, and curated media to encourage curiosity and open exploration. The bespoke media content was selected together with the residents with dementia, their family members, and care practitioners. For the curated media six themes were selected to provoke meaningful responses,

based on literature, these were nature [101], beach [146], flowers [294], and food [89], for an overview, see Figure 5.4. Colors were used to differentiate between the discs, and the bowl was designed to lower the interaction affordance.

5.3.1 Research objectives

We use *AmbientEcho* as a prototype to conduct post-design research [283] to understand the personal experiences with media in a shared residential dementia care context. To do so, we offer both bespoke and curated media. The aim of this study was to 1) explore the responses and experiences of people with dementia evoked by *AmbientEcho* in context, and 2) evaluate the experience of the system in practice as a tool for people with dementia, their family, and care staff. In this study, we look at the potential of such interactive media systems in care practice to energize, soothe, and stimulate residents, or to simply provide a topic to talk about.

5.4 Study method

To study the user experiences of the *AmbientEcho* prototype, we conducted a three-week pilot study between October and November 2018. We conducted post-design research, based on in-context deployment of *AmbientEcho* in a residential dementia care setting, to evaluate the experiences with the design and find opportunities for future design.

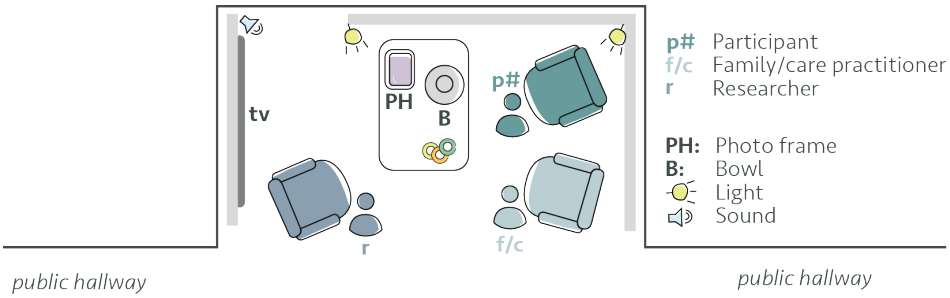

Figure 5.5. Positioning and setting of *AmbientEcho*.

5.4.1 Deployment in residential dementia care

We worked closely together with one care unit of care organization, Pleyade, in the Netherlands. Here residents have a private room to sleep or rest and a shared communal area; these are connected via a public hallway. The care organization embedded *AmbientEcho* as part of their care practice; the residents were either brought or walked independently to the system. The *AmbientEcho* prototype was set-up in the hallway, in a half-open space, which is separated so that residents and visitors can both walk along it on the way to the communal area and can experience it more calmly if they want (see Figure 5.5). Prior to the research, a

meeting was organized for family and care practitioners to inform them about *AmbientEcho* and the related study. Those interested in participating were invited to a one-on-one session to receive information and sign an informed consent form. The inclusion criteria were: the resident is 1) willing to participate, 2) diagnosed with Alzheimer's disease or vascular dementia, 3) a permanent resident of the care home, and 4) able to participate and interact with the system.

5.4.2 Participants

Prior to the research, a meeting was organized to recruit participants. In total, eight participants were included in the study, three residents, two of their spouses living separately at home, and three care practitioners working at the residential care facility. We handed out a form to the residents and family who enrolled for the study to fill in personal background information and preferences. Based on this data, we gathered the bespoke media content. Residents who took part in this study had various diagnoses and comorbidities, resulting in different types of participation. Pseudonyms are used to ensure anonymity. Resident ***Audree***, an eighty-year-old woman, used to live together with her partner, ***Bram***. For several years, she has lived in a care home, as her mid-stage dementia progressed rapidly. She has her own chair in the shared living room, where she sits mostly during the day. From time to time, she answered questions when engaged and is generally in a good mood. Resident ***Chris***, a seventy-five-year-old man with dementia, is married to ***Francis***. He is diagnosed with mid-stage dementia, as his memory and ability to perform activities of daily living were deteriorating. He indicated that he lacked a social connection with other residents. The third resident, ***Deborah***, was introduced by her spouse, ***Erwin***, who expressed interest in exploring new ways to connect with his wife. She was in a late stage of dementia and no longer able to talk or walk and, therefore, in a wheelchair. In this case, non-verbal responses were noted. Most verbal accounts in our data are, therefore, from ***Audree*** and ***Chris***. Since family and care staff knew the residents well, they commented on the observations made.

5.4.3 Procedure

We conducted a three-week in-context evaluation in which participant-observations [95] were combined with semi-structured interviews with the participants twice a week. *AmbientEcho* was available at all times during the pilot study and could be used; however, they saw fit. The best time for a one-on-one session together with the first author was determined with family and care practitioners and considered the wishes and mood of the residents. While participants were using *AmbientEcho*, the first author observed them and asked them about what they liked, disliked, and asked them if they wished to change something. After the pilot study, we carried out a focus group with family

members and care practitioners to reflect on their experiences with and views on the prototype. The first author led the discussion to ensure that all participants had an opportunity to express their views.

5.4.4 Data collection and analysis

Data were collected through field notes of observations, semi-structured interviews and a focus group. We noted down positive and negative affect states of facial expression and verbal reaction (i.e., happiness and smiling), and indicated what people did (i.e., bodily responses). To respect all participants' privacy, only field notes were taken during the sessions. The focus group with family and care practitioners was audio-recorded. We used thematic analysis [45] to process our data set, which involved coding, succeeded by interpretation of the content, followed by generation of themes and sub-themes. In this analysis, we focused on the responses to media and general reactions to *AmbientEcho*.

5.4.5 Ethics

Approval to conduct this study was granted by the residential care institution. Permission required consent from participants, and if this was not possible by their legal guardian. Family members and care practitioners provided consent, together with their relatives with dementia. Time was taken to go through the consent process, along with the family members and residents with dementia. Furthermore, since the design was implemented in a real-life context, it was also available for use by other residents who did not participate in the study, it was considered unethical to keep these residents away from the system. However, these residents are not included in the data presented in this study.

5.5 Findings

In this section, we describe four themes that arose from our thematic analysis describing ways of participating with *AmbientEcho*: 1) recollecting through personal associations, 2) reviving personal identity, 3) reconnecting through a shared experience, and 4) enabling through interaction and aesthetics.

5.5.1 Recollecting through personal associations

AmbientEcho proved to be powerful in prompting personal associations to recollect memories. Participants responded to both bespoke and curated media and related these to their own experiences, resulting in a meaningful experience.

Recollecting past experiences

The media content displayed through *AmbientEcho* elicited numerous recollections by the residents. Bespoke media content seemed to prompt personal associations to recall and recollect experiences from the past. Prompted by the

bespoke media content, *Audree* recognized the castle in her hometown and associated it with a specific memory: *"That is the castle of my hometown. I was born in that neighborhood. We used to ice skate there in winter and hiked in the beautiful surroundings. It reminds me of that moment."* The use of familiar content to associate with past experiences was also illustrated by *Chris*, who made the following association with a soccer stadium: *"I visited every soccer game in the stadium and was a loyal supporter. Everyone knew me there. It was always a fantastic experience."* He continued with a smile and related a memorable moment he once experienced:

> *"I went to a soccer match together with my son, and suddenly we had to climb a steep staircase in the stadium to reach our seats. We had to stay downstairs because I was not able to climb. I can still see that staircase in front of me..."*

Showing bespoke media enabled people to build stories based on past experiences.

We also used curated media content, selected by the researchers to be appropriate for a wider group, which also provided prompts that elicited personal associations with past experiences. For instance, when activating the content **Nature**, *Chris* elaborated on a life event by telling a story of cycling through the area where he had lived: *"When I was younger, I regularly cycled through the beautiful surroundings of [city], because the nature is splendid there. It took me a while to cycle 25 kilometers, but I really enjoyed the wonderful nature."* For *Audree*, the content **Nature** also triggered a specific recollection from when she was younger: *"These are people who are cycling around the [location] forest. We always did that with the family." Chris* associated the same media with another place related to his own experience: *"One time, I went to [location], and a whole group of boars came toward me."* On activating the content **Beach**, *Chris* started to talk about his personal experience of visiting the beach: *"It reminds me of my visits to the nudist beach." Audree* associated the content Beach with taking a refreshing dive: *"I used to dive into the water. I loved it!"* These examples showed the unique responses of the residents to similar content. They revealed that past events were meaningful and influential for them, building their own stories based on the media content. It allowed them to recite and share moments in the present that was personally significant to them. Through associations with both curated and bespoke media, they were able to have a meaningful experience in the now.

Linking bespoke and curated media for new connections

Throughout the observations, it became apparent that residents started to talk about topics that emerged from the content which have not been heard before. The combined bespoke and curated media seemed to trigger new associations. In the following example, *Audree* started to talk about her personal associations prompted by bespoke content, which was followed by the curated content **Nature**, and extended it with new interpretations of the story. The set of curated images consisted of a deer crossing the road, and of people cycling in a nature reserve: *"A deer crossing the street! We often went to the forest around the castle and went cycling there. That is such a beautiful forest! It all evokes these memories!"* When *Audree* was experiencing the content **Relax**, it evoked a new connection, and she started to talk about the fireplace at her childhood home: *"Oh, it was such a cozy atmosphere! At my childhood home, we always sat in front of the fireplace with the entire family."* The combined media allowed residents to experience meaningful moments based on their personal stories to a new extent.

Associations as building blocks for initiating conversation

The curated set of content provided by the researcher was associated with by all residents in their own unique way. When residents engaged with the media, they demonstrated an ability to express their thoughts out loud. Residents even initiated the conversation, including those residents who usually remain silent and apathetic. In the following example, the bespoke media incited *Chris* to respond to the sound of a church choir and tell an autobiographical story about the period he was affiliated with a choir, which suddenly changed into a story about his wedding party:

> *"My parents used to have a café, where I helped my mother with chores. I even celebrated my wedding party in this café. The most peculiar thing about this wedding is that it was almost for free. Nowadays, we cannot imagine that. All my dear friends were there at the wedding. In one word, fantastic!"*

Residents verbalized their thoughts, triggered by the content or even triggered by their own stories which they used as building blocks to initiate conversation. *AmbientEcho* served as a mediator for starting conversations and even choosing the subject. For example, *Chris* continued telling a story about his wedding, which triggered another autobiographical story: *"I used to be a school custodian. A hundred people came to my farewell party when I reached retirement age. It was wonderful that so many people came there especially for me to celebrate my farewell. That makes me a bit sentimental and, at the same time, so tremendously*

thankful!"

Audree and *Chris* shared what they knew about the displayed content and showed signs of feeling comfortable and safe in doing so. For example, *Audree* expressed a slight smile on her face and began to lean backwards in her chair. *Chris* started to sit up straight and talked enthusiastically. Since they could associate with the media that was displayed, they took over the conversation by sharing their personal experiences. For example, *Audree* took the initiative to share her personal story, after which a conversation started:

> *"My grandmother lived across the street. We could easily drop in for a cup of coffee. We did that almost every day."* "

It seemed that when the residents felt personally connected with the media, they were able to share important life experiences and express what is meaningful, which gave them ownership.

Personal perception of repetition

The longer *AmbientEcho* was used in the residential care unit; a resident began to become bored with experiencing the same media content repeatedly. The perception of the repetitive content varied greatly, depending on the resident, the moment, and situation. While engaging with bespoke media, *Audree* said to a care practitioner: *"I have seen these images many times now."* In another session she lost her attention after a couple of minutes and commented that she wanted to go back to the communal living room. For *Chris*, the ongoing content worked as a cue to repeatedly engage with *AmbientEcho*. He even returned to it on his own, playing media from his favorite soccer team continually. Similarly, care practitioners expressed that repetitive media was also becoming boring for them during their care practice.

5.5.2 Reviving personal identity

The use of *AmbientEcho* demonstrated that residents felt engaged with the media content as it evoked lively emotional responses. Interacting with the media content supported the residents in a meaningful engagement.

Vivid responses to media

The bespoke media content proved to be the key in eliciting vigorous lively responses. Even participants with dementia who were usually more introvert and apathetic increased their active participation and 'came to life'. This was especially the case for *Deborah*, who suddenly stopped shaking her body when her bespoke

Figure 5.6. *Audree* (left), *Angeline* (care professional), and *Chris* (right) using *AmbientEcho* together

content was shown to her. Then gradually she looked to her spouse and smiled. She expressed interest and pleasure through her bodily expression. On another occasion, *Audree* walked to *AmbientEcho*, and her attention was drawn to the window displaying her birthplace. She responded joyfully to her bespoke content: *"Wow, amazing –and so beautiful to see that! It gives me goosebumps!"* In a following session, she responded again with great joy: *"Oh, so wonderful to see my hometown. It makes me so happy!"* Another resident, *Chris*, demonstrated a subtle change in emotion during one session. In the beginning, he was grumpy and talked about pain in his stomach. While sharing his thoughts, he became fully engaged: *"Unfortunately, nobody is listening to me, although it's crucial for me."* *[...]* After a minute, he leaned back in his chair and was so intrigued by the content selected for him that he forgot his issues. He listened to the choral singing and started to laugh when talking about his church choir experience. The atmosphere provided a comfortable setting, encouraging enjoyable conversations and instigating positive thoughts. As mentioned by care practitioner *Angeline*, residents became more vivid and kept talking about *AmbientEcho* all day long. She stated that it therefore positively contributes to her care practice as well.

In touch with their inner emotions

Residents engaging with *AmbientEcho* expressed happiness and appreciation that was explicitly evoked by the bespoke media. In the following example, a song caught the attention of *Chris*, and evoked tears of joy, as described in the field notes: The emotion in his face changed while singing along with his favorite soccer club song. When he was in the middle of the chorus, tears were running down his cheeks. When he kept singing, his face turned into a big smile, and he said: "*These were such good times!*" Similarly, in another example, a more explicit expression of appreciation was demonstrated by *Audree*, as observed by the researcher: After visiting *AmbientEcho*, she took a seat in the communal area. While she had tears in her eyes, she whispered in the ears of a care practitioner:

> *"I am delighted to be able to see my hometown again!"* "

These responses to *AmbientEcho* indicated the rich ways in which media that presented a familiar and trusted environment that was reminiscent of home allowed residents to express themselves by emotionally opening up. This underlines the power of specific media to provide evocative experience in a residential care environment.

While people were engaging with *AmbientEcho*, bespoke media provided a mean of evoking nostalgia. Engagement with the bespoke media was mostly perceived

Figure 5.7. *Audree* and *Bram* enjoying bespoke media together and sharing personal stories

as joyful; however, it was sometimes simultaneously coupled with a sense of loss in that the past is not going to return. In the following example, *Chris* first described a sense of happiness when talking about his experience of visiting soccer matches, which in turn was followed by a sense of loss in that he can no longer attend his favorite soccer match: *"I used to go to all the matches in the stadium as a staunch supporter. It was awesome for me to experience that each time again! Unfortunately, I cannot go anymore."* Similarly, when watching the bespoke content, *Audree* started to smile as she was fully immersed in the theme, and she expressed her feelings: *"It reminds me of the past with my parents and grandparents. That was such a good time we had there. Too bad that I'm no longer there. But when I am back home again, we always walk around the beautiful castle."* In another session, she expressed the same feelings:

> *It makes me emotional when I think about the past and recall these memories, but at the same time it makes me happy to think about these moments. These were such lovely moments we experienced there!* "

The media uncovered inner emotions and thoughts when it was associated with a significant life event. While the content reminded them of this moment, they also indicated an awareness that the past is not going to return. From the moment of acceptance, the residents seemed to enjoy the moment of remembering in the now.

5.5.3 Reconnecting through a shared experience

AmbientEcho was designed to encourage residents to share unique personal stories that were important to them with others. The system offered the opportunity to bring people closer together by spending a moment together (see Figure 5.6).

Sharing recollections

The *AmbientEcho* installation with its media and its interaction served as a conversation mediator and was used as a way of bringing people together. The atmosphere of the installation provided residents with a comfortable setting that encouraged them to revisit and share their personal experiences and past events. For instance, a conversation took place between *Audree* and *Chris* in which they start sharing recollections of past experiences, as in Figure 5.6: *"Beautiful, isn't it?"* (*Audree*). *"Yes, it is. I already used the installation this morning"* (*Chris*) The conversation between the residents was stimulated by the different media content. For instance, if the content **Beach** was activated, *Audree* and *Chris* started talking about taking a refreshing dive in the sea. Although *AmbientEcho*

was designed to engage with the content, *Chris* implicitly expressed his appreciation of spending a one-on-one moment with the researcher while experiencing the media: *"I find it much nicer this time than last time. It was really nice to be here! I did not know at all that you were here today."* As we got to know the residents during the research, *AmbientEcho* supported social engagement between residents that would normally not occur in other ways. This showed that *AmbientEcho* gave residents more control over their day-to-day life within the care home and enabled them to express their interests by initiating the action of using *AmbientEcho* together.

Reflections of family and care practitioners

As family and care practitioners were using *AmbientEcho* together with residents, they expressed the importance of engaging in a one-on-one session within a residential dementia care environment that is usually shared with multiple residents. *AmbientEcho* allowed them to spend more time with residents individually, due to its approachable location and technology. While switching between bespoke and curated media, all the care practitioners mentioned that engaging in *AmbientEcho* evoked a dialog about significant life events of the residents which they had never heard before. When sharing these stories, care practitioners found new insights and ways to connect with the residents: *"The media provided us with clues to connect with the residents and start a conversation. I even heard stories I have never heard before."* In these moments, the technology and the resulting conversation provided a way to reconnect with the present reality of the residents. For example, *Angeline* emphasized the importance of getting to know the residents' identity and their accompanying life history in order to ensure that the care practice is well-aligned to each individual. It is therefore a useful tool to deploy in residential care. Residents demonstrated that the media allowed them to express themselves and that it provided family and care practitioners with an opportunity to engage with them or respond to them. They expressed that the media created opportunities to strengthen bonding with residents: *"The media evoked personal life stories that are usually not being told, and thus developed a better relationship with the resident."* *AmbientEcho* allowed family to meaningfully connect again with their relative and created space to spend a memorable moment together (see Figure 5.7). Although *Deborah* was not able to communicate with her spouse *Erwin*, he noticed to be more closely connected and at ease with her when using *AmbientEcho*.

5.5.4 Enabling through interaction and aesthetics

While engaging with *AmbientEcho*, most of the participants found it relatively easy to interact with the technology and media. However, there was a substantial difference in how these interactions took place. Additionally, participants

appreciated the aesthetic qualities of the half-open space.

Adjusting automatically and manually

The media provided by *AmbientEcho* was noticed from a distance by the residents due to the Bluetooth activation. As *Audree* approached the system, it automatically adjusted its media to a scene of her birthplace. Her attention was captured, and she suddenly started to walk faster and respond joyfully: *"That's my hometown. It's great to see it!"* In contrast to our expectations, there was a substantial difference in how each resident used the system. *Chris* used *AmbientEcho* independently and was keen on interacting with it, as described in the field notes: Simultaneously, as *Audree* was interacting with *AmbientEcho*, *Chris* came along when he saw the media from a distance. He absorbed it and started to walk faster. When he arrived, they started a conversation triggered by the media, while suddenly, the media changed to his bespoke content, after which the conversation was stimulated even more. The interplay of automatically adjusted content in a half-open space seemed to encourage active participation and stimulate social interaction.

While some residents were keen on interacting with *AmbientEcho* independently, other residents were reluctant or interacted in direct response to an interaction by another. For example, *Deborah* became restless while her bespoke content was activated. Since she was no longer able to change the media herself, a care practitioner adjusted the media to the content **Relax**: When she saw the fireplace on the virtual window, there was an immediate change in her, and she became relaxed again. She stopped moving her jaws and fingers restlessly. In presenting this example, we highlight the nuanced and diverse nature of participation with the *AmbientEcho* installation. The use of discs to manually interact with *AmbientEcho* interested some of the residents. There was a substantial difference in how each resident interacted with them. For example, on one occasion *Chris* took control of using the discs and adjusting the media to general content so that it was more suitable to his taste: During the afternoon session, he asked the researcher if he could place a disc in the bowl. He placed various discs alternately in the bowl, after which a smile appeared on his face. For *Audree* and *Deborah*, the initiative was subtler and often in direct response to an action by another. In the following example, *Audree* interacted with the discs after someone showed her how to interact with it: *"After she has placed different discs in the bowl, she laughed with joy when the themes subsequently changed"*. These examples showed a willingness to engage with *AmbientEcho* and that it gave them the feeling that they could make sense of the care environment, while expressing agency.

Aesthetically appealing

All participants responded positively to the aesthetic qualities of *AmbientEcho* and expressed a heightened appreciation to the situatedness and appearance of the installation. All three care practitioners expressed a feeling of appreciation and valued the aesthetic qualities of the system and the resulting ambience: "*The ambient lights have an impact on the perception of our residents. It reinforces the atmosphere of the scene.*" All residents engaged differently with the room; for example, when *Audree* had taken a seat in the chair, she was immediately inspired by the design. A smile appeared on her face, and she shared her response by saying to a care practitioner: "*You see how beautiful this is! It's incredible to be in this room!*" *Chris* also expressed his appreciation of *AmbientEcho*: He mentioned that it is always the same in the care home. "*This is a different environment, and it's lots of fun!*" The environment seemed to be aesthetically engaging and evoked a pleasing experience.

5.6 Discussion

Our findings provide insights into how the *AmbientEcho* design was used and experienced in residential dementia care. Our results show that meaningful engagements occurred by people with dementia them self, among them, and between them, their relatives and care practitioners, with both the bespoke and curated media. We found that residents were engaged with the media experience, took ownership of conversations that were instigated by the media and took the initiative to interact with *AmbientEcho* actively. Engagement with both types of media content provided people with a positive moment of recognition as well as strengthened their experience in the present moment. The themes found in our analysis contribute to how media engagement through technology can be improved and applied in residential dementia care. We will further discuss how our contribution complements and extends other work within HCI research in the context of dementia, and outline design considerations for design in residential dementia care.

5.6.1 Moving beyond reminiscence

Previous work in HCI and dementia show that reminiscence is used with a social and therapeutic purpose [349]. Our findings show that it has wider applications since it evokes personal narratives and conversation [212]. Our results confirm previous findings indicating the beneficial effect of reminiscence with people with dementia [14,69,110,189,342], and extend it into the everyday context of residential care.

Besides, our study contributed to an increased sense of agency and self as well. This was particularly the case with examples from *Chris*, who continually returned

to *AmbientEcho* on his own and by himself to experience his bespoke media content from his favorite soccer team. Residents responded to the bespoke media by making meaningful associations with the content and their personal background, which served as a conversational prompt. Similarly, the curated media content supported creating new interpretations of associations that kept the conversation going. This is consistent with the earlier finding that generic content is more likely to prompt longer stories [110]. And it confirms that it is not necessary to use autobiographical material, which can be highly confrontational if people cannot recognize what is displayed [14,183]. Similarly, in our study, we found that people enjoyed recognizing content and associating stories, but also sometimes felt a sense of loss related to the personally bespoke content. This came from understanding the content and reflecting from this on their current situation.

The outcome of this study demonstrates the benefit of a combined use of both bespoke and curated media to support evoking meaningful associations and enhance telling stories. It does not matter if the association is 'correct' – it just needs to provide meaning for them. Additionally, *AmbientEcho* allows people to choose whether to engage with bespoke or curated content, allowing residents to search for something meaningful for them in that moment. It also allowed family and especially care practitioners to use the system to find topics to talk about and get to know the residents better.

5.6.2 Enhancing personal dignity

In our study, residents took various levels of initiative to engage with *AmbientEcho*, depending on their ability and preference. Meaningful media can be used as a mediator to trigger feelings of empowerment and supporting them to initiate conversations. Bespoke media contributed to trigger strong inner emotions, which made it possible for the residents to reconnect with parts of them self.

As demonstrated in our findings, residents felt comfortable interacting with *AmbientEcho*. Offering different modalities in an ambient setting supported different abilities of residents. This builds on recent work that calls for more diversity in applications and content to appeal to individuals with dementia who have varying needs, abilities, and interests that can change with the severity of the condition [188]. Initially, the residents were surprised that the technology automatically adjusted to them; however, they immediately appreciated it and, after seeing the bespoke media content, their attention was captured, and they immediately felt engaged, as many of the examples in our data show. For some residents, for instance, with *Audree*, it was more appropriate to interact in direct

response to an action of someone else, which contributed to a shared experience, while *Chris*, in particular, took the initiative to interact independently. This approach thereby contributes to a recognition of personal dignity and supports residents in having direct access to technology and control it as they desire [319]. These findings contribute to the large body of work arguing for technology that matches the interests, abilities, and self-identity of people with dementia [188,315], and builds further on work that is sensitive to individual needs [96,104,133]. The results show that the prototype did allow residents to express themselves and reconnect with their identity.

5.6.3 Shared meaning

Each resident was encouraged to engage with *AmbientEcho* together with those that were important to them – both with relatives with whom they had an intimate history and with other residents or care practitioners. As demonstrated in our findings, participating in *AmbientEcho* was meaningful for residents as well as for family members and care practitioners. Through exploring bespoke and curated media, they found that using alternations in media content helped them to understand better what was important to *Audree, Chris* and *Deborah* and how to connect with them. *AmbientEcho* thereby enhanced personal relationships and has – for this specific context – lasting effects, as indicated by the example of Audree as she talked about her experiences in the communal space with others. *AmbientEcho* offered residents the possibility to express their perception of current reality and for those around them to engage in this reality to understand their experiences. This builds on a growing corpus of research showing the importance of reconnecting to their current relationship rather than holding on to the past [212]. Therefore, *AmbientEcho* creates shared meaning in the experience and relationship between residents and those around them in the 'now'.

This work demonstrates the importance of conducting research with prototypes in the field to experimentally conduct research in a sensitive care setting. It allows seeing true engagements between individuals and our designed technology. However, more general conclusions cannot be made on the efficacy of the design due to small sample size, which is an inherent unpredictability of an experience-centered approach that earlier researchers have acknowledged as well [225,338]. The approach chosen in this research allows to present and confirm research findings, which were found in different settings and setups, in an ecologically valid way – in-context – and can result in a better understanding on how to design enriching technologies for shared residential dementia care spaces.

5.7 Design considerations

Derived from our findings, we present design considerations for design

researchers when designing interactive technology for use in residential dementia care, aiming to guide person-centered interventions in HCI so that they are sensitive and enrich experiences.

5.7.1 Sensitive inclusion

Our study demonstrated how design can be sensitive to a diverse user group within a dementia care setting. It is important that design proposals match the interests, abilities, and self-expression needs of residents to increase positive outcomes and enjoyment [63,118,176]. In our study, we contribute that the combination of both more generally curated media, and personally bespoke media contribute to meaningful shared experiences. We designed our media system with a degree of openness in the curation so that family and care practitioners could also relate the media to their interests and lived experiences that might be different from that of the residents [133]. The design may also work in other types of communal spaces, as long as a variety of content is available to enable different shared and personal experiences. Thus, the design should be sensitive to the context of use to enable people with dementia and stakeholders in their care at various levels to make sense of the care space, follow appropriate social conventions and leaving space for expressing their agency within it. Therefore, we need to find a balance when designing technology that considers people's unique personal aspects in context to both support them in maintaining agency and evoke shared meanings. As such, we have to be sensitive to the variety of people in the care space and include them as much as we can when designing our interventions.

5.7.2 Adapted levels of interaction

Our findings indicate the importance of facilitating media experiences that do not require difficult physical or cognitive actions from residents, family, or care practitioners. Engaging with technology can be a barrier for people in care environments when it requires technical expertise for setup and operation [189,252]. *AmbientEcho* has lowered these barriers in its design and showed that people felt comfortable interacting with it. This comes forward in the bespoke media that was triggered from a distance via Bluetooth and encourage engaging while also allowing manual input via the RFID discs. *AmbientEcho* seemed to provide a safe environment that was appreciated by residents and family members who visit the residential care home. In addition, it also provides a feasible environment for care practitioners to integrate into their care practice. The half-open space in the hallway allowed the various stakeholders to engage together in a shared experience, and it, therefore, stimulated a meaningful engagement in the daily living space of the residential dementia care home. Our research builds on this suggestion, creating not only a bespoke intervention, but

one which also incorporates technology that supports different levels of use by residents, family, and care practitioners.

For design and research practitioners, we recommend incorporating efforts to make technology adaptive in terms of user control and allow time for care staff to get to know the technology. They need to be able to explore and experiment with it before they can adopt it in their care practice. As yet, further research is required in order to explore what it means to have systems such as *AmbientEcho* in complex, socially situated care practices, and how to adapt to person's social and spatial arrangements [104] that are needed to integrate technology into care.

5.7.3 Variation in content

Finally, we found a necessity to enhance an appropriate application of media, where the media is suitable to an individual's interest and open for curation to support a continuous curiosity in using the system over time. Building on our data, we see that there is space in design to investigate the use of more variation in media on different levels. This content would be open for interpretation to give people with dementia the chance to recall stories that are important to them, in the present moment, instead of determining past experiences and interests beforehand – often solely inspired by family or friends. In this way, media could support family and care practitioners in understanding and reflecting on the resident's experiences in the now and allow them to find a way to be part of this experience [212]. Already in this study, some participants expressed the need for content variation, as they reported boredom and frustration when seeing the same personal media content again when not activating the curated media. Others, however, used the same content as an anchor to come back repeatedly as they felt emotionally connected to this media. In addition, some media also became repetitive for family and care practitioners, which amplifies the fact that the engagement with media needs to be worthwhile for other users as well [133].

Building further on the nature of participation in residential care and how media can contribute to a shared experience, we argue for opening up the design space with appropriate designed dialogue patterns [114]. In this, media interventions should be anchored, and user-specific knowledge should be shared within the system for it to be able to adapt to the context. Following developments in HCI, the inclusion of seeing such technology as non-human agents in care offers vast opportunities for design researchers to explore. Our study results can aid in formulating these opportunities related to the use of bespoke and curated media in residential dementia care.

5.8 Conclusion

In this chapter, we present *AmbientEcho*, an interactive media system that offers bespoke and curated media to people living with dementia in context. This media can engage residents, family, and care practitioners in experiencing meaningful moments together and increase a sense of agency in people living with dementia. Based on our results, we found that design can occupy a new space in offering recommendations concerning sensitive inclusion for shared and meaningful experiences. In this, barriers of complexity for people with dementia, family members, and care practitioners need to be lowered. Therefore, we propose a user- and context-specific approach as a consideration for future designers and design researchers in this field. Our study shows how careful design of media systems and media content can support a person-centered experience in HCI within residential dementia care, setting the stage for future design research in sensitive settings.

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06

LivingMoments: Bespoke social communication for people living with dementia and their relatives

The importance of compensating for internal and external barriers experienced by people with dementia through design are discussed in *Chapter 3*. As came forward in that chapter, people with dementia are more likely to give up modern social technologies, such as mobile phones, due to perceived internal and external barriers. However, we discovered, in contrast, that individuals could engage in social activities more easily if their environment is physically and socially conducive. For example, we found that physical cues in the environment stimulate the initiative to participate in social interactions, which can be applied in design.

Drawing on our insights from *Chapter 3*, we designed ***LivingMoments***, a novel interactive system to help overcome internal and external barriers to using modern social technologies for people with dementia. This chapter explores how *LivingMoments* enables direct access to technology for people with dementia, reducing their perceived barriers to communicating and engaging in social contact. Specifically, we examine how individuals with different technology abilities interact with *LivingMoments* through a field study of the prototype. The study encompassed a focused sample size, consisting of six individuals with dementia, their partners, and 37 relatives. This intentional approach allowed for a person-centered perspective, providing a comprehensive understanding of how the system impacted the participants and their social environment. The close observation and documentation of the participants' experiences with *LivingMoments* provided valuable data, revealing how the system influenced their social interactions and overall well-being.

The inclusion of partners and relatives, coupled with our close observation and individualized attention, provided us with valuable insights into the impact of *LivingMoments* on people with dementia and their social environment. Our findings contribute to the growing body of research on the design of interactive systems for people with dementia and highlight the importance of considering the social environment when designing such systems.

Chapter 6

6.1 Introduction

Dementia is a progressive cognitive condition mostly affecting older adults. Dementia affects each person differently depending on the specific underlying conditions, circumstances, and life experiences. With this also their abilities decrease over time which has a profound negative impact on a person's life and, specifically, the ability to engage with social contacts [7,164,343], let alone via technological means [27,120,173]. Within HCI, there is an increased interest in supporting people with dementia through designing technology to contribute to their lived experience [13,40,139,225,321] and engaging them in digital social interactions to express their agency [75,96,185,342]. These systems are often designed for a specific moment in the process of dementia, for example, addressing specifically early or advanced stages of dementia [76]. However, in the progression of dementia, changes in the ability to use technology are largely unpredictable [215]. It is therefore important to accommodate these dynamics in interventions and design technologies that can be used by them at an adequate level over time [76,319]. To understand people's changing experiences and abilities, we need to perform in context research over an extended period of time and not just at a single point in time [236].

This chapter presents *LivingMoments*, a communication system that enables people with dementia to engage in social contact with their relatives. Relatives can use a digital application to send photos, videos, and voice messages to a person with dementia (see Figure 6.1). This digital message is printed as a postcard via the *LivingMoments* system at the home of the person with dementia. Next, the postcard can then be placed into the *LivingMoments* system so that people with dementia can watch the movie and photo and listen to the audio message. Furthermore, the people with dementia can reply to the message via the *LivingMoments* system in line with their abilities through four response buttons.

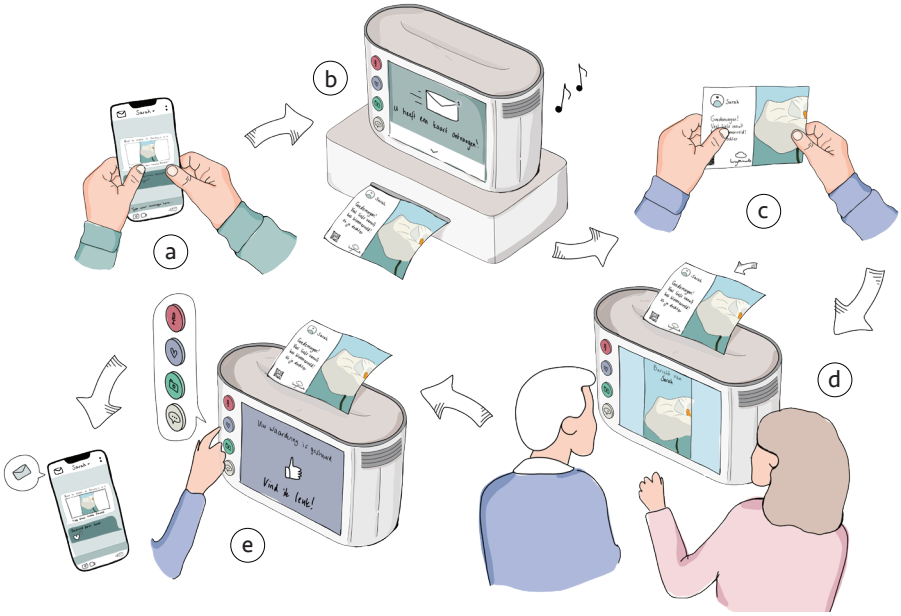


Figure 6.1. *LivingMoments* is a communication system that enables people with dementia to engage in social contact with their relatives. Relatives send digital messages (a) delivered as printed postcards (b). People with dementia can read the message on the postcard (c), watch the interactive content digitally (d), and respond by selecting one of the four options (e). The system can be used autonomously or in a social setting. The postcard and its media content stimulate using the system or offer a conversation topic via other means.

In this design, we move away from a medical view on dementia that is often associated with inabilities and loss; instead, we adhere to a more person-centered perspective on technology, emphasizing inclusivity, uniqueness, and looking at what people still can do [87,153]. Following this perspective, we look at their abilities and focus on providing meaningful personal experiences for people with dementia [168,343]. Besides the individual characteristics and abilities, the nature and quality of the social network around a person with dementia are also decisive in the appropriation of (social) technology [150]. Our previous work also illustrates this [173]. By designing technology well, we aim to support people to experience social contact as pleasant again and leverage their abilities and social relations. In this study, we investigate how digital and physical interactive technology can be used by people with dementia in a social setting, and how such a system can be used by them with different and changing abilities.

A four-week field evaluation was conducted with six participants in different stages of dementia living at home together with their partners and twenty-five of their relatives. Our study aims to answer the following research questions: First,

how do people with dementia with different abilities experience *LivingMoments* in their regular lives? Second, how can *LivingMoments* support social communication and a feeling of connection between people with dementia and their partners and relatives? And third, how is *LivingMoments* adopted by the people with dementia and their social contacts over time? We collected qualitative and quantitative data in order to collect a detailed account of how people with dementia, their partners, and relatives used and experienced *LivingMoments*. Specific findings include their different levels of engagement, the beneficial tangible assets to enable personal interaction, the facilitating role of relatives, and the dynamics of use over time. Based on these insights, we formulate three design recommendations: 1) take a broader perspective on abilities, 2) lower the barrier for communication through personal calibration, and 3) shape a habit for adoption over time. These findings contribute to existing literature with regard to supporting people with dementia with different and changing abilities to engage with their social contacts.

6.2 Related work

Dementia changes people's social life. This section outlines the impact of dementia on social participation, the challenges of using social technologies, and what it means to design for this context.

6.2.1 Supporting social dynamics in dementia

Dementia is a collective term for various progressive and chronic brain conditions. It manifests itself via cognitive and physical changes that impact memory, the ability to perform daily activities [98,105], and the ability to remain socially active [59,324]. Social connectedness is an essential part of general wellbeing in dementia [109,170,207] and for preserving someone's identity [315,341].

As dementia progresses, people will develop communication difficulties [6]. Immediate effects of dementia reveal that individuals can forget how to engage socially with others, experience fears for not finding the right words or names [115], and no longer remember how to schedule an appointment with relatives or communicate by phone [117]. However, the ability to engage socially is different between people depending on their individual course of the condition and other personal factors [352]. Therefore, the progression of dementia is hardly predictable on a personal level [164], which means that people with dementia are not always adequately supported to participate in social interactions [25]. Other researchers also indicate that people's ability to participate actively in social contact is hindered both by the condition and the actions of others [26,34]. The unintended consequence is that people with dementia often do not feel they are equals and often do not experience a reciprocal relationship between themselves

and their social relations [343], resulting in withdrawal from social contact. Arising from this, people might experience a loss of 'self' [120,239]. Since the 'self' is co-constructed through interacting with others and patterned by larger social structures [280], this results in a negative vicious cycle. In order to break this cycle, researchers have looked into the role of design and technology to enrich the interpersonal and social experiences of people with dementia [95,112,166,229,337].

6.2.2 Ability perspective in design for dementia

Technology is increasingly being approached from a more holistic perspective, supporting experiences and abilities to live well with dementia [40,186]. Even though the nature of dementia signals a gradual loss of cognitive and physical abilities [260], people with dementia can still contribute to the present world [168]. From this perspective, dementia care practices are increasingly being acted upon, providing care that supports the psychosocial needs of people with dementia [47]. This person-centered perspective has been adopted in the inclusive framing called - *warm technology* - which emphasizes the importance of looking at abilities that people still possess and supporting human potential in a broader sense through technology [153]. A growing body of research in *Human-Computer Interaction* (HCI) is investigating this individual potential through *Experience-Centered Design* (ECD) research [94,225,338]. When focusing on abilities, design can support people with dementia to retain a sense of autonomy and empowerment [96,217,330,342]. The situated material environment contributes to being in control of a specific action [338]. Physical objects and cues play an instrumental role in facilitating interaction and engagement [146,147,226]. The ability to meaningfully interact in the physical world is related to agency and personhood, as extensively highlighted in contemporary research in HCI and dementia [6,11,133,158,186,284]. In addition, the nature and quality of social relations of a person with dementia are also decisive in preserving agency [34] and for appropriating technology together [150]. Here, it is important that social relations continuously adapt to the changing situation of the person with dementia to prevent friction [343]. Researchers investigate the individual experiences and actions of people with dementia through which they try to get a grip on their life and the surrounding social world [341]. Further research on this topic is needed to understand how the diverse abilities and experiences of persons with dementia can be incorporated into technology design to support their social participation. .

6.2.3 Technology for social interactions in a dementia context

People with dementia can experience increasing difficulties in using social technologies, and so do their caregivers [27]. For example, people with dementia living at home experience difficulties in participating both in online and offline

social interactions [238]. A series of studies show that design and technology can support people with dementia to preserve their agentic social abilities [11,96,133,330,338]. In particular, digital media (i.e., photos, videos, or audio recordings) can support and enrich social interactions between people with dementia and their relatives [75,138,297,321,342]. Media are a means to give people with dementia ownership of conversations [189] and help them reminisce [5]. Having access to digital media in dementia is a topic increasingly being explored in the field of HCI research [320,321]. Based on the knowledge that is currently available, a clear distinction is made between technologies for people with early-stage dementia and for people with more advanced dementia who are often living in a memory care facility [76]. A recent study by Lazar et al. [185] concluded that the physicality of objects, such as a scrapbook, can contribute to the meaning-making process of people with dementia living in a memory care facility and thus encourage them to create agency and engage in digital social interaction. This aligns with work by Foley et al. [96], in which a receipt-based system encouraged physical interaction with technology and indirectly supported people's agency. This work highlights the fact that the dynamic nature of dementia, let alone the changes over time from early to late-stage, provides significant opportunities for technology [289,319]. In this study, we explore how social technology can be appropriately designed to strengthen the preserved abilities of people with dementia while at the same time including their social ecosystems, such as their partners and relatives, as an essential factor.

6.2.4 Summary of related work

In the previous sections of this chapter, we offered literature to illustrate the urgency to support social contact of people living with dementia and their relatives. Despite the benefits of introducing social technologies in this context, there are still several associated challenges, namely a lack of holistic solutions, difficulties with supporting autonomy in dementia, and opportunities for the use of digital media.

In this study, we will evaluate *LivingMoments* which aims to support and facilitate social contact for people living with dementia and their relatives. As such, we contribute knowledge concerning the established challenges of supporting social contact of people with dementia (6.2.1), designing technology to address their different abilities during the progression of dementia (6.2.2), and the role of technology to support social contact adequately (6.2.3).

6.3 *LivingMoments* design

In earlier work, we identified the importance of compensating for internal and external barriers experienced by people with dementia in design [173]. We found

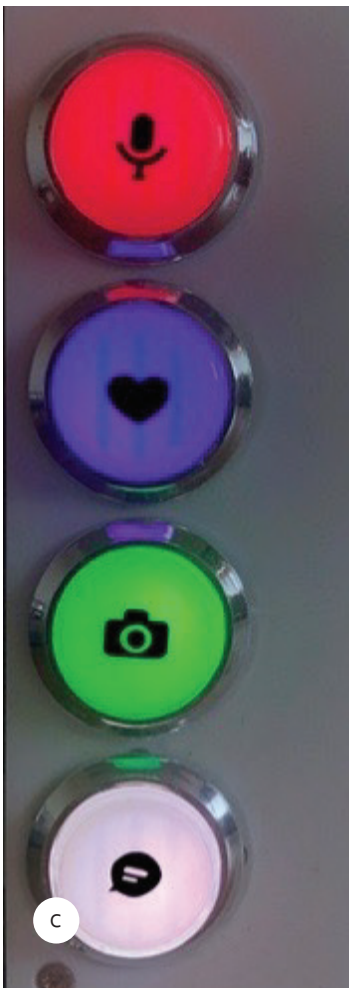


Figure 6.2. *LivingMoments* prompts communication through physical interaction with printed postcards (b|. The printed postcard can be placed in a slot at the top of the system to show the attached media (e.g., photo, video or audio file) (a). Four response modalities to answer a received postcard (c).

that fear of decreasing social competence, a perceived loss of technical competence, and a lack of availability or willingness of the social environment to engage in interactions are factors that lead people with dementia to give up social technologies. However, we found that the physical and social environment can enhance agentic social abilities [173]. These insights served as the starting point for this work. We designed a concept that aimed to reduce the experienced barriers and support people with dementia in their ability to use social technology. The design process of our final design is not discussed in this paper, nor are the technical issues encountered and solved during the study. Instead, we adopted a *"technology-in-use"* approach to understand how people utilize the designed technology in their social context [106].

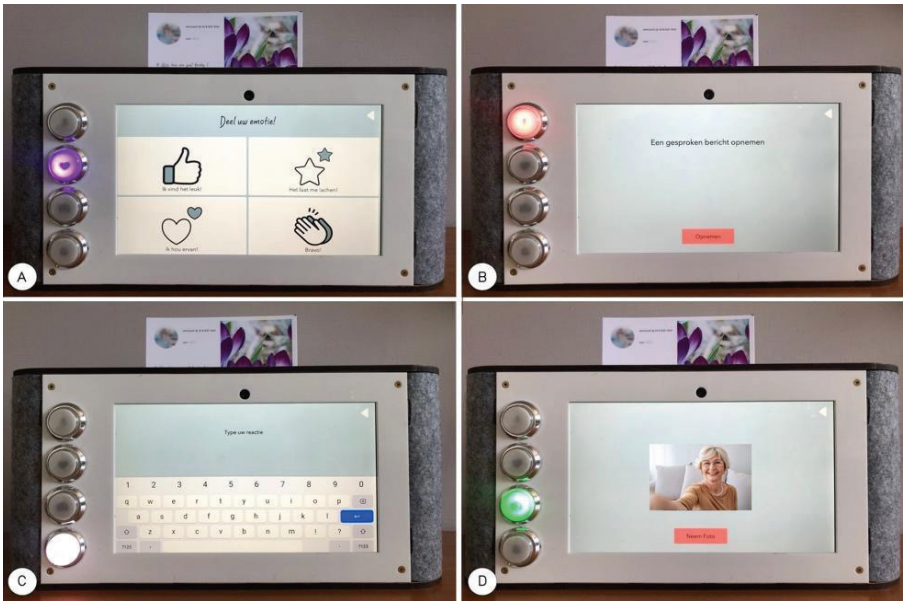


Figure 6.3. The four response modalities of *LivingMoments* to answer a received postcard by sending a) an appreciation or emoticon, b) an audio message, c) a typed message, or d) a photo.

LivingMoments is a tablet-based communication system (see Figure 6.2a) that facilitates asynchronous social contact between people with dementia and their relatives. Relatives can share a message via a web application containing three elements: a photo, a text, and either a video or audio file. The *LivingMoments* system automatically generates a postcard design from this message that is printed by the system at the person with dementia's home (see Figure 6.2b). *LivingMoments* prompts the user with a notification sound when a message is received and a postcard is printed showing the message text, a photo, and a QR code for the video or audio message. The person with dementia can display the media content by placing the postcard in a slot at the top of the *LivingMoments*

system (see Figure 6.2a). By doing so, the system scans the QR code on the postcard and plays the video or audio content. After seeing or listening to the media content, people with dementia can respond in a way that suits them via one of the four response options. The *LivingMoments* system has a base station for printing the cards and a removable top part which can be placed on the table or the lap to watch media in a flexible and comfortable way. To respond, the people with dementia can select one of the four response buttons on the left side of the system (see Figure 6.2c). They can use the system to send a) an appreciation or emoticon, b) an audio message, c) a typed message, or d) a photo (see Figure 6.3). An overview of the interaction can be reviewed in the interaction diagram (see Figure 6.4).

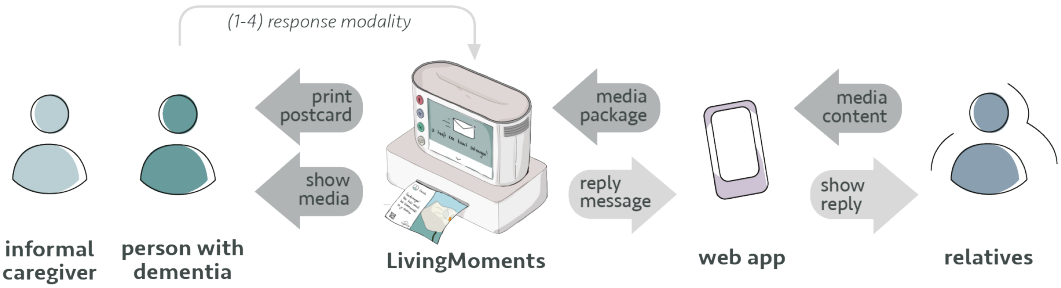


Figure 6.4. An interaction diagram of the *LivingMoments* system between relatives, people with dementia and their caregivers.

Printing the postcards is a crucial part of the design. It is grounded in prior work, which highlighted that prompting initiative with physical cues is a strategy that reduces the impact of dementia on social interactions [173]. In addition, the postcards themselves also serve as non-digital mementos for the participants [37]. Other research also suggests that using physicality in the design (i.e., via postcards) contributes to meaning-making for people with dementia [76,226,337]. Therefore, we foresee the postcards to trigger interest from the person with dementia directly and contribute to engagement with the system. In addition, when designing *LivingMoments,* we hypothesized that *LivingMoments* offers a suitable response option for people in different stages of dementia with these four response options. People can select an option in line with their abilities and thereby engage in social contact on an adequate, personal level. Offering a subset of interaction options builds on earlier research showing that a customizable interface is feasible and can enhance the abilities of people with dementia [319]

6.4 Study design

In order to address our research goals, we studied the *LivingMoments* prototype in the home context of people with dementia. The study included people with dementia living at home together with their partners, as well as formal caregivers,

and a wider social circle (e.g., family members or friends who were willing to participate in the study) whom we will refer to as "*relatives.*" We were interested in how they would use *LivingMoments* and their experiences concerning digital social interactions. We gathered user experiences in both qualitative and quantitative form from all participants to understand how *LivingMoments* was used. We looked at the organic ways the participants made meaning with and creatively adopted the *LivingMoments* in their lives [150]. Data collection for the entire cohort took place between October 2020 and May 2021. Participants were each involved for a minimum of four weeks, meaning that the participants came in and out of the study at different moments during this 8-month period.

6.4.1 Participants and setting

Eight persons with Alzheimer's dementia were recruited together with their partners and relatives. The authors used their network of care partners across the Netherlands for the recruitment. The following inclusion criteria were used: The participants with dementia 1) are diagnosed with dementia caused by Alzheimer's disease, 2) are in a mild to moderate stage of dementia, 3) live at home together with their partners, 4) have access to WIFI at home, 5) have no visual and auditory processing disorders, and 6) have at least one relative willing to participate in the study. From the eight participants, two participants dropped out in this study within the first two weeks due to changing health conditions. Therefore, the study was conducted with six people with dementia, their partners, and their relatives. Table 6.1 and Table 6.2 provide an overview of the involved participants, including their pseudonyms, gender, relational role, use duration, communication devices used, and IDEAL-IC.

Participants who took part in the study had various ability levels. We determined the differences between people with dementia with the "*International Dementia Alliance Instrument for Feasible and Valid Staging of Individuals with Dementia by Informal Caregivers*" (IDEAL-IC) instrument. This allowed us to determine a standardized perspective on the severity of their condition, care needs, and the social system surrounding them [263]. The IDEAL-IC sum score ranges from 0 to 35, with higher scores indicating a more progressive state of the condition. In addition, it provides information about individual abilities related to activities of daily living, physical health, cognitive functioning, social support, behavioral symptoms, and involvement of the caregiver. We extended the form with one question on their use of contemporary communication technology (see Table 6.1). In addition to the couples, 37 social relatives participated in the study. This group used the *LivingMoments* application during the study, from which 25 completed the questionnaires (see Table 6.2).

Participant	Name	Gender	Relational role	Use duration	IDEAL-IC	Communication devices used by PwD
P1	Bob	M	PwD	4 weeks	13.3	None
Partner P1	*Emma*	F	Wife			
P2	Sarah	F	PwD	20 weeks	18.6	None
Partner P2	*Oliver*	M	Husband			
P3	William	M	PwD	6 weeks	14.6	Household phone
Partner P3	*Mia*	F	Wife			
P4	Tom	M	PwD	12 weeks	10	Household phone
Partner P4	*Charlotte*	F	Wife			
P5	James	M	PwD	5 weeks	23.8	None
Partner P5	*Olive*	F	Wife			
P6	Melanie	F	PwD	17 weeks	21.1	Household phone
Partner P6	*John*	M	Husband			

Table 6.1. Background information of the participants. The IDEAL-IC sum score ranges from 0 to 35, with higher scores indicating disease progression; Pseudonyms are used to maintain participant anonymity and protect confidentiality.

Participant	Relative	Gender	Age	Relational role
1	R1.1	M	65+	*Bob's* friend
	R1.2	F	30-45	*Bob's* formal caregiver
	R1.3	M	46-64	*Bob's* son
2	R2.1	F	46-64	*Sarah's* formal caregiver
	R2.2	F	46-64	*Sarah's* daughter
	R2.3	M	46-64	*Sarah's* cousin
	R2.4	M	65+	*Sarah's* friend
	R2.5	F	46-64	*Sarah's* formal caregiver
3	R3.1	F	19-29	*William's* granddaughter
	R3.2	M	46-64	*William's* son
	R3.3	F	19-29	*William's* granddaughter
	R3.4	F	46-64	*William's* daughter-in-law
4	R4.1	M	30-45	*Tom's* son
	R4.2	F	46-64	*Tom's* sister-in-law
	R4.3	F	30-45	*Tom's* daughter-in-law
5	R5.1	F	46-64	*James'* formal caregiver
	R5.2	M	46-64	*James'* son
	R5.3	F	46-64	*James'* daughter
6	R6.1	M	46-64	*Melanie's* son
	R6.2	F	46-64	*Melanie's* duaghter
	R6.3	F	46-64	*Melanie's* daughter-in-law
	R6.4	M	19-29	*Melanie's* grandson
	R6.5	F	19-29	*Melanie's* granddaughter
	R6.6	F	19-29	*Melanie's* granddaughter
	R6.7	F	19-29	*Melanie's* granddaughter

Table 6.2. Demographics of the relatives that filled in the questionnaires.

6.4.2 Ethical considerations

This study was approved by the Ethics Review Board of the Tilburg School of Social and Behavioral Sciences and the Eindhoven University of Technology under number EC-2018.76. The first author conducted the home visits and collected the data; this researcher was experienced with involving people with dementia in research. During the first home visit, the researcher clearly explained what data was going to be gathered and how it was going to be used. Additionally, all participants were informed about their rights to cease the test at any time when experiencing discomfort during the study. After this, the formal consent was signed by both people with dementia and their partners.

Furthermore, in order to ensure people with dementia felt comfortable during the research, the research team informed them about the research project and process and tried to make them feel as safe as possible with every activity. The device was designed and placed in the home context of the participants to reduce the risk to a minimum and avoid any potential negative stimuli to the participants as much as possible. Throughout the study, the first author conducted phone interviews (see section 6.4.3) with the partner to not burden the person with dementia more than necessary.

We carefully reviewed the potential impact of removing a useful supporting technology after the study period, as suggested by Hodge and colleagues [132]. To mitigate this, we allowed participants to use the system for a longer period of time if possible and ensured to leave something meaningful behind. Since *LivingMoments* prints postcards, the participants could keep them and use them as desired.

Furthermore, during the visits, additional precautions were taken since the study was performed during the COVID-19 pandemic. These were, reducing the number of visits to a minimum, keeping a 1.5m distance, wearing face masks, and ensuring only one external visitor per household per day. The visits to the participants were scheduled apart from each other for at least two weeks.

6.4.3 Data collection and analysis

To gather a comprehensive overview of the experiences of participants with dementia, their partners, and their relatives during this field study, we used a mixed-method approach to collect the data (see Figure 6.5).

Qualitative and quantitative data from people with dementia and their partners

We were interested in investigating the individual experiences and how people

with dementia and their partner used *LivingMoments*. Before the study started, participants were given an information brochure explaining the research process and the researchers' expectations. The researcher (first author) introduced herself to the participants and engaged in an informal conversation to put the participants at ease [236]. The IDEAL-IC instrument was handed over to the partner at the end of the introduction.

Subsequently, a semi-structured introduction interview was conducted for each participant to start the field study. During the introduction, the *LivingMoments* prototype was placed in the preferred place at the home of the participant. After the device was placed, it was prepared for use. The researcher sent the first postcard to the device and video recorded the person with dementia's initial response. While the postcard arrived, the researcher took observational field notes. After the participant viewed and responded to the postcard, the researcher asked questions such as: *"What do you think of LivingMoments?"*, *"How do you feel about receiving messages in this way?"* and *"How do you feel about responding to the postcards?"*. Afterwards, a booklet was handed over to the participant to write down their personal experiences with *LivingMoments* during the weeks of the study. It was designed as a diary with weekly reflective questions to give participants the opportunity to discuss and share their experiences with their partners in a relaxed and pleasant atmosphere without the presence of a researcher. The diary allowed participants to capture their feelings, thoughts, perceptions, and overall experiences in the moment more easily, and we invited them to share what they had written down with the researcher in the weekly

Set of questions oriented to the device and technology *(odd weeks)*	**Set of questions oriented to the social experiences *(even weeks)***
• Which of you mainly used the device and how did you use it? • Did your partner with dementia use other technologies to discuss or respond to the postcards? • How were the non-interactive postcards being experienced, and the interactive ones? • When did you usually use the device (i.e., placement of the system, stimulation of system notifications, and used when relatives are visiting)? • What happened with the postcards? (i.e., collected, thrown away, or watched later)	• How did receiving postcards influence your communication? • How often did the person with dementia participate in conversations? How were these conversations initiated? • How often did the person with dementia share his/her experiences with *LivingMoments* with others? • How did postcards stimulate the person with dementia to participate in social activities? • How is the social connection with your relatives since using *LivingMoments*?

Table 6.3. Two sets of questions asked during the weekly interviews with the person with dementia and partner, in total each set of questions was used in an interview two to three times.

interviews if they wanted to. These weekly 30-minute interviews were held via the phone with the partners to track changes in their attitude, perception, and system usage. Two sets of questions alternated over the weeks (see Table 6.3). In the first week, the questions were oriented towards the device and technology. The second set of questions was oriented towards people's social experiences.

Furthermore, each week, the following three questions were asked: *"How did you both experience LivingMoments?"*, *"What problems have you encountered with LivingMoments?"* and *"How did you/your partner with dementia experience receiving and answering postcards?"*. Since the researchers could not be continuously present at the participants' homes, the use of the device was also monitored through data logs. These logs registered the interactions with the devices, such as the number of times a postcard was received and printed, the sender, the number of views for postcards, and the type (but not the content) of answers given via *LivingMoments*. From this data, we aimed to learn more about the use and experiences of people with dementia having various abilities and their partners in using the system. After the field evaluation, the couples were invited to complete a self-reported user experience questionnaire together to better understand people's perception of the system and their interactions with it [329]. Finally, a semi-structured exit interview was performed to conclude the study.

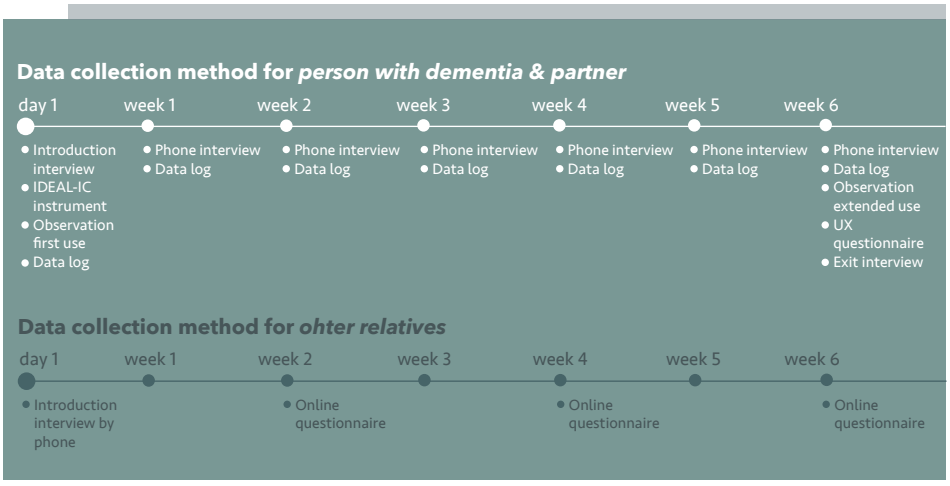


Figure 6.5. Evaluation procedure showing the data collection methods of participants with dementia together with their partner, and the social relatives.

Qualitative and quantitative data from relatives

Since social communication is reciprocal, social relatives were essential for sending messages to the *LivingMoments* device of the person with dementia. Therefore, the relatives' experiences and the nature of their communication with the person with dementia were also studied. We were interested in learning how

social relatives felt supported by *LivingMoments* to contact people with dementia. The relatives were interviewed at the start of the field study. In this interview, the researcher explored the relationship with their loved one with dementia before using *LivingMoments* to understand how satisfied they were with their relationship with the person with dementia and whether this would change through the use of *LivingMoments*. Subsequently, they were asked to fill in a questionnaire sent to them every two weeks over the test period via email (see Figure 6.5). The questionnaire was structured in three fixed questions addressing the use of *LivingMoments*, the communication and the perceived connection with their loved one with dementia, and three changing questions addressing the social experiences or usability of the mobile application each time. These questionnaires aimed to provide information about the influence of using *LivingMoments* on their feeling of social connection over time and the usability of the *LivingMoments* application.

As a result, the data used consisted of: 1) participant information such as name, age, gender and the individual abilities determined by the IDEAL-IC instrument, 2) audio recordings of the weekly phone interviews with the person with dementia and partner, 3) video recordings of the observation during the first home visit, 4) observational field notes, 5) data logs of the actual use, 6) audio recordings of the introduction interviews with the relatives, 7) scoring from the self-reported user experience metrics filled in by the couples, and 8) the questionnaires filled in by the relatives. All interviews were audio-recorded, and later transcribed verbatim.

With the qualitative data gathered during the study, an inductive thematic analysis was performed over the complete data set [45]. Our analysis aimed to answer our research questions. Data were initially coded using broad codes such as *"ability," "social role,"* and "*user experience*." The second round focused on identifying patterns in meaning, leading to the creation of themes such as "*engagement types," "tangible prompting,"* and *"dynamics of use*." In the final stage, we refined the themes to the final themes set, which are portrayed in the result section. We compared these themes with the quantitative data gathered from the data logs. The data log analysis was conducted by showing the data per participant and per week of use. With this quantitative data we were able to verify the insights we gained from the qualitative analysis. In addition, some trends were identified by analyzing the overall number of system activities per week. Finally, the preference for the type of content and the answer modalities were identified by matching the messages with the interview data, responses given in the system, and the total number of views.

6.5 Results

The findings below are described using quotations with the coded representations

of the participants, including their pseudonyms. *Bob* [P1] dropped out after 4 weeks, *William* [P3] after 6 weeks, and *James* [P5] after 5 weeks because of personal circumstances and changing health conditions. In addition, *Bob* experienced relatively more technical issues due to being the first participant. In the study, we focused on exploring the experiences with and use of *LivingMoments* and not regarding the effects of the system on the lives of people with dementia.

6.5.1 Data logs from *LivingMoments*

Over the course of the study, we logged the system activity of the *LivingMoments* system. Figure 6.6 provides an overview of the number of messages printed (blue bar), number of views (yellow bar), and the total number of responses (grey bar) for each participant per week.

While the data was gathered for explorative purposes mainly to support the qualitative findings, some trends can be visible. The data from *Bob* [P1], *William* [P3], and *James* [P5] clearly decreases over time, up to the point they stepped out of the study due to mostly health-related reasons. The data from *Sarah* [P2] and *Melanie* [P6] shows much more consistent use over time; they also opted to use the system much longer after this data collection. *Tom* [P4] shows an interesting dynamic, with a very high number of uses in the first week (skewing the chart scale) and a more balanced use afterwards. Also, *Tom* opted to use the system six weeks longer after data collection.

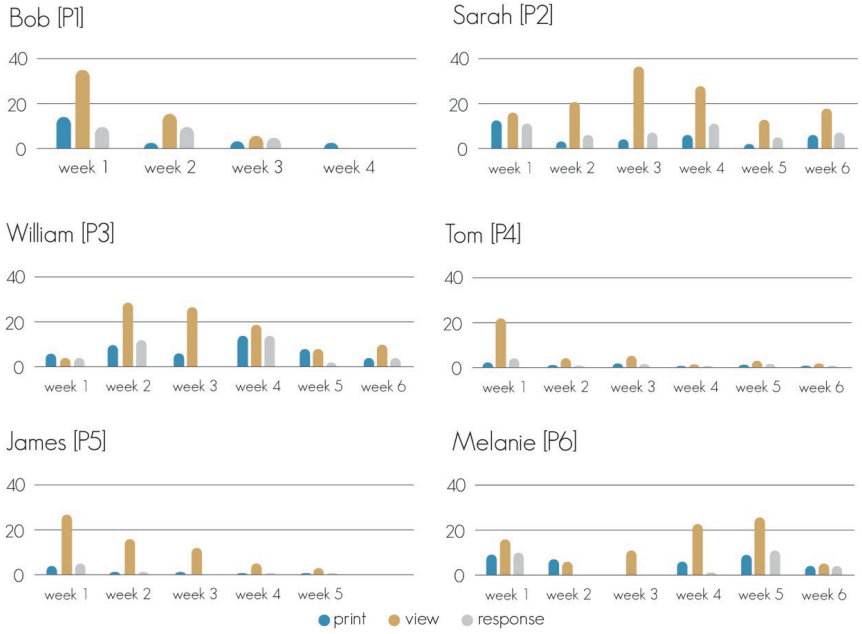


Figure 6.6. The printed messages, number of views, and total number of responses for all participants per week.

The data from Figure 6.6 was used to support the qualitative findings in paragraphs 6.5.2 and onwards.

6.5.2 Types of engagements and experiences of people with dementia

Our analysis identified that participants engaged with *LivingMoments* at an appropriate level that suited their abilities. The immediate social environment can be a collaborative yet directive factor for different participants. Receiving postcards showed to be decisive in evoking personal and vivid emotional responses.

Interaction at an appropriate level

Depending on the full range of personal abilities and social living arrangements of people with dementia, the level of interactions with the system can be defined as autonomous, collaborative, and passive.

Autonomous interaction

With autonomous interaction, we intend a spontaneous use by the person with dementia with no need or limited need of guidance from the partner or formal caregiver. Actions occur as a consequence of specific triggers. For example, ***Tom*** [P4] and his wife made piles of postcards, consisting of answered and unanswered piles, on the table or cupboard. The physical presence of these postcards triggered the actions of ***Tom***: *"What I have also seen is that now and then Tom takes the postcards from the pile and looks at the pictures again. He wants to respond to everything,"* said his wife. Sometimes, the visibility of the tangible postcards enabled ***Tom*** to take his initiative in using *LivingMoments*. The data log indicated that postcards had been reviewed multiple times by ***Tom*** in the *LivingMoments* device. Not all triggers result in an interaction with the system itself. Postcards can trigger the action of making a phone call, as happened for ***Tom***:

> *"This morning another postcard was received, and after the bell rang, He went to take out the postcard and immediately started to call his daughter. He did not call that often, did you Tom?"* said his wife. Tom answered: "No."

Suggested and collaborative interaction

Some participants needed cues from their partners or formal caregivers to use *LivingMoments*. In this suggested and collaborative interaction, the person with dementia was invited or instructed to perform a specific interaction. For instance, the partner of ***Sarah*** [P2] orally instructed her in the process of responding to a postcard: *"Here is the postcard, **Sarah**, and then the postcard has to go into the top*

Figure 6.7. *James* [P5] was supervised by his wife in responding to a postcard

of the slot. ***Sarah***: *I get that. Partner: Then you have to stand up because otherwise, you cannot get it in. You take it, in the slot.*" We observed a similar response for James [P5]. He appeared to be fully engaged with the system, as he eagerly reached out to take the postcard from the print slot the moment he heard the sound of the printer before the device had given the ping signal that the postcard was ready to be picked up. His wife had to slow him down and told him: "*You have to wait for the ping sound.*" He then took the postcard and his wife had to guide him in activating it in the *LivingMoments* device: "*I have to steer him and tell him to put it on top of the device.*" ***James*** and his wife approached *LivingMoments* collaboratively. ***James'*** wife initiated the initial action to press an answer button and then left the choice to James (Figure 6.7): "*I press that button, and James takes the initiative himself to choose for 'makes me laugh' or 'I like it.*" In contrast, ***Melanie*** [P6] and her husband were unable to use the device independently, leading their children to initiate the interaction with the device: "*When I am there, we look at all the received postcards and send a response. I always ask: Do you want to say something, type something, take a picture or send a 'like'? Well, they are not able to use the type functionality. One time, they choose to send a photo, and another time they choose a 'like',*" said their son. It became an everyday social ritual for ***Melanie's*** relatives as an integral part of their daily activities. ***Sarah*** and her husband took a moment every evening after dinner to look at and answer the postcards. Both participants gradually incorporated it into their daily routine, in which the activity became habituated and cherished. Interestingly, formal caregivers accepted the system as part of their daytime activity with the person with dementia and employed it in their care ritual. These examples illustrate the dedicated suggested and collaborative engagement of the social environment towards *LivingMoments*.

Passive use

Especially for people with more advanced symptoms of dementia, the social context took a more directive and dominant role in interacting with the *LivingMoments* device. In some cases, the usage was utterly taken over by the partners or formal caregivers, especially when the participant was not able to perform an action with the system due to the status of dementia. For instance, ***William*** [P3] showed minimal initiative in using the device and did not quite understand how to use it:

> "*Well, William does not do anything with it, but I have worked with it a few times, and I'm doing exactly what was written in the instruction manual you gave me. First, I put that postcard in the device, then I pressed the button three times, and nothing happened.*"

Figure 6.8. *Sarah* [P2] waves her arms to the beat of the music playing on the interactive postcard.

The partner had taken full responsibility for using the device but had some trouble responding to postcards. The children had to explain to the partner how to use the device. Eventually, she was able to perform the responding task. ***Bob*** [P1] also had to be encouraged by his partner to use *LivingMoments*. He did not notice that new postcards were received or did not show any form of initiative to respond to postcards.

Emotional and vivid responses to shared media content

The analysis identified different experiences and reactions to the media content shared by the social circle. The interactive content appeared to stimulate a multi-sensory experience that evoked a personal response of each participant.

Each participant expressed a feeling of enjoyment and appreciated receiving a postcard. Reactions varied based on the format of the content, being it a video or a static picture, and on the content itself. Upon receiving and activating an interactive postcard containing music, ***Sarah*** [P2] began waving her arms to the beat of the music (Figure 6.8): *"When she hears music, she indicates the beat, for example, or she is waving or clapping. A completely different reaction when she only sees a photo."* [R2.1]. She also showed a slight preference in her reaction to animal postcards depicting dogs in particular. These postcards acted as a catalyst for emotional expressions and were repeatedly viewed in the *LivingMoments* device. ***James*** [P5] expressed his emotions through bodily responses to a postcard containing a video. The formal caregiver had sent a postcard in which James was dancing at a daycare facility. Upon activating the postcard, the video started playing, after which he immediately got up from his chair and started dancing.

Tom [P4] expressed his fondness for receiving videos from his grandchildren: *"If the grandchildren say something, then we put the postcard in again and then, in the end, you know what they said, that is very nice to see."* It could be noted from the data log that these videos were viewed repeatedly. In addition to receiving videos, *Tom* also enjoys receiving photos of the daily activities of his family. *Melanie's* [P6] relatives made videos for sharing everyday life events and keeping her informed about what they are doing. Seeing her children or grandchildren on screen evoked here positive emotional reactions as well. In response, memories are recalled at the moment of looking at the postcard together.

Feelings of inclusion

Tom [P4], *James* [P5], and *Melanie* [P6] appeared to feel more involved by receiving postcards from relatives, even if they do not always respond to the postcards. *Melanie's* daughter highlighted that *Melanie* and her husband felt more included in the lives of their family members [R6.2]:

> *"My mom said to her grandchild this morning: "I am delighted I saw you in the picture now." It gives them the possibility to see and experience what we do. Their little world is getting bigger in this way. That is an added value."*

Tom even highlighted that because the postcards are addressed to him, he feels more involved in the lives of his children and grandchildren. *William* [P3] and his partner mentioned that they do not often see their grandchildren since they have busy lives, but they can see and hear them every day by receiving postcards: *"We receive most of the postcards from the grandchildren. We want to read them every day."*

6.5.3 Tangible assets for enabling personally suitable interactions

The physical presence of the device, the visual prompting of the postcards, and the diverse response modalities are qualities in *LivingMoments* that seemed to encourage people to engage in social contact.

The physical presence as a social cue

The physical presence of the *LivingMoments* system encouraged *Tom* [P4] and *James* [P5] to interact with *LivingMoments*. It reminded them to perform an action with the system. The central position in the living room caught the attention of *Tom* by taking a look at the received postcards and responding: *"It is good that the device is so visible, and a postcard sticks out. It is more physical than a telephone, for example."* The children also said: *"We sent messages before via*

Figure 6.9. *Sarah's* [P2] engagement with the collected analogue postcards. A photo made by her caregiver

WhatsApp, but they were then read two weeks later, while now there is a response the same day." Since the device was directed towards him, he expressed that he felt a certain level of control and ownership over the device, making him feel more connected and encouraged to keep using it: *"It is my device. That is also the reason that I keep looking at it. It attracts my attention.*" This also applied to James since the device was prominently placed in the middle of the living room next to the television. ***James'*** wife stated that the obvious presence of the device promotes interaction with it: *"It is nice that he sees the device all the time and notices that he receives a postcard. It has to be visible because otherwise, he will not hear the printing sound of the printer and ringing of the bell afterwards.*"

The postcards stimulated ***Melanie*** [P6] and her husband to review them without the system and talk about them. The recognizability of the analogue postcards offered the couple a familiar form of communication:

> *"The postcards are of course something they are used to, so they take those postcards and use it,"* said their daughter [R6.2].

Together with her formal caregiver, ***Sarah*** [P2] had made a postcard album in which they collected all the postcards. They had decorated this album with old scarves worn by ***Sarah***. The presence of the album prompted *Sarah* to pick up the postcards one by one and fiddle with them (see Figure 6.9):

> *"So we have now put the postcards in an album and placed it every time on the table. When we slide it under her nose, she will play with it."* [R2.1].

Additionally, ***William*** [P3], ***Tom*** [P4] and ***Melanie*** [P6] also projected value onto the postcard and treasured them by keeping them in a prominent place in the living room. They displayed the postcards in front of the device, on a shelf above the device or the cupboard in the living room next to family photographs. Because of the prominent visibility, the postcards served as an incentive to trigger participation in individual and social interactions.

Upon interacting with *LivingMoments*, most participants preferred to separate the interactive module from the printer base. The form and materiality specifically designed to ease the interaction were appreciated, making the system handier and more usable. Bringing the interactive module closer allowed participants to view the postcard on the screen better and respond with their visiting relatives. For instance, ***Melanie*** and her partner, together with their children, used

LivingMoments in a comfortable place on the couch in the living room to view and respond to the postcards. This atmosphere provided a comfortable setting in which they felt encouraged to use the *LivingMoments* device and participate in social interactions.

Diverse interactions with the response modalities

Responding to the postcards was handled differently by the participants. We included four response modalities: typing, taking a picture, recording a message, and sending an emoticon. The use varied considerably among the participants.

All participants experienced difficulties using the type modality and interacting with the touchscreen, depending on how the partner dealt with it. The act of pressing a touchscreen button gave ***Sarah*** [P2] no clarity; it seemed to make her feel insecure and hesitant to press it. Her partner had to support her in this interaction. While for James [P5], it was the digitalization of the keyboard that made it complex. ***Tom*** [P4] was the only one who used the type function every week but needed light collaborative support now and then. ***Melanie*** [P6], ***Bob*** [P1] and ***William*** [P3] never typed a message. The emoticon modality was used most frequently, especially by ***Sarah***, ***Tom, James*** and ***Melanie***. The use of this function strongly depended on the individual capacities and the collaborative support of the social environment. Together with their children, ***Melanie*** and her husband responded to the postcards by sending an emoticon or photo. For ***Sarah***, this was similar; she was more attracted to the photo and emoticon feature. She was supported when she no longer knew the next step in the process of responding. ***Tom*** mainly used the emoticon modality in response to a grandchild or as a delivery notification: *"It depends if he sends a response to a child, then he does that,"* said ***Tom's*** wife. Additionally, he feels comfortable sending an audio message, which was also clearly reflected in the data logs: "*Then you can just think of what you want to say and record it.*" For him, the message on the postcard determined the response modality he used to answer. The opposite applied to James, as changing health conditions resulted in using only the emoticon modality in the last few weeks of the study. In the first two weeks, he used the other three modalities, whether or not with or without support from his wife. On the other end of the spectrum for ***William*** and ***Bob***, responding to a postcard was perceived as too difficult. ***Bob's*** partner mainly sent the answers to the postcards. ***William*** found receiving and viewing the postcards satisfyingly enough. None of the response modalities were therefore used.

Some participants highlighted that part of the response modalities could better be removed from the device since it became difficult for people with dementia to choose between them. The four modalities resulted in an information overload

for *James*, with the result that he no longer knew which button to press. This also applied to *Tom*, but to a slightly lesser extent:

> "*The response choices make it sometimes confusing for him,*" said *Tom's* wife.

While *Sarah* was choosing an appropriate response modality, she was overwhelmed by the four response modalities. She often chooses the purple emotion button, as shown in the data log and mentioned by her partner, since it was her favorite color. It seemed to stimulate her senses and invite her to push them. All these examples illustrate the different needs of people with dementia in responding to messages.

6.5.4 Facilitating communication and social dynamics by relatives

The results show that the social circle is vital in facilitating the use of *LivingMoments*. Relatives showed that having the possibility of sending targeted messages to people with dementia encouraged them to regularly share moments from their daily lives.

Varying types of media content shared

Relatives paid much attention sending appropriate content to the person with dementia. There was a substantial difference between the younger generation and the older generation in the type of media content shared. Younger generations (often grandchildren) mainly sent selfies or vlogs to keep their grandparents informed about their daily life events. For example, a grandchild of *William* [P3] sent a vlog showing her dorm room while she was studying for her exams. The older generation paid more attention to look for autobiographical photos from the past. They also shared content of events or places that the person with dementia had an affinity with or had often visited in the past. For example, the son [R5.2] of *James* [P5] sent a photo of an artwork painted by James when he was younger.

Interestingly, formal caregivers specifically tailored the messages to the preferences and needs of the person with dementia. The formal caregiver [R2.5] of *Sarah* [P2] sent photo slideshows featuring wildlife and dog photos she knew appealed to her. She added music that she knew evoked a vivid response. The formal caregiver of James sent an image or video at the end of each day to capture every day memories through postcards. The diversity of the shared content evoked different associations and responses by people with dementia. Receiving postcards of daily life events from relatives encouraged *William* [P3], *Tom* [P4], and *Melanie* [P6] to participate in conversations and feel more socially involved.

For *Bob* [P1], *Sarah* [P2], *James* [P5], media of mundane daily life events was less meaningful, while content personalized for them stimulated them more. Relatives also noticed the difference in response to different content. Some relatives [R2.1, R6.4] indicated they would like to receive content suggestions about what kind of media content appeals to the person with dementia. Several relatives indicated that they were not aware of the limited number of words for the text message and expressed regret since they could not share full stories. The content was decisive for stimulating social communication by providing tailored conversational topics.

Stimulating content-based conversations

Throughout the *LivingMoments* experience, partners, formal caregivers and relatives could more easily engage in conversations with the person with dementia when physically present. For instance, postcards with a photo from his formerly owned company encouraged *William* [P3] to share stories. It let him lead the conversation:

> *"Nice to surprise someone and talk about it later, especially when sending photos from the past. This creates new interactions between my father and me,"* said ***William's*** son [R3.2]

Tom [P4] received holiday photos of his children and grandchildren, where they happened to stay at a campsite where *Tom* and his partner had been regularly in the past. It stimulated a rich conversation between *Tom* and his partner: *"We received a photo in which the family is parked at a recognizable campsite. Well, then we talk about that again and Tom reminisces about this campsite."* By sharing the content of daily life events, relatives could easily express themselves towards the person with dementia. It made them avoid repetition of current affairs:

> *"I can send my parents content of my life, and that is a nice topic for conversation when I am together with them. We often have to keep the conversation going and talk about the same things, but these are other things that you can talk about with them very easily. It is an addition to our lives."* said Melanie's daughter [R6.2].

One relative [R3.2] saw opportunities in sharing all sent messages within the wider social circle of the person with dementia. Since the events are visually captured in a postcard, it is actively discussed during a visit to the person with dementia.

Contributing to a more inclusive relationship

For relatives, *LivingMoments* makes the relationship feel more reciprocal. It used to be challenging to start a conversation but sending messages about their daily lives fuels the conversation and makes the relationship more mutual: *"I like that my grandparents can now see what's on my mind right from my dorm room. I often call after I have sent her a postcard, which makes calling a lot more fun."* said ***William's*** granddaughter [R3.1]. A grandchild of ***Melanie*** [P6] highlighted that: "*LivingMoments makes it easy to send grandpa and grandma a quick message, so they know we will not forget them!"* [R6.6]. The children of ***Melanie*** came by every day, after which the received postcards were viewed and answered together. They utilized *LivingMoments* as a novel social activity when they visited their parents: "I visit them regularly, and the first thing I do now is look if there are new postcards received," said ***Melanie***'s son [R6.1]. Messages were previously sent to the partner's mobile phone, after which the message was shared with the person with dementia: *"Well, I cannot use WhatsApp anymore, and now I can use the LivingMoments device,"* said ***Tom*** [P4]. *"Last week, you also said that you feel more socially involved now,"* said Tom's partner. With *LivingMoments*, relatives can send targeted messages to the person with dementia, which was also shared by *Tom's* sister-in-law [R4.2]: *"By using LivingMoments, I focus more exclusively on my brother-in-law and friend in the communication."*

6.5.5 Dynamics of use over time

Improved use by building a habit that matches a person's cognitive and physical abilities

Participants showed that continuous and repeated use of *LivingMoments* leads to more comfortable interactions with the device. During the weeks, people mostly became better at using the system matching their cognitive and physical abilities. ***Sarah*** [P2], for example, held the postcard in front of the screen in the first week when she wanted to activate it. After a few weeks, she learnt that she had to put the postcard in the slot to activate it. She was still being stimulated by her partner and formal caregiver in her interaction with the device. However, there was an apparent learning curve that was commensurate with her ability level. For ***Tom*** [P4], the interaction with the device was perceived as so comfortable that, after a few weeks, he started looking at postcards himself and answering on his initiative. He even remembered that he had to respond to specific postcards: "*Two days later he suddenly said that he still had to answer some postcards,"* said his wife. ***Melanie*** [P6] experienced some discomfort at the beginning of the use of *LivingMoments*. She even turned the device off at a particular moment, but the device became integrated into her living environment over the weeks. It became a ritual within their family to look at and answer postcards together. There was even a tinge of sadness by ***Melanie*** and her partner for removing the device from their living

room. They were eager to receive more postcards from their relatives. This also applied to *Sarah* and *Tom*, as they wanted to use the device longer and became really attached to it. All participants were happy to keep the postcards received during the study.

Changing health conditions diminish use over time

For *Bob* [P1], *William* [P3], and *James* [P5], the use of the *LivingMoments* device changed over the period of use due to changing social and health conditions. Bob started with a collaborative interaction. His partner played an important role, but he became more dependent on his partner due to health issues and the progression of his dementia. At one point, his wife showed him the postcards instead of stimulating him to interact with the postcards or the device himself. This was also evident in the data logs (Figure 6.6), which showed a significant decrease in responding and viewing messages.

After a more extended period of use and after gradual changes in health, *James* experienced increasing high expectations from his wife, putting him under tremendous pressure to answer. The formal caregiver noticed that James ended up feeling uncomfortable responding to messages. Hence, as the data log showed, he preferred to repeatedly only view postcards. *William* started to use the system together with his partner; then, his health deteriorated quickly during the study which resulted in him only wanting to look at his grandchildren's postcards without interacting with the system.

6.6 Discussion

In this study, we evaluated the *LivingMoments* system with six people with dementia, their caregivers, and their relatives. We extracted several findings presented as themes by analyzing the qualitative and quantitative data. Our findings contribute to existing research on design and dementia by investigating how different abilities of people with dementia influence experiences with social technology, how adopting it supports communication with their social circle, and how using the system impacts social contact positively and more directly with people with dementia.

6.6.1 A broader perspective on ability

People with dementia are inevitably confronted with personal changes that profoundly affect them, their close relationships, and their surrounding world [25]. The impact of dementia can vary from person to person [249]. Our work confirms this by showing many differences in the interaction with and adoption of the *LivingMoments* system among participants. As the results showed, this mostly depends on their abilities and the support of their social environment.

At the start of the study, the first interview gave some insight into each participant's situation, care needs, and social situation. The participants were all in various stages of dementia, from mild to moderate. We found that in this study, the estimated stage of dementia and familiarity with technology did not inform the ability to use a *LivingMoments*. These factors do not imply more or less ease of adopting the technology. This shows that the ability to interact with technology while having dementia cannot be predicted well. The study revealed very different ways of interacting with and using *LivingMoments*. Designers and researchers should therefore look at the individual abilities still present within people with dementia [51,163] at the moment of using the technology.

In addition, the involvement of the social network is essential to support someone's abilities to participate in social interactions unrelated to the presence of the technology. Our results show that the commitment of the partner to collaboratively appropriate the technology-facilitated adoption enhanced the individual capacities in some participants, such as ***Sarah*** [P2] and ***Melanie*** [P6]. In another case, the partner of ***James*** [P5] reduced the use by putting pressure and high expectations on him. Here, we saw that the role of the partner or children often present in the home environment contributed most to adoption and the relatives who mostly used the web application from a distance and only occasionally visited in person did so less. Relatives, however, contributed by providing customized media content that triggered the use. We observed that if the ability is not decreasing, social support can increase the ability to use the technology. However, if the ability decreases, social support is not sufficient to maintain a stable ability level. Participants with lower abilities did not show an increase in their ability over time since most of them stayed the same or did not improve. We can conclude that some people benefitted from the social support, while for others it did not have much of an impact. Further research needs to be performed to identify the exact relation between these factors.

6.6.2 Lowering the communication barriers through personal calibration

Participants in our study show similar responses to bespoke content and suitable media as presented in previous work [131,139,321]. Our results build further on this since we found different interests in various levels of ability. *Active users* - interacting often with the system - preferred receiving postcards containing photos and videos from daily life events. In contrast, *passive users* - interacting less with the system - preferred receiving postcards which were more catered to their personal interests, such as appealing music or images. This indicates that the content for active users needs to be tailored and actively provided by the social network of the person with dementia, while passive users appreciate more personalized media.

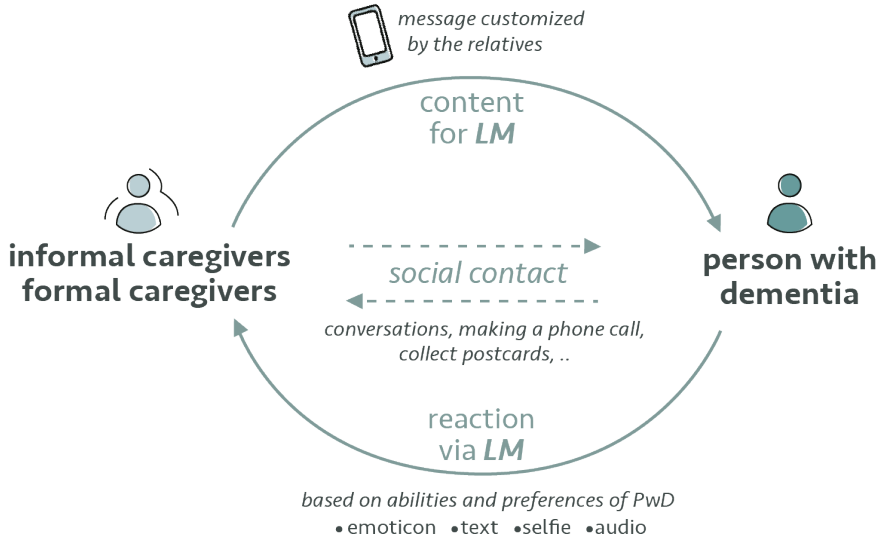


Figure 6.10. Representation of the social contact feedback loop around *LivingMoments* (LM) for the participants with dementia and the involved relatives (informal and formal caregivers).

By allowing person-specific media content to be shared, relatives can express themselves stronger (especially younger relatives) and engage more aptly with the person with dementia. This contributes significantly to their feeling of connectedness and social contact with the person with dementia. The results, furthermore, also revealed new design opportunities such as that relatives could respond to and build on each other's messages and create more rich social stories for the person with dementia. This could further increase social contact and contribute more to shaping people's agency [342].

The physical interaction of *LivingMoments* consisted of the buttons and the tangible postcards. These design attributes contributed further to the experience of agency in people with dementia. In line with our previous work [173], participants benefited from the tangible aspects, in this case postcards as output and input for interacting with *LivingMoments*. This result ties into previous studies wherein tangible and embodied interactions support using technology for people with dementia [23,75,89]. In addition, the physical presence of the postcards stimulated moments of social engagements either with or without using the technology and provided topics for in-the-moment conversations by offering personal topics to talk about [96,342]. Also, the top part of *LivingMoments* that could be taken to a desired place made the social engagement even more comfortable for the person with dementia. The removal part lowered the barrier between relatives and people with dementia to engage in social contact.

By offering more options to cater to the different abilities and preferences of people with dementia, we provided a way to let participants choose an interaction; however, for some participants, the multiple options added confusion which paradoxically reduced accessibility. A similar conclusion was reached by [76,188], highlighting the need to minimize visual overstimulation and reduce the number of options a certain technology offers. Based on our observation, we can say that systems that offer different response modalities provide more chances to adapt to personal abilities and provides opportunities to maintain agency. Systems that are adaptable or have changing interfaces can cater to a diverse range of abilities and needs.

6.6.3 Shaping a habit for adoption over time

We found that the use of *LivingMoments* provides a positive experience due to the social connection with relatives. The evaluation even revealed a learning capacity in some participants, depending on their personal ability and social living arrangements. We know that learning capacity decreases in people with dementia [314]; however, our results show that at least some learning is still possible under the right circumstances. Furthermore, using the technology frequently over six weeks resulted in the formation of a habit in some participants. The use was reinforced by the repeating tangible and recognizable cues in combination with the unique content of the messages that contributed to engaging the person with dementia. These findings are consistent with research showing that cues are helpful to the person with dementia to use or learn using a technology [274].

The postcards and the physical presence of *LivingMoments* were not only a trigger for individual engagements with the technology but also for using the system when receiving visitors. A joint social activity was shaped around the postcards and the use of the device. Thereby, relatives and other social contacts are active actors who co-determine the interaction with the technology. The relatives created unique content and ensured that the person with dementia was involved in a social contact feedback loop (Figure 6.10). The relatives, both informal and formal caregivers, shared content via *LivingMoments* with the person with dementia, who responded via one of the four response modalities. This created a collaborative social activity around *LivingMoments* that encouraged people with dementia and their social environment to keep interacting with the system. The technology can then be seen as a trigger for the action, shaped according to the person's abilities, preferences, and social support.

We, however, have to ensure that relatives do not take over the interaction on behalf of the person with dementia. We found that it is not about the content of the answer but about making the action for as long as the person with dementia

feels capable or enabled. In the case of *LivingMoments*, these actions were divided between interactions with and without the technology by entering the loop by either answering postcards via the device itself or seeing the postcards as triggers for using other communication forms (i.e., starting a conversation or making a phone call). Further research is needed to understand how technology can support the social structure around the person with dementia and consider their ever-changing abilities and personal needs.

Throughout the study, we found that people integrated the *LivingMoments* prototype as a part of their lives and formed social habits around using the system collaboratively. The prototype played a fundamental role in stimulating and maintaining social contact for both the person with dementia and the relatives. Due to the platform used, the number of involved relatives could increase over time, leading to in total 25 relatives being involved. In the cases in which many relatives were involved and active, the overall use improved and caused a more lasting interest and engagement from the person with dementia. However, since the data analyzed relates to a maximum period of six weeks, we cannot make any statements about engagements beyond that point. Further studies are needed to determine how people interact with the system over time. Some participants wanted to keep using the system after the data collection, resulting in people using the system for up to 20 weeks. These preliminary findings show promising design considerations for future research and development.

6.7 Conclusion

In this chapter, we used *LivingMoments* to better understand the different abilities and experiences of people with dementia when using new technology to support social communication. We found that people adopted *LivingMoments* in different ways, depending on their abilities and social situation. This shows that *LivingMoments* operates as a platform that can support various use cases. *LivingMoments* gave people with dementia back a sense of control and agency by enabling them to engage in social contact with their relatives directly and reply to messages of relatives in a way that is suitable for them. This could be via the system or outside of it. Over time, up to six weeks in our study, we see a steady use curve apart from the first week and whether no external circumstances affected using the system.

Furthermore, our results demonstrated that the interaction with *LivingMoments* was not predictable based on their indicated technology abilities or situation. Dementia has different timing and paths, and the learning curve and habits in using a technology vary for each person. This shows that technology can create

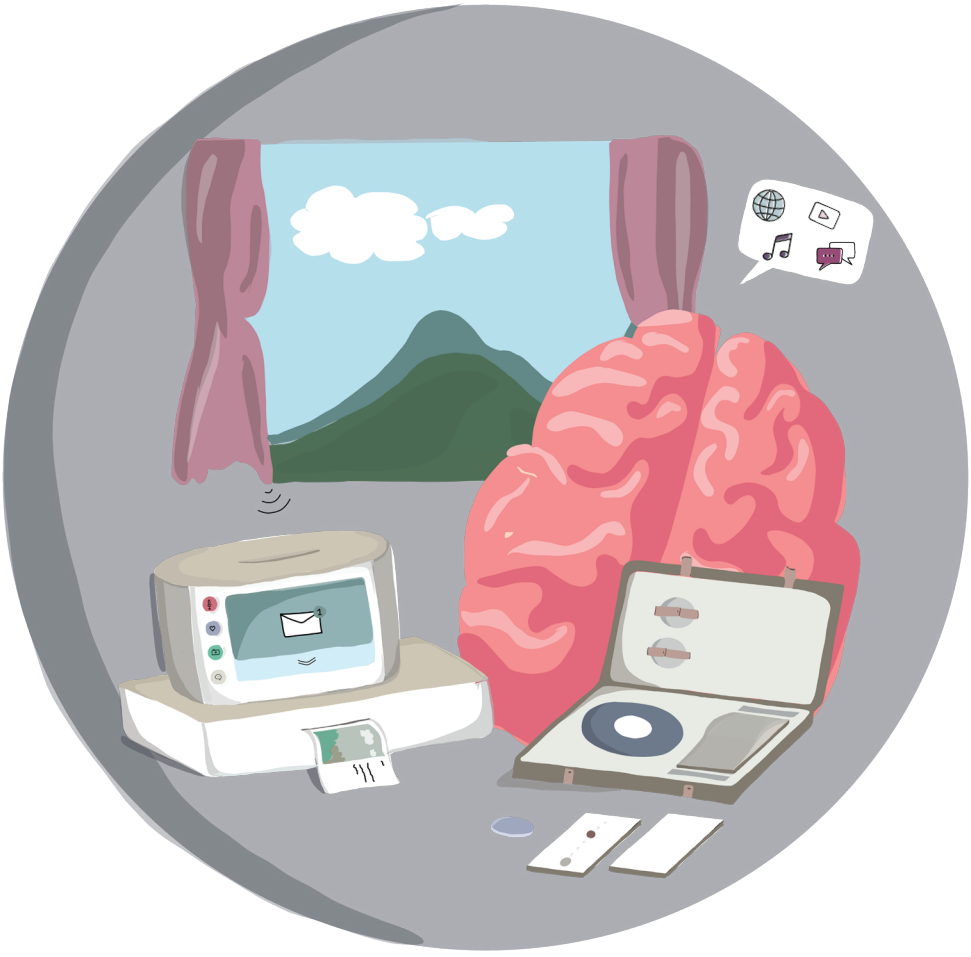
opportunities for different people with dementia to participate in social engagements on different levels. When designing for people with dementia, it is imperative to focus on what they can do and that the involvement of the social network is crucial for successful adoption. How people with dementia and their social network are involved in certain activities depends on ability and preferences.

From the study, we evinced three topics that need to be considered in designing social technology for people with dementia. First, integrating triggers in the physical environment, such as postcards, separated from the central system can motivate effective participation in social interactions. Second, creating personalized content stimulates engagement in social communication for people with dementia. Also, relatives need to be supported in creating this content by giving suggestions on what content appeals to people with dementia. And third, providing multi-sensory feedback to people with dementia can help them to integrate the system into their lives.

To conclude, when the system is designed in line with the abilities of people with dementia and people have a solid social support network, adoption of technology is more likely to be successful. Our findings point to the need for further research concerning how we can continuously calibrate and adapt system functionalities to personal abilities, needs, and social context. Furthermore, it would be interesting to evaluate a system like *LivingMoments* more longitudinal to review the dynamics of use over time and the influence of the progressive nature of dementia. Ultimately, given the irreversible course of dementia, we have to accept that at some point, a certain type of technology might not be suitable anymore. Until then, we can accumulate our research and design efforts to envision and explore considerate and suitable technology to empower people living with dementia and contribute to their quality of life.

6.8 Acknowledgments

The Create Health Program of ZonMw funded this work as part of the '*Dementia Dynamics in Design*' project with project number 443001117. The project was also partly funded by care organization Pleyade. The authors would like to sincerely thank all participating families, relatives, and care organization Pleyade for taking their time and making this research possible.



07

Discussion & conclusion

In this chapter, we discuss our findings and formulate a conclusion to position this work in the literature regarding HCI and dementia. First, in section 7.1, we provide an overview of our findings concerning design for dementia and how this addresses research questions one (7.1.1) and two (7.1.2). We cover each research question separately based on the insights from each chapter. Then, in section 7.2, we provide a further interpretation and positioning of these results in the literature as well as discuss the overarching contribution of this dissertation and future research opportunities in dementia design research based on this work. In section 7.3, we will reflect on the broader contribution and future implications on society and dementia care practices. In section 7.4, we will delve into the limitations of this research. Lastly, the closing section of this chapter will present an overall conclusion of this work.

Chapter 7

7.1 Summary

The studies in this dissertation focus on utilizing technology to cater to the psychosocial needs of individuals with dementia. The research specifically focuses on meeting the psychosocial needs of people living with dementia. These needs include social interaction, emotional well-being, a sense of purpose and fulfillment, and self-esteem. They align with the fundamental psychosocial needs identified in *Maslow's hierarchy of needs* and are essential for promoting a person's overall quality of life [208]. By providing non-pharmacological meaningful care, the study seeks to improve the overall well-being of individuals and enhance their quality of life. This dissertation aimed to explore how interactive systems can be designed to provide people with dementia with direct access to enjoyable, meaningful experiences by catering to their abilities, wishes, and related needs. In this research, we use the principles of *warm technology* in which the technology is not treated as assistive but as personally empowering by embracing the wealth of human sensory and motor abilities of people with dementia and acknowledging their personal context [153]. The focal point of this dissertation is to embrace the preserved cognitive, sensory, and motor abilities and related needs of people with dementia that fit their individual care pathway by designing with and for them in a real-life context. To achieve this, we adopted an inclusive design research approach that considers the full range of human diversity with respect to ability, age, needs, and other forms of human difference. We have applied this approach to gain person-centered insights into the personal challenges that might limit the use and adoption of interactive systems by people with dementia and identify opportunities for design to overcome these challenges. We involved people living with dementia at home and in a residential care facility in participatory design activities, as shown in *Chapters 3* and *4*.

Furthermore, we conducted evaluations of designed research artifacts in real-life contexts, as described in *Chapters 4, 5,* and *6,* to yield insights into the design requirements for designing interactive systems (see Figure 7.1). Through these studies, this dissertation was a first step in exploring how interactive systems could be made more accessible, meaningful, and aesthetically appealing to a diverse group of people with dementia. We found that considering the personal context and including adaptability in interactive systems contributed to empowering people with dementia with different abilities and needs. Designing for the personal dynamics of dementia, in terms of the pathway, personal experience, and ability in technology use, is an unexplored area of research.

7.1.1 Answer to the 1st research question

Our research in this dissertation has been guided by the following research question, which we refer to as the first research question: *how can we design technology to cater for the diverse abilities and needs of people with dementia?*

Throughout this dissertation, we have seen that an inclusive and participatory approach in the design process involving people with dementia offers the potential to understand their different abilities and related needs better [195,338]. In our studies, we found that using props, tangible research prototypes and other stimulating materials together with people with dementia, as described in *Chapters 3* and *4*, can support in recognizing their uniqueness and better understand their perspectives. As such, it can support the gathering of knowledge about the barriers people with dementia experience in using existing technology (e.g., phones, tablets, computers, and music devices) and what each individual needs to be able to access technology directly (see Figure 7.1). In *Chapters 3* and *4*, we explored individual differences in dealing with existing technologies and included these differences in the design of tangible prototypes. Through this design-led approach, we sought to gain insight into the associations, aesthetics, and interactions that individuals with dementia are capable of engaging with in interactive systems. We have shown that this approach can offer a more comprehensive understanding of individuals with dementia, including their cognitive, sensory, physical, and psychosocial or emotional needs and the impact of design on enhancing their experiences.

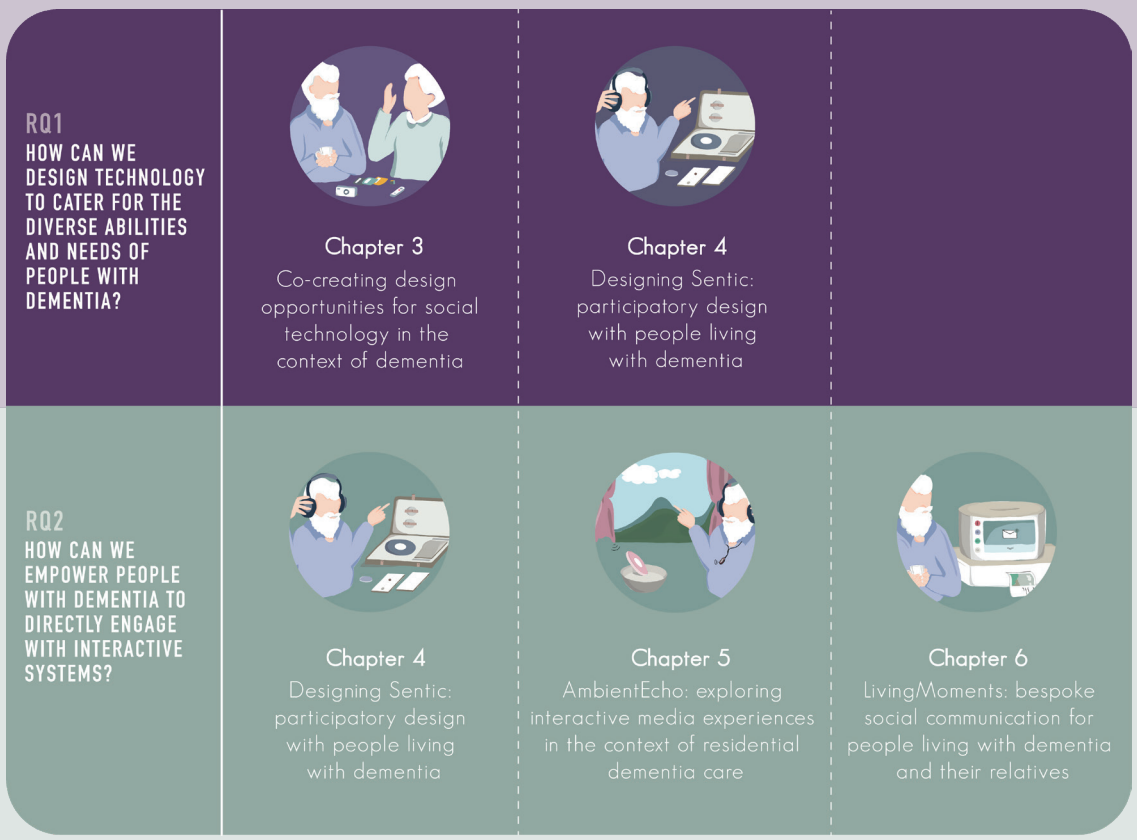


Figure 7.1. The answers to the research questions distributed throughout the chapters.

Chapter 3
Co-creating design opportunities for social technology in the context of dementia

In this dissertation, *Chapter 3* discusses the use of a co-creation approach to identify design opportunities that are informed by the personal experiences of individuals with dementia and their spouses. The study included four co-creation sessions, each of which involved one person with dementia and their spouse. The aim of these sessions was to utilize generative tools to gain insight into the needs, challenges, and facilitators related to social interaction through social technology among people with dementia. The results indicated that people with dementia employ various strategies to overcome the barriers to social participation and the use of social technology. These strategies addressed both internal barriers (such as fear of interacting with digital means) and external barriers (such as the location and complexity of technology).

The co-creation method employed in this chapter, which involved people with dementia and their partners, allowed us to gain insight into the strategies that people with dementia use to maintain social connections. Three main strategies emerged: appropriate levels of assistance, routines, and self-management techniques. For example, people with dementia may adapt their environment with tangible prompts in order to facilitate their interaction with technology. Additionally, incorporating social interactions into daily routines was found to be beneficial for maintaining social connections among people with dementia. By utilizing these strategies, we were able to identify design opportunities that consider the importance of the broader social and physical context in supporting agency with technology for people with dementia.

Chapter 4
Designing Sentic: Participatory design with people living with dementia

In *Chapter 4* of this dissertation, we described an inclusive, participatory design approach in which five people with an early to mid-stage of dementia and five people with a moderate-to-later stage of dementia were involved. We used stimulating material, such as existing music devices, props, and tangible prototypes, to observe their use and personal responses towards the interaction and aesthetics. The objective of this study was to investigate how opportunities can be provided for people with dementia to be empowered and have agency in using interactive technology. The co-creation process allowed for the observation of physical interactions and facilitated dialogues with individuals with dementia regarding their personal experiences and associations with both existing music systems and newly designed artifacts.

Accordingly, the findings of this chapter underscore the importance of designing interactive systems that provide a meaningful and immersive aesthetic experience for people with dementia, aligned with their associations with familiar devices such as a music player. Focusing solely on the appearance of an interactive system undermines the significance of the aesthetic experience it provides for people with dementia. Rather, it is the aesthetic experience facilitated by the artifact that should be the focus, which may include its appearance, but is more importantly about how it is experienced by the users as a familiar object. The aesthetic object is contemplated not merely as an object of sensory pleasure but also as the repository of significance and value. In this study, the design of the system was inspired by the aesthetics and appearance of a record player from the 1950s, with its smooth wooden finish that people with dementia would recognize and enjoy. We found that the chosen aesthetics of the artifact should not deviate greatly from familiar devices that play music. Additionally, the form and physical appearance of the system should be

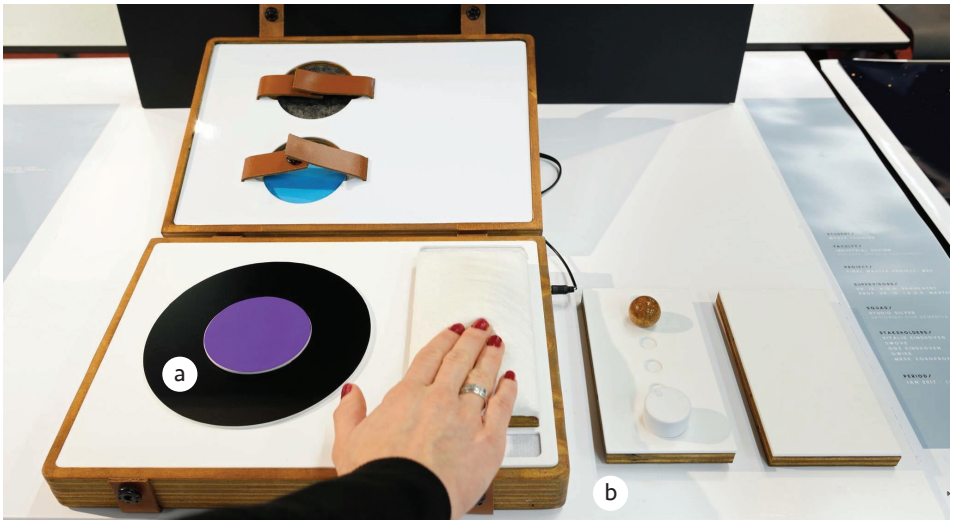


Figure 7.2. *Sentic* has a record player-inspired design with colored music discs that fit inside the large black record (a). The interactive system includes a variety of interaction modalities (b).

designed in such a way that it provokes users to interact with it. Our study revealed that individuals with dementia were able to comfortably interact with the music discs, as they were able to match the shapes of the discs across all stages. This is illustrated in figure 7.2a, which shows the physical appearance of the discs that fit in a large black record.

Besides the aesthetics, the findings of this study revealed that people with dementia have diverse needs and abilities in dealing with interfaces containing multiple functions, regardless of the phase of dementia or age. It is imperative to consider these nuances in the design process, as a generic interaction design is unable to fully address the heterogeneous abilities observed among individuals with dementia. Through the implementation of a co-creation process, involving people with dementia over six consecutive engagement workshops, we identified specific design considerations that respond to the diverse needs and abilities of people with dementia, resulting in a more inclusive and person-centered interactive system.

7.1.2 Answer to the 2nd research question

In this dissertation, we adopted a *research through design* (RtD) approach through the development and evaluation of design artifacts as a means of inquiry [357]. The RtD methodology involved conducting distinct and focused RtD processes, each of which explored a particular aspect of designing for individuals with dementia. It is important to note that these processes were not part of a larger-scale research process but were divided over different research processes.

Three new *high-quality design artifacts* were developed to gain insight into the personal experiences and responses of people with dementia towards our design artifacts:

- The *Sentic* music player resulted from a collaborative process of six engagement workshops. The workshops monitored physical interactions and involved a dialogue with people with dementia about their experiences with existing music systems and new prototypes, leading to the final design of *Sentic* , described in *Chapter 4*.
- *AmbientEcho* was developed by the Pleyade Innovation Team in collaboration with care professionals, designers, researchers, and based on the expressed needs of people with dementia. As being part of a research through design process, the installation was developed to elicit personal experiences from residents, family and care professionals in a real-life care setting, as described in *Chapter 5*. This approach allowed the researchers to gain a deeper understanding of how people with dementia interacted with the system, their needs and experiences, and how it affected their lives, ultimately leading to the development of a more appropriate and meaningful design. The evaluation of *AmbientEcho* resulted in a redesign of the system that incorporated the use of algorithms to further customize the media experience for individuals with dementia, taking into account their unique needs and preferences.
- *LivingMoments* is a design concept based on the findings of *Chapter 3*, aimed at reducing barriers and improving the ability of people with dementia to use social technology. Its use in a social setting was evaluated with people with dementia and their partners, as outlined in *Chapter 6*.

The use of interactive systems by individuals with dementia in their real-life context, whether at home or in a residential care facility, provides high ecological validity and enables researchers to gain valuable insights [41]. By gathering qualitative and quantitative insights, we were able to identify effective ways to empower people with dementia to engage with interactive systems directly. Our research also shed light on some of the challenges that people with dementia face when interacting with technology, giving us a better understanding of their interaction with our systems at specific points in their (care) pathway.

Chapter 4
***Designing Sentic:* Participatory design with people living with dementia**

The findings of *Chapter 4* of this dissertation demonstrated that the interface of an interactive system should contain different levels of interactions, varying from a discrete interaction to a more sensory-stimulating interaction (see Figure 7.2b). We found that many contemporary music systems often require a relatively high cognitive and functional ability level, making them difficult for individuals with dementia to use. To address this issue, we developed *Sentic*. This interactive music system features an interface containing different interaction modalities that provide people with dementia with the possibility to configure their preferred experience (see Figure 7.2). To reflect on the final prototype of *Sentic*, we conducted a co-reflection session with three individuals with dementia, including one diagnosed with early-stage dementia and two with moderate-stage dementia. The evaluation revealed that the design of *Sentic* and its adaptable interface could empower people with dementia. By supporting appropriate inclusion for people with dementia in the use of *Sentic*, all individuals showed varying degrees of emotional and physical response to one of the interfaces. By utilizing *Sentic*, we have shown that it is possible to design for people with dementia in a user-friendly, meaningful, and visually pleasing manner. We found that for people with a milder stage of dementia, a more discrete interaction contributes to the maintenance of autonomy in the interaction. Conversely, individuals in the moderate-to-later stages of dementia exhibit a greater appreciation for stimulating their tactile senses. The findings presented in this chapter suggest that designing simple interactions that can be tailored to individual preferences and strengths is an effective approach for supporting independent engagement and enhancing the perceived usefulness of the technology.

Chapter 5
AmbientEcho: Exploring interactive media experiences in the context of residential dementia care

In *Chapter 5* of this dissertation, we discussed the evaluation of the *AmbientEcho* artifact. We evaluated the interactive installation with a group of participants, including three residents with mid to late-stage dementia who reside in a residential care facility, two of their partners who still lived at home, and three care practitioners working at the residential care facility. *AmbientEcho* is an interactive media system that features a virtual window, photo frame, ambient music, and matching light. It displays bespoke media content when someone is within range through a personal chain (traced by Bluetooth) or displays curated media by placing a colored disc in a bowl. Our evaluation of *AmbientEcho* revealed the importance of systems that can accommodate the diverse abilities and preferences of individuals with dementia living in a care facility. We observed a diverse nature of participation during the evaluation, highlighting the need for systems that can respond to this diversity. We found that providing a range of interaction options allowing for both automated and manual control, lowered the barrier for residents to use the interactive system. The combination of an automatic and manual interaction design gave residents, together with their family and care practitioners, the opportunity to create their own preferred experiences that met their unique requirements. Furthermore, the physical design of *AmbientEcho*, with its half-open space, was aesthetically engaging and provided a comfortable setting, encouraging repeated engagement with the system. The system facilitated the use of both personal and curated media, enabling residents to steer their own media experience and interact with significant content, providing opportunities for them to be empowered and have agency. On the one hand, personal media elicited enthusiastic responses; on the other, curated media stimulated storytelling and associations with personal experiences.

Chapter 6
LivingMoments: Bespoke social communication for people living with dementia and their relatives

In *Chapter 6* of this dissertation, we discussed the evaluation of *LivingMoments*. This artifact uses digital and physical interaction design to enable people with dementia to engage in social contact with their relatives. By using the *LivingMoments* system, relatives can send digital messages to individuals with dementia that are converted into physical postcards. As soon as the postcard has been placed within the *LivingMoments* system, the individual with dementia can view the movie, photograph, and listen to the audio message. Additionally, these individuals may respond to the message through the *LivingMoments* system to the extent of their abilities. The design of *LivingMoments* was based on the outcomes of our study in *Chapter 3*. We evaluated the artifact with six people with dementia, their partner, and relatives. The findings in this chapter revealed that people with dementia adopted *LivingMoments* in various ways, depending on their abilities and social situation. This demonstrated the importance of offering different response modalities in the interaction design to provide more opportunities for them to be empowered and have agency that align with their abilities.

Additionally, the prominent visibility of the interactive system and the triggers in the physical environment were found to be crucial in enabling people with dementia to engage with *LivingMoments*. The physical presence of the *LivingMoments* system and the visibility of the tangible postcards reminded people with dementia to interact with the system. The responses to the media content provided by the *LivingMoments* system, which relatives sent, varied depending on the format of the content (such as video or static images) and the content of the media itself. Based on these findings, we concluded with considerations for the design of interactive systems to support sustained engagement.

In order to facilitate successful engagement with interactive systems among people with dementia, designers and researchers should approach these individuals with a focus on their abilities and tailor the system accordingly. Here, it is essential to recognize the role of the social environment in supporting or hindering interaction with the system. In addition, designers can enhance access to interactive systems and facilitate engagement by calibrating them to the various levels of ability and media content needs of people with dementia. A person with dementia can be passive or active, each with his or her own needs and preferences in terms of interacting with the system and viewing certain media content. Finally, our research suggests that forming a habit over time can improve the adoption of the system, as we observed that the use of *LivingMoments* was reinforced by repeating tangible and recognizable cues, such as the postcards, in combination with unique content that helped to engage the person with dementia.

7.2 Academic contribution and future implications for dementia design research

7.2.1 Contribution in the field of dementia design research

Below, we reflect on the contribution of this dissertation in the field of design research in the context of dementia. The contribution is grouped in four areas: 1) adaptability in the interaction design to address abilities, 2) appropriate calibration of multimedia content, 3) importance of aesthetics for adopting technology, and 4) involving multiple perspectives in design for dementia.

Adaptability in the interaction design to address abilities

People with dementia often encounter challenges when using modern technologies, such as ordinary phones [32,238] or everyday household technologies (e.g., TV, microwave oven) [273]. Several other researchers have confirmed this observation, examining the difficulties people with early-stage dementia experience with other everyday technologies [237,238,264,273]. The complex and multifaceted nature of dementia has implications for the design of these technologies, as highlighted in this dissertation. Previous research has

emphasized the need for personalized and tailored technology to meet the diverse needs of individuals with dementia [76,110,152,215,235], particularly in terms of supporting engagement in meaningful activities [108]. This dissertation builds upon this notion and has made a significant contribution to the field of *Human-Computer Interaction* (HCI) and dementia by demonstrating an innovative approach to designing interactive systems that can accommodate the heterogeneous and unpredictable nature of dementia in terms of both functional, cognitive and psychosocial needs. Traditionally, barriers to technology use for individuals with dementia have been attributed to cognitive deficits resulting from the condition [215,228]. This doctoral research has taken a unique perspective by acknowledging that individuals with dementia possess a diverse range of cognitive, sensory, and motor abilities, irrespective of the stage of their condition, and has therefore gone beyond focusing on cognitive deficits. This approach has allowed for a more comprehensive understanding of the psychosocial needs of people with dementia. By treating design as an empowering tool to strengthen the remaining abilities of individuals with dementia [153], such as in *Chapters 4 - 6*, this research aligns with the paradigm shift in the field of HCI and dementia towards inclusion and a critical perspective on technology [186], placing the lived experiences or needs of individuals with dementia at the center of the design process.

The research conducted in this dissertation has shown that it is necessary to consider the wide range of abilities and needs among individuals with dementia. We demonstrated in *Chapters 3 and 4* that a generic solution, such as an existing mobile phone or music system, could not adequately address the differences in abilities and related needs between people with dementia. A similar conclusion was reached by Seymour and colleagues (2017), showing the importance of an interface that adapts to the particular person and their abilities over time [289]. In their interfaces, they allow adjustments with knobs and buttons specifically for people with dementia. Our results build on this work and shed new light on how the interaction design of interactive systems can best address the different abilities of people with dementia and adapt to their individual pathways. In *Chapter 4*, we found that people with dementia had personal preferences in interacting with an adaptable music player equipped with interchangeable interfaces, depending on their ability. In *Chapter 5*, we discovered that offering automated and manual interaction modalities in an ambient technology setting supported the varying abilities and needs of individuals with dementia living in a care facility. In *Chapter 6*, we found that providing multiple interaction buttons improves the ability and maintenance of agency of individuals with mild to moderate dementia to interact with an interactive system. We provided options for these individuals to choose the type of interaction they prefer.

Furthermore, we have shown that the utilization of printable postcards, as seen in the *LivingMoments* system, can effectively motivate individuals with dementia to engage with the interactive system and participate in social activities that align with their abilities and preferences. In order to provide opportunities for individuals with dementia to be empowered and engage directly with interactive systems, we must consider their personal characteristics and remaining abilities in using technology in the design. As stated earlier, the properties of interactive systems play a significant role in whether or not they are used [76], so if these are not in line with the cognitive, sensory, and motor abilities of the person with dementia, this would lead to cessation of use. Our findings in *Chapters 4 - 6* demonstrate the need for a solution that offers different interaction modalities that can be adapted to the preferences of different individuals with dementia. These results further the understanding of interactive technologies previously obtained from other research [95,96,131,184,226] by showing that interactive systems are primarily intended for people in particular stages, although abilities may vary greatly within these stages still.

According to the findings of this dissertation, people with dementia with strong abilities could maintain control over a system. In contrast, when abilities are diminished, alternative forms of interaction may be appropriate. We described in *Chapter 4* how we used a variety of interaction modes to accommodate varying levels of ability. In this chapter, we saw that people who still could do so benefited from more discrete interactions. Here, in the *Sentic* artifact, we used a discrete interface design that contains buttons that can place relatively high cognitive demands on the user with dementia. When someone with dementia experiences reduced ability, the interaction design could take a different form and avoid placing unnecessary cognitive demands on the person by design. In these cases, a sensory- stimulating interface design that was more open-ended suited some people with dementia who experience difficulties using the discrete interaction. This is consistent with what has been found in previous work showing the use of textiles for stimulating the senses of people with late-stage dementia [326,328]. The utilization of tactile elements can offer opportunities for sensorial exploration by people with dementia living in care homes that meet their preferences and psychological needs, such as comfort or pleasure [156].

When a person's ability to interact with discrete or sensory-rich interfaces decreases, the need for the system to assume control grows. For instance, if someone with dementia no longer comprehends buttons or struggles with a more open-ended and sensory-focused interface, the system can assume control and take a more proactive approach by incorporating automation in its design to assist the user better *(chapters 4 and 5)*. A third interface module for *Sentic*

removed the interaction and gave the system control to play music. Also, in *Chapter 5*, where we designed *AmbientEcho* for people who lived in a residential care facility with reduced interactive and cognitive abilities in such a way that it responded automatically when the person walked into the installation. This is known as an embodied interaction that can contribute to the accessibility for people with a lower ability level [23,186,224,336,338]. However, we have seen that we should offer people with dementia the opportunity to be in control when they can and prefer this. Therefore, we conceived *AmbientEcho* with an additional interaction layer. Residents with dementia could thus choose their own interaction and create their own preferred experience. However, we found that some participants appreciated this, and others did not. We saw that a system needs to be flexible; sometimes, it should take control, and sometimes not. Interactive systems must therefore contain a certain degree of adaptability in the interaction design to suit a wide range of cognitive, sensory, and motor abilities and interests. This adaptability has also emerged in previous work as an essential requirement for interactive systems for people with dementia [146]. However, it has yet to materialize broadly in HCI. In this dissertation, we conducted an initial investigation on the materialization of adaptability in interaction design. As part of the research, various interaction modes were designed and assessed, including discrete interactions, sensory-stimulating interactions (such as a soft fabric surface or tangible objects), and autonomous interactions. However, more research is needed into the effectiveness of other interaction modalities, i.e., self-aware systems [54] or voice-based interactions [56], in empowering people with dementia to interact with interactive systems.

Appropriate calibration of multimedia content

Using multimedia technologies, such as videos, music, and images can provide engaging sensory experiences that elicit positive emotional responses and stimulate reminiscence in individuals with dementia [189]. This is particularly beneficial for individuals with dementia who may have difficulty accessing their own memories or feel isolated and disconnected from the world around them. Furthermore, research has demonstrated that multimedia can be a powerful tool to create social connections and facilitate communication with others [96,101]. For instance, shared viewing of a video or listening to music together can provide a shared experience and create a sense of connection and social engagement among individuals with dementia. The findings of *Chapter 5 (AmbientEcho)* and *Chapter 6 (LivingMoments)* acknowledge the importance of an appropriate use of multimedia content within interactive systems to give people with dementia the opportunity to create their preferred experience. The application of media in interactive systems for people with dementia has received attention in interactive technology applications over recent years [133,189,333]. Other researchers have

shown that personal media (exact media content from a person's life) is not recommended for people with dementia since it requires a certain level of recognition that can be experienced as a memory test, while the use of generic media is encouraged because it allows people with dementia to associate with and tell stories [14]. Our findings indicate that media content should be tailored to an individual's interests and be open to curation to support a continuous sense of curiosity and maintain lasting interest for individuals with dementia. This can be achieved by ensuring that the media is closely aligned with the personal interests of the individual and by providing opportunities for the exploration of new interests and stories through curated media. It is important to note that not all individuals with dementia have the same historical experiences and may not appreciate materials from the same time period. For example, in *Chapter 6,* we saw that people with a higher ability - preferred watching media content of daily life events of their social contacts, while people with a lower ability - preferred watching bespoke media content. In the study of *Chapter 5*, in which we evaluated *AmbientEcho* with residents of a residential care facility, we saw that the bespoke media was experienced by some people with dementia as the key in eliciting vigorous lively responses and to reconnect with parts of them self, but this was also received by some with an experience of loss, in line with [14].

Based on our findings and research, our dissertation research has led us to hypothesize that interactive systems for individuals with dementia should learn from the preferences of users and tailor media content accordingly. This builds on recent work that calls for more diversity in applications and content to appeal to individuals with dementia [188]. However, it remains unclear which media content is best suited at which time for people with dementia to enhance their emotional well-being. Again, we propose adapting to people's changing cognitive, visual, and auditory sensory needs. Based on our work, we hypothesized that people with dementia with high abilities value mostly curated media and people with dementia with lower ability value more personal media. However, it would be interesting to investigate why this would be the case in people with dementia. More research is therefore needed into how we can best match the media to the personal needs of people with dementia. Apart from the personal impact, it is also imperative to examine the impact of media content on loved ones and care professionals surrounding the individual. Previously, researchers had involved the social circle surrounding the person with dementia in the development of media experiences through technology [133], which also presents an opportunity for further research.

Importance of aesthetics for adopting technology by people with dementia

In the realm of dementia care, it has been observed that aesthetic experiences

are often overlooked [92]. Therefore, in this dissertation, we have given particular attention to the aesthetic qualities of the artifacts that we have designed. The artifacts used in this dissertation were consciously designed with aesthetics in mind, as they were to be evaluated in everyday life contexts of individuals with dementia, such as at home or in a residential care facility. The importance of refined artifacts to be evaluated in real-life contexts has shown merit [240]. The refinement and finish of an artifact can impact the accuracy of research and provide valuable insights into the strengths and weaknesses of the design, thereby informing the development of more effective and user-friendly technologies for individuals with dementia.

Most disturbingly, we see that many products designed for individuals with dementia still adopt a childlike aesthetic characterized by using primary colors, images associated with childhood, and materials similar to those used in toys [92]. On the other hand, some products focus on reminiscence, which often has an old-fashioned aesthetic, such as an old radio [345]. These designs may use beige-brown wood to evoke products and systems from the past or infectious disease wards [144]. However, both design directions can perpetuate stigma toward individuals with dementia. This stigma can lead to some individuals feeling ashamed to use assistive technology in public and raises the question of how to design assistive technology in a way that does not perpetuate these stereotypes and instead appears more mainstream [144]. Using childlike aesthetics and materials similar to toys for products for people with dementia can be seen as stigmatizing because it implies that they cannot use more sophisticated products. This can be disrespectful and belittling, ignoring the dignity and autonomy of the user. Similarly, old-fashioned aesthetics can be seen as stigmatizing due to reliance on stereotypes about the interests or abilities of people with dementia, which can be demeaning and fail to recognize their individuality and diversity.

To avoid these issues, we moved away from these directions. Instead, we emphasized accessible and modern aesthetics, exceptionally since visual aesthetic responses are preserved throughout the course of dementia [52]. Therefore, we have used a modern design language with an elegant touch (see, for example, Figure 7.3). Combining white elements with wood gives the design a neutral appearance that fits many home decors. This is especially evident in the *LivingMoments* and the *Sentic* designs. However, a product's or system's aesthetics is not solely the look and feel of a design but considers the whole human and sensory experience [130,354]. This was evident in our studies, which demonstrated that interactive systems should not only provide an accessible interaction design that is understandable to people with dementia but also

Figure 7.3. The consistent design language we applied in the three designed artifacts; a) *LivingMoments*, b) *Sentic*, and c) *AmbientEcho*.

consider the emotional and psychological responses that an individual has to use a particular product or system. This can include the enjoyment, satisfaction, or engagement that the person experiences, as well as any deeper meanings or associations that the interaction may hold for them [275]. The latter is extensively explored in the field of HCI [190] and in the field of design and dementia [140,155,225,226].

To begin with, our findings, presented in *Chapters 4 - 6*, suggest that incorporating aesthetic qualities, such as situatedness, material texture, and tangible assets, on a product-system level can enhance sensory experiences and provide a sense of meaning and satisfaction. This hypothesis is supported by our observations that these aesthetic qualities, exemplified by the tangible postcards of *LivingMoments* and the ambiance of the *AmbientEcho* environment, can increase engagement with interactive systems and evoke more vivid emotional responses, as evidenced by the positive emotional reactions displayed by individuals with dementia upon entering *AmbientEcho*, such as smiling. This ultimately enhances the overall experience of the system. Moreover, our analysis suggests that incorporating these aesthetic qualities in the design of interactive systems can also address the psychosocial needs of individuals with dementia. For example, by providing a sense of familiarity and personal connection, tangible assets and situatedness can help alleviate feelings of loneliness and social isolation. We demonstrated in the *Sentic* study that we used varied materials for the interfaces that each had its own aesthetic properties. We found out during the engagement workshops that the aesthetics of interaction should match the severity of the dementia. For example, some perceived an interaction based on a shape sorter as childish, and others thought it was a pleasant experience. Therefore, the interaction with an artifact should not be perceived as juvenile or childish to support dignity and respect for the individual with dementia [156]. The soft fabric of the sensory-stimulating interface invited people with more severe cognitive abilities to touch the fabric, contributing to an enriching experience for them. This aligns with research demonstrating the importance of sensory experiences for individuals with dementia who have reduced abilities, as they may be at risk of sensory deprivation [62] and rely on sensory cues [154]. In this case, tangible designs can facilitate embodied in-the-moment activities by utilizing the remaining sensory abilities of individuals with dementia [107]. Given this, it is crucial to consider the individual's frame of reference and abilities when designing technology for people with dementia, as the aesthetics of interaction should be appropriate for the severity of the dementia and not be perceived as childish to preserve dignity and respect.

Additionally, our research in *Chapter 5* showed that the *AmbientEcho* artifact had

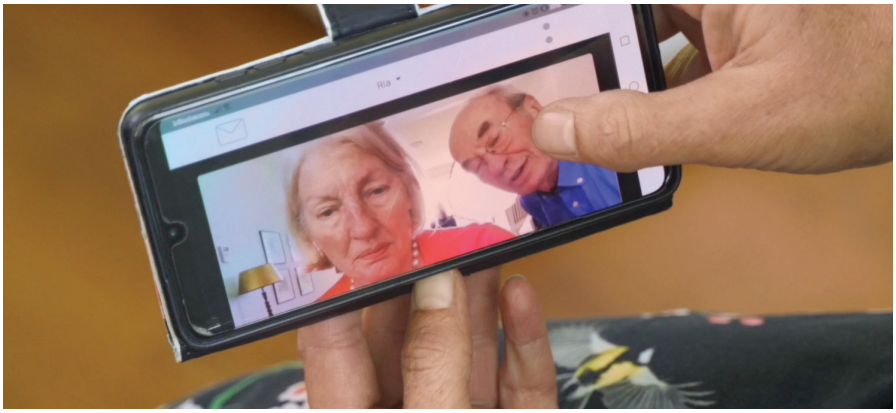


Figure 7.4. An individual with dementia photographed her husband and herself with the *LivingMoments* system and shared it with her care professional.

a solid material aesthetic value for individuals with dementia, who were attracted to its visually appealing and immersive design. Moreover, the findings presented in *Chapter 6* of the *LivingMoments* study highlight the importance of materiality in aesthetics. The visually and tangibly appealing design of the *LivingMoments* artifact motivated participants to keep it in a visible location in their homes and interact with it frequently. The ability to remove the interaction module and view the postcards in a preferred location added to the aesthetic appeal of the *LivingMoments* artifact and enhanced the overall enjoyment of the experience. Also, participants in the *LivingMoments* study projected special value onto the postcard and treasured them by keeping them in a prominent place in the living room. These postcards were used as mementos reminding them of using the interactive system. These visual and physical factors all contributed to enriching the aesthetic experience of the artifact. This is particularly important because people with dementia often struggle with initiating and participating in meaningful, recreational activities that improve their quality of life [247]. The results of this study are consistent with previous findings suggesting that the sensory experience of objects within a space or the space itself can impact a person's aesthetic perception [281], and enable meaningful engagements [154,328]. Our findings align with this research. As noted in *Chapters 5 and 6*, the presence of tangible objects in the space may serve as a cue for people with dementia to initiate and engage with technology.

An aesthetic experience goes beyond merely the product-system level. For instance, our designed artifacts not only provided a pleasant aesthetic experience for individuals with dementia, but also facilitated social interactions between them and their loved ones or formal caregivers, creating opportunities for shared positive experiences and fostering a sense of connection and engagement. This is

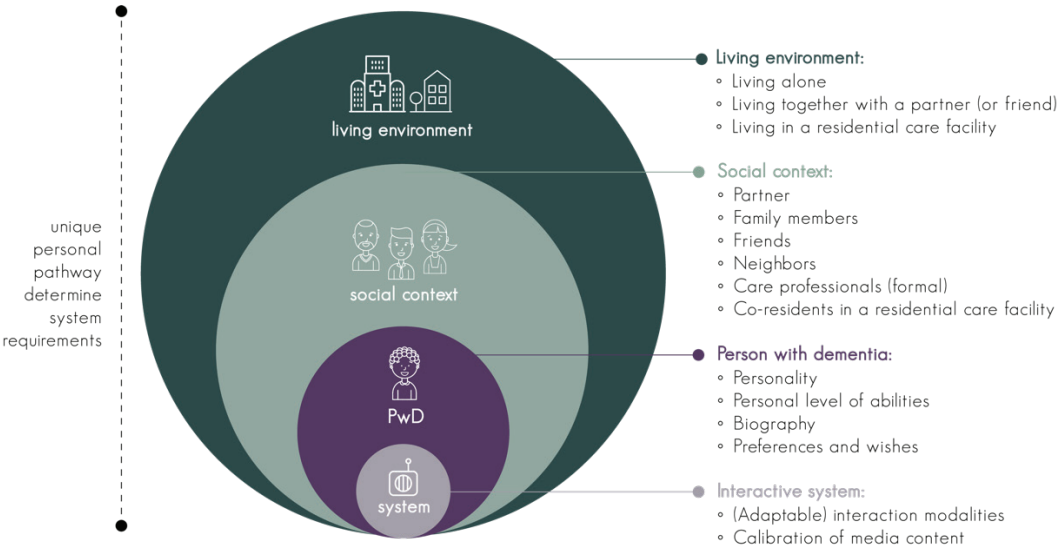


Figure 7.5. The complex and individual context that shapes the unique personal pathway of people with dementia. In addition, the unique conditions of people with dementia determine the system requirements (i.e., interaction modalities and media content). This must be carefully accounted for in the design of interactive systems.

consistent with earlier research, showing that people can experience beauty in social interactions [275]. Such social engagement and connection have been linked to various long-term benefits for individuals with dementia, including improved mood, behavior, and overall well-being [79]. Therefore, by designing for aesthetic and social experiences, our approach has the potential to generate positive long-term outcomes for individuals with dementia and their caregivers. An aesthetic experience encompasses more than its appearance and cannot be understood without its socio-cultural context. We saw the social facet of experience in *AmbientEcho* and *LivingMoments*. The experience of participating in *AmbientEcho* and *LivingMoments* was not solely meaningful to those with dementia but also their loved ones and related care professionals (see Figure 7.4). The design acted as an enabler in maintaining relationships with loved ones or others in the care home or in a home setting.

We contribute with our work to an ongoing trend in the design field that relates aesthetics in design to enable meaningful experiences with technology for people with dementia [140,337,338]. We confirm that providing adequate aesthetic experiences is essential for people with dementia to attract and stimulate them. The impact of aesthetic qualities on the adoption and use of interactive systems particularly needs to be investigated in more depth. Specifically, it would be worthwhile to conduct more in-depth studies on the impact of aesthetic qualities on the engagement and satisfaction of individuals with dementia. The impact of

varying aesthetics in design on different demographic groups, such as age, gender, and cultural background, would be another area for further study.

Involving multiple perspectives in the design for dementia

In our design research presented in *Chapters 4-6* of this dissertation, we involved an array of perspectives from people with dementia and their partner, relatives, or care practitioners. The high-quality design artifacts, or research products (*Chapters 4-6*), were used to learn what it would be if the product existed, where it would be used, and where family members, relatives, or care practitioners were present on a daily basis. Our design research activities included active participation by people with dementia through the utilization of design artifacts, a method which has been extensively examined in past literature [39,205,338]. Involving people with dementia in a design research process shows clear merit with regard to understanding their needs and preferences, as demonstrated by several studies [38,127,195,296]. However, in our research, we found that it is important to consider not only the perspectives of people with dementia but also those of their partners, social networks, and care professionals. To do so, we adopted a research through design approach [358] in which we developed tools and artifacts to aid in retrieving experiences. This allowed us to document the experiences of people with dementia and those involved in their ecosystem. By involving a diverse group of stakeholders in the design process, we were able to identify the importance of both the social environment and the living environment in the design of interactive systems (as depicted in Figure 7.5). This aligns with prior research demonstrating that an individual's use of technology is influenced by the complex and personalized context in which he or she lives and participates [194] as well as the crucial role the social environment plays in technology mediation and social appropriation [330].

The social and cultural context of the living environment may enhance an individual's abilities and encourage the adoption of technology by individuals with dementia. However, they may also diminish them at times. For example, if the social norms in the living environment discourage the use of technology (e.g., due to stigma or lack of awareness), or if there is a lack of support or guidance in using technology, it may be less likely that individuals with dementia will adopt and use technology *(chapter 3)*. On the other hand, if the social context is supportive of and encourages the use of technology, it may be more likely that individuals with dementia will adopt and utilize technology. The findings from the *LivingMoments* study described in *Chapter 6* showed that the partner's level of commitment could either facilitate or hinder an individual with dementia's ability to use *LivingMoments*, depending on the specific context. In some cases, the partner's commitment may enhance the individual's abilities of people with dementia (e.g.,

through oral instruction in tasks such as responding to a postcard), enabling the individual to perform the action independently. However, in other cases, the partner's commitment may place undue expectations or responsibilities on the individual with dementia, reducing their ability level. Besides the partner, relatives contributed to this study by providing customized media content that triggered the use of *LivingMoments* by people with dementia. We found that relatives and formal caregivers are fundamental in constituting a meaningful and rich social experience for the person with dementia. The presence of relatives and formal caregivers as social actors and engagement with the person with dementia stimulated by the interactive system enhances the experience. As another example, we demonstrated in *Chapter 5* that family members and care professionals embraced *AmbientEcho* as a tool to spend time with individuals with dementia. By exploring bespoke and curated media, they could better understand the preferences and interests of the person with dementia. Additionally, the use of *AmbientEcho* fostered a shared experience among residents, family members, and care professionals and seemed meaningful for all parties involved. The incorporation of *AmbientEcho* into care provision, therefore, not only had practical benefits but also had the potential to enhance social connections and facilitate meaningful engagement for residents with dementia, as well as for their caregivers.

In the process of designing technology that accommodates the preserved and diverse abilities of individuals with dementia, it is crucial to consider the ecosystem in which they exist. This includes the various stakeholders and factors that can impact the person's experience with technology, such as their personal characteristics, social context, and living environment. Further research is necessary in this field to examine how we can incorporate the perspectives and experiences of all stakeholders, as well as the experience of individuals with dementia, into the design of interactive systems to make them as meaningful and beneficial as possible for all parties involved.

7.2.2 Future implications in dementia design research

In this section, we delve into how this dissertation contributes to advancing dementia design research by providing valuable insights for designing interactive systems in the context of dementia care.

Long-term effects of changing artifacts

Dementia is a progressive condition that can bring significant changes to people's abilities, both between and within individuals, and the course of the condition can be unpredictable. This unpredictability was evident in our research and was confirmed through our observations and findings.

While our research provided valuable insights into the use of artifacts for a short period and the clear difference between the abilities and needs of people, further investigation is needed to understand how these technologies may perform over a more prolonged period for people with dementia. Our study did not allow us to fully assess the long-term effects of these technologies on people with dementia, as the condition can change and evolve over time, as discussed in *Chapter 6*, potentially impacting the effectiveness of an artifact. The adaptable interface of *Sentic*, as shown in *Chapter 4*, may be a potential solution for individuals with dementia to adapt along with their evolving condition. However, it is not known whether or not adjusting the interface during use causes confusion or increases comfort or how it affects the user's experience. To gain a more comprehensive understanding of how changing artifacts work for people with dementia over the long term, additional research and long-term evaluations are necessary. It is necessary to broaden our understanding of the skills maintained throughout the course of dementia, which could offer a variety of potential design opportunities. Therefore, there is a need to understand further the substantial changes in abilities evolving over time [194], how these differ between individuals, and how design should adapt over time to give people with dementia prolonged access to interactive systems.

Data-enabled design for personal calibration

In the studies in this dissertation, we have seen that an appropriate personal calibration of the interaction design and the media content can contribute to the accessibility of an interactive system, as shown in *Chapters 4 – 6*. We intensively tracked the use of our interactive systems with people with dementia and other vital actors using interviews (*chapters 4 - 6*), observations (*chapters 4 - 5*), and data logs *(chapter 6)*.

To adequately capture day-to-day changes in people with dementia, ongoing, intensified data collection on the use of the interactive system is needed. *Data-enabled design* could be used to achieve this since designers can use this approach to map in detail how people use systems [30]. This allows in the future to even better calibrate interactive systems to the fluctuating changes in abilities and needs of people with dementia. Based on these continuously and remotely collected insights, it is possible to dynamically make changes to the design prototypes [31]. Using data-enabled design in developing products for dementia care can be a valuable approach, as it allows designers to draw on real-world data more directly and use these insights to inform the design process further. Data-enabled design can play a role in exploring when individuals may need changes to the settings or properties of interactive systems. However, it is crucial to ensure that the data collected is representative of the diverse needs and experiences of

people with dementia, taking into account individual differences rather than just a subset of the population. The insights gained from this design method can then be applied to future systems to further improve the design of interactive systems for people with dementia. The following section delves into the integration of shape-changing interfaces and *Artificial Intelligence* (AI) to enhance the personalization and performance of interactive systems for people with dementia. Data plays a crucial role in this process; analyzing and interpreting data collected through techniques such as data-enabled design, shape-changing interfaces, and AI can be considered a potential next step for future systems for people with dementia.

Shape-changing interfaces for adaptive interfaces

In this dissertation, we have demonstrated that the physical interaction design of interactive systems for people with dementia should match the skills they still possess. Each individual with dementia experiences their own challenges with contemporary technology *(chapters 3 - 4*) and has their own preferences for interacting with an interactive system (*chapters 4 - 6*). In this dissertation, it was evident that each individual had unique needs associated with his or her abilities that may even change over time, as outlined in *Chapter 6*.

Shape-changing interfaces, which involve the physical manipulation or transformation of an interface in response to user input or environmental stimuli [259], may be a useful option for interactive systems designed for individuals with dementia whose abilities and needs change over time. The shape of these interfaces can be changed both physically by the user as a means of input and digitally by the interface as a means of output. For example, shape-changing interfaces can contain buttons capable of modifying their shape [121], allowing them to adapt their form to the changing abilities of individuals with dementia. As noted by Alexander and his colleagues (2018), this adaptability enhances the practical value and longevity of interfaces by enabling them to be used in a broader range of situations and potentially perform new or different functions [3].

The adaptability of shape-changing interfaces can prove to be particularly beneficial in the context of the *LivingMoments* device. This is because it enables the interface to adapt its button shape to align with the preferences and requirements of individuals with dementia. Similarly, the *Sentic* artifact can also leverage this shape-changing principle to ensure continued accessibility for the user. As the individual's condition and abilities change over time, the interface can adapt by assuming a different shape, such as a soft surface emphasizing touch-based interaction, to continue meeting the user's needs as they progress through the stages of dementia.

Shape-changing interfaces have the potential to provide an embodied and sensory interaction that can support access to interactive systems and enhance the well-being of individuals with dementia. Despite the promise they hold, these interfaces have not yet been widely implemented in specific domains [3], making the field of HCI and dementia an area ripe for future exploration and application. These interfaces can offer a unique way of providing personalized, intuitive, and accessible interactions to individuals with dementia. Therefore, it is essential to conduct further research in this area to understand the potential and limitations of shape-changing interfaces to support access to interactive systems in people with dementia.

Artificial Intelligence for adaptive systems

This dissertation demonstrates the importance of designing interactive systems tailored to the needs of individuals with dementia. The accessibility and usefulness of such systems will be determined by how well they are tailored and adaptable to the abilities and needs of this population. One potential approach to achieving this is through the use of *Artificial Intelligence* (AI). By incorporating AI into interactive systems for people with dementia, there is a potential for a transformative impact on learning experiences, particularly in terms of recognizing changes in abilities and preferences over time [305]. AI algorithms can analyze data patterns and offer predictions or recommendations based on that analysis, allowing for a personalized user experience that aligns with individual needs.

AI for dynamic interaction options

In this dissertation, we demonstrate that offering a variety of interaction modalities can empower individuals with dementia by meeting their fluctuating abilities and needs. Using AI algorithms, it is possible to identify patterns of interaction with systems and use these patterns to recommend the most suitable level of interaction for an individual with dementia. For example, researchers have started to explore AI-driven adaptive interfaces that can evolve with the person with dementia to match their unpredictable and fluctuating abilities and related needs and adjust the way they present information based on the user's preferences [76]. These interfaces can respond to reduced capacity to process words by summarizing information sources. Moreover, AI can gather information about a person's daily routine and habits by positioning sensors in the environment so that it can provide relevant cues and reminders at the right time, improving the person's interaction with technology [203]. This application of AI has the potential for a revised version of the *LivingMoments* artifact, as described in *Chapter 6*, by using algorithms to learn about a person's daily rituals and to send them a prompt or postcard at a convenient time to encourage them to

engage with the system and in a social context.

As we have read in the previous section, a shape-changing interface offers opportunities for adapting to the abilities of people with dementia. The learning capacity of AI could be used to analyze user behavior and adjust the tangible interface on the fly to optimize its usability and effectiveness [203]. A shape-changing mechanism can, for example, be applied to the adaptable interface of *Sentic*, as described in *Chapter 4*, to create an interface that grows and adapts to a person's abilities and related needs. By using AI algorithms to create customized tangible interaction options tailored to the unique needs and characteristics of each individual with dementia, it is possible to enhance access to these systems and improve the user experience.

AI for recommending media content

In this dissertation, we have shown the importance of offering bespoke and curated media appropriate to an individual's preferences and needs. While the interactive systems developed in this dissertation currently require input from family members or care professionals to select media content, it is possible that AI could be used to automate this process. Systems that utilize AI could potentially track a user's history of watched media content and learn their unique patterns of preferences, in order to proactively adjust the media content accordingly [305]. For example, YouTube uses a complex algorithm to decide the placement of videos in its recommendations and lists [68]. In this way, AI can also help to alleviate the burden on care professionals [191] by automating tasks such as recommending media content. This allows care professionals to focus on more high-level, person-centered care, such as spending more time with their clients and providing more personalized care.

New role for designers and ethical concerns

AI has the capability to augment or support human abilities, while sensing and responding to the user's needs and adapting to the changing environment [179]. It is even possible to train the system to adjust to the sensory needs of a person with dementia in preparation for a time when their condition has progressed to a point where they are no longer able to make these adjustments independently. When applying this approach in the design of interactive systems, designers need to take a different role. Designers should create something that allows for teaching the system in a proper way.

While there are many potential benefits to using AI in interactive systems for people with dementia, it is also important to carefully consider the ethical and practical implications of using AI and continuously collecting data in this context.

This includes addressing concerns such as data privacy, bias in algorithms, and the potential for AI to be used in ways that may not align with the values and preferences of individuals with dementia.

The ethical implications of using AI in dementia care are complex and multifaceted [223]. Two key considerations include the practical and ethical ramifications of using AI in the context of dementia care, and the reliability of the data used to operate these systems. The use of AI-powered devices and systems to monitor the behavior and health of individuals with dementia raises concerns about privacy and autonomy [223]. Additionally, there is a risk that AI-empowered systems may not be able to accurately account for the unpredictable variations in the condition of individuals with dementia due to the need for standardized data [276]. These systems often assume a "normal" condition, but this cannot be accurately predicted in dementia due to fluctuations in daily ability and needs [76]. AI-based systems rely on pattern detection, but dementia can be difficult to capture in fixed patterns or formal assessments of cognitive ability (e.g., IDEAL-IC instrument), as shown in the *LivingMoments* study. In order to address the issue of the unpredictable variations in the condition of dementia and the limitations of AI-based systems in accurately accounting for these variations, it may be helpful to incorporate human input such as the family or caregivers of the person with dementia. The social environment of someone with dementia knows better than anyone else how to deal with specific situations. Therefore, human input will continue to be needed in the near future to provide this kind of information for smart systems. Technology cannot completely replace this human measure. Therefore, the use of AI in the care of individuals with dementia should be carefully considered in light of these and other ethical issues. This is because failing to do so could lead to significant consequences for individuals and their families. The right balance must be sought. This balance could be further explored in future research.

7.3 Contribution and future implications on society and care practices

7.3.1 Contribution to society and care practice

In the following, we will consider the societal and practical implications of this dissertation for caring for individuals with dementia, and how it contributes to the development of new and improved dementia care practices.

Personalized dementia care in the Netherlands

In the Netherlands and around the world, innovative solutions are desperately needed to address the increasing number of people living with chronic conditions such as dementia [314]. Over the past decade, much attention has been devoted

to supporting people with dementia in the Netherlands. The fourth mission of the *Social Theme for Health and Care*, drawn up by the Dutch Ministry of Health, Welfare and Sport, states that the quality of life of people with dementia will have increased by 25% by 2030 [219]. This goal is part of the *Dutch national dementia strategy 2021-2030*, which aims, among other things, to further improve support and care for people with dementia and their relatives. To achieve this, the Dutch Ministry of Health, Welfare and Sport has been encouraging the use of technology through various programs and incentive arrangements [218].

Despite the focus on supporting people with dementia in the Netherlands, there are still few products and services that find their way to people with dementia and their family, and the technologies that have been developed often remain in the realm of research [267]. Research by the *Trimbos Institute* has shown that the adoption of care technology can be improved by making it more tailored to the needs of individuals with dementia, with one-fifth of healthcare workers stating that more personalized technology would lead to increased adoption [177]. According to the director of *Alzheimer Nederland*, the needs of individuals living with dementia can vary greatly from person to person and even day to day [231]. Therefore, it is important for technology designed for people with dementia to be tailored to their individual needs, wishes, and preferences – as we have demonstrated in this dissertation. Also we know from literature that individualized, digital technologies can have a positive impact on the well-being of people living with dementia [108]. However, there is still a lack of understanding about how to effectively match technological solutions to the personal situations and needs of individuals with dementia in practice [231]. This dissertation presents the results of an exploration into how we can better do this and tailor technology, specifically interactive systems that provide support and contribute to the needs of people with dementia. The findings indicate that a generic solution is not effective for people with dementia and that the technology should be adaptable or offer the possibility to be calibrated to the abilities and preferences of the individual with dementia to encourage adoption in dementia care facilities and home care settings.

Collaborating for increasing technology adoption in dementia care

In this dissertation, we sought to explore the use of interactive systems in care practices for individuals with dementia. We have taken a step outside the research community by bringing interactive systems to the homes of people living with dementia – among which were people living in formal care settings. Through our studies, we designed prototypes in collaboration with people with dementia and evaluated them in real-life settings with the involvement of people with dementia, their relatives, and care professionals [42]. We conducted this work in close

partnership with the *Pleyade Innovation Team (PIT)*, a team of care professionals, designers, researchers, and technicians working in the care practice [361]. Our close connection to the care practice allowed us to develop and directly evaluate innovations with people with dementia and other key stakeholders. This helped us to understand how to make technology more responsive to the needs of people with dementia.

Our collaboration with PIT illustrates the significance of including people with dementia and other vital actors, such as relatives, care professionals, and significant others, in the design and implementation of novel technologies. This is a key insight that has been recently emphasized by other researchers in the field [193]. During our collaboration with PIT, we have observed that involving care professionals other than people with dementia in the participatory process can lead to increased awareness of technology among these professionals in care practice, as has been demonstrated by other researchers [142]. Moreover, our studies went beyond merely developing and evaluating interactive systems together with people with dementia, their relatives, and caregivers. After the study was completed, the developed systems were put into long-term use in the care organization Pleyade and utilized by family and care practitioners. Following the completion of the studies, the prototypes of *AmbientEcho (chapter 5)* and *LivingMoments (chapter 6)* were subsequently implemented at various Pleyade nursing homes. While this trend is not revolutionary, there is still a need for more widespread implementation in care practices. In conclusion, we suggest that designers should collaborate more closely with organizations that provide care to people with dementia, and with people with dementia themselves, to create technologies that are more responsive to their functional and psychosocial needs. While pharmacological interventions have traditionally been used to address these needs, design engagement and artifacts have the potential to provide alternative and complementary solutions. By taking a more holistic approach that considers the social, emotional, and cognitive needs of those they design for, designers can create interactive systems that facilitate meaningful and engaging experiences for people with dementia.

Widespread implementation of interactive systems in care practices is still needed, and we encourage the continued exploration of interactive systems in care practices and the expansion of their use in real-life settings. By prioritizing the psychosocial needs of people with dementia in the design process, we can create technologies that not only improve their quality of life but also contribute to the broader goal of reducing the reliance on pharmacological interventions in dementia care.

7.3.2 Future implications in society and care practice

Interdisciplinary teams and labs within dementia care

Technological advances can contribute to the well-being of people with dementia, as demonstrated in this dissertation, but can also improve efficiency in care delivery. However, the use of technology in care continues to lag behind [264], and the COVID-19 pandemic has emphasized the need for technology in care organizations, such as digital communication tools for keeping in touch with loved ones. Unfortunately, this had the lateral effect of creating inequities in access to these applications. However, it also sparked a movement towards multidisciplinary and interdisciplinary teams to quickly develop high-quality, person-centered innovations [232,261].

The findings of this dissertation suggest that technology adoption can be improved by using an interdisciplinary approach that involves teams of professionals from different fields and key stakeholders in the design process [42]. Interdisciplinary refers to the collaboration between professionals from various fields to address complex problems and create comprehensive solutions. Such teams should comprise individuals from diverse fields, including design, engineering, healthcare, and social work, as well as representatives from the community and people with dementia and their caregivers. By transcending disciplinary boundaries and adopting a user-centered approach, these teams can tailor technological products to meet the unique needs and requirements of stakeholders [261]. Despite the lack of a precise definition of *"Living Labs"* [137], we propose that integrating collaborative, interdisciplinary research and design teams into care practices and community settings can serve as an innovative hub for co-creating appropriate and meaningful innovations with end-users. This approach can lead to the development of solutions that are better suited to the real-world challenges faced by people with dementia and their caregivers, by incorporating diverse perspectives and expertise.

To bring together professionals from various disciplines and promote collaboration with people with dementia or other target groups, one promising solution is the integration of physical *makerspaces* in care and well-being practices [58] or within the community, which provide a collaborative and creative environment for individuals from diverse backgrounds and skills to design, prototype, and test creative ideas. This can aid in communication, meaningful activities, navigation, and access to information and resources for people with dementia and provide an opportunity for them to engage in activities that promote creativity, social interaction, and a sense of accomplishment. Among the many benefits of these spaces is their close relationship to real-life living

environments and the ability to bring people with dementia, their caregivers, and other essential stakeholders together as they can provide valuable insights and perspectives on their needs and preferences [299] for equal participation in the design process. Creating these labs or spaces can serve as a platform for people with dementia, both in neighborhoods and residential care facilities, to come together, share experiences, and develop practical solutions for the unique needs of people with dementia, as well as their families and caregivers. With its potential for collaboration, innovation, and community building, the use of such labs should be further explored as a way to support those with dementia, as noted in the study on the formation of an older adult-led makerspace [187].

A multi-stakeholder approach for tailoring technology for dementia care

In our design research, we involved not only individuals with dementia but also their relatives and caregivers. Through this process, we discovered that these stakeholders all have their own needs and preferences, and they all want what is best for the person with dementia. By involving these vital stakeholders in our design research, we observed in our studies that they also desire the best for the person with dementia, but equally have their personal preferences. When all stakeholders are included, their unique perspectives and requirements can be considered, leading to a solution that is more comprehensive and meets the needs of everyone involved. Including all stakeholders in the design process can help to foster support for the technology and increase the likelihood that it will be used as intended. In future design efforts, it will be important to consider the needs and experiences of all vital stakeholders, not just the person with dementia. By considering the needs of caregivers, relatives, and individuals with dementia, we can create technology that is better suited to the realities of their lives and more likely to be successful.

A cross-domain approach in designing personalized technology

The increasing pressure on healthcare, compounded by the shortage of healthcare staff, has necessitated more innovative approaches to healthcare delivery. One potential solution is the use of technology that is adaptable to the individual, enabling personalized care solutions that can be tailored to meet the specific needs of each person. For example, the same technology could potentially be used to provide care for older adults, individuals with non-congenital brain injury, or people with Down syndrome, as long as it can be modified to meet the individual's care needs. It is crucial not to assume that the experiences of individuals with dementia are the same as those of older adults without cognitive impairments, as each group has its own unique abilities and related needs [20]. Recognizing and respecting these differences is crucial in the design of technology.

Designing technology for different domains in the field of care allows for flexibility in the application of technology. Rather than developing different technologies for each specific group, a single technology can be modified and adapted to meet the needs of multiple groups, which is more efficient and cost-effective. By considering the needs of multiple groups in the design process, technology can be developed that is more applicable and relevant in a range of care settings, ultimately improving the delivery of care services.

To address these challenges, we propose that future systems be designed with a cross-domain approach, allowing flexibility and customization to suit personal circumstances and situations. This approach could also help address the lagging technology implementation in care practice. By considering the needs of various groups, we can create more adaptable and applicable technology in a range of care settings, ultimately improving the delivery of healthcare services.

Cultural dimensions in design

The healthcare delivery system in each country is influenced by the cultural values and norms of that society. In the Netherlands, the emphasis is on respect for autonomy in care, and institutional care is well-developed. In contrast, in many Asian countries, family values play a central role in caring for individuals, especially those with dementia who are often dependent on home care [266]. Each culture has its own pattern of living with its own norms and values [134], which shape the healthcare delivery system. Due to the one-child policy and the resulting lack of available family-based care options, these countries are increasingly turning towards institutional care as a solution. These cultural differences inevitably impact the use of interactive systems. The interactive systems in this dissertation were mainly studied in the Dutch culture, which served as a starting point, but there are opportunities to utilize them in other cultures. Therefore, it would be valuable to conduct further research on the impact of interactive systems on people with dementia and care professionals in different cultural contexts. Such studies should consider the unique cultures and values of each country, as well as the specific needs of people with dementia and their caregivers. By examining the effectiveness of these systems in a variety of cultural settings, we can gain a better understanding of their potential to improve care delivery and enhance the quality of life for people with dementia and their caregivers.

7.4 Limitations

Before we reflect on the contribution of this dissertation, several limitations of the research in this dissertation need to be noted.

7.4.1 Involving people with dementia in design research

A long-term commitment that requires more than a one-time participation from people with dementia in a design research project is challenging. As we have seen during the field study in *Chapter 6*, the probability that people with dementia will drop out during the study due to a deterioration in their condition is very high. It may not only be related to a decline of their physical status, but it may also be related to mood changes in people with dementia that make them no longer willing to participate or incapable of participating in the study. Due to the unpredictable nature of the dementia process, it is impossible to prevent this drop out from occurring. Consequently, the study could be delayed because the researcher had to look for a replacement participant. It might also affect the quality of the data collection. Since this research focused on the dynamics of dementia development, this dropout became part of the dynamics and therefore had limited impact on answering our research question.

7.4.2 The duration of our interventions

While we were able to provide new insights on how design could cater to the individual variability of people with dementia, we have not yet found evidence or the effect of such personalized designs in our studies. In this dissertation, we have not been able to conduct long-term research to understand the changing abilities and related needs of an individual with dementia in relation to adapting the interaction design of a system. In this dissertation, we mostly did exploratory design research. With the designed research artifacts in *Chapters 5 and 6*, we conducted research over several weeks. We would have appreciated collecting data for a longer period of time, from 3 months to up to multiple years in order to better understand the fluctuating changes in dementia progression and how adapting interfaces would work in practice. We would have been able to gain a better understanding of the fluctuating changes or shifts in the condition of people with dementia and how these affect their acceptance, use, and adoption of technology over time. The duration of Alzheimer's disease can range from two to ten years [48], so multiple changes will occur during this time period. A similar conclusion was reached by Liddle et al. (2022) that suggest that the timeframe of technology research needs to be expanded given the processes and issues that develop over time by people with dementia [194]. In light of this, future research should involve long-term participation by people with dementia over at least several years in order to explore design ideas in the context of their daily lives. It is important to note that this type of research builds upon our initial exploratory work, which was essential in understanding the potential of these design ideas and establishing the appropriate design modalities. This initial work was necessary to lay the foundation for more in-depth and long-term research in the future.

7.4.3 Small sample size

The studies conducted in this dissertation utilized a small sample size, which may limit the generalizability of the findings to a broader population. While the small sample size allowed for the collection of rich, in-depth insights, it is essential to recognize the inherent unpredictability of working with individuals with dementia, as noted by previous researchers [225,338].

While both qualitative and quantitative research approaches are essential for investigating individuals with dementia, the heterogeneity in terms of symptoms and condition among this population necessitates prioritizing research quality over participant quantity [278]. This was particularly relevant in this dissertation, which focused on achieving a deeper understanding of the personal experiences of people with dementia. By emphasizing the quality and depth of the data, researchers can conduct more detailed and thorough analysis of the data, leading to a deeper understanding of the experiences and needs of individuals with dementia. This approach allows for a focus on the individual, consistent with the person-centered approach. In particular, our research focuses on how individuals experience technology, how they integrate it into their lives, and what aspects of the technology are effective or ineffective for them. Additionally, smaller sample sizes may lead to more engaged and involved participants, resulting in more meaningful data and insights. While this approach focuses on how individuals experience technology and integrate it into their lives, it is important to note that if technology is to be implemented in practice, it is necessary to gather evidence on a larger scale to identify common advantages for people with dementia as a group and understand the potential impact of the technology. Therefore, while small sample sizes may provide rich insights, future studies should aim to balance sample size with diversity and rigor to produce findings that are both generalizable and meaningful. Prioritizing the quality of research can ultimately lead to more impactful and personalized interventions for individuals with dementia.

7.4.4 Diversity in research population

One limitation of our research is that it focused mainly on people with dementia living in high-income western countries, while nearly two-thirds of all people with dementia live in low or middle-income countries [350]. This means that it is unclear to what extent our findings are applicable to these other populations, who may have different cultures, languages, ethnicities, norms, and values, as well as different living conditions. It is therefore worth considering whether our results could differ when applied to low and middle-income countries. This is particularly important in the field of dementia care, where there is a need for effective interventions that can be tailored to the needs and preferences of people with dementia and their caregivers, regardless of their cultural and economic

A further limitation of our studies is that they included participants older than 65 years of age. Although we focused on the experiences of older people with dementia, it is pertinent to note that the number of young people with dementia has increased dramatically in recent years [128]. We did not include these individuals in our study, which may limit the generalizability of our findings. Also, this group might offer new opportunities in terms of technological abilities.

7.4.5 Impact of COVID-19 on research

The COVID-19 pandemic has had a significant impact on research in general, and our research was no exception. The outbreak of the virus and the measures taken to slow its spread, such as lockdowns and social distancing, presented some challenges for conducting research in real-life contexts. These challenges included difficulty in recruiting participants due to concerns about health risks, increased stress or anxiety among individuals that could affect their willingness or ability to participate in research, and difficulties in conducting field studies for collecting in-person data due to social distancing requirements. These factors may have impacted the validity and generalizability of the findings.

As a result, our *LivingMoments* study *(chapter 6)* had to rely on remote methods for data collection, which made it difficult to observe the use of the interactive system in person. We had to rely on verbal explanations from participants via phone calls and system usage data from logs to collect data, which may have introduced some uncertainty or bias into the data and could impact the validity of our findings. Despite this limitation, the use of phone calls as a data collection method was a valuable means of collecting qualitative data, allowing us to gather in-depth insights into the experiences and perspectives of people with dementia. These calls helped to provide a more comprehensive understanding of the potential benefits and challenges of using the interactive systems and were an important complement to the data collected from system usage logs.

Despite these limitations, our research still contributed significantly to the field of design research and dementia care practices.

7.5 Conclusion

In conclusion, this dissertation presents work that expands our understanding of the challenges faced by individuals with dementia in utilizing technology, as well as ways to enhance their direct access to it. This dissertation offers an innovative contribution to the field of HCI and design for dementia and dementia care practices, as it departs from the conventional, technology-centric approach to designing interactive systems for individuals with dementia. Instead, this research adopts an inclusive research through design methodology, which involves developing and evaluating design artifacts that consider the personal needs, desires, and abilities in technology use of people with dementia. The close collaboration with a multidisciplinary team and the established connection to the care practice in this research allowed for the direct development and evaluation of design artifacts with individuals with dementia and their caregivers, leading to a deeper comprehension of how to design technology that is better attuned to the needs of individuals with dementia.

Furthermore, this research emphasizes the importance of incorporating psychosocial aspects when designing for individuals with dementia. By considering emotional and social needs alongside functional requirements, designers can create more person-centered technology that can have a positive impact on the lives of individuals with dementia. Consequently, this work presents novel ways to design interactive (multi) media systems catering to individuals with dementia, focusing on augmenting and improving their unique abilities and needs, considering that the nature of dementia can vary among individuals and can change over time as the condition progresses. The results of this research provide valuable insights into the design of "*warm technology*" that can support the diverse care journeys of individuals with dementia and highlight the importance of adaptability in the interaction design of interactive systems, an appropriate calibration of multimedia content, the significance of aesthetics for adopting technology, as well as considering the ecosystem in which individuals with dementia live.

This dissertation is a call to action for designers, developers, and researchers to embrace this person-centered approach to technology design (i.e. designing for emotional as well as functional needs) and create interactive systems that genuinely make a difference and enhance the lives of people with dementia. The results of this dissertation open up new directions for designing future systems for and with people with dementia that focus on strengthening their abilities and augmenting their preferences through design, resulting in tailored technology that can improve the quality of life of those with dementia. Future research should continue to explore the efficacy of multidisciplinary teams and labs, and the use of a multi-stakeholder approach in designing personalized technology solutions for dementia care.

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Samenvatting

Wereldwijd zijn er naar schatting 57,4 miljoen mensen met dementie. De verwachting is dat dit aantal tegen 2050 zal stijgen tot 152,8 miljoen. Zonder effectieve farmaceutische behandelingen om dementie te voorkomen, te behandelen of te genezen, zal dit aantal verder toenemen en zal het invloed hebben op individuen, gezinnen, zorgverleners, gezondheidssystemen en overheden over de hele wereld.

Dementie is een overkoepelende term voor een chronische en progressieve neurodegeneratieve aandoening die de hersenen aantast en leidt tot een achteruitgang van de cognitieve, zintuiglijke en motorische vaardigheden, wat het dagelijks leven verstoort. Dementie is een complexe aandoening die de hersenen op een manier beïnvloedt waarvan onderzoekers nog niet volledig begrijpen hoe het precies werkt. Daarom worden naast inspanningen in de medische sector ook wereldwijd alternatieve initiatieven gelanceerd om een goede levenskwaliteit te bevorderen bij mensen met dementie. Een van deze initiatieven is het gebruik van technologie en interactieve systemen die (multi)media benutten om niet-farmaceutische zorg te bieden. Deze systemen kunnen helpen om betrokkenheid te bevorderen en de sociale en emotionele behoeften van mensen met dementie te ondersteunen. Hoewel deze interactieve systemen potentieel hebben, blijven er nog steeds veel uitdagingen bestaan met betrekking tot het ontwerp en de acceptatie ervan.

Bestaande interactieve systemen die ontwikkeld zijn voor mensen met dementie worden vaak bedacht en ontworpen vanuit een technologiegerichte benadering, waarbij de persoonlijke behoeften, wensen en mogelijkheden van mensen met dementie over het hoofd worden gezien. Gezien de uiteenlopende aard van dementie is het van cruciaal belang om bij het ontwerp van deze systemen rekening te houden met diversiteit.

Onderzoekers op het gebied van *Human Computer Interaction* (HCI) zijn onlangs overgestapt op een persoonsgerichte en inclusieve benadering, waardoor meer beteknisvolle en warmere technologieën worden gecreëerd. Deze benadering erkent de rijke diversiteit onder mensen met dementie, ondersteunt hun sociale en emotionele behoeften en streeft ernaar technologie inclusiever te maken. Ondanks deze ontwikkelingen blijft er nog steeds veel onderzoek nodig om te bepalen hoe

technologie, met name interactieve (multi)media systemen, optimaal kunnen worden ontworpen om rekening te houden met de unieke interesses, vaardigheden en behoeften van elk individu. Willen deze systemen mensen met dementie ondersteunen in het behouden van een aangename levenskwaliteit, dan is het van belang om te onderzoeken hoe deze systemen kunnen worden ontworpen als aanvulling op de nog aanwezige vaardigheden en ervaringen waarover zij nog beschikken.

Dit proefschrift breidt het domein van HCI en ontwerp voor dementie verder uit door het onderzoeken van het ontwerp van interactieve systemen die zinvolle ervaringen bieden en mensen met dementie helpen bij het benutten van hun persoonlijke vaardigheden en behoeften bij de toegang tot en het gebruik van deze systemen. Het proefschrift richt zich daarom op de volgende onderzoeksvragen:

OV1: Hoe kunnen we technologie ontwerpen om tegemoet te komen aan de verschillende vaardigheden en behoeften van mensen met dementie?

OV2: Hoe kunnen we mensen met dementie in staat stellen zich rechtstreeks toegang te krijgen tot interactieve systemen?

Dit proefschrift hanteert een *inclusieve ontwerpgerichte onderzoeksbenadering,* waarbij de ontwikkeling en evaluatie van ontwerpartefacten en het gebruik van andere tools, zoals stimulerende materialen, worden ingezet om kwalitatieve en kwantitatieve inzichten te verkrijgen in de subjectieve ervaringen, diverse capaciteiten en gerelateerde behoeften van mensen met dementie en hun zorgverleners (bijvoorbeeld hun partner, familie of professionele zorgverleners). Het doel van dit proefschrift is om te onderzoeken in hoeverre en op welke manier het ontwerp van interactieve systemen gepersonaliseerd of aangepast kan worden om tegemoet te komen aan de diverse capaciteiten, verlangens en behoeften van mensen met dementie. Om dit doel te bereiken, maakt elke gepresenteerde studie gebruik van een ander ontwerpgericht onderzoeksproces dat een specifiek aspect van het ontwerpen voor individuen met dementie en relevante belanghebbenden verkent. In de ontwikkeling en het ontwerp van technologie wordt een "*warme technologie*" benadering toegepast, met als doel plezierige en stimulerende ervaringen te creëren voor mensen met dementie.

In **deel 1** van dit proefschrift wordt een verkenning gepresenteerd van de barrières en faciliterende factoren van hedendaagse technologie die zowel de sociale participatie van individuen met dementie en hun partners belemmert als mogelijk maakt. Het onderzoek dat wordt gepresenteerd in ***hoofdstuk 3*** rapporteert de resultaten van vier co-creatie sessies waarin mensen met dementie die thuis wonen en hun partners centraal stonden in het proces. Het biedt een eerste inzicht in de belangrijkste beperkingen en uitdagingen die onze deelnemers ervaren in de context van sociale

interacties en het gebruik van technologie, en onderzoekt welke vaardigheden en aanpassingsstrategieën kunnen helpen bij het overwinnen van deze barrières, die vervolgens kunnen worden gebruikt voor het ontwerp van nieuwe systemen.

Deel 2 bouwt verder op deze inzichten door te onderzoeken hoe technologie effectief kan worden ontworpen om betekenisvolle activiteiten en sociale betrokkenheid te ondersteunen door gebruik te maken van multimedia. Om een beter begrip te krijgen van de verschillende tijdslijnen en paden van dementie, hebben drie verkennende veldstudies uitgevoerd met drie ontworpen artefacten. Om de validiteit van deze artefacten te bepalen, hebben we ze geëvalueerd in verschillende contexten: met individuen met dementie die thuis wonen en met individuen die in een verzorgingshuis wonen. In ***hoofdstuk 4*** worden een reeks inclusieve workshops gepresenteerd, die inzicht bieden in de individuele ervaringen, bekendheid en begrip van mensen met dementie met betrekking tot verschillende bestaande muzieksystemen en ontwikkelde artefacten. Dit leidde tot de creatie en evaluatie van het *Sentic* systeem met een aanpasbare interface die aansluit bij de capaciteiten en behoeften van mensen met dementie. ***Hoofdstuk 5*** rapporteert de resultaten van een veldstudie met *AmbientEcho*, een interactief systeem voor mensen met dementie die in een verzorgingshuis wonen en op maat gemaakte en samengestelde (multi)media biedt via verschillende interactiemodaliteiten. De studie geeft inzicht in hoe een interactief systeem kan inspelen op de individuele variabiliteit van bewoners in een zorginstelling. Voortbouwend op de inzichten uit *hoofdstuk 3*, presenteert ***hoofdstuk 6*** de resultaten van een veldstudie uitgevoerd met het *LivingMoments* artefact, een communicatiesysteem dat digitale en fysieke interacties combineert. Het doel van deze studie was om tegemoet te komen aan de variabele en veranderende capaciteiten van individuen met dementie en tegelijkertijd de obstakels voor communicatie en sociale betrokkenheid te verminderen, zoals geïdentificeerd in *deel 1.*

Deel 3 benadrukt het belang van het ontwerpen van interactieve systemen die aansluiten bij de capaciteiten en bijbehorende behoeften van mensen met dementie, met als doel zinvolle ervaringen te bieden en de toegang tot deze systemen te vergemakkelijken. We hebben gebruik gemaakt van een inclusieve ontwerpgerichte onderzoeksmethode waarbij het ontwerpen en evalueren van tastbare ontwerpelartefacten plaatsvond, met actieve betrokkenheid van zowel mensen met dementie als hun dierbaren en zorgverleners. Door deze aanpak hebben we inzicht gekregen in hoe we interactieve systemen kunnen ontwerpen vanuit het perspectief van *"warme technologie"*, zodat ze kunnen voldoen aan de unieke, interesses, behoeften en vaardigheden van mensen met dementie gedurende hun individuele zorgtraject. ***Hoofdstuk 7*** vat de belangrijkste onderzoeksconclusies samen, die antwoord geven op de twee gestelde onderzoeksvragen. Daarnaast wordt de belangrijkste bijdrage van dit onderzoek op het gebied van ontwerpgericht onderzoek

binnen de context van dementie besproken en wordt de nadruk gelegd op de volgende aspecten: 1) aanpasbaarheid in het interactieontwerp om in te spelen op de persoonlijke vaardigheden, 2) passende kalibratie en afstemming van multimedia-inhoud, 3) het belang van esthetiek voor de adoptie van technologie, en 4) het betrekken van meerdere perspectieven bij het ontwerpen voor dementie. Daarnaast wordt in *hoofdstuk 7* de praktische en maatschappelijke impact van dit proefschrift op de zorg voor mensen met dementie verkend, evenals de bijdrage aan de vooruitgang van innovatieve zorgpraktijken. Samenwerken met een multidisciplinair innovatieteam met professionals die verbonden zijn met de praktijk draagt bij aan de ontwikkeling en acceptatie van geschikte technologieën in zorgpraktijken. Ten slotte worden in dit hoofdstuk de beperkingen van het proefschrift erkend en worden aanbevelingen gedaan voor toekomstig onderzoek.

Dit proefschrift benadrukt het onbenutte potentieel van het aanpassen en op maat maken van interactieve systemen voor mensen met dementie, waarmee een belangrijke leemte in het onderzoeksveld wordt opgevuld.

Publications

2022

1. **Adaptivity in Research Practice with People Living with Dementia: A Designer's Reflection**
   Sandra Suijkerbuijk, **Myrte Thoolen**, Henk Herman Nap, Mirella Minkman, Wijnand IJsselsteijn, Rens Brankaert, and Yvonne de Kort. In *Dementia Lab Conference 2022: The Residue of Design* ***(D-Lab '22)***

2. **LivingMoments: Bespoke Social Communication for People living with Dementia and their Relatives**
   Myrte Thoolen, Francesca Toso, Sebastiaan Peek, Yuan Lu, and Rens Brankaert. In *Proceedings of the 2022 CHI Conference on Human Factors in Computing Systems* ***(CHI '22)***

2021

3. **CoasterChat: Exploring Digital Communication between People with Early Stage Dementia and Family Members Embedded in a Daily Routine**
   Sabeth Diks, Timothy Hendrik Coen Muyrers, Guangyu Chen, Tzu-Jou Huang, **Myrte Thoolen**, and Rens Brankaert. In *Extended Abstracts of the 2021 CHI Conference on Human Factors in Computing Systems* ***(CHI EA '21)***

4. **Co-creating Design Opportunities for Social Technology in the Context of Dementia**
   Agnieszka Barbara Kolasinska, **Myrte Thoolen**, Sebastiaan Peek, Yuan Lu, and Rens Brankaert. In *Dementia Lab Conference 2021: Supporting Ability Through Design* ***(D-Lab '21)***

2020

5. **AmbientEcho: Exploring Interactive Media Experiences in the Context of Residential Dementia Care**
   Myrte Thoolen, Rens Brankaert, and Yuan Lu. In *Proceedings of the 2020 ACM Designing Interactive Systems Conference* ***(DIS '20)***

6. **Designing Sentic: Participatory Design with People Living with Dementia**
   Myrte Thoolen, Rens Brankaert, and Yuan Lu. *Chapter in HCI and Design in the Context of Dementia. 2020. Human-Computer Interaction Series. Springer.*

2019

7. **Sentic: A Tailored Interface Design for People with Dementia to Access Music**
   Myrte Thoolen, Rens Brankaert, and Yuan Lu. In *Companion Publication of the 2019 on Designing Interactive Systems Conference 2019 Companion* ***(DIS '19)***

8. **EVE: A Combined Physical-Digital Interface for Insomnia Sleep Diary**
   Linkai Tao, **Myrte Thoolen**, Bram de Vogel, Loe Feijs, Wei Chen, and Jun Hu. *Chapter in Intelligent Systems and Applications* ***(IntelliSys '18)***

Design output

This dissertation has led to the creation of three artifacts that were not only utilized for research purposes, but also presented to professionals in the care community and designers in the relevant field. The presentation of the artifacts to the care community and designers in the field showcases the practical relevance and applicability of the research, in addition to its scholarly merit.

2021
LivingMoments

Chapter 6

2020
AmbientEcho

Chapter 5

2019
Sentic

Chapter 4

LivingMoments exhibited at the Dutch Design Week 2021

A creative workshop with people with dementia to introduce *LivingMoments*

2021

***LivingMoments* is the culmination of an extensive research effort conducted in partnership with *Tranzo - Tilburg University.* Through interviews with individuals with dementia and their partners *(manuscript in preparation)*, as well as co-creation sessions *(chapter 3)*, opportunities for design were identified. Insights gained from these activities led to the development of various design concepts, which were then evaluated by informal caregivers and care professionals with extensive experience working with people with dementia.**

Given the restrictions imposed by the pandemic, the decision was made to expedite the development of the *LivingMoments* prototype to enable individuals with dementia to remain connected with their loved ones. My primary responsibility, as the co-designer of the *LivingMoments* system alongside Agnieszka Kolasinska and Rens Brankaert, was to develop a design that integrated the needs of individuals with dementia while also incorporating valuable insights from care professionals. This involved synthesizing various design concepts to create a design that effectively addressed the distinctive challenges experienced by people with dementia, as elucidated in *Chapter 3*, while remaining receptive to the opinions and feedback of professionals in this field. Due to Covid-19 restrictions, we conducted an online focus group session with care professionals as we were unable to visit a dementia care organization. We valued the input of these professionals and incorporated their feedback into the design process. Interactive Matters, consisting of Serge Offermans, Freek Olivier, and Teun Vinken, focuses on building prototypes and developing interactive electronics and software. They took the initial design concepts and improved upon them to create four physically functional models.

LivingMoments' success was recognized at the *Dutch Design Week 2021* where it was showcased and nominated for the Social Design Talent Award 2021, eventually earning the 2nd prize. The *LivingMoments* project has received further recognition through the selection of the ZonMw - *Create Health* program for the Dissemination and Implementation Impulse (VIMP) grant. This grant enabled the investigation of *LivingMoments*' potential for implementation in care practices, and further development of the project. These achievements highlight the impact and potential of *LivingMoments* in the care field

The success of *LivingMoments* can be attributed to our collaborative approach and our commitment to creating a design that addressed the unique needs of individuals with dementia during the COVID-19 pandemic. By actively engaging individuals with dementia in the design process and integrating their feedback into the final design, we were able to create a solution that not only met their needs but also reflected their preferences and priorities.

2020

***AmbientEcho* is a novel design developed in collaboration with the Pleyade Innovation Team, a group of experts in dementia care. The design process involved extensive consultations with people with dementia, their loved ones, and care professionals to ensure that the final product met their needs and preferences. The design went through multiple phases of feedback and iteration to incorporate the perspectives of all stakeholders. As a result of this process, *AmbientEcho* has received substantial attention in Dutch media due to its effectiveness in enhancing the lives of people with dementia.**

Pleyade is still utilizing the system in Arnhem, and based on the positive feedback and success of *AmbientEcho*, a second version called *Ekko* was created. *Ekko* has an intelligent algorithm that can identify usage patterns and adjust the experience accordingly. Additionally, it is integrated with YouTube, providing an added level of convenience and customization.

As part of my contribution to the *AmbientEcho* project, I collaborated with the designers and engineers associated with the Pleyade Innovation Team to finalize the physical appearance and attributes of the room, such as the interactive disks, and create various scenes for research purposes. Together, we made design choices that were evaluated in a real-life care environment to explore the user experiences of people with dementia, their relatives (e.g., partners), and care professionals. *Chapter 5* of the *AmbientEcho* study reflects the findings from this research process.

The development of the *AmbientEcho* prototype was a collaborative effort between designers, engineers, and stakeholders. Rens Brankaert (designer and assistant professor in Industrial Design), Serge Offermans (founder and head developer of Interactive Matter, a technical company), and Hugo Nagtzaam (head designer of Bende, a product and interior design agency) worked together to create a functional and innovative design that has the potential to improve the quality of life for people with dementia and those who care for them. The success of this project highlights the importance of involving all stakeholders in the design process, including residents, caregivers, and care professionals, to ensure that the final prototype meets the needs and expectations of those who will use it. Overall, *AmbientEcho* and *Ekko* represent a promising step forward in the development of technologies that can support individuals with dementia and their caregivers, and ultimately improve their quality of life.

AmbienEcho at Pleyade

Ekko: smart algorithm with individual usage pattern identification and YouTube integration for enhanced user experience

Sentic exhibited at the Dutch Design Week 2018

Sentic exhibited at the Dubai Design Week 2018

2019

The innovative design of *Sentic*, as showcased in *Chapter 4*, has been presented at major design events, including the Dutch Design Week 2018 and the Dubai Design Week 2018, where it received substantial attention and recognition. Additionally, *Sentic* was nominated for the Social Design Talent Award 2018, further emphasizing its relevance and impact in the field.

As the designer of the *Sentic* prototype, I aimed to address the unique needs and preferences of people with dementia. To accomplish this goal, I involved people with dementia in the design process, from ideation to sketching to creating a physical prototype. Every step of the process was under the designer's responsibility, who incorporated a modern style that reflected their design aesthetic while meeting the unique needs and preferences of people with dementia.

To ensure the prototype was technically sound, I collaborated with a skilled programmer with expertise in Raspberry Pi, music, and NFC technologies. Combining our knowledge and experience, we brought the prototype to life and ensured it met the desired specifications. Throughout the development process, I actively sought input from people with dementia, incorporating their wishes and needs into the design and functionality of the prototype, as outlined in *Chapter 4*. This collaborative approach was instrumental in ensuring that the final artefact met the needs and preferences of its intended users.

Overall, the process of seeing the *Sentic* prototype come to fruition was challenging yet fulfilling. I am proud to have been part of the team that made it happen and to have contributed to the development of a design that has the potential to make a significant impact in the field of dementia care. The prototype's showcase at high-profile events and recognition through award nominations demonstrate the design's significance and potential in addressing societal challenges and its impact in the design field.

Curriculum Vitae

Myrte Elise Thoolen was born on November 17th, 1991, in Breda, the Netherlands. After graduating with her bachelor's degree in Information and Communication Technology in 2015 at Avans University of Applied Sciences in Breda, the Netherlands, she graduated in 2018 with the Master of Science in Industrial Design from Eindhoven University of Technology. In her master thesis, Myrte explored how a music system should be designed for people with dementia to access it. Her solution was *Sentic*, an interactive music player with an interface that can be adapted to meet the preserved abilities and needs of different people with dementia. Before starting her PhD, Myrte discovered her enthusiasm for teaching young designers. She did this at the Avans University of Applied Sciences in Breda as part of the curriculum renewal of the Communication and Multimedia Design program, in which participatory and human-centered design became one of the design labs.

In 2018 she started her PhD research at the department of Industrial Design at Eindhoven University of Technology and at the care organization Pleyade of which the results are presented in this dissertation. In her PhD, she explored how to effectively design interactive systems that cater to the abilities, wishes, and related needs of people with dementia to give them access to enjoyable and meaningful experiences. Throughout her research, Myrte has favored using *Warm Technology* principles to better understand the preserved wealth of experiences and abilities of people with dementia in using technology. Her research was a part of the "Dementia Dynamics in Design" project, funded by a ZonMW grant through the Create Health program in close collaboration with Eindhoven University of Technology, Tranzo Tilburg University, GGZ Eindhoven, and Slimmer Leven. As part of her research, she was a member of the Pleyade Innovation Team, a project funded by the care organization Pleyade.

Myrte has published and presented her work at international peer-reviewed conferences, such as the CHI and DIS conferences. She has peer-reviewed for DIS,

CHI and the Dementia Lab. During the final months of her PhD, starting in April 2022, she worked as a program manager and researcher at the research group *"Jeugd, Gezin & Samenleving"* at Avans University of Applied Sciences, where she applied participatory design and meaningful technology principles to the group's research program. In February 2023, she took on an additional role as project leader of the technology and innovation lab at the academy of well-being, education, and health at Avans University of Applied Sciences. The lab strives to create a makerspace that serves as a center for creativity, both within and outside of academic circles. It brings together individuals from various disciplines and collaborates with all key stakeholders, including communities, residents, students, and others, to address real-world challenges affecting health and well-being. Her goal is to utilize design thinking to confront social challenges and create solutions in collaboration with all stakeholders, ultimately improving the quality of care and fostering a better future. In addition to her research, as a member of the Pleyade Innovation Team, she facilitated brainstorming sessions and co-design workshops to develop innovations together with care professionals, people with dementia and their families. She aimed to explicitly implement the developed interactive systems, which were part of her PhD research, in the care practice of Pleyade.

Myrte considered it imperative to expose her research projects to the design community and participated in the Dutch and Dubai Design Weeks (2018 and 2022). Her design work received recognition as she was nominated with '*Sentic*' and '*LivingMoments'* by the Social Design Talent Award during the Dutch Design Week in 2018 and 2021. *LivingMoments* was awarded the second prize in the Social Design Talent Award 2021. In addition, in 2019, the Eindhoven University of Technology organized the Dementia Lab conference attended by international researchers and designers working on the topic of dementia. Myrte collaborated closely with the dementia team of the university and conceptualized and realized the exhibition design of this conference.

As a design researcher, Myrte is dedicated to using her skills to improve the lives of vulnerable individuals who need care or support in their daily lives. She believes that the best way to do this is by involving individuals in the design process from beginning to end. To achieve this, she employs a *research through design* approach, working closely with all relevant stakeholders to co-create and evaluate design artifacts that could be used in care settings. Myrte also conducts participatory design activities, allowing her participants to actively contribute to every stage of the design process, from idea generation to prototyping to evaluating. Through this approach, she strives to gain valuable insights and perspectives from her participants, enabling her to create designs that are meaningful and useful to people.

Personal reflection

The research presented in this dissertation focuses on the design of *warm technology* to contribute to meaningful and enjoyable moments in the daily lives of people with dementia. The inclusive participatory approach in this research has placed the interests, needs and abilities of individuals with dementia at the forefront of the design process. Upon reflecting on the research process and its outcomes, it becomes evident that this study has had a positive impact on the lives of individuals living with dementia and holds the potential for continued impact in the future.

When I first began my doctoral research, I observed a lack of engagement and reluctance towards technology among individuals with dementia living in care facilities. However, through my research, I have come to understand the potential for design as a discipline to facilitate the activation and engagement of individuals with dementia in the use of technology and support the engagement of relatives and care professionals. The interactive systems developed as part of this dissertation, *Sentic, AmbientEcho,* and *LivingMoments*, are examples of this potential. As the research findings demonstrate, technology undeniably holds the capacity to enhance the daily lives of individuals with dementia and improve the practices of care professionals, when designed appropriately. Nevertheless, it is disheartening to observe that despite the potential benefits offered by interactive systems and other emerging technologies, they often fail to meet the needs of all stakeholders and struggle to seamlessly integrate into dementia care practices as a whole. This disconnect underscores the necessity for a more user-centered approach in the design process, one that takes into account the organizational structure and workload of care professionals, ensuring that the technology and other innovative services align better with the context of their use. As a design researcher, I am motivated to work towards finding solutions to bridge this gap and fully realize the potential of co-designed technologies to improve the lives of individuals with dementia.

Throughout my research, I engaged in an in-depth process that involved immersing myself in the lives of individuals with dementia. I became part of the complex social-ecological systems within dementia care, which required me to understand

and navigate the various personal and environmental factors (i.e., individuals, interpersonal relationships, organizations, communities, and sociocultural contexts) and to effectively communicate and coordinate with multiple stakeholders who have different needs, interests, and aspirations. Through this process, I learned that a design researcher must possess additional skills such as organization skills, empathy, collaboration skills, and the ability to effectively communicate and persuade stakeholders in order to understand and navigate these complex social-ecological systems. The designer's responsibility is to engage with all stakeholders in the dementia care system, ensure the designs are well-embedded within the social-ecological system of the person with dementia, and that the designs are responsive to the changing needs of people with dementia, their relatives, and care professionals. This requires active listening, coordination, and engagement with all stakeholders throughout the research and design process to achieve desired outcomes.

As a design researcher in the field of dementia care, I encountered challenges dealing with emotionally sensitive situations. Navigating the mental challenges of dementia can be difficult for design researchers. For example, during the beginning of my research, I participated in a workshop where I listened to music with people with dementia. One participant became very emotional when a specific song reminded him of his military years, allowing him to relive some of his most intense experiences during his military service. As designers, we are not typically trained to handle emotional situations of this nature, which can make it challenging to manage. In order to help future designers navigate these situations, design students should be exposed to emotionally charged situations as early as possible in their education. Role-playing exercises in classroom training programs could be an option for this. This way, they will be more prepared for the real-life situations they will encounter in this line of work.

Design and innovation will play an increasingly crucial role in future-proof care practices, and it will be critical for care professionals to be more familiar with the process underlying innovation to be able to make the most of it. During my research, I became aware of the fact that care professionals, who play a vital role in implementing new technologies or interventions in care settings, may not always be familiar with design research or design in general, which leads to confusion and illustrates the need for more active participation of care professionals in design research activities. As an action, I plan to advocate for the inclusion of design and innovation skills in the education of future care professionals and work towards fostering a culture of collaboration between design researchers and care professionals to improve the communication and implementation of design-based approaches in care settings.

During the course of my research, I had the privilege of collaborating with the Pleyade Innovation Team (PIT), an experience that presented its own set of challenges and advantages. Working with people with dementia can be difficult due to cognitive decline affecting their ability to participate in design research activities. However, the PIT team provided me with direct access to a diverse population of individuals with dementia and the knowledge and expertise of care professionals. This enabled me to conduct my research in and with practice with the intended people, which led to more efficient and effective research and design processes. However, since the majority of PIT members did not work at Pleyade and only one member (the care professionals) was employed by Pleyade, decision-making and implementation often took a long time. This made me realize that having a design innovation team within the care organization would lead to better communication, collaboration, and coordination. This would allow for faster identification of problems, testing, and implementation of solutions, and better alignment of design goals with the care organization's mission and values. Additionally, it could lead to the development of more effective and efficient innovations specifically tailored to the needs of people with dementia and care practitioners. Reflecting on this experience, I envision the potential of exploring the concept of *makerspaces* or *hubs* within care settings, such as care facilities and community centers. These spaces would empower individuals with dementia to create their own innovative artifacts to address real societal challenges encountered in their daily lives. This avenue warrants further exploration in future endeavors.

During my research, I encountered a tension between the exploratory nature of my research and the desire of the care facility for immediate results. The artifacts produced together with the Pleyade Innovation Team took longer to develop as they needed to be self-sufficient and able to function on their own during the research. Additionally, the high-quality appearance of the artifacts may have led to unrealistic expectations among research participants. They assumed the artifacts would function similarly to the technological systems they were accustomed to, but this was not always the case, leading to disappointment when the artifacts malfunctioned. This raises the question of how we, as design researchers, can effectively manage this process. One role of a design researcher could be to bridge the gap between design practice and the implementation of those designs in care practice. However, it can be unclear what responsibilities fall to the design researcher and which are the responsibility of the care provider or organization. If they are unwilling to change their way of working, a new design has no chance. Managing expectations is an essential consideration for design researchers working with care facilities and services, as it can affect the care professionals and individuals with dementia.

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UNIQUE EXPERIENCES

DESIGNING WARM TECHNOLOGY TO SUPPORT PERSONAL DYNAMICS IN DEMENTIA

Myrte Elise Thoolen