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A transactional perspective on the use of individualized technology for co-constructing narrative identity in dementia care

Doctoral thesis

NTNU
Norwegian University of Science and Technology
Thesis for the Degree of
Philosophiae Doctor
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Science

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Stories from SENSE-GARDEN

A transactional perspective on the use of individualized technology for co-constructing narrative identity in dementia care

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Norsk sammendrag

Fortellinger fra SENSE-GARDEN: Et transaksjonelt perspektiv på hvordan individuelt tilpasset teknologi kan støtte identitetsivaretakelse hos personer med demens

Demens er et samlebegrep som beskriver kroniske sykdommer som rammer hjernen og fører til endringer i språk, hukommelse og væremåte. Personer med demens kan oppleve å gradvis miste seg selv når sykdommen utvikler seg, og derfor kan meningsfulle aktiviteter, som for eksempel mimring, være med å synliggjøre identitet og relasjoner, som kanskje er spesielt viktig for de som bor på sykehjem. Det kan være vanskelig for helsepersonell å integrere nye aktiviteter i en arbeidshverdag som preges av høyt tempo, slik det ofte er på sykehjem, og teknologi som kan støtte integrering av meningsfulle aktiviteter i hverdagen har derfor fått økt interesse de senere år.

Doktorgradsarbeidet har hatt fokus på en ny teknologisk løsning, kalt SENSE-GARDEN, som benytter digitale media (for eksempel musikk, filmer og bilder) og multisensorisk stimuli (for eksempel dufter) for å skape gode opplevelser for å fremme livshistorien og interessene til personer med moderat til alvorlig demens. Målsettingen med prosjektet har vært å bruke en teoretisk modell for å forklare hvordan SENSE-GARDEN kan fasilitere og støtte identitet og relasjoner mellom personer med demens som bor på sykehjem og deres pårørende. Arbeidet inkluderer en systematisk litteraturgjennomgang og tre kvalitative studier som intervjuet 1) potensielle brukere av SENSE-GARDEN, 2) personer med demens, familie, venner, og ansatte om deres erfaringer etter 12-16 uker der de benyttet SENSE-GARDEN, og 3) ansatte om bruk av SENSE-GARDEN i arbeid med demente. Resultatene viser at teknologi kan benyttes for å fasilitere meningsfulle aktiviteter i demensomsorgen. Deltakernes erfaringer med SENSE-GARDEN viser hvordan identitet kan skapes gjennom holdninger, meningsfulle opplevelser, og gjennom teknologi som skaper nye muligheter for å engasjere seg i livshistorien til den enkelte.

Det er behov for videre arbeid med å implementere ny teknologi i praksisfeltet. Tidsbruk, kostnader og opplæring er faktorer som er viktig å vurdere. Samtidig vil bruken av teoretisk kunnskap være nyttig for å forstå hvordan teknologi oppleves og mottas av de som skal benytte dette.

Preface

This PhD has stemmed from a life-long enthusiasm for creativity, expression, and music. There are countless reasons why I am an advocate for the use of the arts in everyday life, but one of the most prominent impressions that has stuck with me is rooted in a memory from just over a decade ago. At 16 years old I was volunteering as an organist for my local hospital's chapel. One winter morning, before a Sunday service, I was playing a selection of Christmas carols. As I started to play *Silent Night*, an elderly lady sat in the make-shift pews (consisting of rows of chairs) began to cry. I immediately stopped playing, worried that I had done something wrong. The lady, warm and kind in her expression, explained to me that this was the favourite hymn of her late husband, who had unfortunately passed away a few months prior. I offered my condolences and asked if I should switch to a different piece, but she insisted I carried on. As I did so, she said that she felt more connected to him.

Since then, I have been fascinated by the way that people – strangers and friends alike – can be brought together through music. Over the last 10 years I have completed my Bachelor's degree in Music, my Master's degree in the Psychology of Music, performed as a musician, volunteered at dementia cafés, assisted with singing groups for people with dementia and their caregivers – and on occasions had the opportunity to lead the group myself. I have seen and experienced how music can provide transformative encounters between people with dementia, family members, and strangers. Music seems to reach those even in advanced stages of dementia; offering individuals a way to express themselves, a way to connect, or a way to just simply enjoy the pleasure of listening to a song.

Carrying on down this path, I undertook an internship as a research ambassador for The Arts and Dementia Doctoral Training Centre, based at the University of Nottingham. During my time in this role I had the fantastic opportunity to collaborate with an interdisciplinary arts and dementia project "Created Out of Mind", based at the Wellcome Collection in London. I was able to join workshops on music and on theatre, engage with the general public about dementia, and I was able to connect with other early career researchers who are just as captivated by this field as I am.

As a result of these experiences, I knew I wanted to continue a career in research, looking specifically at how the arts could promote the wellbeing of people with dementia through creativity, engagement, and connection. My wonderful supervisor at the University of Nottingham, Justine Schneider, emailed me the advertisement for a PhD position within a project called “SENSE-GARDEN”. The advertisement described that the project would create “a mixture of natural and technological environments which are automatically adaptable to the individual memories” of people with dementia. Being highly intrigued by the concept of automatically adaptable multisensory environments, I decided to apply for the position.

This is all led me here, to Norway, to pursue this PhD in Medical Technology. At times, medical technology seems to be a field situated far away from music and the arts in general. However, I have been fortunate enough to be able to situate myself at the interaction of these disciplines and thus learn the ways in which these fields can complement one another. This thesis is an account and reflection of the knowledge and life experience I applied to SENSE-GARDEN and it is also, in turn, an account and reflection of the knowledge and experiences that the project gave to me, my colleagues, and the field of dementia studies.

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First, I would like to thank my main supervisor, Artur Serrano, who made SENSE-GARDEN and this PhD possible. Thank you for everything you have done for me over the past few years – both inside and outside of academia. From conferences to tango classes, I am grateful for all of the new learning experiences you introduced me to.

I would like to thank my co-supervisor, Kristin Taraldsen, for her constant support and guidance throughout the entirety of this PhD. I would also like to thank my co-supervisors, Jon Sørgaard and Walter Maetzler, and my mentor, Ingvild Saltvedt. I would also like to thank Randi Granbo for her valuable insights and input on the final paper of this thesis.

I would like to give warm thanks to the entire SENSE-GARDEN consortium. Working with such a diverse, motivated, and compassionate group of individuals has made this PhD an unforgettable experience. I feel incredibly lucky to have been given the opportunity to travel across the world to not only collaborate with you all, but to also enjoy some breath-taking adventures. I would also like to thank the participants that were involved in all stages of the SENSE-GARDEN project and studies. Thank you for openly sharing your time, enthusiasm, and personal histories with us. They have given life to the SENSE-GARDEN project, and stories to this thesis.

Completing a PhD under any circumstances is a feat, but in the midst of a global pandemic there were times when it felt almost impossible. However, thanks to my amazing office mates Phillipp Anders, Ronny Bergquist, and Yngvild Gagnat, giving up was never an option. Thank you all for becoming like family to me, and for making Trondheim feel like home. I especially want to thank Karoline Blix Grønvik for being my closest friend and rock throughout the entire PhD. Thank you for the "emergency brownies", the early morning coffee chats, and for the strength training (both physical and mental!).

I would like to thank all my friends and family back in the UK for constantly supporting me throughout my entire education and for shaping me into the person I am today. I want to especially thank my sisters, Emily and Chloe, for always being there for me, for helping me stay strong in times of stress, and for keeping my day-to-day life wonderfully sassy.

I want to give my heartfelt thanks to my parents, Paul and Clare, who epitomize what it is to unconditionally love and care for others. Thank you for always believing in me and for supporting me every step of the way. Words cannot express how grateful I am to you both. And Mum, thank you for slipping that letter into my suitcase four years ago. It has been the greatest source of advice, a comfort in times of uncertainty, and a reminder to keep on going.

Finally, I want to thank Phillipp once again, not as a colleague but as my partner. Going from sharing an office to sharing a home with you was one of the most unexpected – but most amazing – things to come out of this journey. Thank you for lifting me up during the darkest days of my PhD, even as you were battling with your own. Thank you for putting up with the tears, the copious amounts of Taylor Swift, and for never letting me forget my worth. I love you.

“As individuals we are stories: we are composed and those compositions remain”

David Aldridge[1]

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[1] Aldridge, D. (2000). *Music therapy in dementia care.* Jessica Kingsley Publishers. pp. 16

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Paper II	**User perspectives towards SENSE-GARDEN** Goodall, G., Ciobanu, I., Broekx, R., ..., Maetzler, W., Berteanu, M., Serrano, J.A. (2019). The role of adaptive immersive technology in creating personalised environments for emotional connection and preservation of identity in dementia care: Insights from user perspectives towards SENSE-GARDEN. *International Journal on Advances in Life Sciences. 11*(1&2), 13-22.
Paper III	**A transactional approach to understanding narrative and relational experiences within SENSE-GARDEN** Goodall, G., Andre, L., Taraldsen, K., Serrano, J.A. (2021) Supporting identity and relationships amongst people with dementia through the use of technology: A qualitative interview study. *International Journal of Qualitative Studies in Health and Well-being. 16*(1), 1920349.
Paper IV	**Professional perspectives on using SENSE-GARDEN in care** Goodall, G., Taraldsen, K., Granbo, R., Serrano, J.A. (2021). Towards personalized dementia care through meaningful activities supported by technology: A multisite qualitative study with care professionals *Submitted for publication14th April 2021.*

Abbreviations

AD	Alzheimer's disease
ALMA	Arts of Life Memory Album
BvFTD	Behavioural variant frontotemporal dementia
CDR	Clinical Dementia Rating Scale
DEEP	Dementia Engagement and Empowerment Project
IPA	Interpretative phenomenological analysis
MCI	Mild cognitive impairment
NCD	Neurocognitive disorder
OECD	Organisation for Economic Co-Operation and Development
PCA	Posterior cortical atrophy
PPA	Primary progressive aphasia
PwD	Person with dementia
QCA	Qualitative content analysis
RTA	Reflexive thematic analysis
TA	Thematic analysis
UCD	User-centred design
WDC	World Dementia Council
WHO	World Health Organization

Frequently used terms

Identity – The product of personal traits, characteristics, social relations, roles, and social group memberships that define who an individual is (Oyserman, Elmore, and Smith, 2012).

Meaningful activity – An activity that is engaging, enjoyable, suited to an individual's abilities and preferences, related to personally relevant goals, and related to an aspect of an individual's identity (Tierney and Beattie 2020).

Narrative identity – An individual's internalized and evolving life story that a person constructs to make sense and meaning out of his or her life (McAdams, 2011).

Reminiscence – The act of recalling and reflecting upon people, places, past events, and experiences (Butler, 1963).

Self – The thoughts, beliefs, and feelings an individual (as a subject) ascribes to themselves (as an object) i.e. a sense of self (Oyserman, Elmore, and Smith, 2012).

SENSE-GARDEN space – A physical room that combines digital technologies and multisensory stimuli to create an immersive, individualized environment for a person with dementia.

SENSE-GARDEN intervention – A psychosocial intervention that takes place within the SENSE-GARDEN space. This intervention is delivered by formal care staff at a care facility.

Symbolic interactionism – A sociological theory which poses that identities and meanings are formed through interaction with other individuals.

Transactional perspective – A perspective which draws upon John Dewey's philosophy concerning human experience as one of constant interaction with the environment and the things within it.

Transactional relationship – The constant, reciprocal interaction between a human, their surrounding environment, and the things within that environment.

Abstract

Common misconceptions and stereotypes surrounding dementia tend to reduce the disease down to an experience of deterioration and loss, particularly with regards to identity. However, people with dementia can still retain a sense of identity, even in later stages of the disease. There is a wealth of evidence on the importance of providing meaningful activities for people living with dementia in order to promote identity and interpersonal relationships, especially for those living in care homes. Emerging work on technological solutions suggests that technology can support the facilitation and individualization of such activities.

The topic of this thesis is the use of technology in preserving narrative identity and promoting interpersonal relationships for people with dementia. In particular, the thesis explores the use of a new technological solution, SENSE-GARDEN, which combines immersive technologies and multisensory stimuli to create individualized environments for people with moderate to severe dementia. Taking a transactional perspective informed by Deweyan philosophy and symbolic interactionism, a holistic approach is adopted in understanding experiences within SENSE-GARDEN. This thesis includes one systematic literature review and three in-depth qualitative studies which explored various user groups' perspectives, experiences of people with dementia and caregivers, and care professionals' experiences, respectively. The specific aims of the thesis were as follows:

1) To review research on existing digital technologies used in creating individualized activities for people with dementia
2) To explore user attitudes towards the SENSE-GARDEN concept
3) To develop a transactional model of how narrative identity and relationships are shaped through the use of SENSE-GARDEN by drawing upon user experiences from people with dementia, informal caregivers, and formal caregivers
4) To explore care professionals' experiences of using SENSE-GARDEN

The systematic literature review identified 29 studies that used technology to create individualized, meaningful activities for people with dementia. The technologies were grouped into four main categories of purpose: reminiscence/memory support, behaviour management, stimulating engagement, and conversation/communication support. Overall, the evidence suggests that there are promising effects of these technologies on the well-

being of people with dementia in terms of improving behaviour and promoting relationships with others. However, the review highlighted the specific need for further research on how these technologies can be integrated into care home environments.

User responses towards the SENSE-GARDEN concept, reported in Paper II, were overall positive. Thematic analysis of interviews with 52 users (including people with mild cognitive impairment, informal caregivers, and formal caregivers) resulted in six themes: benefits for all, focus on the individual, past and present, emotional stimulation, shared experiences, and challenges to consider. An initial model of the transactional relationship that takes place within SENSE-GARDEN was created based on the users' comments on providing meaningful experiences through individualization and shared "emotional" environments.

A study on the experiences of people with dementia and their caregivers within SENSE-GARDEN, reported in Paper III, resulted in three themes: openness, learning, and connecting. The detailed accounts provided by participants gave insight into how technology facilitates meaningful activities within SENSE-GARDEN. One key point is that whilst the technology is important for projecting the life story to participants in an innovative way, it is ultimately the relationships and interactions between people inside the space that creates a meaningful experience. Additionally, through a theoretical approach, a transactional model of how the narrative identity and relationships of people with dementia are shaped through the use of SENSE-GARDEN was created. The model acknowledges the multitudinous factors and processes that take place to form an overall experience in which the person with dementia may feel understood and connected.

Finally, a study of professional perspectives on SENSE-GARDEN, reported in Paper IV, found that care professionals had overall positive experiences of using the SENSE-GARDEN in care. Three themes were generated in an interview with 8 care professionals: shifting focus onto personalized care, building and fostering relationships, and continuous discoveries. Care professionals across four countries highlighted the value of being able to deliver personalized care and having the opportunity to better know people with dementia. Furthermore, the care professionals felt that the SENSE-GARDEN provided them with a sense of achievement in helping people with dementia. However, the professionals found the preparation and facilitation of the intervention to be time-consuming and emphasized the need to improve the technology if SENSE-GARDEN is to be used on a long-term basis.

Overall, this thesis provides argument for the integration of meaningful activities in dementia care, and sheds light on how technology may be able to facilitate such activities. Considering narrative identity in particular, the thesis demonstrates that the use of individualized technology can be a means of creating opportunities to portray the life story and interests of people with dementia in new ways. This can prompt a shift away from the limitations that dementia presents and instead onto the person as an individual, resulting in enriched, reciprocal interactions that teach the caregiver more about the person, and thus, promote a sense of narrative identity within the person with dementia. However, future work should focus on further evaluating time consumption, costs, and training requirements in order for technological solutions, such as SENSE-GARDEN, to be efficiently integrated into care homes. As seen in the literature review, there is still the need to consider how technological solutions can be implemented into care practice. The work in this thesis suggests that if staff invest time and effort into new solutions, it can result in meaningful moments for both care professionals and people with dementia. This is particularly important for people with moderate to severe dementia, where communication may be hindered and opportunities for meaningful activity may be harder to come by. Care facilities may benefit from having a dedicated space in which people with dementia can express themselves through the help of technology, and – most importantly – through the help of others.

Chapter 1

Introduction

As human beings, we are all highly individualistic by nature. Our identities are made up of the things that we take an interest in, the relationships we have with other individuals, and the connections that we hold to the world around us. Yet, whilst we are each unique in our own way, the human identity does not exist in isolation. Paul Eakin writes "*All* identity is relational" (1999:43). In other words, the way we perceive ourselves is dependent on our relationship to others and the contexts in which we find ourselves. We act, think, and feel in relation to situations we encounter and to how we are treated. In this relational context, experience can be understood in terms of stories (Eakin, 1999). Our life stories are not just individual, but entangled with the stories of a larger whole – stories of others, stories of the world.

However, these stories do not always play out as hoped for. When an individual is faced with a serious illness, or disease, it is all too common for that person to be become defined solely by their adversity. Aspects of what constitutes their unique identity fade into the background and, instead, one is viewed through the lens of a diagnosis. When a person is diagnosed with dementia, the individual is often subject to such stigmatization. In a particularly moving article on dementia and stigma, Kate Swaffer (2014) sheds light on how people living with dementia – including herself – experience social isolation, discrimination, and disrespect as a result of misconceptions and stereotypes surrounding dementia. According to a recent policy brief by the Organisation for Economic Co-Operation and Development (OECD, 2018), stigma is one of the biggest impediments to living well with dementia.

Though we may be individualistic by nature, we are expected to conform to social norms that enable us to ‘fit in’ with mainstream society. To deviate from these norms would result in the risk of being stigmatized. The most renowned definition of stigma comes from Erving Goffman, who writes that stigma refers to the possession of “an attribute that is deeply discrediting” which results in an individual being viewed as “not quite human” by others (Goffman, 2009). In other words, a person is treated differently by members of society based on a certain behaviour, characteristic, or quality. But how do we define a “deeply discrediting” attribute? This can be complex, as attributes that are stigmatized are often bound by cultural beliefs held to a particular group or society (Ainlay, Coleman and Becker, 1986). Therefore, it is important to recognise that stigma is not something that is possessed by an individual, but it is instead a perspective (Goffman, 2009).

In the context of dementia, common symptoms such as memory impairment can cause difficulties in social interactions and retaining a sense of identity, resulting in a deviation from social norms, and therefore leading to misunderstanding by others (Mukadam and Livingston, 2012). As an example, let’s consider a person with dementia who struggles to recall recent conversations with friends and family. Confusion and frustration could lead to friends and family members deciding to phase out contact with the person with dementia all together, resulting in the experience of loneliness for the individual. In other words, people with dementia are not stigmatized by their own doing. It is instead the behaviours and actions of others that lead to stigmatization.

In recent years, efforts to reduce stigma and increase understanding and awareness of dementia have been made globally. In 2018, Dementia Friends – an initiative that provides educational sessions on what it means to live with dementia – had been implemented in 41 countries (World Dementia Council, 2018). Such efforts are also being made in Norway. For instance, Norway’s Dementia Plan 2020 focuses on building a more dementia-friendly society through addressing areas such as housing and physical environments, health and care services, information communication technology and welfare technology (Norwegian Ministry of Health and Care Services, 2015). The Norwegian Minister of Health and Care services writes “Each one of us has the right to be a whole person, even when we are ill” (Norwegian Ministry of Health and Care Services, 2015:3).

Efforts to challenge stigma surrounding dementia are also being undertaken in research. In the United Kingdom, a transdisciplinary project “Created Out of Mind” integrated creative arts and science to provide multiple workshops, talks, and events to the general public that helped explore, challenge, and shape perceptions and understandings of dementia (Created Out of Mind, n.d.; Brotherhood et al., 2017). Similarly, the Artful Dementia Research Lab at the Arctic University of Norway in Tromsø uses experimental creative art interventions to provide innovative understandings of ageing and dementia (Artful Dementia, n.d.).

An overarching goal of this thesis is to contribute to this shift in dementia research, which is now adopting a more holistic approach compared to traditional biomedical studies. Whilst medical approaches to care primarily focus on controlling and managing a disease, holistic approaches acknowledge a disease's impact on the person as a whole, including their social, emotional, and psychological well-being. This relates aptly to the definition of health as given by the World Health Organization (WHO), which describes health as "a state of complete physical, mental, and social well-being, not merely the absence of disease." (WHO, 1995). By adopting a holistic lens towards dementia, research in this field is increasingly seeking ways of supporting people with dementia as whole individuals, rather than as "sufferers" of a disease.

By acknowledging the impact that dementia has on an individual's overall well-being, holistic approaches to dementia care and treatment go beyond pharmaceutical solutions, and often include the use of psychosocial interventions and activities (as explained in Section 1.3). However, holistic approaches can be hard to implement in care as they require interdisciplinary collaboration between healthcare providers, researchers, caregivers, and – importantly – people with dementia themselves (Jackson et al., 2020).

Through drawing upon interdisciplinary work that combines the perspectives of staff, family, and people living with dementia, this thesis sheds light on how technology may be used to contribute to holistic dementia care. The specific focus is on the use of individualized technology for creating meaningful activities that may support the co-construction of narrative identity and promote interpersonal relationships amongst people living with dementia and caregivers.

1.1. Dementia: An overview

Dementia is a syndrome caused by a variety of diseases that affect the brain. In most common types of dementia, memory, cognition, language, and behaviour are primarily impacted and as the disease progresses, the ability to perform everyday activities becomes more difficult. There is currently no cure for dementia in any of its variations.

1.1.1. The shifting discourse on dementia

The word dementia derives from the Latin *de* (without) and *mens* (mind) which are joined to mean out of mind, or madness. Up until the 19th century, dementia was considered an inevitable feature of ageing, and those suspected with it were subject to confinement in prison-like asylums (Berchtold and Cotman, 1998). However, the way in which dementia was understood and approached changed significantly throughout the 19th century. French physician Phillipe Pinel led the humanitarian reforms that saw mentally insane patients (which would have included people with dementia) be freed from incarceration in prisons and instead placed in institutions that provided more humane care (Pinel, 1806/1962; Berchtold and Cotman, 1998). Subsequent work by Pinel and his student Jean Etienne Esquirol generated a scientific approach to observing and classifying mental disorders, which resulted in dementia being differentiated from other mental disorders (Berchtold and Cotman, 1998). At the beginning of the 20th century, Alzheimer's Disease (AD) was identified by Alois Alzheimer, and this new understanding of neuropathology of the disease led to AD (as well as other types of dementia) being understood as not an unavoidable part of ageing, but something caused by abnormalities in the brain (Boller and Forbes, 1998).

Today, the current version of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) (American Psychiatric Association, 2013), does not use the term dementia, but it instead uses major neurocognitive disorder (major NCD). However, dementia is still recognised as an acceptable alternative term. The DSM-V lists the following which may be affected in NCD: complex attention, executive function, learning and memory, language, perceptual-motor function, and social cognition.

More precise definitions of dementia vary and are somewhat hard to come by, due to the fluctuating perspectives of disciplines in which the term is situated. For example, biomedical definitions of dementia have been criticised for their reductionist discourse, often describing the disease in terms of loss (Beard, Knauss, and Moyer, 2009). In the field of social gerontology, Zeilig (2014) poignantly discusses the ways in which social and political discourses surrounding dementia have caused it to become a cultural metaphor; a term loaded with emotional value. She highlights the stories and stereotypes surrounding dementia that portray the condition to be one of darkness and disaster – something that separates "us" (those living without dementia) from "them" (those living with dementia) (Zeilig, 2014). However, she argues that by listening to the personal accounts from people living with dementia themselves, these negative attitudes and narratives can be challenged and questioned.

Despite the copious amount of progress made on understanding, treating, and caring for those with dementia since the 19th century, misunderstandings still exist due to stigma. For example, established online dictionaries such as Merriam-Webster (2020) and Lexico (2020) suggest *derangement*, *insanity*, *lunacy* and, *mania* as synonyms for dementia. However, researchers, journalists, and policy makers are being encouraged to be mindful of the language they use when writing and speaking about dementia. For example, the Dementia Engagement and Empowerment Project (DEEP) produced a guide on language use, based on opinions and recommendations from people living with dementia (Dementia Engagement and Empowerment Project, 2014). The DEEP guide lists terms such as *dementia sufferer, demented, burden, victim,* and *epidemic* as words that create stereotypes and attach negative connotation to the person, rather than the condition of dementia. As noted by Hughes, Louw, and Sabat (2006), dementia is more than just a brain disease. It affects the person as a whole, and therefore it should be studied in terms of personhood (Hughes et al., 2006).

This thesis will use the word dementia as an umbrella term for the various neurocognitive disorders that fall under this term, as described in the next section.

1.1.2. Prevalence, types, and the progression of dementia

Currently, there are approximately 50 million people living with dementia worldwide, and this number is expected to rise above 131 million by 2050 (Prince et al., 2015). There are over 100 types of dementia, however, the most common type of dementia is Alzheimer's Disease, which is thought to account for 60 – 70% of total dementia cases (World Health

Organization, 2017). Caused by an abnormal build-up of amyloid and tau proteins in and around brain cells, AD is primarily characterised by progressive memory loss, behaviour changes, and confusion with time, place, or situation.

Other common types of dementia include vascular dementia and dementia with Lewy bodies. Accounting for 5 – 10% of cases, vascular dementia primarily affects thinking skills and presents symptoms such as confusion, disorientation, and speaking difficulties (Alzheimer's Association, 2020). A person with vascular dementia may also experience physical stroke symptoms, such as sudden headaches or dizziness. Accounting for another 5 – 10% of cases, Lewy body dementia causes a decline in thinking, reasoning, and independent function (Alzheimer's Association, 2020). In addition, people with Lewy body dementia may experience shifts in behaviour and mood as a result of changes in the nervous system.

There are less common types of dementia, which have very different effects compared to that of memory impairment. For example, posterior cortical atrophy (PCA) primarily effects vision, causing difficulties with reading, coordination, and being able to see what and where things are (Rare Dementia Support, 2020). Primary progressive aphasia (PPA) is a group of various dementias, including semantic dementia, that impacts an individual's speech and language (Rare Dementia Support, 2020). Behaviour variant frontotemporal dementia (BvFTD) is a result of nerve cell loss that occurs in areas controlling judgement, empathy, and foresight, which can lead to changes in an individual's personality and behaviour (Alzheimer's Association, 2020). There are also people living with mixed dementia, in which more than one type of dementia occurs simultaneously in the brain (Alzheimer's Association, 2020).

In addition to different types of dementia, the progression of the disease can also impact individuals in varying ways. The onset of dementia may be gradual and preceded by mild cognitive impairment (MCI), which is considered as a transition state between "normal ageing" and dementia (Gauthier et al., 2006). People with MCI experience memory impairments but are generally able to continue activities of daily living. Whilst some people remain stable over time, more than half of people with MCI develop dementia within 5 years (Gauthier et al., 2006). The progression of dementia is then a continuous process in which cognitive function worsens at a varying rate. As dementia develops from an early stage to a more moderate or even severe stage of dementia, a person may experience an increasing number and severity of symptoms such as disorientation, memory loss, loss of verbal abilities, and reduced psychomotor skills.

As symptoms worsen, the ability to function independently is reduced to the point where it may be no longer possible to live in one's own home (Reisberg et al., 1982: Hughes et al., 1982). Whilst evidence suggests that it is important for people with dementia to remain living in their own homes for as long as possible (Aminzadeh et al., 2010), most people with moderate to severe dementia will eventually need to move into a long-term care facility. Given that our private homes are places of comfort, identity, meaning, and familiarity (Oswald and Wahl, 2005), moving into care home is a major life transition made up of both hopes and fears (Thein, D'Souza and Sheehan, 2011; Aminzadeh et al., 2009). This challenge of 'residential discontinuity', in addition to other disruptions experienced with the progression of dementia, may further aggravate feelings of alienation and disconnection (Aminzadeh et al., 2009). It is thus important that people in later stages of dementia are supported when having to make the transition to unfamiliar and potentially unsettling environments.

Residential care facilities should support residents with dementia in living the best quality of life possible. However, the quality of life and well-being of people living with advanced dementia in care homes has received little attention to date (Hughes et al., 2021). One study found that quality of life and cognitive function declines more rapidly among people with dementia when living in a care home, compared to living in one's own home with family members (Harsányiová and Prokop, 2018). In recognising social isolation's contribution to this decline in well-being, the authors called for an increased emphasis on social interactions and meaningful activities in care. Others in this field have also stressed the need to provide opportunities for social interactions in care homes (Baldwin et al., 2008; Lee et al., 2017; Örulv, 2010).

Despite these calls for social interaction, a recent literature review found that living in long-term care with dementia was associated with monotonous living, a loss of abilities and freedom, isolation, and poor social interactions (Førsund et al., 2018). Another recent study observed that care home residents with severe and persistent vocalisations were often left isolated in their rooms (Sefcik, Ersek, and Cacchione, 2020). These vocalisations were often provoked or worsened by care being provided by nursing assistants without any communication e.g. attempting to wipe a resident's hands without speaking to the resident

(Sefcik et al., 2020). This evidence points to a clear need to improve communication and understanding between staff and residents. However, as dementia progresses, people are less able to express their needs in a verbal manner and instead communicate through means of non-verbal communication (Hughes et al., 2021). It is thus important that care home staff are able to interpret and respond to these non-verbal behaviours in a holistic, person-centred manner.

1.2. Understanding responsive behaviours and meanings in action

People living with dementia may experience hearing difficulties, visuospatial confusion, impaired vocabulary, and impaired word fluency (Bryan and Maxim, 2003). Living with such impairments can therefore hinder communication with others, making it harder to express oneself. This can result in behaviours that are commonly perceived and referred to as ‘problem behaviours’. Common examples include aggression, agitation, wandering, and restlessness (Alzheimer Society, 2021). However, when behaviours displayed by a person with dementia are viewed as problematic, the person is then often met with judgement and misunderstanding (Fazio, Seman, and Stansell, 1999).

To shift attitudes and responses to behaviours of people with dementia, there is growing use of the term ‘responsive behaviours’ as a means of placing emphasis on behaviour being based on an individual’s inability to communicate a particular need (Dupuis and Luh, 2005; Clifford and Doody, 2018). For example, a person with dementia living in a care facility may be overwhelmed or frightened in their unfamiliar surrounding which can result in a particular behavioural response (Dupius and Luh, 2005). According to Dupuis, Wiersma, and Loiselle (2012), all actions can be considered meaningful or purposeful. Rather than judging and controlling the behaviours of a person with dementia, caregivers should assess and alter the broader social and physical environment as a way of connecting with the individual and thus supporting them in expressing their personhood (Dupuis et al., 2012; Clifford and Doody, 2018). Despite this recommendation, however, dementia care still varies widely. The next sections discuss dementia in the context of long-term care facilities, and address what is needed to improve care moving forward.

1.3. Dementia care: Approaches and challenges

Traditional dementia care is underpinned by a biomedical model of acute care with physical needs, such as safety and hygiene, often being prioritized over psychological needs, such as emotional well-being and quality of life (Chenoweth et al., 2009; Brooker, Woolley, and Lee, 2007). In the same way that the understanding of dementia has shifted, models and approaches to care have also progressed in recent years. Whilst person-centred care is now widely considered the 'gold standard' in dementia care (WHO, 2017), there is still a lack of evidence on how challenges in implementing person-centred dementia care in practice can be overcome.

The next sub-sections outline the medical model of dementia care (1.3.1.) and the shift towards person-centred care (1.3.2.). However, person-centred dementia care can be difficult to implement into practice due to numerous challenges, which are discussed in subsection 1.3.3. In addressing the need to find ways of promoting the delivery of person-centred care, evidence on meaningful activities is discussed in section 1.3.4. as an example of how staff may be supported in adopting a person-centred approach. Challenges in implementing meaningful activities are also discussed before introducing the potential of technological solutions in section 1.4.

1.3.1. The medical model of dementia care

The medical model provides people with dementia with basic custodial care, often accompanied by anti-psychotic drugs to manage symptoms of dementia, such as agitation (Taft et al., 1997; Lyman, 1989). It justifies control as appropriate treatment for the "good of the patient" (Bond, 1992: 401). However, the medical model has been heavily criticised for its reductionist approach towards dementia (Bond, 1992; Taft et al., 1997; Lyman, 1989; Kitwood, 1997). The model assumes a simple causal relationship between neuropathology and dementia, with social and psychological factors being ignored (Bond, 1992). Little attention is given to the person in the wider social context (Bond, 1992; Lyman, 1989).

The medical model has also been questioned from a political perspective, with policies calling for the use of anti-psychotic treatment to be reduced. A 2018 policy brief from OECD, for instance, reported that antipsychotic usage for people with dementia had increased in one-third of reporting OECD countries between 2011 and 2015, despite guidelines for more conservative use (OECD, 2018). Similarly, the World Dementia Council (2018) recommends minimising the use of antipsychotics and other approaches that are contrary to person-centred care.

1.3.2. Person-centred care

Kitwood's theory of person-centred care towards people with dementia has, for two decades now, influenced both research and practice into shifting the focus away from disease and onto the unique personhood of an individual with dementia (Kitwood and Bredin, 1992; Kitwood, 1993; Kitwood, 1997; Brooker, 2004). In defining personhood as "a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being" (Kitwood, 1997: 8), Kitwood stressed the need to go beyond a simple medical model when caring for people with dementia. According to Kitwood, the psychological needs of people with dementia include comfort, attachment, inclusion, occupation, and identity (1997). In meeting these needs, the overall well-being of an individual with dementia can be supported.

An example of how the above needs can be met is through the use of life story work, which has been found to enhance person-centred care for people with dementia, as well as their families (McKeown et al., 2010). There are many different approaches to conducting life story work, but the overall concept involves collaborating with a person and/or their family to gain information on their life, recording the gained information in some way, and then using the information with the person in care to benefit them in their present situation e.g. giving the individual an opportunity to talk about their life experiences (McKeown, Clarke, and Repper, 2006).

It is important to note that person-centred care is not just care that is individualized to a person; it is an approach that acknowledges the role of the social environment and interpersonal relationships in supporting the well-being of the individual. To address the complexity and over-use of the term "person-centred care", Dawn Brooker created a framework that depicts the four main elements of delivering person-centred care in the context of dementia (2004). Brooker's VIPS framework consists of the following four elements: 1) Valuing people with dementia and those who care for them (V); 2) Treating people as individuals (I), 3) Looking at the world from the perspective of the person with dementia (P), and 4) A positive social environment in which the person living with dementia can experience relative well-being (S) (Brooker, 2004). As such, person-centred care has much to do with others as it does the individual living with dementia, which is why there has been an increased amount of efforts over recent years in training care providers to deliver such care (Maslow et al., 2013; Ballard et al., 2018).

To promote person-centred care in Norway, the Norwegian Advisory Unit on Ageing and Health developed the Dementia ABC educational programme (Norwegian Ministry of Health and Care Services, 2008). This 2-year programme was directed at municipal facilities that provide care for people with dementia, and placed a focus on educating staff about person-centred care as well as increasing their consciousness of their own values and approaches to people with dementia. An evaluation of the programme's impact on 580 members of staff found significant increases in scores of person-centredness and job satisfaction (Rokstad et al., 2016). Similar findings are reflected in more recent studies, with a study of 175 nursing home units across Norway suggesting that providing person-centred care is closely linked to how staff members experience their job situation, with high job satisfaction being strongly associated with a high level of person-centred care (Røen et al., 2018). However, despite this evidence, the delivery of dementia care in Norway still tends to be oriented towards physical needs rather than psychosocial needs (Hansen, Hauge, and Bergland, 2017). Residents with dementia in Norwegian care homes often experience boredom and desire more meaningful relations and activities (Shiells et al., 2020; Nygaard et al., 2020). This is an issue faced on an international level, with numerous studies highlighting the fact that most care practices still tend to adopt the medical model of care, especially for people in later stages of dementia (Bartley et al., 2018; Walmsley and McCormack, 2016). As such, there is a need to address why this is the case.

1.3.3. Implementing person-centred dementia care into practice: What are the barriers?

Despite the amount of evidence on the benefits of adopting and delivering person-centred care, there is still a need to implement this evidence from paper into practice. For instance, the OECD policy brief on renewing priority for dementia suggests that people with dementia often receive sub-optimal care (2018). This is a concern that has been echoed throughout research for at least 10 years. For example, Baldwin et al. (2008) described some care homes as "disabling social environments" in which persons with dementia "are essentially warehoused until death". Care home facilities should be considered as more than just straightforward sites for care (Wiles, 2005). In Norway, it has been reported that over 80% of nursing home residents have some form of dementia (Selbæk, Kirkevold, and Engedal, 2007). In a recent survey of 277 municipalities across Norway, it was reported that 89% of nursing homes specialised in dementia care (Rostad et al., 2020). However, precise details of what this care consisted of were not reported. Norway's Dementia Plan 2020 states that there is still a need for new knowledge and competence in the health and care services (Norwegian Ministry of Health and Care Services, 2015). It also acknowledges the lack of meaningful activities for people living with dementia, and states that future health and care services will be oriented towards the individual's wishes, interests, and habits (Norwegian Ministry of Health and Care Services, 2015).

This disparity between policy and practice is likely due to the challenges of implementing person-centred care within long-term care settings. Recent studies have identified numerous barriers to delivering person-centred care including insufficient resources, high staff turnover, a lack of understanding on dementia, negative mindsets, poor relationships, work and time pressures, and a lack of consistency in care personnel (Kong, Kim and Kim, 2021; Karrer et al., 2020; Kormelinck et al., 2020; Hennelly and O'Shea, 2021). Furthermore, delivering person-centred care through staff-led interventions face additional barriers such as the complexity of the intervention and the staffs' perceived value of the intervention (Karrer et al., 2020; Hirt et al., 2021).

With current evidence identifying numerous barriers to delivering person-centred care, there is a need for research to now look at how these barriers can be addressed. Barriers such as poor communication, a lack of understanding, and negative attitudes hold particular importance for residents with moderate and severe dementia, where verbal ability becomes impaired and alternative approaches towards communication are needed. Rather than just being cared for, residents with dementia have expressed the desire to be empowered and supported in doing things for themselves (Hennelly and O'Shea, 2021). However, if misunderstandings around dementia remain common, the medical model in which people are "managed" rather than supported in their holistic well-being will continue to be the main approach adopted in care practice.

Over recent years there has been a rise in the study of meaningful activities in dementia care as a means of providing person-centred care and fostering interpersonal relationships.

The next sub-section briefly outlines meaningful activities and gives reason for why it is important to identify methods of supporting meaningful activities in care.

1.3.4. Creating opportunities for connection through meaningful activities

The term “meaningful activity” has been widely used in dementia literature, and until very recently, no clear consensus had been developed on what actually constitutes a meaningful activity for people with dementia. Previous work has been done in describing meaningful activities from the perspective of people with dementia, their family, and healthcare professionals (Harmer and Orrell, 2008: Phinney, Chaudhury, and Connor, 2007). However, a recent concept analysis of meaningful activity for older adults with dementia provides a timely definition of this term. Through an analysis of 29 studies on meaningful activities, Tierney and Beattie (2020) identified five attributes that make activities meaningful for people with dementia. These attributes are: 1) enjoyable; 2) suited to the individual’s skills, abilities, and preferences; 3) related to personally relevant goals; 4) engaging; 5) related to an aspect of identity. Examples of meaningful activities included painting, cooking, and physical games (Tierney and Beattie, 2020). Importantly, the authors acknowledged that specific meaningful activities differ for each individual. Painting, for instance, may be a meaningful activity for one person as they consider it a way of expressing themselves, however it may be meaningful in a different way for another individual e.g. it is an activity they do weekly with a friend (Tierney and Beattie, 2020). Meaningful activities are discussed in more detail in Chapter 2 along with meaning making.

Despite recommendations from both research and policy-makers to incorporate meaningful activities into dementia care (Milte et al., 2016; Norwegian Ministry of Health and Care Services, 2015), there are still challenges that need to be addressed in order to support staff in providing such activities. As seen with barriers to implementing person-centred care, factors such as the lack of opportunities, lack of staff resources, and the heavy workload of care staff make it difficult for staff to implement activities that are clearly essential for the well-being of residents (Harmer and Orrell, 2008; Machiels et al., 2017). Therefore, it is important to identify methods of integrating meaningful activities into care in a way that can be sustainable and useful to both staff and residents. The next section discusses the potential of technological solutions for promoting meaningful activities in care.

1.4. The potential of technological solutions

Arthur (2009) defines technologies as assemblies of practices and components put to use in order to fulfil a specific purpose. In the context of dementia care, technology can offer solutions for a variety of purposes. In a review on technology studies to meet the needs of people with dementia and their caregivers, Topo (2009) found that most technologies only focused on the needs of formal caregivers. Similarly, a more recent review on touchscreen technology for people with dementia found that the primary use of such technology has been to deliver assessments and screening tests, and the authors suggested that future work should explore how touchscreen technology can be used to deliver activities for meaningful occupation and fun (Joddrell and Astell, 2016). With this said, the field has been rapidly growing, and in a very recent overview of technology and dementia, Astell et al. (2019) found that technology – such as smartphones, tablets, wearables, robots, virtual reality, and artificial intelligence – is prompting thought on how care services can be better delivered to address the well-being of people with dementia.

A fairly recent Lancet Commission on Dementia Prevention, Intervention, and Care (Livingston et al., 2017) included recommendations for the individualisation of dementia care and the use of technology amongst their key recommendations. The potential of technology in dementia care has also been recognised on a policy level, with the World Dementia Council (2018) calling for the use of new technology as a way to connect with others. The report also recognises that there has been much innovation over recent years, yet these innovations are not always evidence based. Authors of the report call for research on how technology can impact quality of life in particular (World Dementia Council, 2018). A similar message was given in the Norwegian Ministry of Health and Care Services' white paper *The Primary Health and Care Services of Tomorrow – Localised and Integrated*, which stated developments within technology offer new opportunities that have not been sufficiently exploited (Meld. St. 26, 2014-2015).

One opportunity that technology offers is its potential to facilitate meaningful activities. Digital technologies, such as mobile and tablet apps, have been suggested to support collaborative explorations of life events by people with dementia and caregivers, encouraging the caregiver to reflect and learn more about the individual (Maiden et al., 2013). Virtual reality is also being increasingly explored as a way to provide people with dementia the opportunity to virtually interact with certain places and moments in time when the option to do so in person is no longer available (Hodge et al., 2018).

However, despite these promising developments in technology, Astell (2006) warns that technology-based interventions run a risk of crossing the line into doing things *to* people with dementia, rather than *with* them. Despite good intentions, there are technologies aimed at providing meaningful activities which arguably take away from an individual's agency, rather than promoting it. For example, SenseCam is a digital life-logging device in which photographs are taken during the day and then reviewed later on together with a caregiver as a means of promoting conversation and improving short-term memory (Piasek et al., 2012; Woodberry et al., 2015; Karlsson et al., 2017). However, this involves people with dementia having to wear a camera around their neck as they go about their everyday lives. Some participants found this to be stigmatising, and other participants were frustrated in not knowing where the photographs came from when reviewing the images with a caregiver (Piasek et al., 2012; Woodberry et al., 2015). Another example is the use of simulated presence therapy delivered using iPads (O'Connor et al., 2011; Hung et al., 2018). From one perspective, giving the resident video messages from their family could be seen as meaningful to that individual. However, Astell critiques the use of technology for simulated presence therapy in arguing that it "is both a passive and isolated activity for people with dementia… [it] is applied to a person with dementia on their own, essentially to keep them quiet" (2006: 20).

Therefore, although there are new methods that may potentially help integrate meaningful activities into care, there is a need to make sure they are used to support the delivery of person-centred care and not used as a means of behaviour management. This can be challenging, given the view that technology is sometimes seen as "a threat to 'natural' ways of being and acting human" (Tuuri and Koskela, 2020: 2). In the context of delivering dementia care, technology is commonly feared as a replacement for human contact and social interaction with others. For instance, a recent article found that technologies driven by artificial intelligence (such as robotic companions) are perceived as enabling the reduction of human contact, and are viewed as a substitute for maintaining personhood (Berridge, Demiris, and Kaye, 2021). A recent study exploring health care personnel and researchers' perceptions of intelligent assistive technologies care highlighted concerns regarding deception (e.g. with the use of zoomorphic robots such as PARO), affordability, and – again – the concern of human contact being replaced by technology (Wangmo et al., 2019). One participant stated “I think [technologies] are the last option. I think after everything, if the alternative is that the people have no care at all then it is of course a replacement to take care of different personal needs” (Wangmo et al., 2019: 7).

Nevertheless, there is evidence to suggest that technologies can provide meaningful and person-centred interactions in dementia care. Subramaniam and Woods (2016) suggest that digital life books can encourage the delivery of person-centred care amongst staff, whilst improving the quality of life and autobiographical memory of people with dementia. Even in later stages of the disease, digital story apps may help in supporting people with dementia retain a sense of self-identity and empowerment (Critten and Kucirkova, 2019; Park et al., 2017). In recognizing the role that multimedia technologies (e.g., digital life stories) have on conveying the narrative of people living with dementia, Purves and colleagues (2011) stress that further work needs to be done in understanding how these technologies can be used in everyday practice. Furthermore, the authors recently suggested that as health care environments become increasingly depersonalized and fast-paced, there may be increased pressure on developing technologies that can promote social engagement (Astell et al., 2018).

1.5. Developing technology for dementia care in care homes

As discussed earlier in the introduction, the progression of dementia means that people in later stages of the disease most likely need to move to a nursing home in order to receive continuous care. However, recent evidence suggests that people living in care homes lack opportunities for social interaction and meaningful activities – thus contributing further to the progressive decline in quality of life and well-being. As such, there is a clear need for exploring approaches to how person-centred care may be promoted within care homes.

The potential benefits of using technology, as described in the section above, may be able to support the delivery of person-centred care towards people living with dementia in institutional settings – yet evidence in this area is lacking. Moyle (2019) suggests technologies that complement existing care have the potential to maximize autonomy and promote social participation, but notes that these technologies have rarely been used in dementia care. In noting that the primary use of touchscreen technology has been to deliver assessments and screening tests, Joddrell and Astell (2016) called for a focus on how these technologies can be used for meaningful occupation, entertainment, and fun. A recent literature review of technology-based tools and services for people with dementia and caregivers found that the largest number of technologies for moderate to severe dementia was aimed towards the safety and security of people with dementia in the community (Lorenz et al., 2019). The authors note that the further dementia progresses, the more technologies are targeted towards family carers and health care professionals, rather than the people with dementia themselves (Lorenz et al., 2019).

Going forward, there is a need to address how technology can be used together with people living with moderate to severe dementia as a means of promoting a sense of identity and relationships in long-term care settings, rather than being used as a tool for monitoring and behaviour management. Therefore, it seems timely to study a new technological solution, SENSE-GARDEN, that may be able to contribute and provide further insights to this area of work.

1.6. SENSE-GARDEN: A novel technological solution for dementia care

The focus of this thesis is on a novel, technological solution that was developed under the scope of an interdisciplinary European project, SENSE-GARDEN, which started in 2017 ("SENSE-GARDEN", 2018). The SENSE-GARDEN space integrates digital technologies, biographical media, and multisensory stimuli to create personalized environments for individuals with dementia. The SENSE-GARDEN is a physical room built inside a dementia care environment, such as a care home or hospital. Inside this room personalized music, films, imagery, and scents are combined to create an immersive environment tailored to the individual's life story and interests. The approach to using SENSE-GARDEN builds on techniques from reminiscence therapy, which encourages the individual to remember and reflect upon people, places, and events from their lives (Butler, 1963). During the course of this project, a SENSE-GARDEN room has been built at each of the four partnering countries within the consortium: Norway, Belgium, Portugal, and Romania.

1.6.1. The development of SENSE-GARDEN through user-centred design

The SENSE-GARDEN project has embraced a user-centred design (UCD) approach throughout the course of the project. UCD is a term used to describe design processes in which end-users influence how a design takes shape (Abras, Maloney-Krichmar, and Preece, 2004). In this project, end-users were distinguished between primary users and secondary users. A primary user was defined as a person with moderate to severe dementia. A secondary user was defined as either a family member or close friend of the person with dementia (also referred to as an informal caregiver), or a professional caregiver at the care facility (also referred to as a formal caregiver).

At the project's first kick-off meeting, a group brainstorming session was held between the project consortium, which consists of individuals across varying disciplines and professions including healthcare, technology, architecture, business, and research (Sørgaard, Berteanu, and Serrano, 2018). As a result of this session, it was agreed that the essence of the project should be to use this technological solution as a means for promoting emotional reconnection between people with dementia, their family and friends, and their own life story. Early sketches of the SENSE-GARDEN concept are shown in Figure 1.

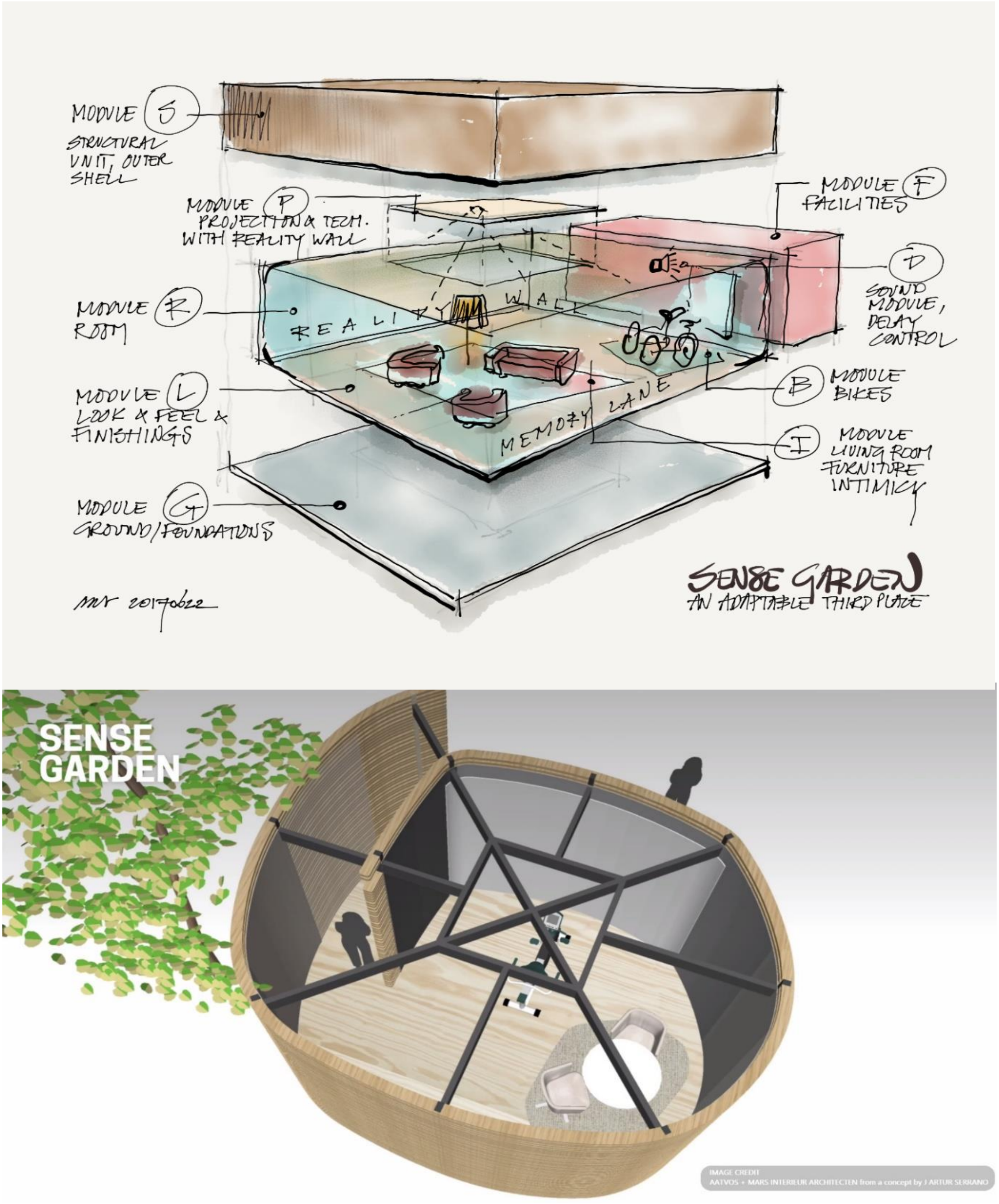


Figure 1. Early sketches of SENSE-GARDEN by Aat Vos. Concept by J Artur Serrano.

From then onwards, user-centred design took place through three phases. The first phase involved collecting initial responses towards the SENSE-GARDEN concept, which contributed towards user specification requirements in the development of the SENSE-GARDEN space and system. A prototype of SENSE-GARDEN was made, integrating the users' feedback. The second phase of the UCD approach involved testing this prototype, first with technical experts (technicians and researchers) to identify any issues with the system. In order to gain a deeper understanding of the users' needs and requirements, SENSE-GARDEN sessions were then conducted at each site using the prototype system together with older adults with and without dementia, family members, and care staff. In Norway, the users were interviewed after the sessions by the PhD candidate. Photos of the prototype SENSE-GARDEN in Norway are shown in Figure 2. Whilst the results of the interviews were not used for publication or for the thesis, the findings were used to contribute to the development and facilitation of SENSE-GARDEN.

In the third and final phase, final improvements to the SENSE-GARDEN system were made and the spaces at each site were made ready for a multisite trial (described in the next section, 1.5.2.). During this final phase, instructions and video tutorials were made by the PhD candidate for each test site so that team members would know how to find and prepare media contents, how to conduct sessions using the SENSE-GARDEN app, and how to report feedback. Further technical issues were addressed and fixed, resulting in the version of SENSE-GARDEN on which this thesis focuses. An illustration of the space is shown in Figure 3.

Figure 2. Testing the SENSE-GARDEN prototype at the Norwegian test site, March 2018

Figure 3. Illustration of SENSE-GARDEN by Gemma Goodall.

1.6.2. The SENSE-GARDEN multisite trial

One of the main scientific activities of the SENSE-GARDEN project was a multisite trial which aimed to assess whether the SENSE-GARDEN intervention can improve the well-being of older adults with moderate to severe dementia (for the study protocol see Goodall et al., 2019). The trial followed a controlled, before-after study design. This PhD is not a report of the trial. However, the trial is referred to throughout this thesis as some of data (Paper III) was collected within the scope of this trial.

1.6.3. The role of the PhD candidate in the SENSE-GARDEN project

The SENSE-GARDEN project began in June 2017, and I started this PhD shortly after, in August 2017. By the time I joined the SENSE-GARDEN project, the concept behind the SENSE-GARDEN had already been developed by my main supervisor, Artur Serrano, and the project's first kick-off meeting (described in Sørgaard et al., 2018) had already taken place. As described in the preface to this thesis, my background is in music psychology and the use of the arts for people with dementia. Therefore, my role in the project was centred on the social and emotional well-being of participants by studying emotions, identity, and interpersonal relationships.

My contribution to the project was to first help capture the users' reactions and needs as part of the user-centred design process described above. This formulated Paper II of the thesis and is described further in the methods chapter. I also contributed to the 2nd and 3rd phases of the UCD process by setting up a prototype of the SENSE-GARDEN system in Trondheim, conducting sessions with expert users, and creating instructions and video tutorials for all test sites. In addition, I travelled to the Norwegian test site to assist with user testing with older adults with and without dementia during which I also conducted interviews. In doing this, I was able to contribute to the integration of user needs in the development process. During my time on the project, I also travelled to the test sites in Belgium and Portugal where I observed test sessions of the new SENSE-GARDEN rooms. I also travelled to the test site in Romania and took part in a demo session in which I played the role of the primary user.

After the completion of the SENSE-GARDEN's working prototype, my focus was on the testing of SENSE-GARDEN. At the beginning of the multisite trial, I visited the Norwegian test site again to help set up study materials, and to observe how a newly built SENSE-GARDEN room was being used. At the end of my visit I interviewed two members of staff at the facility, data which was used for Paper IV of this thesis. During the multisite trial, my responsibilities laid in assisting with the organization of data collection (e.g. getting permission for the use and translation of scales and questionnaires, writing clear instructions on when data should be collected and delivered to NTNU) for each of the test sites and data processing for both for the quantitative and qualitative data. In later stages of the PhD, my focus was mainly directed to the qualitative data, where I led the analysis and writing of Paper III of this thesis.

Alongside the work for my PhD, I took a dynamic role within the project that involved managing task forces in user experience and study design, assisting with social media, managing and producing content for the project's website, and acting as a point of contact for all test sites should they have any questions about data collection or reporting (during all phases of user testing as well as the SENSE-GARDEN trial). Additionally, I undertook administrative tasks such as helping to write and prepare project deliverables. Engaging in these tasks offered essential context for the PhD, meaning that the thesis is an accurate representation of not only the studies, but also the larger project at hand.

It should also be noted that the wider aim of the SENSE-GARDEN project, beyond the scope of this thesis, is to determine whether the delivery of the technology developed in SENSE-GARDEN can improve well-being in older adults with intermediate to advanced dementia (Goodall et al., 2019). The work in this thesis contributes to the project's overall aim from a sociological and emotional perspective.

1.7. Scope of the thesis

This thesis expands upon current work conducted on the use of technology in dementia care by drawing upon interdisciplinary research conducted within the scope of the SENSE-GARDEN project. It explores how digital technologies can be used together with multisensory stimuli to improve the social and emotional well-being of people living with moderate to severe dementia, focusing particularly on narrative identity and interpersonal relationships.

1.8. Rationale for the thesis

Despite the wealth of evidence supporting person-centred care and meaningful activities in dementia care environments, there are areas in this field which would benefit from further knowledge. As seen throughout the introduction, challenges in implementing person-centred care into practice remain largely unsolved. Technologies may be one solution to helping deliver person-centred care through the facilitation of meaningful activities, however, there is scarce evidence on how they are implemented and what benefits they provide to people with moderate to severe dementia in particular. The specific gaps in evidence which this thesis addresses are outlined further below.

First, **there needs to be a stronger focus on supporting the identities and social relationships of people living with dementia in care homes**. Traditionally, care is not focused towards the whole person which presents the risk of loneliness, boredom, and isolation among residents and – consequently – a potentially faster decline in quality of life and overall well-being. People with moderate to severe dementia are less likely to be able to verbally communicate their needs to staff, which presents further threat to having their well-being and sense of self being supported by others. It is therefore important to identify ways of providing opportunities for understanding, social interaction, and promotion of identities in care homes.

Second, **technology could be one solution to improve care – but there is little known on how to use and implement it in care facilities.** In recent years, most research on technology has focused on solutions for use in the private home. SENSE-GARDEN could be a tool used in care facilities to provide staff members the opportunity to get to know residents with dementia, thus enabling them to provide a more person-centred approach throughout the day. As such, studying SENSE-GARDEN with regards to identity and interpersonal relationships may offer insights into how technology can be used as a tool for person-centred care in practice going forward.

To address these gaps, this thesis adopts theoretical understandings of identity and relationships. In previous literature, the use of theoretical frameworks has been shown to provide useful insights into technology use by people with dementia (Rosenberg and Nygård, 2012). As such, this thesis adopts a theoretical approach to studying SENSE-GARDEN. Through adopting a transactional perspective, along with ideas from symbolic interactionism, user experience may be understood beyond terms of system usability and ease of use. The focus is instead placed on how the technology may shape the relationships between the users and their surrounding environment, and how these interact with one another to co-construct identity, promote interpersonal relationships, and ultimately create meaningful experiences. By studying SENSE-GARDEN from a theoretical perspective, this PhD offers new insight into how technology can be used creatively together with people in later stages of dementia in order to promote the co-construction and expression of identity.

1.9. Disposition of the thesis

The remainder of this thesis is split into six chapters. The next chapter, Background, defines and describes the phenomena that this thesis draws upon. The third chapter outlines the specific aims of the thesis. Methods of the included Papers are described in the fourth chapter. Results of the included Papers are summarized in the fifth chapter. Methodological considerations are discussed in chapter 6. A discussion of the results takes place in chapter 7 and, finally, conclusions are given in chapter 8.

Chapter 2

Background

The purpose of this chapter is to describe the theoretical positioning of the thesis and give an overview of concepts such as identity, meaning-making, storytelling, and interpersonal relationships. Since this PhD seeks to contribute to current knowledge on how identity can be promoted in people with moderate and advanced dementia through meaningful activities and meaning making, it is first important to clarify how these phenomena are understood in the context of this thesis.

2.1. Theoretical positioning

This thesis draws upon two theoretical perspectives: symbolic interactionism and transactional relationships. Symbolic interactionism and the Deweyan theory of transactional relationships complement each other well in the sense that both theories are primarily concerned with how our identities and our meanings towards objects, events, and people constantly change based on our interactions.

2.1.1. Symbolic interactionism

Deriving from George Mead's (1934) notion that the development of self and self-reflection is made possible through communication with others, symbolic interactionism is a sociological theory that focuses on how individuals interact with one another reciprocally to form meaning and symbols in the mind. Herbert Blumer, who refined and built upon Mead's ideas, describes three key premises on which symbolic interactionism is built (1986:2). First, the ways in which an individual behaves towards objects and other individuals is based on personal meanings that the individual has given to them. Second, the meaning of these objects is based on the social interaction that the individual has with others and with society as a whole. Third, these meanings are handled in, and modified through, an interpretive process. In other words, our meaning of the world around us constantly changes through the influence of social interactions.

Symbolic interactionism has been used to study interpersonal relationships, communication, and couple well-being in dementia care (Hayes, Boylstein, and Zimmeran, 2009; Walmsley and McCormack, 2014; Davies, 2011; McGovern, 2010). In a fairly recent article, Johnson, Kelch, and Johnson (2017) used a symbolic interactionist perspective to outline the ways in which caregivers can communicate with people living with advanced dementia. The authors present non-verbal methods such as sensory engagement and a “trip back in time” as alternatives to pharmaceutical approaches. They argue that sociological interventions can provide meaningful social connections for people with dementia, and through interacting with the person with dementia on a symbolic level, e.g. using photos, expressions and gestures, powerful connections can be made (Johnson et al., 2017).

2.1.2. Transactional relationships

The modern-day definition of transaction is “a communicative action or activity involving two parties or things that reciprocally affect or influence each other” (Merriam-Webster, 2020). Although still in agreement with such definition, this thesis specifically draws upon the idea of transaction as given by philosopher John Dewey, who believed that humans are in constant, continuous interaction with their environment and the things within it. He writes, “Everything that exists in far as it is known and knowable is in interaction with other things. It is associated, as well as solitary, single.” (Dewey, 1929, p.175). In other words, individual components of an environment interact with each other in ways that form an overall relationship. In a Deweyan context, transaction does not only involve two parties, but it instead concerns multiple factors within an environment. The way in which these factors reciprocally interact with one another can be referred to as a transactional relationship.

In the context of this thesis, it could be insightful to consider the ways in which the users within SENSE-GARDEN not only reciprocally interact with one another, but also with the multisensory stimuli and digital media surrounding them. Dewey stresses the dynamic intercourse between object (for example, a photograph) and subject (the individual). He writes:

> “In an experience, things and events belonging to the world, physical and social, are transformed through the context they enter, while the live creature is changed and developed through its intercourse with things previously external to it” (Dewey, 1934: 246).

This highlights that our experiences are not merely personal, nor are they just interpersonal, but they are multifaceted. A theory of this nature may provide useful insights into creating meaningful experiences for people living with dementia. Whilst a transactional perspective has been applied to areas such as occupational therapy (Dickie, Malcolm, and Humphry, 2011; Cutchin and Dickie, 2013), and the care of cancer patients (Schumacher et al., 2006), it has been seldom used within dementia research.

To date, and to our knowledge, the only research on dementia that explicitly refers to Dewey’s philosophy concerning transaction is a study by Rosenberg and Nygård (2012), that looked at the unfolding transactions of assistive technology use amongst people living with dementia and their significant others. Findings suggested that assistive technology use was influenced by a number of factors including the choice of problem that the technology was meant to address, the user’s experiences and views of the situation, views on how and when the technology should be used, and – most prominently – the view of the individual who had the most power in the decision making. From these insights, the authors concluded that flexibility and a process-oriented approach are key issues when introducing and prescribing assistive technology to people with dementia (Rosenberg and Nygård, 2012). Whilst this study was conducted with people living with dementia in their own home environment, a similar approach may have important implications for designing technological solutions to be used in care homes.

2.2. Preservation and co-construction of identity in dementia

> "Are we diminished persons, when we can no longer say who we are? And while we can, what are our ethical responsibilities to those who can't?" (Eakin, 1999: 8).

Before discussing identity in relation to dementia, it is first important to define what identity is. It is commonly used interchangeably with the term 'self' and, as such, it can be difficult to grasp a solid understanding of what is meant by identity or self. However, in their work on self and identity, Oyserman, Elmore, and Smith (2012) offer a clear distinction between the two as well as a comprehensive explanation of how the two are connected. The authors define identities as "the traits and characteristics, social relations, roles, and social group memberships that define who one is" (2012:69). Self, on the other hand, is used to refer to a sense that something is "about me" or "about us". It is characterized by possessing the reflexive capacity of being able to not only think about oneself as an object, i.e. *I* (subject) think about *me* (object), but also being aware of these thoughts (2012: 71). In other words, in reflecting upon the identities one has chosen to embody and portray to the rest of the world, an individual can create a sense of self.

However, a more critical examination of identity can offer insights into the mechanisms by which we create, co-construct, and perform identities – and they provide arguments for why these mechanisms are necessary if one is to live a meaningful life. First and foremost, identity can be considered as a process that takes place through interaction. In his book on social identity, Richard Jenkins writes:

> "Identity is our understanding of who we are and who other people are, and, reciprocally, other people's understanding of themselves and of others (which includes us). It is a very practical matter, synthesizing relationships of similarity and difference" (Jenkins, 2014: 19).

This appears to be line with the writings of Dewey, who expresses "personality, selfhood, subjectivity are eventual functions that emerge with complexly organized interactions, organic and social" (1929:208). It is important to acknowledge that from this perspective, there is no "fixed" self. Our identities constantly adapt in response to what we experience, the people the meet, and the goals we set for ourselves as a result of these experiences.

By viewing identity as constructed through interaction, we can place further emphasis on the importance of social interaction in dementia care. Environments such as care homes and hospitals can be spaces characterised by carer-"patient" hierarchies and imbalanced power relationships. To date, people across all stages of dementia still experience restrictions in being able to influence the care they receive, being able to assert agency and autonomy, and being able to participate in a shared decision-making process (Groen-van de Ven et al., 2016; Aaltonen et al., 2021). Understanding that identity is not fixed and is shaped through interaction and interpretation of one's environment highlights the importance of the role others play in helping people with dementia assert and express their identities.

Research on dementia has used a variety of models and concepts of self and identity to explore how people living with dementia experience and express their sense of self. Caddell and Clare (2010) identified the following models and concepts used in studies examining self and identity in dementia: social constructionism, interactionism, embodied selfhood, self/identity as narrative, autobiographical memory in relation to self, role identities as a component of self, self as self-recognition, self as self-knowledge. Whilst acknowledging the complexity of self and identity, this thesis will primarily refer to self and identity in terms of narrative (explained in section 2.2.1).

The next sub-sections discuss meaning making, storytelling, and interpersonal relationships, all of which shape the concept of constructing and expressing identity.

2.2.1. Narrative identity

> "We have, each of us, a life-story, an inner narrative – whose continuity, whose sense, is our lives. It might be said that each of us constructs and lives, a 'narrative', and that this narrative is us, our identities" (Sacks, 1986: 105-106).

Narrative identity is defined as "an internalized and evolving story of the self that provides a person's life with some semblance of unity, purpose, and meaning" (McAdams, 2011: 100). Drawing on the idea that people create identity through constructing stories about their lives, narrative identity is a combination of an individual's reconstructed past and imagined future that serves to create a subjective account of one's self (McAdams and

McLean, 2013; McAdams, 2011). In other words, we piece together the various moments, events, and people in our lives – along with our goals and desires for the future – in order to be able to create a story of who we are as individuals – a story of which we tell to others, as well as to ourselves.

Given that the formation of narrative identity seems to be reliant on reconstructed memories, how then, can people living with dementias that primarily effect memory, such as Alzheimer's Disease, be supported in creating a sense of narrative? One of the most prominent researchers in this area is Marie Mills, whose work on narrative identity in dementia suggests that people with dementia still possess a narrative as well as emotional memories, even in later stages of the disease (Mills, 1997). Whilst narrative identity begins to "dissolve" as dementia progresses, Mills (1997) argues that the personal narrative of people with dementia is never lost. She highlights the important role of others in "filling in the gaps". Similarly, Kitwood (1997) recommends that caregivers should help in maintaining the identity of the person with dementia.

Other research has suggested that the process of co-constructing identities can be beneficial for both the person with dementia and the caregiver. In reflecting on how loved ones such as spouses are transformed into "caregivers" within familial dyads, Karner and Bobbit-Zeher (2005) argue that an individual's biography and social attributes continue to exist even if the individual can no longer remember their lives. As such, family members often cling to this biography and memories of their loved one prior to the onset of dementia in order to retain their own identity as part of a couple (Karner and Bobbit-Zeher, 2005). Similarly, Davies (2011) adopted a relationship-centred approach to studying how people with dementia and their spouses preserve the "us-identity" throughout the course of the disease. She found that relationships remained intact despite the challenge of dementia and suggests that the couples' individual histories can be considered as "interacting story lines" (Davies, 2011). As Hydén and Nilsson (2015) also argue, spouses share their identities through their couplehood, meaning that their identities become mutually dependent on each other. Therefore, finding ways of promoting identity amongst people with dementia is vital for not only the diagnosed individual, but also for their loved ones.

However, to suggest that others can, or should, "fill in the gaps" in an individual's narrative is to suggest that there is only one valid narrative that can be promoted – one based on historical 'truth'. This arguably takes away the agency of the person with dementia as his or her own narrator. Instead of filling in gaps, perhaps the role of caregivers could be to co-construct meaning and identity out of expressions, remarks, and gestures made in the present moment.

2.2.2. Meaning making and meaningful activities

As mentioned in the introduction, there have been many studies on meaningful activities in dementia care – yet few of these offer a definition. Whilst Tierney and Beattie (2020) offer a useful description of the attributes that make activities meaningful, there is still a lack of knowledge on *how* meaning is made in these activities. As such, it is important to examine the concept of meaning making.

There is no one definition of meaning making. In the context of learning, Zittoun and Brinkmann define meaning making as "the process by which people interpret situations, events, objects, or discourses, in light of their previous knowledge and experience" (2012). The authors distinguish between three level of meaning: semantic, pragmatic, and existential. Semantic meaning refers to the meaning of language, signs, and symbols and pragmatic meaning refers to the social practices of a culture (Zittoun and Brinkmann, 2012). Existential meaning, the authors explain, is "located within a person's life trajectory, and, as it often triggered by situations of rupture or uncertainty, it might question or reshape his or her whole perspective on her past and future possibilities – that is, a life-meaning" (Zittoun and Brikmann, 2012:2).

In taking the short account given in the preface of this thesis as an example, we can see how the situation in the hospital chapel was interpreted by myself and the patient in a way that involved these different levels of meaning. At the level of pragmatic meaning, we can assume that the two of us both associated *Silent Night* with Christmas, as this is a carol that is often sang at Christmas in Western culture. However, at the existential level of meaning, the difference in our personal experiences and life trajectories meant that we had our own meanings towards and interpretation of the carol. For me, it was a carol I enjoyed listening to and playing, especially with my family at Christmas. I attributed feelings of warmth, joy, and togetherness to the carol. However, for the elderly lady, it was her late husband's favourite carol and thus served as a reminder that he was no longer with her at Christmas. Whilst she may have also attributed feelings of warmth and togetherness to the carol, it was also something she had attributed to her late husbands' identity. Thus, her hearing me playing it brought forth the memory of him and, as such, she displayed an emotional response of sadness and nostalgia. I initially interpreted this response as negative and, thus, stopped playing. However, through talking (thus, making sense of the semantic meaning of what we were each telling one another), I was able to understand her situation and she was able to share a story of her husband with a stranger. As a result of this interaction, my meaning towards *Silent Night* has changed so that I now always think of this memory, and this lady. And, on a larger level, it changed my meaning towards music itself.

With the knowledge that meaning making is a reciprocal process, what does meaning making involve for people with dementia? Especially for those in later stages of the disease, when communicating with others can be difficult? The next section explores meaningful activities and the co-construction of identities with regards to storytelling.

2.2.3. "We are co-authors of our stories": The co-construction of identities through storytelling

> "...since we are co-authors of our stories, we can *be* for each other, professionally and interpersonally; we are in any case, authentically or inauthentically" (Kenyon, 1996: 37)

In his chapter on the meaning and value of personal storytelling, Kenyon (1996) argues that people have a basic need to tell their stories and have them listened to in a non-judgemental environment, where no 'therapeutic plot' is placed upon the narrator. This is especially important for people with dementia. Thus, supporting narrative identity in people with dementia has often been studied from the context of storytelling (Fels and Astell, 2011; Hydén, 2013; Heggestad and Slettebø, 2015). Similar to Kenyon's argument, Fels and Astell (2011) note the importance of the conversational partner in listening to the person with dementia, and argue that allowing a person to tell their story without judgement can make the individual feel heard and valued. In this way, a person with dementia can be supported in maintaining a sense of identity. The authors recommend storytelling as a model of conversation for people with dementia and their caregivers. The authors found that people in varying stages of dementia were able to recall and talk about memories or topics in response to being shown photographs and, in doing this, were able to make connections with other people by sharing experiences and finding points of similarity or common interests.

Here, Tarman's (1988) interpretive approach to reminiscence with older adults is particularly relevant. Drawing on Goffman's dramaturgical model of social interaction, Tarman suggests that older adults present (or perform) positive impressions of themselves through autobiography as a means of combatting the social stigma of ageing. However, people with dementia may have difficulty in telling stories that comply with implicit narrative norms which expect stories to have a coherent beginning, middle, and end (Hydén, 2013). As such, Jane Crisp (1995) builds on Tarman's interpretive perspective by reflecting on the stories told by her mother with Alzheimer's Disease. In arguing that the amount of stigma given to dementia is larger than that given to ageing, Crisp advocates for the acceptance of confabulatory storytelling (i.e. stories in which historical and temporal facts are either inaccurate, jumbled, or missing entirely) as a valuable means of social interaction. She stresses the importance of listening to an individual with dementia's story with attention and interest, even if that story is not an accurate retelling of the past. In using a metaphor of patchwork, Crisp illustrates how fragmented memories can be woven together in new ways:

> "We can think of these fragments of past and recent memories and the present environment as being the mental equivalent of pieces of patchwork, scraps of fabric which are all that survive from previous garments, some of them garments worn by us and others given to us by others. All these fragments are freed from their original context and organized into a new whole around a central person – the teller – to a pattern provided by the basic structures of narrative" (Crisp, 1995: 137)

Beyond the context of dementia studies, storytelling is not a simple act of telling and retelling. According to assumptions of symbolic interactionism, whenever a memory is recalled it is symbolically reconstructed in the present moment and assigned new meaning based on an anticipated future (Mead, 1932; Maines, 2001). In other words, each time a story is retold, new meaning is added. Here, Dewey's transactional theory is again relevant. In his book on identity as meaning-making practice, Urs Fuhrer highlights what transactional theory can offer to other theories of meaning:

> "Dewey's transactional theory of meaning takes something into account that many theories of meaning unfortunately neglect: the generative way that the genuinely new is created or co-created in experienced by means of transaction" (Fuhrer, 2004: 21)

Similarly, returning to the context of dementia, McLean (2006) argues it is the *construction* of a story that provides meaning to the narrator – it is not the historical facts. One example of how storytelling does not need to rely on facts is a method created by Anne Basting called "*TimeSlips*" (TimeSlips, 2019). The storytelling method involves using a photograph to prompt joint, free-form storytelling amongst people with dementia (referred to as storytellers) and facilitators (for example, staff). The story is formed through questions about the photograph asked by the facilitators which are worded in a way that give the storytellers ownership of the story e.g. by asking "What would you like to call him?" instead of "What is his name?" (Basting, 2006: 181). In removing the pressure to conform to a coherent narrative or to say the 'right thing', Basting argues that shifting focus from memory to creativity can provide opportunities for communication. She writes: "Where broken communication skills fracture relationships… creative storytelling can provide a way for individuals to forge new relationships through poetic and openly symbolic expression" (Basting, 2006: 193).

2.3. The importance of interpersonal relationships

Identities are influenced and constructed by our interaction with others. There is also evidence to suggest that a person's overall sense of well-being is affected by social interaction. In the context of dementia, social interaction between care home residents has been highlighted as an important resource in helping maintain continuity with previous social life (Örulv, 2010). A large-scale study recently indicated the importance of social interaction on the psychological well-being of people living with dementia in residential care (Lee et al., 2017). However, given that dementia commonly impacts verbal methods of communication in later stages of the disease – how can social interaction be facilitated in residential care?

2.3.1. Facilitating communication and social interaction in dementia care

> "[Communication] is instrumental as liberating us from the otherwise overwhelming pressure of events and enabling us to live in a world of things that have meaning. It is final as a sharing in the objects and arts precious to a community, a sharing whereby meanings are enhanced, deepened and solidified in the sense of communion… in such ends man is lifted from his immediate isolation and shared in a communion of meanings" (Dewey, 1925: 204-205).

Dewey speaks of man being lifted from his immediate isolation through communication, and this holds extreme relevance for people living with dementia. Communication is a key element of establishing and fostering relationships with others. However, the impact of dementia can make it difficult for an individual, particularly in the later stages of the disease, to communicate in a clear and coherent manner. This is why it is important to identify ways of supporting people with dementia to communicate in alternative ways, particularly through the use of non-verbal communication.

There is an ever-growing evidence base for the use of the arts in dementia care, and how they can be used to enable and empower people living with dementia to express themselves creatively (Zeilig, West, and van der Byl Williams, 2018; Camic et al., 2018). Aldridge writes "Although verbal communication fails, we can offer contexts of expression and understanding where gesture, movement and vocalization make communicative sense" (2000: 15). For example, the use of music and caregiver singing in care has been shown to improve communication between residents with dementia and care staff by increasing mutual engagement, enhancing positive emotions, and enhancing a sense of sincerity and intimacy in the caregiving relationship (Clair, 2002; Götell, Brown, and Ekman, 2002). Furthermore, individual musical preference is preserved throughout the process of dementia and sustaining musical and interpersonal connectedness within dementia care can help value "who the person is" (McDermott et al., 2013).

The above evidence all links back to the importance of providing meaningful activities in care, as discussed in the previous chapter. Through providing activities that incorporate aspects of an individual's interests, preferences, and life history, care facilities may be able to provide opportunities for people with dementia to co-construct their narratives together with caregivers, including family members.

Chapter 3

Aims of the thesis

The overall aim of this thesis is to explore the role of a novel technological solution, SENSE-GARDEN, in promoting a sense of identity and meaningful relationships between people with dementia and their caregivers (both familial and professional). This thesis explores how narrative identity can be maintained, preserved, promoted, and shared between people with dementia and caregivers through the use of digital media in SENSE-GARDEN. To achieve this, the work consists of one systematic literature review and three in-depth, qualitative studies.

The specific aims were as follows:

1. To review existing digital technologies used to create individualized activities for people with dementia, and to assess how these are facilitated, how they are individualized, and to assess what is known about their effects on the well-being of people living with dementia.

2. To explore the users' attitudes towards the concept of SENSE-GARDEN, and to describe the benefits users think SENSE-GARDEN could provide in the care of people living with dementia.

3. To develop a transactional model of how narrative identity and relationships are shaped through the use of SENSE-GARDEN by drawing upon user experiences from people with dementia, informal caregivers, and formal caregivers.

4. To explore professionals' experiences of using the SENSE-GARDEN, and to assess what they consider as benefits and challenges of using the SENSE-GARDEN within care environments.

Chapter 4

Methods

The work in this thesis was conducted as part of the EU-funded SENSE-GARDEN project (AAL/Call2016/054-b/2017). The search for papers in the systematic literature review (Paper I) was conducted in February 2019. The data for Paper II was collected across all four SENSE-GARDEN test sites in Norway, Portugal, Belgium, and Romania in November 2017. The data for Paper III was collected across two of the test sites, in Norway and Portugal, from December 2019 to May 2020. The data for Paper IV, was collected in September 2019 at the Norwegian test site and electronically with all test sites in January 2021.

4.1. Theoretical positioning of the studies

The orientation of this thesis, as previously established, is rooted in a) a symbolic interactionist perspective and b) a transactional perspective. Interactionists agree that human interactions form the central source of data (Berg, 2004). Deweyan philosophy aims to seek meaning and knowledge to make the world a better place:

> “Dewey’s pragmatism and the transactional perspective are optimistic points of view. Although they do not solve social problems theoretically or practically, they give us a method of inquiry – through the concepts and analysis they enable- to act in order to make a better world” Cutchin and Dickie (2013:9).

Qualitative research offers an in-depth exploration of meanings, concepts, definitions, characteristics, metaphors, symbols, and descriptions of things (Lune and Berg, 2017). As such, adopting a qualitative approach to the studies can be considered in line with the theoretical positioning of the thesis. In the same way that Mead and Dewey sought to define experience in terms of continuity and interaction, qualitative researchers are interested in how people make sense of their surroundings through symbols and social structures (Lune and Berg, 2017). Qualitative methodology is thus a justified approach to studying how people with dementia and their caregivers make sense of their experiences with regards to SENSE-GARDEN.

Braun and Clarke (2019) describe qualitative research as being focused on meaning and meaning-making, with qualitative data analysis being about the telling of 'stories'. It is not, as the authors state, about finding 'truth'. The original research studies within this thesis (Papers II-IV) all use qualitative methodology as a method of making meaning of participant perspectives, experiences, and relationships. In other words, the papers present the stories of SENSE-GARDEN and the individuals who experienced it.

4.2. Study designs

The study designs used in this thesis include one systematic literature review and three qualitative interview studies. An overview of the designs and study populations for the Papers is presented in Table 1.

Paper I describes a systematic literature review on the use of individualized technology in creating meaningful activities for people living with dementia. The Cochrane Qualitative and Implementation Methods Group Guidance Series highlights the important role of qualitative and mixed-method reviews in understanding how interventions work and how they are implemented (Noyes et al., 2018). Therefore, this design was chosen to gain a thorough understanding of the work being conducted in this field.

Table 1. Study design and populations included in Papers I-IV

Paper	Design	Population	N included
I	Systematic literature review	People living with dementia	29 studies with 231 participants in total
II	Qualitative interview study	People with mild cognitive impairment, family caregivers and professional care staff	52 (16 MCI; 19 family; 17 professionals)
III	Qualitative interview study	People with dementia (CDR level 2 or 3, aged 55 or over), informal caregivers and formal caregivers	20 (7 PwD; 8 informal caregivers; 5 formal caregivers)
IV	Qualitative interview study	Care professionals	8

CDR: Clinical dementia rating scale; MCI: Mild Cognitive Impairment; PwD: Person with dementia; Informal caregiver: family member or close friend; Formal caregiver: professional care staff

Paper II describes an interview study that was conducted as the first phase of the SENSE-GARDEN project's UCD work. This involved 52 participants (consisting of 16 people with mild cognitive impairment, 19 family members, and 17 care professionals) being asked for their responses and ideas towards the SENSE-GARDEN concept. Data was collected at all four of the SENSE-GARDEN test sites: 13 from Belgium, 12 from Norway, 9 from Portugal, and 18 from Romania.

Paper III describes a qualitative interview study that reports on the qualitative data collected during the SENSE-GARDEN multisite trial. Semi-structured interviews were conducted with 7 people with dementia, 8 informal caregivers, and 5 formal caregivers to explore their experiences of using SENSE-GARDEN for 12-16 weeks. Data for this study was collected from two of the SENSE-GARDEN test sites: Norway and Portugal.

Paper IV describes a qualitative interview study that aimed to explore care professionals' experiences of and attitudes towards using SENSE-GARDEN in practice. Three care homes across Norway, Portugal, and Belgium and one hospital rehabilitation clinic in Romania used the SENSE-GARDEN for over the course of one year. Data was collected in two parts. The first part included observations of SENSE-GARDEN sessions at the Norwegian test site and a face-to-face interview with 2 care professionals at the care home to capture initial impressions towards the newly built SENSE-GARDEN room. The second part included virtual interviews (using Zoom and Microsoft Teams) with 8 care professionals across all 4 test sites (including the 2 care professionals interviewed in 2019) to capture their experience of using SENSE-GARDEN for approximately one year.

4.3. Study settings

The study reported in Paper II was conducted across the four test sites within the project consortium: Norway, Belgium, Portugal, and Romania. The study reported in Paper III was conducted at the Norwegian and Portuguese test sites. The study reported in Paper IV was conducted over Zoom and Microsoft Teams with professionals based at all four test sites.

The SENSE-GARDEN in Norway is situated in a municipality-based care home for the older adults. The care home is located in a remote town with under 10,000 inhabitants. The facility provides residents with a communal dining area and a day centre where individuals can participate in leisure activities such as group singing.

The SENSE-GARDEN in Belgium is based in a care home located in a picturesque village. The care home is part of a larger care organisation that consists of 22 elderly care homes. The facility focuses on providing tailored care based on the individual needs of its 90 residents. The care home offers a large, scenic garden for the residents to enjoy. Residents are also provided with leisure activities such as monthly visits to the pool.

The SENSE-GARDEN in Portugal is in a care home for the elderly. The care home is located in one of Portugal's largest cities, with a population of over 500,000 inhabitants. The care home is part of a large, non-profit organization. The organization operates according to a humanitarian goal, and its care homes focus on promoting the quality of life of its residents.

The final SENSE-GARDEN is based in the rehabilitation centre of a Romanian hospital. The hospital is located in one of Romania's largest cities which has a population of over 1.8 million people. Including a hospital in the study gave the opportunity for more scope on understanding how the SENSE-GARDEN works in various settings. Photographs of the SENSE-GARDEN rooms at each test site are shown in Figure 4.

a b c d e

Figure 4. SENSE-GARDEN exterior in Norway *(Photograph by Tale Hauso, NRK)* (a), SENSE-GARDEN interior in Norway *(Photograph by Tale Hauso, NRK)* (b), SENSE-GARDEN interior in Belgium (c), SENSE-GARDEN interior in Portugal (d), SENSE-GARDEN interior in Romania (e)

4.4. Study samples and recruitment

The primary target population for the work in this thesis is people with moderate to severe dementia. However, due to the focus on interpersonal relationships, research with family members and professional caregivers is also included. Study samples included people with varying types and severity of dementia (Paper I), people with mild cognitive impairment (MCI), family members, and professional caregivers (Paper II), people with moderate to severe dementia, along with their family members or close friends (Paper III), and care professionals (Papers III and IV). Characteristics and recruitment for each paper are described below.

Paper I was a systematic review of 29 papers. Use of digital technologies for people with dementia was identified in 29 papers, including a total of 231 participants. The mean age of participants ranged from 52 to 87 years. The most common type of dementia amongst the participants was Alzheimer's Disease. Severity varied from mild to severe dementia. However, some studies did not specify age nor dementia type and severity.

Paper II included a convenience sample of 52 participants. Participants were recruited from the SENSE-GARDEN test sites in Belgium, Norway, Portugal, and Romania by members of staff at each care facility. Each care facility had been involved in other research projects with predetermined reference groups consisting of residents with mild cognitive impairment, or "super-users". In Romania, these users were inpatients at the hospital's rehabilitation clinic. Although the main target group of SENSE-GARDEN is people with moderate to severe dementia, people with mild cognitive impairment were recruited for this study as they would be more able to provide feedback that could be easily interpreted and implemented into the design of SENSE-GARDEN. In total, sixteen people with mild cognitive impairment (mean age 77.9 years, 11 female), 19 informal caregivers (mean age 55.3 years, 18 female), and 17 formal caregivers (mean age 39.4 years, 13 female) participated.

Paper III was an interview study including 12 dyads, with each dyad consisting of one person with dementia and one formal or informal caregiver. Participants were recruited from the sample of participants who completed their study period in the SENSE-GARDEN multisite trial across Norway, Portugal, and Belgium. Inclusion criteria in this trial was being aged 55 years or above and having moderate to severe dementia defined by use of the

Clinical Dementia Rating Scale (CDR), including participants with an CDR of 2 (moderate dementia) or CDR of 3 (severe dementia) as rated by a professional. Exclusion criteria included other severe psychiatric disturbances diagnosed by the DSM-IV or concurrent severe medical conditions. For our study, we included participants from this trial who had used SENSE-GARDEN for 12 or 16 weeks. An overview of the 12 dyads (totalling 24 participants) and participant demographics is shown in Table 2. Seven of the dyads (14 participants) were interviewed face-to-face, either individually or together. Due to the COVID-pandemic, we were not allowed to continue face-to-face interviews after March 2020. Interviews with the remaining 5 dyads (10 participants) thus had to be conducted over the phone. However, phone interviews could only be conducted with the caregiver in each dyad. An additional caregiver was interviewed in relation to one participant with dementia, though this caregiver was not originally part of the dyad. Thus, in total, 7 people with dementia, and 13 caregivers (8 informal and 5 formal) were interviewed. This is detailed further in section 4.9.2.

Table 2. Overview of dyads in Paper III

Dyad number	Site	PWD participant code	Age	Type of dementia	CDR Level	SG Use (weeks)	Caregiver participant code	Relationship
1	NO	NOp01	94	Unspecified	2	16	NOic01	Mother-daughter
2	NO	NOp02	83	Unspecified	2	12	NOic02	Husband-wife
3	NO	NOp03	79	Alzheimer's Disease	2	12	NOic03	Father-daughter
4	PT	PTp01	88	Dementia with Lewy Bodies and Parkinson's	2	12	PTic01	Close family friends for a considerable amount of years
5	PT	PTp03	71	Vascular Dementia	2	16	PTfc03	Care home staff
6	PT	PTp04	89	Dementia with Parkinson's	2	16	PTic04	Close friends
7	PT	PTp05	81	Unspecified	2	16	PTfc05	Care home staff
8	PT	PTp06	69	Alcohol-related dementia	3	12	PTic06	Close friends
9	PT	PTp07	77	Unspecified	2	12	PTfc07	Care home staff
10	PT	PTp08	92	Unspecified	2	16	PTic08	Father-Daughter
11	PT	PTp09	97	Unspecified	2	16	PTic09	Aunt-niece
12	PT	PTp10	89	Dementia with Parkinson's	3	12	PTfc010	Care home staff

PWD: Person with dementia; ic; Informal caregiver (family/friend); fc: formal caregiver (professional care staff); NO: Norway; PT: Portugal; CDR: Clinical Dementia Rating Scale; SG: SENSE-GARDEN

Paper IV was a qualitative study with 8 care professionals across Norway, Portugal, Belgium, and Romania who were experienced users of SENSE-GARDEN. Purposeful sampling was used. For the first part of the study, the PhD candidate contacted the manager of the Norwegian care home to arrange a visit for conducting observations of the new SENSE-GARDEN room in use and an interview with 2 members of staff. In the second part of the study, the PhD candidate contacted care professionals at each care facility via email with an invitation for interview. The PhD candidate also asked for contact details for any other care professionals in the facility who had experience of using SENSE-GARDEN. Inclusion criteria for this study was having used the SENSE-GARDEN together with residents/patients with dementia. Table 3 offers an overview of the participants' job experience and educational background. All participants were women, with a mean age of 41.75 years.

Table 3. Overview of care professionals in Paper IV

Test Site	Gender	Age	Job Title	Years of experience in dementia care	Educational background
1	Female	37	Psychologist	4	Psychology
1	Female	33	Sociologist	5	Sociology and Social Work
1	Female	58	Board member of care organization	10	Social politics and creative leadership
2	Female	37	Occupational therapist	16	Occupational therapy
3	Female	51	Researcher in Physical and Rehabilitation Medicine	25	Rehabilitation Medicine
3	Female	41	Clinical psychologist	10	Rehabilitation
4	Female	37	Nurse	14	Nursing
4	Female	40	Institution manager	16	Nursing

4.5. Ethical approval and considerations

4.5.1. Ethical approval

Papers III-IV reported on qualitative data collected across different sites that were part of the SENSE-GARDEN multisite trial. Each of these test sites followed ethical guidelines in accordance with the national regulations at each of the sites involved. In Norway, the trial was approved by the Regional Committee for Medical and Health Research Ethics (REK nord reference 10015). In Portugal, approval from an ethics review committee was not needed. Portugal's National Ethics Committee for Clinical Research only requires applications for trials on "medicinal products", of which the SENSE-GARDEN does not fall under, according to the committee's guidelines on what constitutes a medicinal product. In Romania, the trial was approved by the hospital's ethics committee (reference number 8223, 09.11.2018). In Belgium, the situation was similar to Portugal, whereby formal ethical approval was not required as the Belgian Advisory Committee on Bioethics only requires formal approval for clinical trials.

Despite the lack of formal ethical approval in Portugal and Belgium, the SENSE-GARDEN trial and the work described in this thesis was conducted in accordance with the principles of the Declaration of Helsinki at all test sites in order to ensure the safety of the participants. The Declaration of Helsinki was developed by the World Medical Association as a means of providing guidance and ethical principles for medical research involving human subjects (participants) (World Medical Association, 2018). It prioritizes protecting the life, health, privacy, and dignity of the participant during all stages of the study, including the dissemination of results.

4.5.2. Consent

Informed consent was collected from all participants (either directly or via proxy) in Papers II-IV. Across these studies, participants were made aware of their right to withdraw from the study at any time.

For Paper II, written informed consent was given by the participants prior to the interviews. In order to protect the identity of participants, participant information and data was pseudonymised using participant codes.

For Paper III, written informed consent was given by the participants prior to participation in the SENSE-GARDEN sessions and interviews. In the case that a participant with dementia did not have the capacity to give consent, an informal caregiver (family member) signed as proxy. Given that people in more moderate and late stages of dementia were participants in the study, we ensured that all formal caregivers were professionals who had experience of working with people with dementia, and who were confident in handling any adverse situations. In Norway, sessions were conducted by a nurse who has 14 years of experience caring for people with dementia. In Portugal, sessions were conducted by two psychologists who have 8 and 4 years of experience in dementia care, respectively, and an occupational therapist who has 17 years of experience. In Belgium, the sessions were conducted by an occupational therapist with 16 years of experience. In Romania, the sessions were conducted by a clinical psychologist with 10 years of experience. All participant information and data were pseudonymised using participant codes. Photographs and video recordings of the sessions were taken with consent. Participants were happy to have these photographs disseminated. However, in the paper, the faces of participants are blurred to respect their privacy.

For Paper IV, informed consent was collected from the care professionals electronically. Information about the study was emailed to the participants, and further details on the handling and management of data was sent via Google Forms. In the reporting of data, the interview quotes were kept completely anonymous to protect the identity of the care professionals. Personal data including age, gender, job title, years of experience in care, and educational background under test site pseudonyms (i.e. Test site 1, 2, 3 or 4).

4.5.3. The use of personal media

Another ethical consideration is the SENSE-GARDEN system's use of highly personal and identifiable media contents during the sessions (e.g. family photographs, photographs of children etc.). It is vital that these contents are stored securely. To ensure the security of the media contents, local clouds were used at each site to store and manage content for the sessions, which were protected by each organization's firewalls. Furthermore, data privacy was secured through requiring caregivers to log into the system before accessing and editing media contents for sessions. It should also be noted that no media content was accessible from NTNU.

We also anticipated that using photographs from the participant's past may provoke negative reactions. For example, showing pictures of a deceased significant other may result in sadness or confusion (this was found in similar studies such as Damianakis et al., 2010 and Ryan et al., 2020). Participants were free to stop the session at any time, and the formal caregiver could also stop the session if they deemed it necessary to do so.

A separate publication on the safety of participants with dementia in the SENSE-GARDEN trial was published, which outlines the project's approach to ensuring the safety and privacy of users (Ciobanu et al., 2019).

4.6. SENSE-GARDEN Intervention

The SENSE-GARDEN is a space in which the "SENSE-GARDEN intervention" takes place. The project has described the SENSE-GARDEN intervention as a psychosocial intervention (Goodall et al., 2019). Psychosocial interventions are defined as "interpersonal or informational activities, techniques, or strategies that target biological, behavioural, cognitive, emotional, interpersonal, social or environmental factors with the aim of improving health, functioning and well-being" (England, Butler, and Gonzalez, 2015:31). In the context of dementia, most psychosocial interventions aim to improve cognitive skills, mood, or behaviour (Rabins, Blacker, and Rovner 2007).

In short, the SENSE-GARDEN intervention provides a multisensory, individualized intervention to people with moderate to severe dementia. The following sub-sections explain how the intervention is individualized, what activities are included, and how the intervention is facilitated.

4.6.1. Method of individualization

The most vital aspect of SENSE-GARDEN is that the space is fully individualized to the person with dementia. This is achieved through the process shown in Figure 5. First, the family of the person with dementia is contacted and asked to provide information about the life story of the individual. They are asked to fill out a questionnaire which was designed by researchers within the SENSE-GARDEN project. Questions concern the family history, education, work life, hobbies, and personal preferences of the person with dementia.

Additionally, family members are also asked to provide any photographs and videos that are significant to the person with dementia. Using this collected material, a user profile, designated as the "Arts of Life Memory Album" (ALMA), is created for each person with dementia by the formal caregiver.

The formal caregiver then uses the contents of the ALMA to compose media flows for the SENSE-GARDEN session, which are sequences of photos, videos, and music that are relevant to the person with dementia. A tablet app, developed by the SENSE-GARDEN technical team, is used by the formal caregiver to create these flows for each of the activities within the SENSE-GARDEN space.

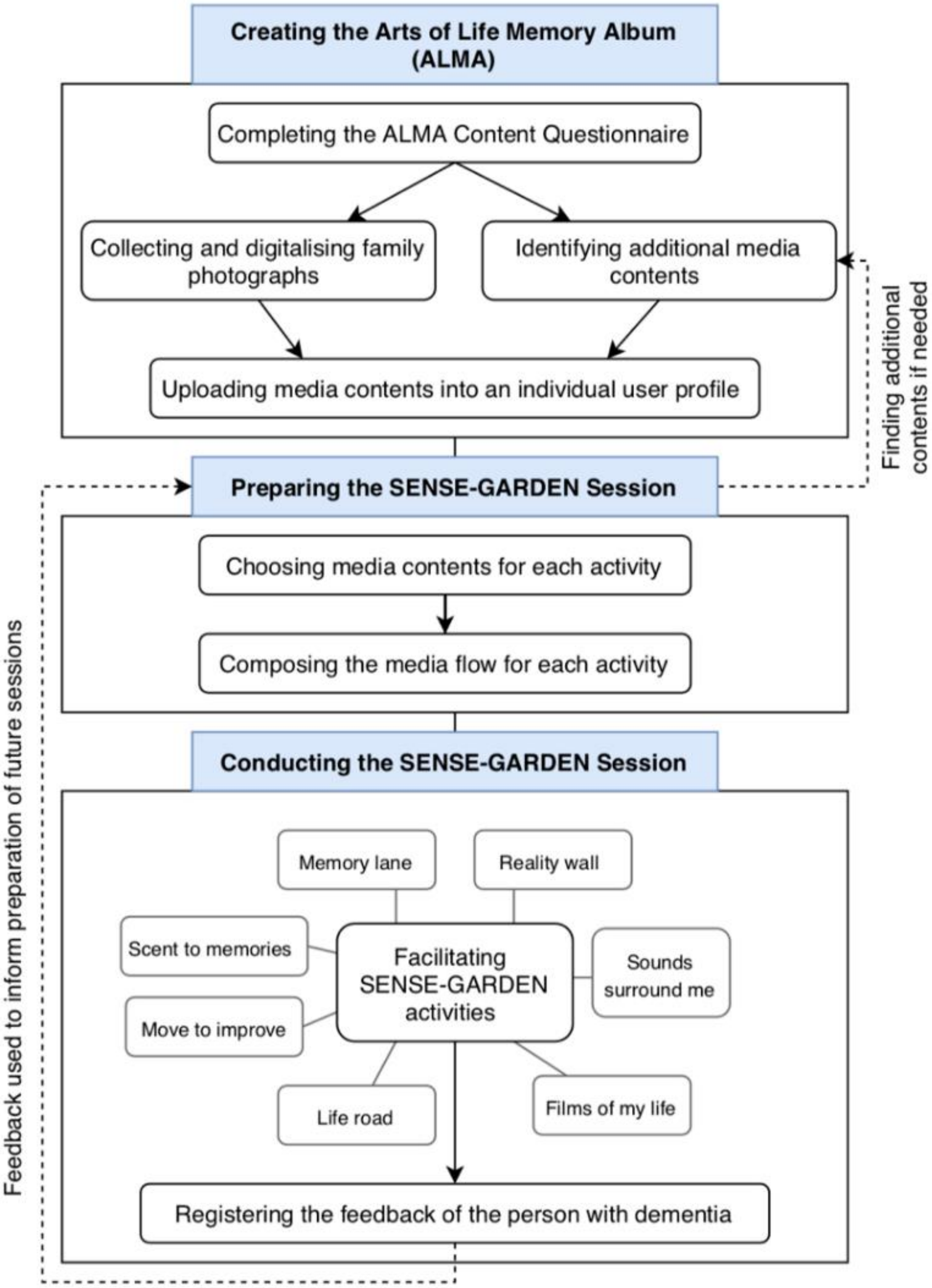


Figure 5. Overview of the SENSE-GARDEN preparation and facilitation process

4.6.2. Components and activities

The SENSE-GARDEN combines multisensory stimulation, physical activity, and techniques from reminiscence therapy through a variety of components and activities (shown in Figure 6). When a person with dementia visits the SENSE-GARDEN together with a caregiver, they can move around the space to engage with the various activities. These activities are as follows:

Reality Wall consists of imagery and film being projected in high-definition onto a large wall inside the SENSE-GARDEN. If possible, the wall should be curved to create a sense of immersion.

Sounds Surround Me uses a surround sound system to provide an immersive sonic experience to the user. The individual is surrounded by their favourite music, sounds that complement the imagery within the space, or songs that hold personally significant meaning to them.

Films of My Life is a collection of classic film excerpts that are meaningful for the user, as well as home-made family movies.

Memory Lane is an activity in which the user can interact with personal digital media, such as family photos, through the use of a medium-sized touchscreen.

Move to Improve involves the use of an exergame to promote balance and physical activity amongst users. The game currently installed in the SENSE-GARDEN presents users with the task of matching coloured butterflies to a corresponding coloured flower.

Life Road consists of a stationary bike placed in front of a projected film. The film shows a route of familiar places that are recognizable to the user.

Scent to Memories involves the use of an olfactory dispense system to disperse a familiar scent throughout the space. It can be used to combine scents with imagery and film showed on the Reality Wall, enhancing to the sense of immersion.

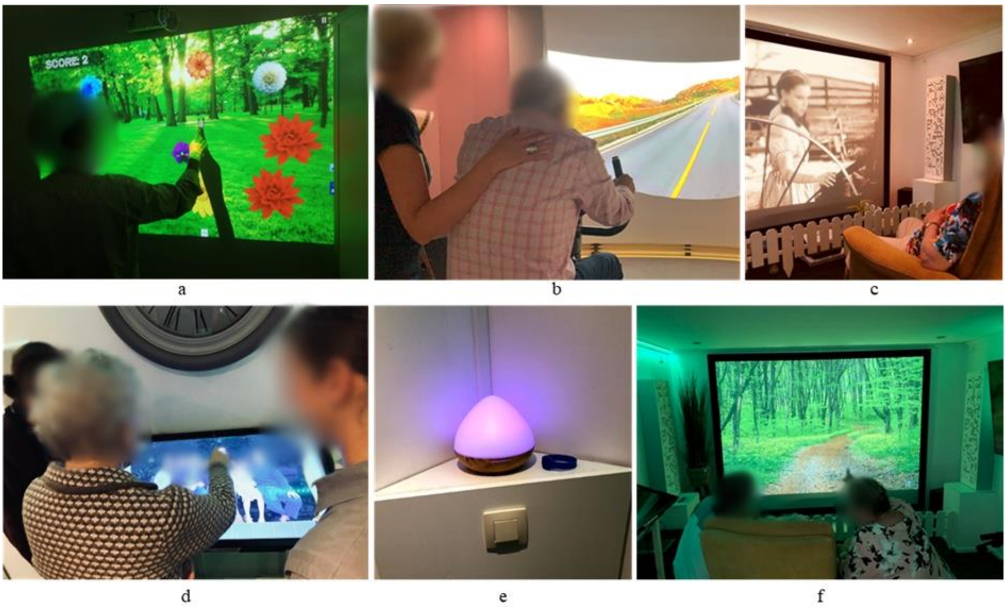


Figure 6. Move to Improve (a); Life Road (b); Films of My Life (c); Memory Lane (d); Scent to Memories (e); Reality Wall (f)

4.6.3. Facilitation

The SENSE-GARDEN intervention is facilitated by a member of care staff at the care home (a formal caregiver). It is intended that the caregiver and person with dementia interact with the various stimuli and activities in the space. Family members (informal caregivers) may also join sessions, participating in the activities together with the formal caregiver and the person with dementia.

As well as facilitating the session, the formal caregiver is also asked to use the SENSE-GARDEN app to register feedback in response to the media contents used in the session. This feedback is based on both verbal and non-verbal reactions of the resident, and it is used to improve the selection of media contents for subsequent SENSE-GARDEN sessions.

4.7. Data collection

4.7.1. Systematic literature search and data extraction

Data for the systematic literature review (Paper I) were collected adhering to the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) guidelines (Moher et al., 2009). As the first author, I selected the articles for review by first screening all abstracts, and then assessing full-text articles for eligibility. Additionally, relevant articles were also identified from backward citation searching and forward citation tracking. The two co-authors independently checked the final selection of articles against the inclusion and criteria, which was approved by both co-authors.

For data extraction, data relating to study aims, design, demographics, data collection, methods, and findings was collected for each article. Data regarding the technology was also extracted. This included: technology purpose, technology type, media contents and services, individualization process, environment of use, training, and facilitation.

4.7.2. Interviews

Papers II-IV used semi-structured interviews. An interview, as defined by Berg (2004), is a conversation with a purpose. More specifically, it is a method of learning about people's interior experiences; their perceptions, their interpretations of these perceptions, their thoughts, feelings, and the meanings that they ascribe to themselves and their relationships with others (Weiss, 1995). The interview method was chosen as the primary method of inquiry for this thesis due to the exploratory nature into the experiences and feelings of participants.

Paper II consisted of 16 group interviews, with a total of 52 participants overall. Group interviews provide an environment for discussion to occur naturally between participants, allowing for useful data to arise. The groups were homogenous to allow participants to feel comfortable expressing their thoughts and feelings with one another. For example, the perceived authority of a professional caregiver may have influenced answers given by a participant with mild cognitive impairment. An overview of the groups is shown in Table 4.

Table 4. Overview of interview groups in Paper II

	PwMCI	Informal carer	Formal carer
Norway	1 group (N=4)	1 group (N=4)	1 group (N=4)
Belgium	1 group (N=3)	2 groups (N=3, N=3)	1 group (N=4)
Portugal	1 group (N=3)	1 group (N=3)	1 group (N=3)
Romania	2 groups (N=3, N=3)	2 groups (N=3, N=3)	2 groups (N=2, N=4)

MCI= Mild cognitive impairment, N= number of participants in each group

The questions were focused on the participants' perspectives towards the SENSE-GARDEN concept. These questions were open-ended, giving the participant the opportunity to answer freely. The semi-structured interview guide (see Appendix A) was designed by me and co-authors JAS and MD. It included questions regarding the overall concept and ideas surrounding SENSE-GARDEN, the individual components of the intervention, and potential benefits and challenges. I did not conduct the interviews for this study. Instead, they were conducted by a researcher or SENSE-GARDEN project member located at each test site. The language of the interviews varied based on each test site, with them being conducted in either Dutch, Norwegian, Portuguese, or Romanian. The interviews were not audio recorded. Instead, a second person at each test site observed the interview and wrote down the participants' answers and remarks. These answers were then translated into English for analysis.

Paper III used a mix of individual interviews (n=12) and group interviews (n=4). An overview of interviews is shown in Table 5. Data collection took place at two test sites: Norway and Portugal. In Norway, one interviewer – the member of care staff who had been facilitating the SENSE-GARDEN sessions – conducted the interviews. In Portugal, two interviewers – both of whom had been facilitating SENSE-GARDEN sessions – conducted the interviews. The same semi-structured interview guide (see Appendix B) was given to all interviewers in the study, containing open-ended questions and prompts for discussion if needed. This interview guide was designed by me, along with input from co-author JAS. There were 10 questions which asked participants about their experiences within SENSE-GARDEN, including how they felt during the sessions, how they felt about using the SENSE-GARDEN with others, and they ways in which SENSE-GARDEN compares to regular, everyday activities.

Table 5. Overview of interviews

Dyad	Interview	Interview type	Participants	Interviewer(s)
1	1	Individual	PwD	SG Facilitator
	2	Individual	ICG	SG Facilitator
2	3	Individual	PwD	SG Facilitator
	4	Individual	ICG	SG Facilitator
3	5	Individual	PwD	SG Facilitator
	6	Individual	ICG	SG Facilitator
4	7	Group	PwD, ICG	Researcher + SG Facilitator
5	8	Individual	PwD	Researcher + SG Facilitator
	9	Individual	FCG[a]	Researcher + SG Facilitator
6	10	Group	PwD, ICG	Researcher + SG Facilitator
7	11	Group*	FCG, FCG**	Researcher + SG Facilitator
8	12	Individual*	ICG	Researcher + SG Facilitator
9	13	Group	PwD, FCG	Researcher + SG Facilitator
10	14	Individual*	ICG	Researcher
11	15	Individual*	ICG	Researcher + SG Facilitator
12	16	Individual*	FCG[a]	Researcher

PwD: Person with dementia; ICG: Informal caregiver; FCG: Formal caregiver; SG Facilitator: SENSE-GARDEN Facilitator

[a]The caregiver did not join any SENSE-GARDEN sessions

*Interview had to be conducted over the phone due to the coronavirus pandemic. It was not possible to interview the PwD in the dyad during this time.

**The PwD in this case had become seriously ill at the end of the study and it was not possible to conduct an interview with him. Another member of care staff who had helped facilitate some SENSE-GARDEN sessions with the resident joined the interview.

Eleven interviews were conducted face-to-face, however 5 had to be conducted over the phone due to the onset of the COVID-19 pandemic in March 2020. The interviews were conducted by the facilitators of the SENSE-GARDEN sessions in Norway and Portugal. In addition, researcher and co-author LA helped conduct interviews in Portugal. All interviews were audio recorded, except in one instance in which one participant asked not to be recorded. For this interview, the interviewer made written notes of the answers. Interviews were conducted in either Norwegian or Portuguese, and transcripts were translated into English for analysis.

Paper IV consisted of interviews with care professionals at the SENSE-GARDEN test sites. The data was collected in two parts. Data was first collected at the beginning of the SENSE-GARDEN intervention period in September 2019. During this time, I visited the Norwegian test site to observe four SENSE-GARDEN sessions and conduct an interview with two members of care staff at the care home. The purpose of this interview was to collect the staff members' initial responses to using the new SENSE-GARDEN room. The interview guide (see Appendix C) was designed by me, with input from co-author JAS. Questions asked the care staff for their initial impressions of the newly built SENSE-GARDEN, their experiences of using it with residents, the process of preparing sessions, and their anticipations on whether the SENSE-GARDEN could be integrated into care. The interview was conducted in English. The interview was audio recorded and then transcribed verbatim by me for analysis.

In the second part of data collection, I conducted interviews with 8 care professionals across Norway, Belgium, Portugal, and Romania. These interviews took place at the beginning of January 2021, shortly after the end of the SENSE-GARDEN intervention period. The two members of care staff who were interviewed in September 2019 were included in the 8 participants interviewed in January 2021. The focus of these interviews was on the overall experience and reflections of using SENSE-GARDEN for approximately 1 year. The interview guide for these interviews (see Appendix D) was again designed by me with help from co-author JAS. One interview was conducted with each test site over Microsoft Teams or Zoom. Three care professionals were interviewed at test site 1, one care professional was interviewed at test site 2, and two care professionals were interviewed at test sites 3 and 4. The interviews were conducted in English, audio recorded, and transcribed verbatim by me for analysis. In total, there was approximately 4.5 hours of recording and 47 pages of transcripts.

4.7.3. Observations and field notes

To provide further context to the study on care staff experiences, Paper IV included the use of observations and field notes. The use of observations in healthcare research has been recommended for helping to explain social processes and phenomena in a way that can contribute to improving clinical practice (Walshe, Ewing, and Griffiths, 2011). In addition, observations may reveal skills and actions of healthcare professionals that are not described in interviews (Walshe et al., 2011).

Seeking to understand how the SENSE-GARDEN is used between staff and residents, I visited the Norwegian test site in September 2019. During the visit, I observed 4 sessions and compiled field notes which were to be used in developing the interview guide and informing the analysis of data. Whilst I had initially planned to make direct observations, the process became much more like participant observation (Kawulich, 2005). Being familiar with the technology behind SENSE-GARDEN, I was able to assist in the preparation of sessions if needed, and I was able to take note of how the care staff were interacting with the SENSE-GARDEN system and app. During the SENSE-GARDEN sessions themselves, I initially stood towards the back of the room and watched the care staff and resident engage with media content. However, I ended up engaging in the session and on one occasion dancing with a resident. Reflective field notes from the observations were made at the end of each day, in an effort not to hinder the atmosphere during the sessions or time spent with care staff (Walshe et al., 2011). These field notes were then used to inform the design of the interview guide, and they also provided contextual understanding in the analysis of data.

Whilst observations were not used in any of the other studies in this PhD, my experiences during the sessions at the Norwegian test site (in addition to visits to other SENSE-GARDEN sites outside of the context of the studies) may have influenced the analysis of data in Paper III. This is reflected upon in a reflexive discussion in chapter 6.

4.8. Data analyses

4.8.1. Narrative synthesis (Paper I)

Due to the heterogeneity of the results, and the novelty of this topic, a meta-analysis of the included studies for the review in Paper I was not conducted. The application of technology for meaningful activities in dementia care is an emerging area of work, with many different approaches and devices being used. Therefore, results were presented through a narrative synthesis. The synthesis adhered to the PRISMA guidelines (Moher et al., 2009) which state that for each study, a summary of results and relationship to other studies under the review must be included in the synthesis. Additionally, the guidelines advise authors to include the strength of the evidence for each main outcome and consider their relevance to key groups such as healthcare providers, users, and policy makers.

Narrative synthesis involves adopting a textual approach towards synthesising results in order to summarise or “tell the story” of findings from included studies (Popay et al., 2006:5). This approach to synthesis is useful for systematic reviews that focus on a wide range of questions other than just the effects of an intervention (Popay et al., 2006). I conducted the synthesis by summarising the findings from the studies to answer each research question of the review. In doing so, I aimed to not only describe the effect of individualized technologies, but also the factors shaping their implementation (i.e. individualization process and approaches to facilitation).

4.8.2. Thematic analysis/Reflexive thematic analysis (Papers II-IV)

Reflexive thematic analysis (RTA) was used in Papers II-IV. RTA aims to generate themes that reflect a pattern of shared meaning around a central organizing concept (Braun and Clarke, 2006; Braun and Clarke, 2019; Braun, Clarke, Hayfield, and Terry, 2019). This approach to analysing data embraces researcher subjectivity as a resource, viewing the researcher as an individual with an active role in the production of knowledge (Braun et al., 2019).

Originally referred to as just “Thematic Analysis” (TA), Braun and Clarke’s 2006 paper has been cited over 96,000 times. In order to address some of the misunderstandings surrounding TA, Braun and Clarke have since published revised guidelines for the method which they now prefer to call “reflexive” thematic analysis (Braun and Clarke, 2019). Paper II followed the 2006 guidelines on conducting TA. Papers III and IV followed this same guide but integrated the authors’ 2019 revisions on the concept and process of conducting RTA. Each process of TA/RTA is outlined briefly below, followed by more detailed explanations for the analytical process for each paper in turn.

Familiarisation with the data

This first phase involves transcribing, reading, and re-reading data whilst noting any initial ideas (Braun and Clarke, 2006). The authors note the importance of becoming immersed in the data.

Generating initial codes

This next phase involves systematically coding interesting features of the data across the entire dataset (Braun and Clarke, 2006). The recent updated guidelines from Braun and Clarke (2019) clarified that different coding approaches are acceptable within RTA.

Generating (initial themes)

Originally referred to as “Searching for themes” (Braun and Clarke, 2006), the authors now prefer the term “Generating (initial) themes” to emphasize that themes are not within the data, awaiting retrieval (Braun and Clarke, 2019). This phase involves collating codes into potential themes in a thoughtful and reflective manner.

Reviewing themes

This phase involves checking if the themes work in relation to the coded extracts and to the entire dataset. Braun and Clarke (2006) also suggest constructing a thematic map during this phase. A thematic map was made for each of the qualitative studies in this paper to aid the process of reviewing themes, and to gain an overview of how the themes interlink with one another. The thematic map for each paper is shown in the results section (section 5).

Defining and naming themes

This phase includes refining the specifics of each theme, refining the overall story the analysis tells, and generating clear definitions and names.

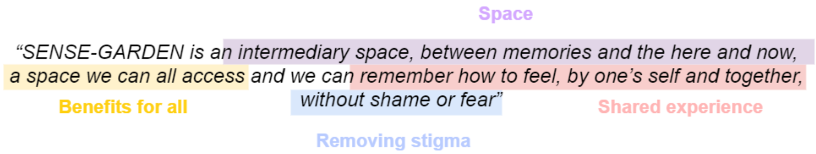
Producing the report

This process involves a final analysis and write-up of the report, providing a concise, coherence and interesting account of the story the data tells.

4.8.3. Analytic process for Paper II

The analytic procedure for Paper II followed Braun and Clarke's 2006 guidelines for thematic analysis. The interview data – which was noted by project team members at each test site – was translated into English for analysis. Leading the analysis of this data, I began by thoroughly reading and re-reading the data whilst noting initial ideas of the dataset. In some instances, I was unsure of the contextual meaning of a translation. However, I had support from co-authors who were native speakers across the test sites, and they were able to clarify any confusion in the dataset.

After familiarising myself with the data and noting my ideas and reflections, I coded the data manually, in an inductive manner. In other words, the codes were developed based directly on the data, without any guidance from theoretical frameworks. An example of this process is shown in Figure 7. This quote from an informal caregiver illustrates how the participant considered the SENSE-GARDEN space as more than just physical – they contextualized it as being a safe space situated between past and present. Codes were drawn from excerpts of the text to identify interesting features e.g. "a space we can all access" indicates that the participant may have believed that the SENSE-GARDEN room could be useful for not only the person with dementia, but for caregivers too.



"SENSE-GARDEN is an intermediary space, between memories and the here and now, a space we can all access and we can remember how to feel, by one's self and together, without shame or fear"

Figure 7. Coded extract from Paper II

Once I had come up with ideas for themes based on the codes, I sent a write-up of my analytic process along with the coded dataset to the 21 co-authors, inviting them to share their inputs and ideas on the themes. Whilst most co-authors were unfamiliar with thematic analysis, a few of them engaged in discussion, and together we reviewed and refined the themes. After joint discussion, we decided on six themes. I then wrote the manuscript, tying in direct quotes from the participants to support the overall narrative of the paper. The other co-authors critically reviewed the manuscript and I edited it based on their suggestions and input.

4.8.4. Analytic process for Paper III

As with the case for Paper II, I had not collected the data for Paper III and it was therefore important that I became familiar with the dataset. This was done by reading and re-reading the translated transcripts sent by the interviewers in Portugal and Norway. This paper used a hybrid approach of deductive and inductive coding, as outlined by Fereday and Muir-Cochrane (2006). This approach integrates theory-driven (deductive) codes with data-driven (inductive) codes. Based on theory from symbolic interactionism and Deweyan transaction, the deductive codes for Paper IV were originally: temporal focus, shared identity, meaning, interpersonal relationships, social interaction, space and aesthetics, and emotions. The codes were developed using the key principles from these theories whilst remaining relevant to the research questions and the context of the SENSE-GARDEN intervention. Table 3 provides an overview of how these theory-driven codes were developed.

Table 3. Development of deductive codes

Code name	Theoretical foundation for code	Code definition
Temporal focus	Building on the work of Mead, symbolic interactionists believe that the past is symbolically reconstructed in the present, and assigned new meaning based on an anticipated future (Mead, 1932; Maines, 2001). Given the SENSE-GARDEN's focus on the life story of the person with dementia, it is important to understand how the participants refer to past, present, and future as a result of interacting with personally significant media.	Referring to past, present, and/or future
Shared identity	Symbolic interactionists believe that meaning, emotions, and pasts can be shared between individuals through joint interaction (Mattley, 2002). As such, social – or shared – identities can be co-constructed as a result of these interactions and shared values. The code "shared identity" is to reflect on how dyads in the study – particularly familial dyads – may feel that their identity is shared based on the meaning they assign to their experiences.	Referring to identity as co-constructed between two or more people
Meaning	People assign meanings to objects, places, events, others etc. and these meanings are constantly reinterpreted as a result of interaction with these objects etc. (Blumer, 1986). The meaning that an individual has attributed to the world around them may influence how they experience the SENSE-GARDEN intervention.	Attributing meaning to media contents, object, place, event, or memory
Interpersonal relationships	Given that symbolic interactionism concerns how behaviour is shaped through interaction with others, the exploration of how participants perceive and describe their relationships with others may provide insight into how these relationships are experienced in the context of SENSE-GARDEN.	Referring to relationships with other individuals
Behaviour and actions	Symbolic interactionism concerns human behaviour and how it is shaped through social interaction. The way that participants perceive and interpret their own behaviours and the behaviours of others, as well as how they interpret their interactions, will contribute to the overall understanding of experiences within SENSE-GARDEN.	Referring to verbal and/or non-verbal behaviours and actions
Space and aesthetics	Transactionalism emphasizes that human experience is shaped through an individual's interaction with their environment (Dewey, 1934). Understanding the participants' awareness and perceptions of their surrounding environment is therefore vital to making sense of their experiences both in and outside of SENSE-GARDEN.	Referring to SENSE-GARDEN space or space of other environments
Emotions	Both Dewey and Mead viewed emotion as embedded in social interaction (Ward and Throop, 1989). According to a symbolic interactionist perspective, emotions are not only experienced and reflected upon in response to situations, but the ways in which they are expressed – or not expressed – can shape social interactions and relationships (Mattley, 2002). Exploring how the participants experience and make sense of their emotions, as well as the emotions of others, may provide insight into the relationships they hold with one another.	Referring to both positive and/or negative emotions and feelings

Myself and two other coders (co-authors LA and JAS) independently read the transcripts and conducted deductive coding using the initial codebook. We also noted down any other codes that we thought should be included, i.e. inductive codes. Braun and Clarke (2019) stress that when using multiple coders in RTA, the aim should not be seeking consensus, but rather to develop a more nuanced understanding of the data through collaboration. Others have also commented on the value of including multiple coders with varying backgrounds to enhance qualitative analysis (Berends and Johnston, 2005). The coders in this paper had a background in music psychology (coder 1), sociology (coder 2), and care and assistive technologies (coder 3).

Once coding was complete, we shared our coded transcripts with one another and discussed our impression of the data. After this discussion, I merged our suggested inductive codes to form three new codes. Figure 8 shows the inductive codes suggested by each of the three coders, and the merging of these into three codes for inclusion in the final codebook. Moreover, two deductive codes (temporal focus and shared identity) were removed from the codebook, as these codes were sparsely used by the coders during coding. The final codebook consisted of the following 8 codes (5 deductive codes and 3 inductive codes): meaning; interpersonal relationships; social interaction; space and aesthetics; emotions; professional caregiving relationship; impact of the intervention; components of SENSE-GARDEN. The entire dataset was coded again by me using qualitative data analysis software NVivo (QSR International) according to the final version of the codebook. The final codebook is shown in table 4.

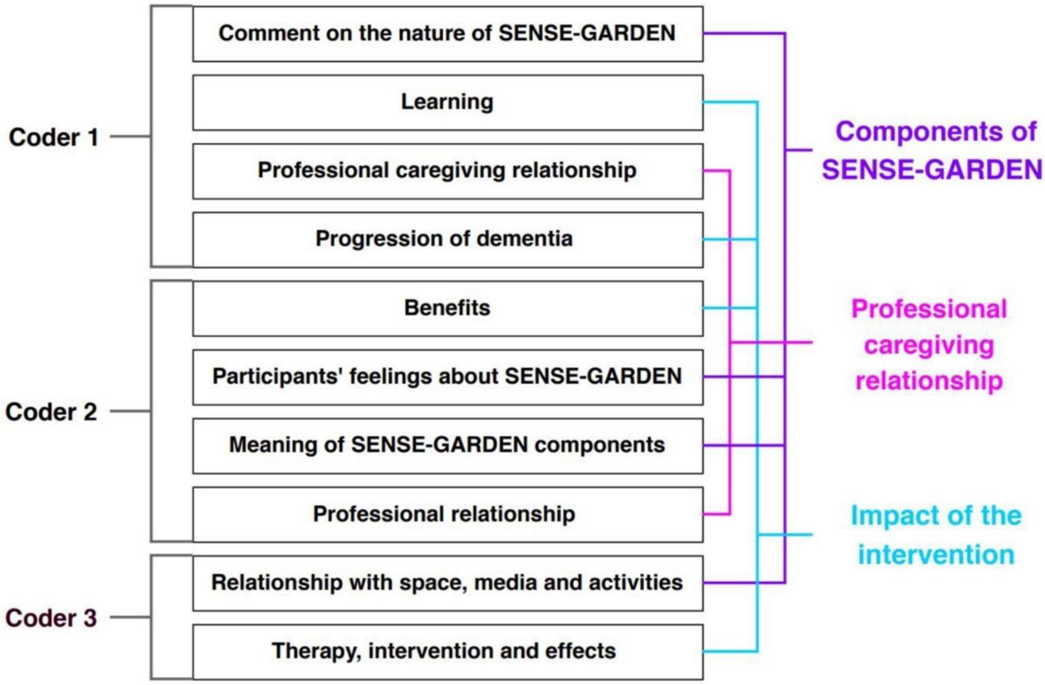


Figure 8. Merging individual coder's inductive codes into agreed codes to use in analysis

Table 4. Final codebook for Paper III

Code name	Definition	Description	Example
Meaning	Meaning is attributed to a place, event, media, or memory	The participant talks about the meaning/significance of media (music, photographs etc.), places (e.g. hometown), events or memories	"I know that Fátima* is very important to her, and the religious part touches her a lot"
Interpersonal relationships	Discusses interpersonal relationships with other individuals	Interpersonal relationships with other individuals (living or deceased, inside and/or outside of SENSE-GARDEN). The emotional and/or social nature of the relationship may be discussed	"I've learned more about appreciating our 60 years of life and all of the 21,000 days we have had. Most of them have been happy. It has not been said that we have never quarrelled, but we have never gone to bed as enemies. We have taught ourselves to pay attention to each other"
Behaviour and Actions	Interaction (verbal and/or non-verbal)	May refer to gestures, body language, facial expressions as well as verbal communication. Can refer to interaction either inside or outside of SENSE-GARDEN	I generally think it has become easier to talk to her even when she is not in the SENSE-GARDEN. She is more sharp and able to hold the thread of the conversation better than she did before.
Space and aesthetics	Participant discusses space and/or comments on aesthetics	Can refer to the SENSE-GARDEN space, or space of other environments (e.g. other areas of the care facility)	"It's the design of the room, the fact that there are no sharp edges, no corners, it's carpeted. It is shielded from the rest of the world. One goes into something else, one forgets time."
Emotions	Emotions are discussed	Emotions experienced either inside or outside SENSE-GARDEN are discussed. The nature of the emotion can be mixed (does not have to be only positive or negative).	"I even cried while playing the children's song. it was a powerful experience…it was strong for me when my mother sang along to these songs. I think my mom is happy when she is here, happy and bright at heart."
Professional caregiving relationship	Discusses the care given to the PwD by the professional caregiver	Refers to how professional caregiver interacts with the PwD, how they facilitate the SENSE-GARDEN session or the caregiving relationship outside of sessions	"I do not believe all the caregivers have become involved in his life situation and there is always a reason why they are angry or sad. I think the staff misinterprets the user. One must find the reason why the user is the way he is."
Impact of the intervention	Discusses benefits or issues as a result of the SENSE-GARDEN intervention	Refers to either immediate or long-term effects (both positive and negative) of the intervention on the person with dementia and/or caregivers	"I generally think it has become easier to talk to her even when she is not in the sensory garden. she is more sharp and able to hold the thread of the conversation better than she did before. She doesn't ask the same question again. if I switch topic and then comes back to the previous conversation the topic, she manages to remember what we talk about 3 minutes ago. It has become much easier to talk to her now on the phone. It is probably the change that I think I have seen."
Components of SENSE-GARDEN	Discusses aspects of the SENSE-GARDEN	Refers to activities, media and/or technology within the SENSE-GARDEN space	"It was especially the pictures combined with the music I liked the best. The family pictures I liked a lot. It is so wonderful, and it is accurate that I want to burst with enthusiasm. Quite phenomenal."

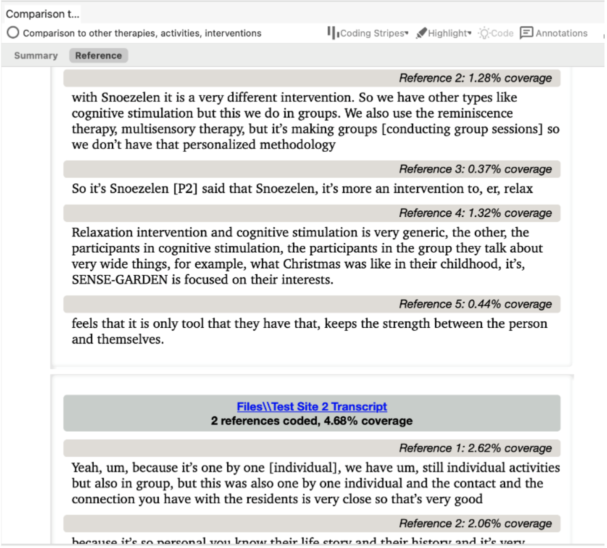
* Fátima is a Portuguese town that's home to the "Sanctuary of Fátima", a well-known Catholic pilgrimage destination.
PwD: Person with dementia

Once the data was recoded, I generated ideas for initial themes. These were discussed together with all co-authors before being refined into final themes. I then wrote the manuscript. The three other co-authors critically reviewed the manuscript and offered their inputs before it was submitted for publication.

4.8.5. Analytic process for Paper IV

Transcripts from parts 1 and 2 of the study were initially analysed separately. The transcripts from interviews conducted in 2019 were analysed in winter 2019, and the transcripts from interviews conducted in 2021 were analysed in January 2021. The same group of authors (GG, KT, RG, and JAS) analysed the transcripts in both parts of the study.

Having conducted all interviews myself, I was able to familiarise myself with the data through repeated listening of the audio recordings whilst transcribing the data. During this familiarization process, I also repeatedly read the transcripts and made initial notes. The other co-authors also read through the transcripts and shared their notes with me. We met to discuss our initial ideas with one another. I then coded the data in an inductive and semantic manner using NVivo. An example of the coding process is shown in Figure 9.



Reference 2: 1.28% coverage

with Snoezelen it is a very different intervention. So we have other types like cognitive stimulation but this we do in groups. We also use the reminiscence therapy, multisensory therapy, but it's making groups [conducting group sessions] so we don't have that personalized methodology

Reference 3: 0.37% coverage

So it's Snoezelen [P2] said that Snoezelen, it's more an intervention to, er, relax

Reference 4: 1.32% coverage

Relaxation intervention and cognitive stimulation is very generic, the other, the participants in cognitive stimulation, the participants in the group they talk about very wide things, for example, what Christmas was like in their childhood, it's, SENSE-GARDEN is focused on their interests.

Reference 5: 0.44% coverage

feels that it is only tool that they have that, keeps the strength between the person and themselves.

Files\\Test Site 2 Transcript
2 references coded, 4.68% coverage

Reference 1: 2.62% coverage

Yeah, um, because it's one by one [individual], we have um, still individual activities but also in group, but this was also one by one individual and the contact and the connection you have with the residents is very close so that's very good

Reference 2: 2.06% coverage

because it's so personal you know their life story and their history and it's very

Figure 9. Examples of references for the code "Comparison to other therapies, activities, interventions" in NVivo.

I used the codes to generate ideas for initial themes, which I illustrated on a mind map (see Figure 10) and sent to my co-authors. We met again to discuss the meaning of each theme, as well as discussing how the themes related to the research questions at hand. Together, we defined and named the themes and clarified the focus behind each one. During the discussion of the themes from part 2 of the study, we also reflected on how the new themes compared with those from generated from the interviews conducted in part 1 of the study.

Once we had decided on the themes, the write up was conducted by me. During the writing process I was able to reflect on the study aim, my time spent at the Norwegian test site, the field notes and early familiarization of the transcripts to ensure the final themes remained close to the data and research questions at hand. The three other co-authors critically reviewed the manuscript I had sent to them, and they all contributed suggestions and ideas before it was submitted for publication.

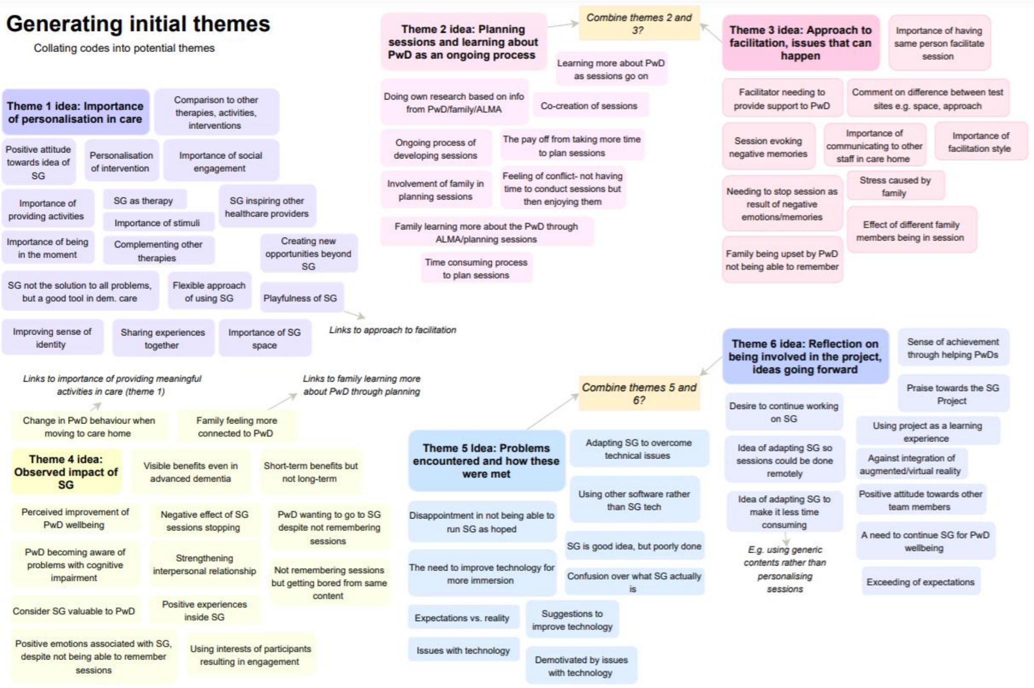


Figure 10. Mind map of the process of generating initial themes from codes

Chapter 5

Summary of results

5.1. Paper I – Systematic literature review

The review provided an overview of the evidence on using technology to create individualized, meaningful activities for people with dementia. The literature search from 4 databases returned 1414 articles. Abstracts from 906 articles were evaluated and 69 articles were assessed for eligibility. Of these articles, 21 articles were included. After reference list checking and forward citation tracking on the 69 full-text articles, eight articles were identified. This resulted in a total of 29 articles for the final full-text review.

From the 29 studies (reported in 29 separate articles), 12 were qualitative, 13 used mixed-methods, and 4 were quantitative. Case studies were the most common study design (N=12). A total of 213 participants were included across the 29 studies, and the mean age of participants ranged from 52 to 87. The severity of dementia among the participants varied from mild to severe, with Alzheimer's Disease being the most common type (N=14). However, there were inconsistencies in the reporting of participant demographics, and four studies did not report on either type or severity of dementia. Most studies aimed to assess the effects of these technologies on memory, communication, or engagement.

The findings of the review indicate that a wide array of digital technologies have been explored for creating individualized, meaningful activities for people with dementia. The purposes of the technologies included in the studies were grouped into four main categories: reminiscence/memory support, behaviour management, stimulating engagement, and conversation/communication support. Regarding the environment in which the technology was used, the majority of the studies were conducted within the homes of the participants, who were living in the community (N=18). In most studies, the presence of another person was required for the full facilitation of the intervention/activity, with family members being the facilitator in most cases.

The individualization of the technology was often a collaboration between the person with dementia, their family member, and a researcher. A variety of approaches to the process of individualization were used, including the use of structured workbooks, the listing of major life chapters, capturing stories in a conversational style, life story interview, questionnaire, participatory design, in-app prompts, and participants uploading their own media content to the apps. The use of photographs, music and narration for individualization was common across the technologies. Theories and paradigms such as positioning theory, narrative knowing, constructivism, and person-centred care were used to inform the individualization process in some studies. Studies that used theoretical foundations for the individualization process of the technology found positive impacts on a sense of self and/or engagement.

The effects of the technologies on the well-being of the participants with dementia were grouped into the following domains: memory, behaviour and mood, self-identity, social relationships and engagement, and emotional well-being. Overall, the evidence from the included studies suggest that individualized, digital technologies can have positive effects on the well-being of people living with dementia. Particularly promising areas of improvement are behaviour and mood, sense of identity, and relationships and engagement with others.

5.2. Paper II – User perspectives towards SENSE-GARDEN

> "A special emotional environment must be created for SENSE-GARDEN to work."
> *Person with mild cognitive impairment, Paper II.*

This study explored the initial responses towards the SENSE-GARDEN concept from user groups across Belgium, Norway, Portugal, and Romania. Through exploring these responses, subsequent development of the SENSE-GARDEN could be shaped to meet the desires and needs of the users. Additionally, it was important to identify any potential concerns that the users may have had.

Six themes were generated from thematic analysis of the interview transcripts. These included: benefits for all, focus on the individual, past and present, emotional stimulation, shared experiences, and challenges to consider. A thematic map is shown in Figure 11 to provide a visual summary of all six themes and their respective subthemes.

The first theme, *(A)* Benefits for All, reflects the way in which the users believed that the use of SENSE-GARDEN may be able to provide benefits to not only the person with dementia, but also to family caregivers, professional caregivers, practice, and contexts beyond dementia care. The second theme, *(B)* Focus on the Individual, captures the users' beliefs concerning the importance of providing not only an individualized environment through the use of familiarity and personally meaningful stimuli, but also the importance of allowing the person with dementia to actively express themselves. The next theme, *(C)* Past and Present, reflects the complex nature of memory, and how reminiscing together on memories of the past can simultaneously create meaningful moments in the present. Whilst the topic of emotion was resonated throughout all themes, theme *(D),* Emotional Stimulation, captures a more detailed account of the users' perspectives towards emotion. The users highlight the intricate nature of emotions by sharing their thoughts on how emotions are manifested through the stimulation of senses, through the remembrance of past events, and through relationships with others.

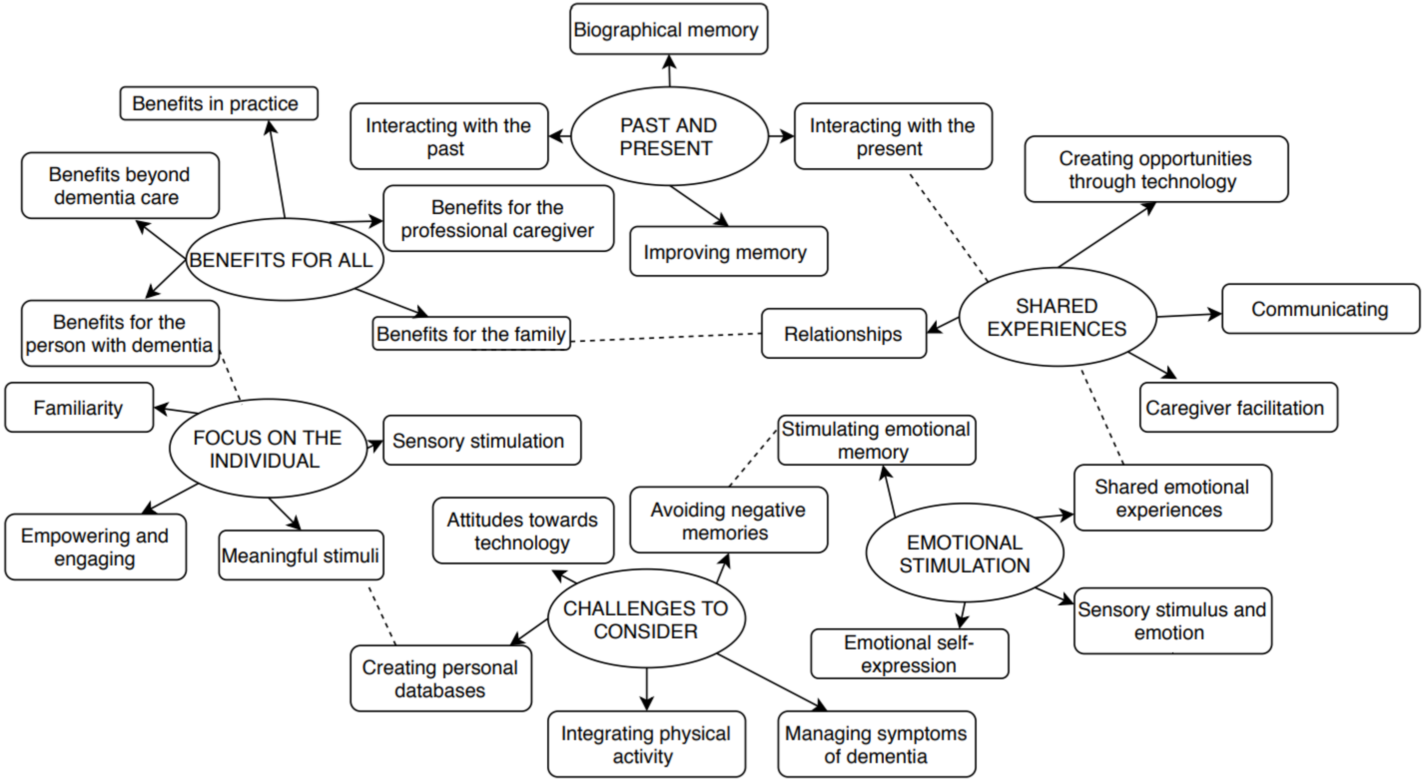


Figure 11. Thematic map from Paper II.

The penultimate theme, *(E)* Shared Experiences, focuses on the users' high regard for the importance of sharing moments together within the SENSE-GARDEN. Not only should relationships between family members be fostered, but the users also emphasized the importance of the facilitation from professional caregivers. Finally, theme *(F),* Challenges to Consider, summarizes the issues that users identified during the interviews regarding potentially challenges. These included challenges regarding the management of symptoms of dementia, the suggestion to avoid negative memories, and warnings about attitudes towards technology.

Overall, the paper encapsulates the users' values towards providing individualized experiences and fostering interpersonal relationships through the use of SENSE-GARDEN. As indicated in the thematic map (Figure 8), the themes are interrelated and demonstrate the multitude of factors that have to be considered in the development and execution of SENSE-GARDEN. With this in mind, an initial conceptual model of the transactional relationship within SENSE-GARDEN was devised. Acknowledging the importance of contextual, environmental, and relational factors in the use of technology, this paper set a broad, yet solid, foundation on which future work within the PhD could be based.

5.3. Paper III – A transactional approach to understanding user experiences within SENSE-GARDEN

"The experience itself has probably caused me to open my eyes to small things that I have not noticed before. Things I had no idea meant anything to him... [I have] learned more about appreciating our 60 years of life and all of the 21,000 days we have had."
Wife of a person with dementia, Paper III.

This study explored the experiences of people with dementia and their caregivers within the SENSE-GARDEN from a transactional perspective. Three themes were generated from reflective thematic analysis: openness, learning and connection. An overview of the themes and their respective subthemes are shown in Figure 12.

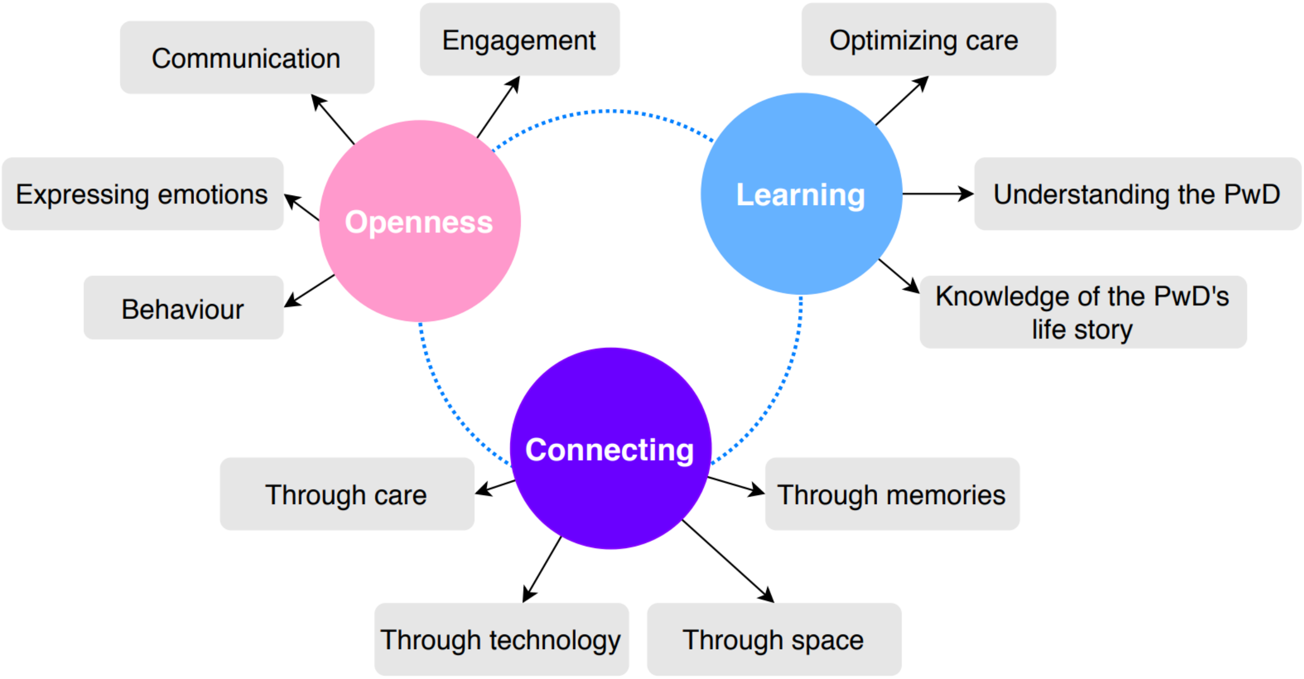


Figure 12. Thematic map from Paper III.

The first theme, openness, reflects the way in which SENSE-GARDEN encouraged individuals (not only participants with dementia) to become more open in their communication with one another, particularly with regards to expressing emotions and discussing personal subjects. The second theme, learning, addresses the way in which SENSE-GARDEN can provide knowledge on a) optimizing care through the use of personalized environments and individual focus on the resident, b) understanding the person with dementia, and c) learning more about the unique life story of the resident, even for family members. The third theme, connecting, captures the way in which opportunities for connecting can be created through a) high quality care, b) through the use of technology and digital media and c) through space, and d) through memories and stories. All three themes are interlinked and are dependent on one another. Openness is dependent on having an opportunity to connect, but to be able to connect one must be willing to learn about the person beyond dementia. However, learning is hindered when people aren't open with another and there are no opportunities for connection.

Overall, the participants offered touching and nuanced accounts of their time in the SENSE-GARDEN, which provided insights into how this intervention provides opportunity for meaningful activities in dementia care. One key aspect is that whilst the technology is important for projecting the life story to participants in an innovative way (e.g. through an immersive environment), it is ultimately the relationships between people inside the room that makes the intervention meaningful. The findings were used to develop a transactional model of how narrative identity and relationships are shaped through the use of SENSE-GARDEN, as shown in Figure 13. The model acknowledges the multitudinous factors and processes that take place to form an overall experience in which the person with dementia feels understood and connected to.

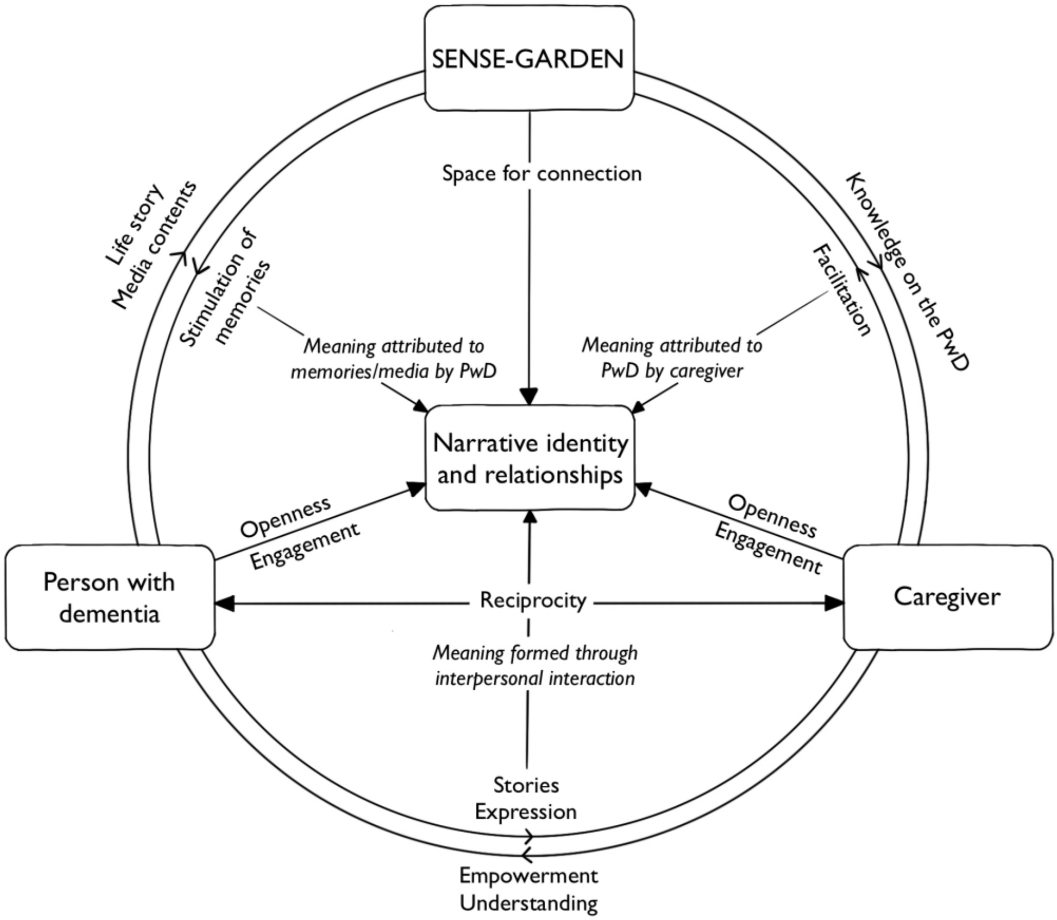


Figure 13. Transactional model of how narrative identity and relationships are shaped through the use of SENSE-GARDEN.

5.4. Paper IV – Professional perspectives of SENSE-GARDEN

> "You see the person and not the patient... and that's a big difference"
> ''The more we learn about our residents, the more we can provide care – individually adapted care."
>
> *Care professionals, Paper IV.*

This study explored the experiences of care professionals who had used SENSE-GARDEN for approximately one year. The first part of the study aimed to capture the initial reactions and responses towards the newly built SENSE-GARDEN at the Norwegian test site, whereas the second part of the study focused on exploring more detailed reflections from care professionals having used the SENSE-GARDEN for a longer period of time.

Findings from the interview conducted at the beginning of the SENSE-GARDEN intervention period (September 2019) were positive, though the technological aspects of SENSE-GARDEN were not complete. Despite frustrations caused by technological issues, the two care professionals were enthusiastic towards SENSE-GARDEN. Three themes were generated from the interview conducted in 2019: space for interaction, shift in focus, and planning and involvement. An overview of the themes and subthemes are shown in Figure 14, where interactions between subthemes are depicted using dotted lines.

The first theme, space for interaction, captures the ways in which the care staff considered the SENSE-GARDEN space not only in terms of environmental factors, but also in terms of sensory, emotional, and social features. The second theme, shift in focus, reflects the ways in which the staff members' views of the residents changed through using the SENSE-GARDEN with them. The SENSE-GARDEN offered staff a new way of learning about the life story of the person with dementia, encouraging them to shift their attention away from dementia and instead focus on the person as an individual. The final theme, planning and involvement, concerns the input from care staff in the development of the project, and their involvement in preparing and facilitating SENSE-GARDEN sessions.

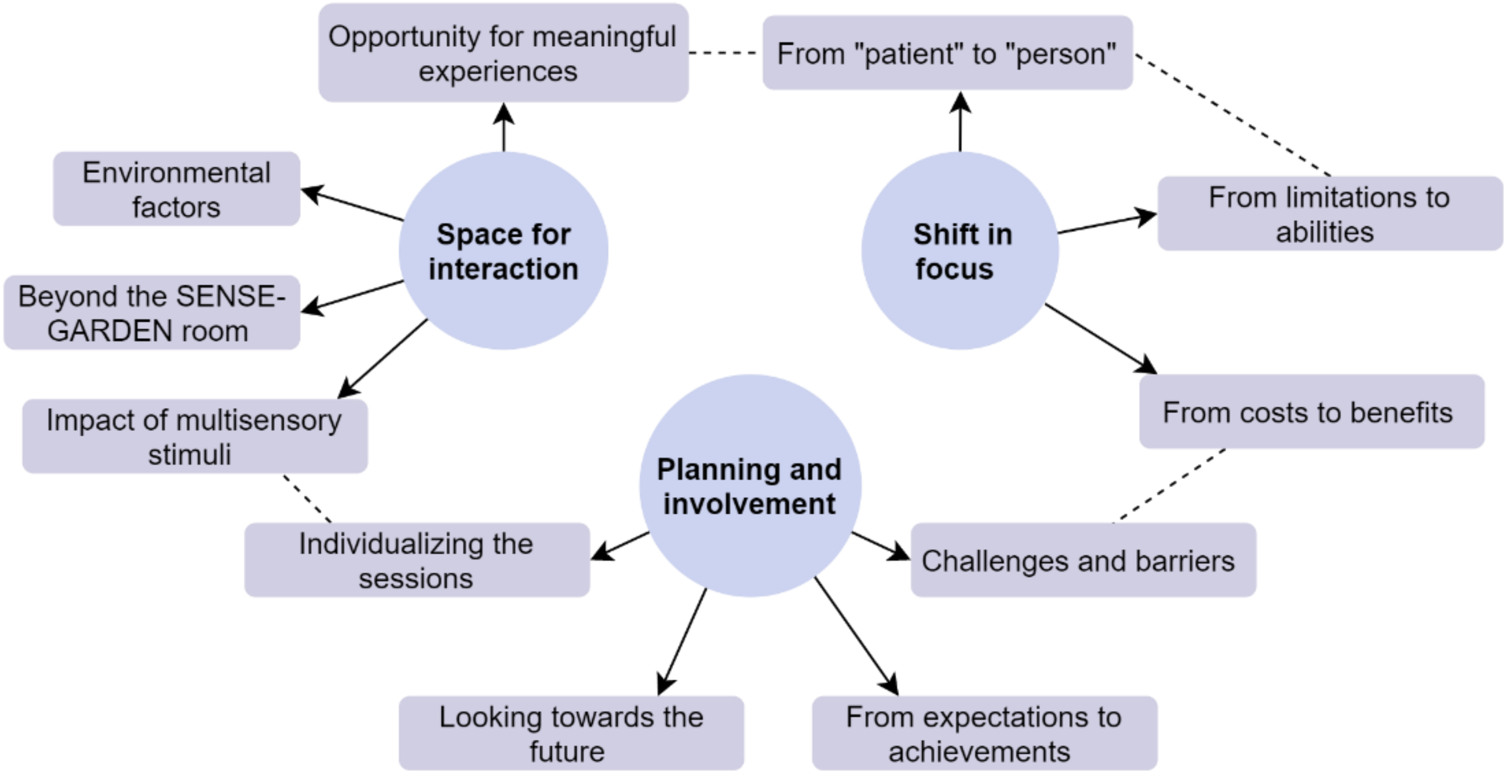


Figure 14. Thematic map of themes and subthemes generated from interview conducted in 2019

Findings from the interviews conducted in 2021 suggested that the care professionals considered SENSE-GARDEN as being a tool for delivering personalized care and adding value to their work. Three themes were generated through analysis of these interview transcripts: shifting focus onto personalized care, building and fostering relationships, and continuous discoveries. A thematic map is shown in Figure 15 where dotted lines indicate the interaction between the different themes and subthemes.

The first theme, “shifting focus onto personalized care” captures the idea that the care professionals felt that they were able to deliver care in a more playful, flexible, and personalized manner compared to traditional care approaches such as cognitive stimulation. The second theme, “building and fostering relationships” reflects the process of building relationships over the course of using SENSE-GARDEN together with residents and hospital patients with dementia. The care professionals felt that spending time with the person with dementia inside the SENSE-GARDEN, interacting with them as a unique individual, and taking the time to learn about the person contributes to the caregiving relationship. Finally, the third theme, “continuous discoveries” represents the ongoing process of learning about the person with dementia and adapting sessions in response to this learning. The theme also captures professionals’ reflections on the challenges and barriers they encountered during their time using SENSE-GARDEN.

Overall, the care professionals across all four countries highlighted the value of an intervention like SENSE-GARDEN in terms of being able to create meaningful experiences for people with dementia and in turn being able to improve their sense of achievement at work. The biggest frustration reported by the professionals was the technology not working as it was supposed to have done – meaning that the preparation and facilitation of sessions was not as seamless as initially hoped. This may have also impacted the time consumption spent by care professionals when preparing and facilitating sessions. However, the care professionals felt that this was a worthwhile investment of time as it enabled them to deliver care in a more personalized way.

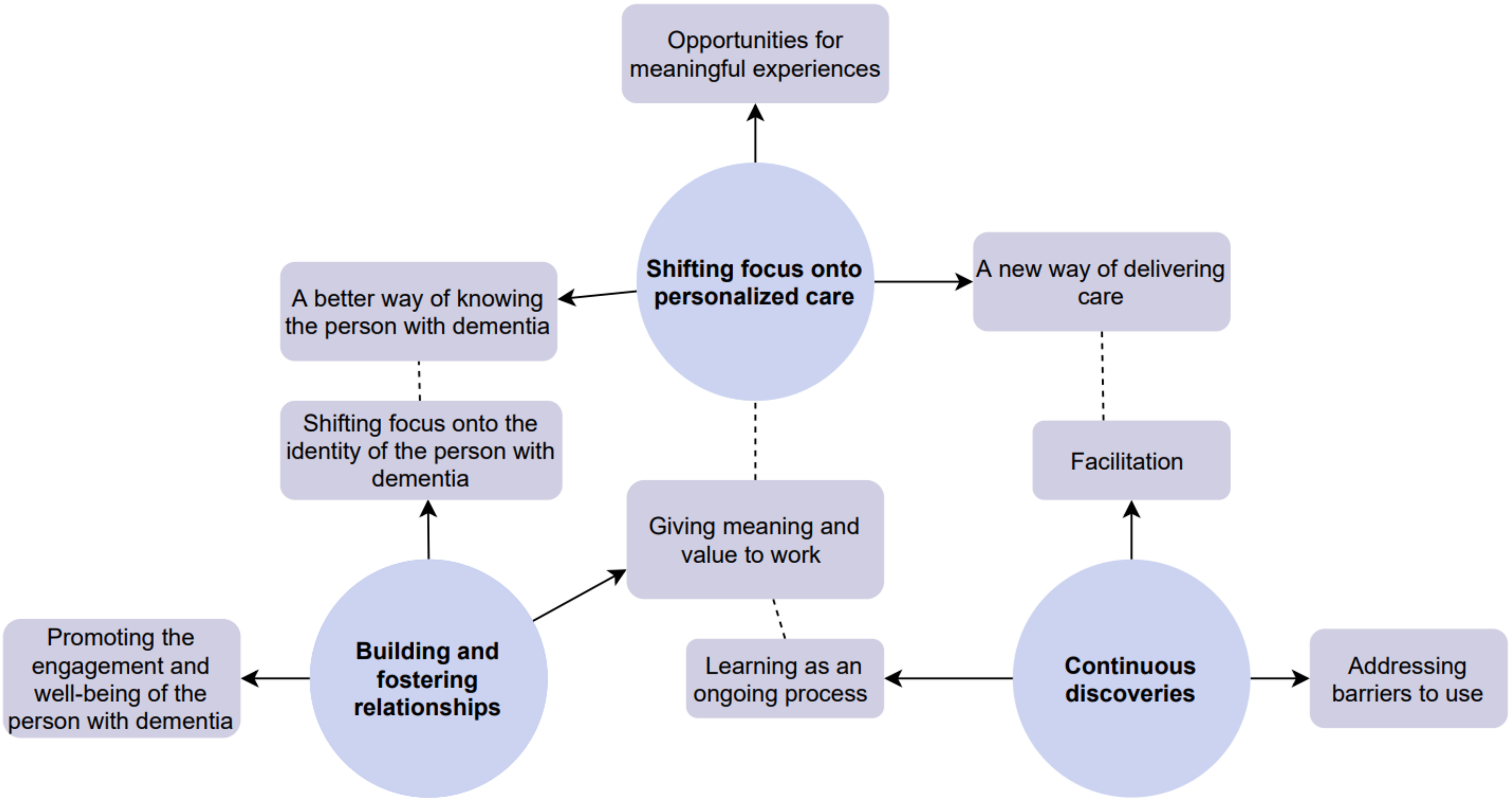


Figure 15. Thematic map of themes and subthemes generated from interviews conducted in 2021

5.5. Reflexive synthesis of findings

In reflecting upon all the themes generated throughout Papers II, III, and IV, there are connections that can be made across all three papers. Figure 16 illustrates three prominent connections that were identified across these papers, with each connection being represented by a different colour.

Firstly, the users in Paper II anticipated that the SENSE-GARDEN would be used as an opportunity for shared experiences between people with dementia and their caregivers. In Paper III, the participants commented on the way in which SENSE GARDEN provided moments for connection. This was confirmed by the care professionals' experiences in which they expressed SENSE-GARDEN presented the opportunity of providing meaningful experiences which contributed towards the fostering of relationships.

Moving onto another theme from Paper II, challenges to consider, the user groups predicted issues that could arise throughout the project, such as difficulties with individualizing the sessions. However, as reflected in Paper III, the effort that goes into individualizing the session results in an increased understanding of the person with dementia – not only for professional caregivers, but for family members too. This is echoed by the care professionals in Paper IV, who expressed that investing time and effort into

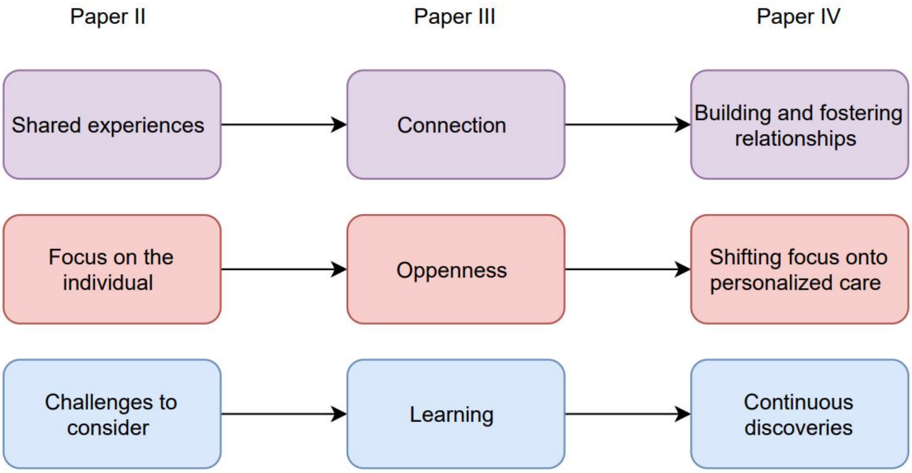


Figure 16. Reflecting on themes throughout Papers II-IV

individualizing session is a continuous process in which they learn more about the person with dementia as they take part in more sessions with them. However, the care professionals emphasized the importance of fixing the technology so that the seamless solution to individualizing sessions could be implemented, perhaps making it less time consuming to prepare the sessions.

Finally, the red thread that appears to connect these three papers together is the shift in perceptions towards people with dementia, and also to dementia itself. In Paper II, the users emphasized the importance of focusing on the individual with dementia, making sure that their wishes and needs were prioritised above all else. In Paper III, many participants spoke about the openness they had experienced from others and had also experienced within themselves. Finally, in Paper IV, the care professionals commented on how using the SENSE-GARDEN together with people with dementia resulted in them seeing the person in a different way.

It is this shift in focus away from dementia and to the individual – a shift facilitated by the use of SENSE-GARDEN – that is key for connection, openness, and learning. When one looks beyond dementia, there are opportunities for connecting with the individual on a deeper level, opportunities for openness and vulnerability, and the opportunity to learn more about their life and the stories that it is composed of.

Chapter 6

Discussion of methods

6.1. Choice of study designs, data collection and methods for analysis

The studies in this PhD utilized qualitative methodology as a means of exploring how the participants made sense of SENSE-GARDEN through symbols and social structures (Lune and Berg, 2017). This is an approach that was in line with the theoretical positioning of this thesis. The work in this PhD relied heavily on the use of interviews. However, alternative approaches were discussed prior to data collection. In discussing how to best capture how narrative identity is co-constructed during the SENSE-GARDEN sessions, my main supervisor and I decided conversation analysis (CA) of video recorded SENSE-GARDEN sessions would be a good approach. CA is known for its rigorous and well-established method of identifying structures and processes within social interaction. Importantly, CA also includes the analysis of non-verbal behaviour which is a vital component of communication for people with dementia. Furthermore, this method has been shown to inform the development and quality of care environments (Chatwin, 2014). As such, we planned to perform conversation analysis on video-recordings of the SENSE-GARDEN sessions at each test site.

However, we ran into several problems in trying to take this approach. Firstly, the sessions were being conducted in Norwegian, Portuguese, Dutch, or Romanian – depending on the test site. As a native English speaker with only a basic understanding of Norwegian, I would not have been able to perform analysis on any of the recorded sessions by myself. In an attempt to solve this issue, I looked for speech-to-text software that could help translate what was being said, with the ability to transcribe multiple languages. However, this would have meant I would not have been able to analyse the nuances of the participants' speech such as intonations of each word/phrase. Despite this, I still looked for software so I could at least understand what was being said in the sessions. After trying out a couple of programs, I found that the presence of music in the sessions was causing issues for the software in detecting in what the participants were saying. Therefore, conversation analysis was not used for the PhD.

In line with the literature discussed in the background, incorporating ethnographic methods may have been an appropriate choice for the study of how identity is co-constructed in the context of SENSE-GARDEN sessions. Ethnography seeks to reveal social structures and interactions through first-hand experience of a setting i.e. conducting intensive fieldwork and participant observations (Holloway and Todres, 2003). Participant observations could have been included in Paper III as means of understanding in the moment experiences and how these contribute to the co-construction of identity. Participant observation is well recognised as a tool for collecting rich data about people, processes, and cultures (Kawulich, 2005). However, given that the background of the majority of researchers on the SENSE-GARDEN project lays within quantitative methodology, incorporating ethnographic methods would not have been possible. Furthermore, ethnography relies heavily on the naturally occurring language of participants in the field (Holloway and Todres, 2003). Therefore, my ability to conduct intensive fieldwork at the care homes would have been hindered by the language barrier at each test site.

Interviews were considered an appropriate choice as they capture how participants make sense of and ascribe meaning to their experiences, to themselves, and to their relationships with others (Weiss, 1995). Furthermore, having experience in interviewing, I was able to provide guidance to researchers/facilitators on the project who had no or little experience in conducting interviews. However, reflecting on the gaps in research regarding the implementation of person-centred interventions in practice, adopting a case study approach in this PhD would have been beneficial. Berg defines a case study as "a method involving systematically gathering enough information about a particular person, social setting, event or group to permit the researcher to effectively understand how the subject operates or functions" (Berg, 2009:317). Organizational case studies of each facility in

Norway, Portugal, Belgium, and Romania could have provided an in-depth understanding of how each facility operates in standard practice and how the SENSE-GARDEN intervention may have fit into this. Conducting data collection in this way could have provided useful insights on how these interventions may be implemented on a long-term basis in the future.

6.1.1. Choice of analytic approach

One of the first considerations for analysing interview data was Interpretative Phenomenological Analysis (IPA). The aim of IPA is to explore individuals' meanings of their own everyday lives and experiences (Smith, Flowers, and Larkin, 2009). Adopting IPA would have allowed for an in-depth exploration of how individuals make sense of their experiences within SENSE-GARDEN. However, IPA is recommended for small samples of approximately 10 participants or less (Alase, 2017). Therefore, it may not have been the most appropriate choice for Paper II (with 52 participants) or Paper III (with 20 participants). It may have been appropriate for Paper IV, which only had 8 participants. However, Braun and Clarke have recently recommended that thematic analysis be used instead of IPA when there is a need for the research to have clear implications for practice (Braun and Clarke, 2021). Given that the aim of Paper IV was to consider how SENSE-GARDEN may be integrated into practice into the future, clear 'thematic statements' based on shared meaning (Braun and Clarke, 2021) would not have likely been achievable with IPA.

Therefore, thematic analysis was chosen for its high level of flexibility. Thematic analysis is a method that can be adapted to varying needs and requirements of research projects (Braun and Clarke, 2014). For instance, approaches to coding can either be inductive (data-driven) or deductive (theory-driven) which suit the UCD work in Paper II and the theory-driven exploration of experiences in Paper III, respectively. However, this flexibility can lead to an inconsistent and incoherent development of themes (Holloway and Todres, 2003). It is therefore vital that researchers are transparent when reporting all phases of analysis.

On reflection, another approach which would have been highly relevant to the topic of this thesis is narrative analysis. Narrative analysis is a mode of inquiry that seeks complex patterns and descriptions of identity, knowledge, and social relations from specific cultural points of view (Daiute and Lightfoot, 2004). In the context of this thesis, collecting stories from participants on their experiences inside SENSE-GARDEN could have provided more open and detailed accounts (in comparison to semi-structured interview questions). However, similar to conversation analysis, narrative analysis should also consider the observable and hearable details of talk and text (Stanley and Billig, 2004). The subtle nuances of the conversations (e.g. pauses, intonation, emphasis, precise wording of phrases) collected during narrative inquiry would have most likely been lost in translation to English, therefore losing the essence of the storyteller.

6.2. Reflexivity in planning, data collection, analysis, and reporting of studies

Qualitative research has often been criticized, particularly within health policy and practice, for its potential bias when collecting, analysis, and reporting data (Galdas, 2017). The researcher's own subjectivity, past experiences, and relationship to the participants is very likely to shape the interpretation and reporting of results. However, through reflexivity, a researcher can be aware of and address the influence their background and position may have had on the study. According to Berger:

> "reflexivity is commonly viewed as the process of a continual internal dialogue and critical self-evaluation of researcher's positionality as well as active acknowledgement and explicit recognition that this position may affect the research process and outcome" (2015: 220).

In practicing reflexivity, a researcher is aware of their own relationship to the research topic at hand, and their relationship to the participants (Dowling, 2006). Etherington (2004) suggests four questions to ask oneself in the practice of reflexivity: 1) How has my personal history led to my interest in this topic? 2) What are my presuppositions about knowledge in this field? 3) How am I positioned in relation to this knowledge? 4) How does my gender/social class/ethnicity/culture influence my positioning in relation to this topic/my informants? Over this section I draw on my personal history, background, relationships, and demographics to reflect on how these may have influenced the PhD studies throughout all stages.

6.2.1. Planning of the studies

The choice of methods for this PhD were influenced by my background as a qualitative researcher, particularly within the field of music psychology. However, with the PhD being conducted within the scope of a European project, it was important to design studies that would not only meet the aims of the PhD, but also contribute to the larger project at hand. It was decided that the data on the participants' experiences of using SENSE-GARDEN (described in Paper III) would be collected within the context of the multisite trial. This complicates the methodological implications for Paper III, as the paper is positioned on qualitative methodology. However, the SENSE-GARDEN multisite trial consisted of a controlled before-after design, which is why some participants in Paper III used the SENSE-GARDEN for 16 weeks, and others used it for only 12. Such a design is not in line with qualitative methodology. However, the experiences of participants were studied as a whole rather than in terms of a comparison between groups.

In terms of my personal and professional background, I am a trained musician with experience of volunteering with singing groups for people with dementia and their families. I also have a BA degree in Music and an MA in the Psychology of Music. This background could have led me to pay more attention to the musical aspect of the SENSE-GARDEN intervention and promote the use of music above all other components. However, by keeping the aim of the PhD broad with regards to the components of the intervention (i.e. considering SENSE-GARDEN as a whole), I decided I would give focus to the components that were most often spoken about during the interviews. Second, I had little knowledge of technology use for dementia care prior to the PhD. With my main interests being in the arts, I held both scepticism and curiosity towards the use of technology in dementia care. This scepticism may have influenced me in choosing to focus on the emotional and social aspects of SENSE-GARDEN, rather than studying the technology itself (e.g. in terms of system design).

6.2.2. Data collection and analysis

In understanding the researcher as instrument in the generation of data (Pezalla, Pettigrew and Miller-Day, 2012), I consider how – and to what extent – I contributed to the generation of data amongst the three empirical studies. Being an English native speaker who moved to

Norway to conduct this PhD, I lacked the ability to speak in the native language of any of the four test sites. As such, interviewing in any other language than English would not have been possible for me. This meant that the interviews in Papers II and III had to be conducted by native speakers at each test site before transcripts were translated into English for analysis. Having not collected the data myself, I was not actively involved in the generation of data. This means that my interpretation of the data may not reflect the feelings of the interviewers and respondents. However, all interviewers in Paper II were co-authors and supported the narrative I had created about the data. In Paper III, one of the three interviewers was a co-author on the Paper. The other co-authors were native speakers in Norwegian and Portuguese, meaning that we worked together on a narrative that best represented the voices of the participants.

Additionally, some of the nuances connected to expressing oneself in their native language may have been lost during the translation of transcripts. However, the co-authors on these papers consisted of native speakers of the language local to each test site (i.e. in Paper II co-authors consisted of Romanian, Dutch, Norwegian, and Portuguese collaborators) and, through their involvement, we aimed to ensure that the final publications were accurate representations of the participants' original statements.

For Paper IV, I collected the data myself through interviews and observations. Reflecting on my experience of observing the SENSE-GARDEN sessions at the Norwegian test site, I could be considered an outsider due to the fact that a) I was a researcher and not a member of care staff at the facility and b) I could only speak a little Norwegian. However, I believe that not being able to fully understand or communicate with the residents through verbal means provided me with heightened insight into what can be achieved through non-verbal communication. In my field notes I wrote:

> "[The caregiver] put on traditional Norwegian folk music, and [the resident] said he wanted to dance. In Norwegian, he asked me to dance with him *(Skal vi danse?)* and so I did. It was an enjoyable experience. I managed (or at least tried) to speak some Norwegian with him (he laughed after I tried to tell him he was good at dancing), but I felt that the music and dancing facilitated our laughter, smiling, and eye contact..."

Despite these field notes being a part of the study reported in Paper IV, I believe the experience also influenced my analysis of the data for Paper III. I was particularly drawn to participants' remarks about dancing and singing to music, mainly due to my background as a musician but also perhaps because of my time spent in the SENSE-GARDEN space at the Norwegian test site.

Finally, it is also important to note that I am the PhD student of the project coordinator, who is the primary investigator of the SENSE-GARDEN project. This may have influenced the responses from the care professionals in Paper IV. All participants knew that the project coordinator was my main supervisor and therefore they may have answered my questions in a way that would please him, despite me assuring the participants I would anonymize the responses before sending my supervisor and other co-authors at NTNU the transcripts. This was seen by one of the participants apologizing for her negative remarks on certain aspects of the project being a "bad experience".

6.2.3. Reporting of the studies

Given that this PhD is qualitative, the PhD papers should have used more appropriate language to reflect the methodological and theoretical positioning of the studies. As Galdas (2017) argues, the challenge with qualitative research lays not with convincing others that qualitative work reflects objective, opinion-free neutrality. Rather, he argues, it is to better communicate the value that qualitative derived knowledge can offer with a system that measures impact through an evidence-based, decision making lens:

> "Although it may be more difficult to quantify the impact of qualitative research, we should resist the temptation to reach for a positivist tape measure to solve this problem. To do so will lead us to become apologists for the subjectivity that is the very strength of interpretive work" (Galdas, 2017).

The effort to resist positivism can be particularly challenging when working within interdisciplinary teams in which members hold different values. The SENSE-GARDEN project itself (e.g. the project's multisite trial) is arguably based on positivist values. Furthermore, this PhD is in Medical Technology, conducted in NTNU's Department of Neuromedicine and Movement Science, where most of the research is quantitative and driven on positivist approaches. Thus, whilst attempting to avoid the use of positivist language and values in my own writing, I acknowledge that there are times and places where I did ‘slip’ into positivist thinking by using terms such as “sample size” and “validity”. Terms such as ‘trustworthiness’ and ‘credibility’ would have been more appropriate.

6.3. Conducting multisite, cross-border research

Collaborating across countries presents both benefits and challenges. Benefits included being able to gain insight into dementia care across different countries and being able to explore social and cultural differences between the test sites. Additionally, it was interesting to see how each test site facilitated the SENSE-GARDEN in different ways. However, there were challenges regarding, issues with data collection, and a lack of consensus on how the SENSE-GARDEN system should be used. These benefits and challenges are discussed in further detail below.

Firstly, dementia is a challenge faced on a global level. Therefore, being able to conduct research across different countries presents opportunities to explore social and cultural differences. With three of the test sites being in Western Europe and one being in Eastern Europe, it was interesting to see that the professionals across all test sites valued a person-centred approach to care. Additionally, a lack of person-centred care in current practice was noted amongst most participants in Papers III and IV. This suggests that more work is needed in this field on an international level.

Another observation was the varying methods of facilitation of the SENSE-GARDEN sessions, based on both cultural differences and disciplinary differences. The individualized nature of SENSE-GARDEN may have prompted improvisatory approaches to facilitating sessions. Whilst the results from Belgium were not available for Paper III, it is important to note that some of the SENSE-GARDEN sessions there included the use of stimuli and material not specified in the study protocol. For example, drinks and food (e.g. tea and biscuits) were included as part of the multisensory experience. On another occasion, a dog accompanied the person with dementia in the session. Likewise, in Portugal, there were extra elements to the sessions that were not specified in the protocol such as board games. This suggests that more natural elements are needed in addition to the technology inside SENSE-GARDEN. Allowing each test site to make the space their own is perhaps what made the care professionals enthusiastic about the SENSE-GARDEN spaces. Returning to the challenges of implementing interventions into practice, Kormelinck et al. (2020) suggest that interventions need to be tailored to the local characteristics of the organization if they are to be effective.

Difficulties were present in ensuring that each test site followed the same protocol with regards to data collection. For Paper III, it was intended that interviews from the Belgian test site would have been included. However, the team members at the site did not conduct interviews as the participants at this site were in a more advanced stage of dementia, which impaired their communicative abilities. Collecting data from participants with severe dementia would have added important value to the study, especially considering the target group of this PhD is people with moderate to severe dementia. Given the limitations of using interviews with people in later stages of dementia, researchers have called for the use of innovative participatory approaches that incorporate innovative approaches into qualitative research methods (Phillipson and Hammond, 2018). For example, semi-structured interviews can be adapted to include visual and sensory stimuli. Future work within SENSE-GARDEN could adopt such methods in order to capture the views of people with advanced dementia.

Finally, one criticism on current evidence in this field is the lack of information on how care staff are trained to use technological solutions in dementia care (Lazar, Thompson, and Demiris, 2014; Goodall, Taraldsen, and Serrano, 2020). The SENSE-GARDEN study also failed to provide a clear consensus on how staff should be trained or how sessions should be facilitated. Whilst there was a task force in place to define and coordinate this procedure, and there were calls between the project's technical partner and the test sites, and basic video tutorials were made by the author of this thesis (the PhD candidate), cultural and operational differences created difficulties in the process. Furthermore, as seen in Paper IV, all test sites experienced problems with the technology and, as such, came up with their own solutions to using SENSE-GARDEN e.g. through Windows Movie Maker or PowerPoint.

6.4. Addressing potential impacts on participant responses

It is important to acknowledge that the responses from participants during the interviews may have been affected in numerous ways. Factors such as leading questions, differences in interview styles, recruitment, and researcher-participant relationships must be acknowledged.

In qualitative research methods such as semi-structured interviews, the researcher is the instrument (i.e. the means by which data is collected) and, therefore, unique researcher attributes can influence data collection (Pezalla et al., 2012). In arguing that qualitative researchers are “differently calibrated instruments”, Pezalla and colleagues (2012) call for researchers to be aware of varying characteristics and how these characteristics influence participants responses. Whilst an advantage of semi-structured interviews is being able to expand on participant responses to probe a particular point of interest in further detail, the freedom to deviate from the guide presents the potential for individual interviewers in a study to shape responses in different ways.

The differences in interviewer characteristics were seen in Paper III, particularly with an interviewer in Portugal. From having thoroughly read the transcripts, the interviewer seemed affirming and energetic, characteristics which can generate detailed responses from interview participants (Pezella et al., 2012). However, I noticed the use of closed, leading questions such as “It made you feel happy, right?” Furthermore, there were close-ended questions which seemed to be more of a test of memory rather than an exploration of experiences e.g. “What are the names of your parents?” and “Do you remember this...?” It seemed that the interviewer’s own positive experiences as a facilitator of the SENSE-GARDEN sessions may have prompted her to use the interviews as a way of affirming the positive results of the intervention. However, despite this, the transcripts were considerably longer than the Norwegian interviews, and participants went into great detail about their experiences.

Returning to the issue of leading questions, I acknowledge that some of the questions in the interview guides could have been worded in a less influential manner. For example, asking care professionals the question “What do you think about the potential of SENSE-GARDEN being used to help staff to get to know residents better?” gives the impression that the SENSE-GARDEN *can* help staff get to know residents better. A more neutral way of phrasing the question would be to ask "How do you see the SENSE-GARDEN being used between staff and residents?" This would leave the question up to the participants' own interpretation.

Another potential influential factor in the studies is that of recruitment. First, for Paper II, the participants were a convenience sample of "super-users" who had been involved in other research projects. Therefore, their attitudes towards new concepts involving technology may have been more enthusiastic compared to a random sample of user groups. For Paper III, the participants with dementia were only recruited if they (or their family member) had expressed an interest in taking part in the study. This willingness to participate may mean that the participants with dementia were more receptive to the intervention compared to other residents in the care facilities (this is often referred to as "self-selection bias"). For Paper IV, the care professionals were recruited by the PhD candidate on the SENSE-GARDEN project, and therefore may have felt pressured to not only participate, but also to give positive feedback. However, as seen in the transcripts, the care professionals voiced their concerns and accounts of negative experiences.

Finally, whilst I have addressed my own relationships to the participants in the sub-section on reflexivity, it is important to address the relationships between participants and other project members. In the study reported in Paper III, the interviews were conducted by people who had been facilitating the SENSE-GARDEN sessions. As such, the participants may have felt pressured to answer questions in a more positive light. However, we decided that the interviewer should be somebody who is familiar to the participants. The advantage of having the facilitator conduct the interview was the fact that they could make the participants feel more at ease compared to somebody unknown to them. Additionally, the facilitator could also refer back to moments experienced together in the SENSE-GARDEN space as prompts during the interview and therefore generate more in-depth data.

6.5. Limitations of the included samples

A limitation of work in this area identified in the literature review (Paper I) was the small number of participants. The same limitation applies to the studies conducted as part of this thesis – particularly the studies reported in Papers III and IV.

Paper III aimed to capture the experiences of people with dementia and caregivers (both formal and informal) who had used SENSE-GARDEN. As such, the sample included a mix of people with dementia, family, friends, and professional care staff. However, a total of 20 people was interviewed, and only 7 of these participants were people with dementia. Given that the main target population of this PhD was people with moderate and severe dementia, it is unfortunate that not more people in this group were included in the studies. However, other target users for involvement in the SENSE-GARDEN intervention are informal and formal caregivers. The work in this thesis included their perspectives and reflections on SENSE-GARDEN, which provided important insights for future work in this area.

Thus, despite the small number of participants across the studies, this work managed to capture multiple perspectives by involving a variety of individuals, including people with dementia, family, friends, and care professionals. Including these multiple perspectives is important when working to create ways of facilitating meaningful activities, especially in the initial stages. However, going forward, larger studies are needed to evaluate the feasibility of activities of these types in order for them to be implemented into routine care.

6.6. Including the voice of users: Is user-centred design enough?

In the literature review (Paper I), most studies included the person with dementia in the individualization process of the technology, indicating that research in this area is adopting a more inclusive approach. The SENSE-GARDEN project sought out to implement a UCD approach into the development of the SENSE-GARDEN, and the results from Paper II reported on the findings from the first phase of the UCD approach. The information collected from the interviews was used to develop user specification requirements for the SENSE-GARDEN system. However, people involved in this early stage of the project were people with mild cognitive impairment, not people with moderate to severe dementia (the target group of SENSE-GARDEN). The reasoning for this was that the technicians in the project required clear, verbal feedback in order to develop the system.

However, future work should seek to involve persons at a later stage of dementia from the outset of projects, even if it means adapting more traditional methods of UCD approaches. For example, a recent article by Kenning (2018) offers guidance and ideas for engaging people living with advanced dementia in group workshop environments and co-production processes. In the context of the SENSE-GARDEN project, perhaps a mediator between people with advanced dementia and technicians could have been involved to integrate a more co-productive, co-creative element within the project's UCD approach.

One criticism is that SENSE-GARDEN was not co-creatively designed with people with dementia or their family members. For instance, a publication on the project's first kick-off meeting describes a group session between care staff, medical doctors, and researchers/technologists/designers (Sørgaard et al., 2018). Including people with lived experience of dementia may have shaped the development of the intervention in a different way. Furthermore, whilst there were interviews and user sessions, the hierarchy between "researcher" and "participant" still existed and thus a power relationship was still in play. One way of removing these hierarchies is through co-creativity.

There is a growing interest in using co-creative methods with people with dementia, particularly within the arts. While the term is "co-creativity" is still fairly new in the context of research, Zeilig, West, and Van der Byl Williams describe co-creativity as being characterised by a focus on shared process, shared ownership as opposed to a single author or outcome, inclusivity, reciprocity, and relationality (Zeilig et al., 2019: 138). The authors describe an experimental, co-creative arts project "With All" which involved weekly sessions including people with dementia, their partners, dancers, and musicians. The sessions did not work towards a particular artistic output, but instead embraced improvisation and expression in which everyone was treated as equal. In reflecting on the project, the authors write:

> "At the foundation of co-creativity, is the understanding that everyone has something to offer and that even apparent passivity and quiet affects and helps to direct the mutual creation. Thus, co-creativity is an innately democratic and non-hierarchal version of creativity in which the diverse capacities of all those involved are woven into a cohesive process." (Zeilig et al., 2019: 141).

The participants in the PhD studies responded positively and enthusiastically to the SENSE-GARDEN concept. However, it would be interesting to see if the SENSE-GARDEN and/or the sessions would have been different had the intervention and space been developed in a co-creative manner. In Paper IV, the care professionals spoke about the "playfulness" of the SENSE-GARDEN intervention, something which is at the heart of co-creative art sessions such as those in the "With All" project (Zeilig et al., 2019). The care professionals also spoke about the ways in which they continuously took the time to learn what the residents liked – whether that was through listening or responding to gestures – and then adapted future sessions based on this knowledge. In one way, this may be considered a co-creative development of the sessions. With this being said, future interdisciplinary projects that lay at the intersection of arts and technology should aim not to create technological solutions *for* people with dementia, but instead *with* people with dementia.

6.7. Ethical considerations

6.7.1. Cross-national differences in approval procedures

With the SENSE-GARDEN being a multisite project, each participating country had to seek ethical approval in accordance with their national guidelines. In contrast to Norway and Romania, formal ethical approval was not needed for the test sites in Portugal and Belgium. Despite differences in approval procedures, good ethical practice was ensured through a joint consensus on how to conduct and report the studies. Belgium and Portugal were following the same study protocol as Norway, which had ethical approval from Norway's Regional Ethics Committee. Therefore, it can be assumed that Belgium and Portugal were conducting the study ethically. The test site in Romania had a different protocol due to the difference in study setting (a hospital instead of a care home).

Though the study was conducted in an ethical manner, implications of these cross-national differences need to be addressed – particularly with regards to Portugal and Belgium. These two sites lacked formal approval but conducted the study in accordance with the principles of the Declaration of Helsinki. However, the principles emphasize that potential risks must not outweigh potential benefits. I draw specifically to principle 28 on the inclusion of participants who are incapable of providing informed consent:

> "These individuals must not be included in a research study that has no likelihood of benefit for them unless it is intended to promote the health of the group represented by the potential subject, the research cannot instead be performed

> with persons capable of providing informed consent, and the research entails only minimal risk and minimal burden." (WMA, 2018: 3).

When an ethical committee does not give approval, who evaluates that an intervention's risks are minimal? It is of course the duty of the researcher to ensure that their intervention is based on previous evidence and knowledge, but the input of an ethics committee is valuable. One of the roles of an ethics committee is to consider the potential risks and benefits of a proposed study in order to evaluate whether the inclusion of participants who are unable to provide consent is justified (WHO, 2009). In the case of Portugal and Belgium, there was no decision from an ethics committee, meaning that the potential risks of SENSE-GARDEN at these sites may not have been evaluated by somebody independent of the project. As such, I believe there need to be changes in national legalisation so that formal ethical approval is needed for all research studies, even if those projects are not considered clinical or medicinal.

6.7.2. Consent

Whilst people with dementia are being increasingly involved in research, there are always important ethical concerns to consider, particularly with regards to informed consent. It is important that participants feel comfortable in their environment – particularly in new ones such as SENSE-GARDEN. Therefore, the participants' needs were always adhered to. One example of this can be seen from my field notes collected during the study for Paper IV:

> "The resident told [the member of care staff] that he would not want to come to the [SENSE-GARDEN] room alone. I am not sure if this is because he enjoys the company, or whether it is due to the unfamiliarity of the space... me and [the member of care staff] decided on a brighter colour for the room for his next visit, to try and make it more comfortable for him" Field notes, Paper IV

Despite informed consent being provided by proxy, efforts were made to assess whether or not the participants were happy to take part in the sessions. Before each SENSE-GARDEN session, the care professional facilitating the session would greet the participant and invite them to look at some photos and play some music inside the SENSE-GARDEN. Based on the resident's verbal and non-verbal response(s), the professional caregiver would then decide whether or not to take the resident to the SENSE-GARDEN. This could be considered in line with Dewing's (2007) guidelines for ongoing consent monitoring, in which ensuring initial consent is revisited and re-established on every occasion throughout the study. Furthermore, the staff facilitating the sessions were sure to stop the session at any time in case the participants showed any sign of distress or discomfort.

6.7.3. A picture speaks a thousand words: Deciding whether to include photographs in scientific dissemination

To respect the privacy of participants, participants' faces are blurred in all photos used in the PhD papers and thesis. However, it was considered important to include this visual data as a means of communicating the experiences of SENSE-GARDEN in a way that goes beyond textual descriptions.

A nurse who had facilitated the SENSE-GARDEN sessions in Norway made a compilation of photos and videos she had taken herself during her time on the project. Whilst this was not asked of the care professionals, watching the caregiver's video gave me insight into the SENSE-GARDEN experience from her point of view. Residents looked happy, they were dancing with their family members, and they were engaging with activities inside the room. This goes against the usual imagery attached to dementia (Brookes et al., 2018).

With the rise of technology in everyday life, it is interesting to see how social media platforms can be used to shape empowering narratives on ageing and dementia amongst society. For instance, on the 9th November 2020, Musica Para Despertar (Music to Awaken) posted a video of Marta Cinta González Saldaña, a former ballet dancer with Alzheimer's Disease, which has since gone viral. The video shows a frail Marta listening to Tchaikovsky's Swan Lake whilst sat in a wheelchair. However, as the music is turned up, we see Marta blossoming into movement, re-enacting the dance of Odette, the swan queen. With over 2 million views on YouTube, and almost 20,000 comments on Facebook, the video has sparked the wonderment of many. It has elicited emotional and compassionate responses that are in line with the person-centred approach of recognising the unique personhood of individuals with dementia. Similarly, on a video-sharing social media platform, TikTok, a woman with advanced Alzheimer's Disease has gone viral for her skilled renditions on the piano. Having over 155,000 followers on the platform, with video views of up to 7.5 million users, the comments on the videos are ones of compassion and curiosity towards learning more about dementia.

This is beyond the scope of this thesis, but this point is raised to argue that a larger ethical discussion is warranted. If identity is performed through movement and gesture, how do we as researchers communicate this in scientific dissemination? As long as we only use words, the communication of participants' narratives will be limited to how we as researchers interpret them. Others have suggested working with illustrators to create cartoon-like depictions to portray story in a meaningful way whilst still maintaining the anonymity of participants (Mannay, 2020). Whilst this is still an interpretation, it is perhaps the best balance between communicating findings in a visual way and upholding good ethical practice.

6.8. Impact of the COVID-19 pandemic on the directions and scope of the studies

The original plan for Paper III was to report not only qualitative findings, but also quantitative findings from the SENSE-GARDEN multisite trial. However, this trial, originally due to finish in May 2020, was suspended in March 2020 due to the global pandemic concerning COVID-19. The uncertainty of when the trial would begin again, if at all, meant that I had to decide on what direction to take the PhD. Whilst I could have included a scarce amount of quantitative data from a small number of participants, it was decided that the PhD should become entirely qualitative and focus on interview data collected in the trial thus far. This change in plan means that the conclusions drawn in Paper II may be confusing to readers when taken together with the other studies in the PhD, as well as this thesis. In the paper, I wrote:

> "Whilst qualitative methods capture rich personal accounts of user experiences, it is important to recognise the value of quantitative measures. Therefore, physiological data will be collected in addition to data from questionnaires, interviews and observation measures [...] Combining this data with qualitative accounts of the SENSE-GARDEN experience will provide a stronger overview of the processes that occur within the intervention" (Paper II: 21).

On reflection, I do not think it was right to suggest that including quantitative data would result in a "stronger" overview of the processes that take place inside SENSE-GARDEN. However, it is important to acknowledge the quantitative measures I would have included, had I stuck to the original plan before COVID-19. Outcome measures that would have been included in this PhD were the Quality of Carer Patient Relationship (QCPR) (Spruytte et al., 2000), Quality of Life in Late Stage Dementia (QUALID) (Wiener et al., 2000), and the following observation measures: Verbal and Non-Verbal Interaction Scale (VNVIS-CR) (Williams, Newman, and Hammar, 2017); Observed Emotion Rating Scale (OERS) (Lawton, Van Haitsma, and Klapper, 1996); Observational Measure of Engagement (OME) (Cohen-Mansfield, Dakheel-Ali, and Marx, 2009). The results from the outcome measures would have been synthesised with the qualitative findings in a mixed-methods approach.

Despite the methodological shortcomings of the studies, discussed throughout this chapter, I believe that this thesis still presents a strong argument for the use of SENSE-GARDEN for people living with dementia. It seems fitting to present a quote from an 83-year-old participant with dementia captured in Paper III:

> "It gives me a great moment. Things that you have experienced come back and that is very nice. It's probably what the SENSE-GARDEN is all about. The things that you have experienced long time ago get into your head again ... I think it was an amazing experience and that is how it should be. It is absolutely the truth. You have to remember that what I say is my opinion. **It is not nonsense, it is the truth**. And that is good."

Additionally, there are lessons to be learned from the COVID-19 pandemic. Could something similar to SENSE-GARDEN help in the time of a similar crisis? Whilst the current version of SENSE-GARDEN is designed for joint interaction between multiple people being in the room at once, perhaps it could be adapted for social connectivity. Integrating a telepresence component into the SENSE-GARDEN may allow for individuals to share meaningful moments with one another remotely. However, the importance of human contact cannot be forgotten. During the pandemic, the world stood at a standstill, and perhaps we all got a sense of the loneliness that people living with dementia are often subjected to. Whilst we were able to stay connected to family and friends through technical solutions such as Skype and Zoom, it could not compare to the physical presence of another person with whom a moment could be shared.

Chapter 7

Discussion of results

7.1. Summary of results

The main findings of this thesis suggest that technological solutions can be used to create meaningful activities that support the preservation of narrative identity and interpersonal relationships in dementia care. The success of these solutions is based on embracing a user-centred design, working together with care staff, and adopting a holistic approach into investigating how the technology is experienced. In the context of SENSE-GARDEN, the findings suggest that providing a dedicated space in which people with dementia and caregivers can interact with the life story of the individual through music, film, and pictures may promote a sense of connection within caregiving relationships.

These findings reflect similar research in this field, which suggests that technology is a way of making residents' life stories easier to gather and apply in care practice (Subramanian and Woods, 2016; Purves et al., 2011). In line with findings from the literature review (Paper I) that suggests individualized technologies can benefit people with dementia in terms of promoting social engagement and a sense of self, the studies in this thesis suggest that technology such as SENSE-GARDEN can be a tool for promoting interpersonal relationships and a sense of identity. However, as indicated in the literature review and confirmed in the qualitative studies, technological solutions such as SENSE-GARDEN take time to set up and use, and therefore may potentially be unsustainable in the daily routines of care environments which are often hectic and under-staffed.

The next subsections of this chapter discuss the results of this thesis in the context of attitudes towards technology, rhetoric on dementia, implementing complex interventions into care, using theory to inform research and practice, co-constructing narrative identity and relationships, and connecting through in-the-moment experiences. The discussion ends with reflections on whether SENSE-GARDEN is worth the cost. Finally, implications for future research and practice are given.

7.2. Attitudes towards technology

In Paper II, one of the challenges identified was “attitudes towards technology”. Some participants had said that people with dementia may be wary about the technology in SENSE-GARDEN. However, as apparent in the participants’ experiences reported in Paper IV, this was not the case. References to the technology itself were scarce, suggesting that the technology was just a tool in facilitating meaningful experiences – it was not the main focus. During the interviews, the participants spoke mainly of life events, and of experiences shared with one another both inside and outside of the SENSE-GARDEN.

One participant said it was great to see the photos in a large size, projected onto a wall. Here, we can return to Purves and colleagues’ (2011) suggestion of multimedia technologies being able to convey and harness the power of personal stories of people living with dementia. The authors argue that there is a very real sense in which history is brought to life through photographs, films, and music (Purves et al., 2011):

> These digital tools seem to have some way of extending the reach of these stories – they are no longer “merely” personal, some kind of possession of the individual, but rather are something to which we all belong in some way.” (Purves et al., 2011: 241).

Returning to Dawn Brooker’s work on person-centred care in dementia, she argues “filing cabinets in care facilities around the world are full of information about people’s lives, but still care staff will not know even the rudimentary facts” (Brooker, 2004: 220). The findings from this thesis suggest that technology can be a means to engaging staff with this information about people’s lives. The SENSE-GARDEN provided residents and caregivers the opportunity to be immersed in the life story of the individual, and having this dedicated space resulted in meaningful experiences in which people got to connect with one another. By looking at what technology has to offer, attitudes towards technology may shift from scepticism to trust.

7.3. “A fading past and no future”: Rewriting the rhetoric of dementia

The work conducted as part of this PhD indicates that people with moderate to severe dementia can still retain a sense of self, are able to engage socially and emotionally with other individuals, and are able to benefit from meaningful activity. This is in line with other research in this area (Mills, 1997; Phinney et al., 2007; Fells and Astell, 2011; Astell et al., 2019; Hydén, 2013; Johnson et al., 2017; Kontos, Miller, and Kontos, 2017; Machiels et al., 2017).

However, despite the copious amount of progress that has been made with regards to challenging stigma in dementia, there is still a harmful narrative within research, e.g.: “[Alzheimer’s Disease] Patients become more and more unaware of the world and of themselves, until they eventually slide in a meaningless present with a fading past and no future” (Pietrini, Salmon and Nichelli, 2009: 207). Unfortunately, Zeilig’s (2014) stark observation of dementia being portrayed as a disaster that separates “us” (people without dementia) and “them” (people with dementia) is still present today. In a very recent article on the use of social robots and artificial intelligence in care, Sætra (2020) writes “No wonder then, that we are looking for ways to deal with this troubling wave of old and demented people. We must prepare and fortify.” Sætra’s “we” versus the “troubling wave of old and demented people” is a harmful narrative that not only provokes separation, but one that also provokes fear.

However, as Zeilig (2014) noted, people with dementia are increasingly speaking for themselves, and their personal accounts provide narratives that challenge the association of dementia with “decline and fall”. By listening to individual accounts, new perspectives on what the experience of living with dementia may entail can be created (Zeilig, 2014). The work within this thesis, Paper III in particular, has aimed to share the accounts of people with dementia in their own words. In addition, this thesis argues that creative ways of being able to identify and facilitate meaningful activities are needed in care, and the use of technology can help contribute to this. Technology can be a creative solution for providing meaningful activities that not only provide benefits to users in terms of social and emotional well-being, but that also provide family and caregivers with new knowledge on the individual with dementia, and, as a result, new attitudes towards dementia itself.

7.4. Making sense of complex interventions: can they work in care?

At the 2019 Nordic Arts and Health Conference, Nils Fietje, a research officer for the WHO, called for the development of complex interventions within the context of arts and health (Goodall, 2019). The nature of SENSE-GARDEN is undoubtedly complex. With different types of sensory stimuli, numerous activities including reminiscence, cycling, gaming, varying facilitation styles, and use by different countries within Europe, making sense of how the SENSE-GARDEN intervention works is a challenge – one which it still somewhat unaddressed. Whilst a transactional model was developed to understand how narrative identity can be co-constructed within the space, understanding how the intervention works as a whole is challenging. For instance, do certain activities within the space provide more benefits? Should the activities be conducted in a particular order? What is the optimal number of sessions per week, and how long should they last? What type of media contents is most effective in prompting engagement? These are all questions that future research on the concept may want to address.

The work in this thesis draws similarities to that of arts and health research. In a case study on art in health projects, MacNaughton, White, and Stacy (2005) summarised the varying approaches of creative arts interventions to produce a model of how art can be integrated into healthcare. Rather than implying that the arts alone can improve health, the model shows how art can work in unison with health services, social settings, and caregivers. Arguably, the same can be said for technology. It is not the SENSE-GARDEN alone that will have an impact on people with dementia, but it is the way in which it is implemented into care services and used by caregivers that will improve the lives of residents.

The work in this thesis focused on the overall experiences of SENSE-GARDEN. In terms of further evaluation, an intervention of this kind presents challenges. The complex nature makes it difficult to pinpoint exactly what it is about SENSE-GARDEN that produces any beneficial effect in its users. Is it the sensory stimuli? The activities? Or is it just the fact that a person has taken the time out of the normal care routine to talk about the life story of the person with dementia? Drawing again on MacNaughton and colleagues (2005), there is an urge for future researchers of art in health to reject “straitjackets of a medical model or research with medical outcomes” (2005, p.338). Whilst medical outcomes are arguably still important and of value, this thesis has demonstrated the usefulness of qualitative data to understand overall experiences of interventions as a whole.

In their review of cultural arts interventions for people with dementia, De Medeiros and Basting (2014) also address this issue of evaluation. The authors make the point that what is meaningful to one person may be different for another, and cultural arts interventions must not be limited to the tools of the clinical trial model. They also recommend that the measurement of such interventions should include larger networks of care staff and family, and they call for new study designs which consider not only the effects of cultural arts interventions, but *what* they comprise of and *how* they are delivered. All of this is arguably applicable to technological interventions such as SENSE-GARDEN, and future research within this area should similarly aim to go beyond traditional methods.

7.5. From Kitwood to Dewey: Using theory to inform research and practice

Just as Kitwood's theory of person-centred dementia care has influenced and informed research and practice, there is scope to use other theories to contribute in this way. Whilst the facilitation of SENSE-GARDEN was not based on theoretical knowledge, the theoretical positioning of this thesis shaped the ways in which the experiences of the intervention was analysed and understood. More specifically, the principles of symbolic interactionism and Deweyan transactionalism influenced how the findings were interpreted – particularly in Paper III. Theory was used as a way of understanding in-the-moment experiences within SENSE-GARDEN as being interconnected with memories, meanings, and relationships to time, space, and others at the broader level of experiences throughout one's life. Deductive coding of the data allowed us to pinpoint the instances in which these connections were made amongst the participants.

The participants often spoke of emotions being evoked from photographs shown during the sessions. Sometimes the attachment to these photographs was made explicit, for example, "It was very special to see pictures from when our son saved 3 lives from a drowning accident… it was strong to see [the pictures] on the big screen (the Reality Wall). As parents, we were terribly proud of our son." In other instances, the meaning behind the photographs was not so clear and the emotions elicited were perhaps feelings of nostalgia e.g. "[It was] fabulous, the first trip (inside the SENSE-GARDEN) was by ferry and to

Nordkapp. I remember that trip very well, [I] became emotional and cried a lot." During one interview, one man with dementia stated "I must say that I don't remember. It probably didn't mean that much to me..." which further emphasizes the significance of meaning-making. This is articulated in Urs Fuhrer's work on identity as meaning-making practice, in which he applies of Dewey's transactional theory person-artifact transactions:

> "...when one values an intimate place, or a cherished photo, these transactions are intentional activities that reflect what one considers significant and which involve real outcomes. The sense of being emotionally attached to an intimate place one has visited or in touch with a loved one, expresses what we consider significant and reveals the purpose that motivates us to invest psychic energy in certain artifacts and meanings rather than in others [...] The artifacts one selects to endow with special meaning out of the total cultural environment of artifacts are both models of the self as well as opportunities for further development. In this way, artifacts serve to give a tangible expression, and thus a continued existence, through signs to one's relationships, experience and values." (Fuhrer, 2004: 36).

In the context of SENSE-GARDEN, the media contents could be considered as digital artifacts which are endowed with meaning and thus symbolise identities, relationships, experiences, and values amongst the participants in the studies. The transactional model developed in Paper III was made in the attempt of making sense of how this meaning is made amongst the complex web of factors that come into play when being inside the SENSE-GARDEN. Arguably, factors within the model – developed on theory – can be linked to outcomes on well-being. Drawing on Kitwood and Bredin's (1992) global states of well-being for people with dementia (sense of personal worth, sense of agency, social confidence, sense of hope), implications from the transactional model can be discussed in relation to informing the well-being of people with dementia. For instance, the model illustrates the importance of understanding and empowerment from the caregiver in order to facilitate reciprocity, thus contributing towards the co-construction of narrative identity and relationships. This was noticed in one of the participants with dementia in Paper III who said "I was encouraged to tell", with his wife stating in a separate interview: "He does not have the same opportunity in the nursing home, that he can master something [as he does in SENSE-GARDEN]. No one expects anything from him". By being treated in a different way (being “encouraged to tell” his stories), the resident may have experienced a sense of agency. This is reflected in another quote where he says “You could talk about everything” which also suggests being at ease with others – something that is vital for a sense of social confidence (Kitwood and Bredin, 1992).

On reflection, it would have been appropriate to also draw upon other theories within dementia studies as opposed to placing emphasis on Kitwood’s theory of person-centred care. There have been criticisms towards person-centred care which were not addressed in this PhD. For example, Nolan et al. (2002) argues:

> “Person-centred care may well have ‘transformed’ thinking and, to a degree, practice in dementia, but it does not fully capture the interdependencies and reciprocities that underpin caring relationships” (Nolan et al., 2002: 203).

This thesis could have thus drawn on ideas from relationship-centred care (Nolan et al., 2004) or narrative citizenship (Baldwin et al., 2008). Despite this, however, I believe the PhD captured the reciprocities not only between people, but also between people and the wider situational context at hand. With the aim being to study not only the caring relationships, but the relationship to the wider environment (i.e. the SENSE-GARDEN), I believe adopting transactional theory was an appropriate approach to the studies. The focus on transactional relationships is not to say that care should not be person-centred, but it needs to be acknowledged that a person is fundamentally at one with their surrounding i.e. “human-as-organism-in-environment” (Dewey, 1929). Building on person-centred care with a transactional perspective allows for a truly holistic approach towards understanding and evaluating approaches to dementia care.

7.6. Co-construction of narrative identity and interpersonal relationships

One of the main aims of this thesis was to explore how narrative identity and interpersonal relationships are shaped by the use of technology, SENSE-GARDEN in particular. By drawing on theory, existing evidence, and the accounts of the individuals who have used SENSE-GARDEN, this thesis has emphasized the importance of creating meaningful activities that allow other individuals to learn about the person with dementia, activities that encourage openness, and a space that feels safe and fosters connection and engagement for the preservation and shaping of narrative identity.

The findings suggest that SENSE-GARDEN is a space in which the person with dementia could talk about their life experiences, and this was shown to give both staff and family members new knowledge on the individual. This is in agreement with other research in this area. For example, in their work on storytelling in care, Fels and Astell (2011) found that one of the most important aspects of engaging in reminiscence with people with dementia reported by caregivers is finding out new things about the people they care for. Similarly, Kuosa, Elstad, and Norman (2015) suggest that through a person's stories, care personnel can acquire a rich and nuanced picture of that person's life. Through providing a dedicated space in an otherwise fast-paced care environment, staff can be given the time to focus their attention on the individual and listen to accounts of their life experiences. In this way, narrative identity can be supported and, thus, interpersonal relationships may be strengthened within care environments.

In the context of family relationships, the SENSE-GARDEN provided a space and opportunity for family members to spend time together whilst sharing a meaningful experience, e.g. reminiscing over old photos. As such, this is a way of supporting families to connect with the identity of the person with dementia, in spite of the challenge that dementia presents. Karner and Bobbitt-Zeher describe family caregiving as a "process of transformed identities and reconstructed relations" (2005:566). In a dementia caregiving dyad, the identities of a married couple transform from spouses to "person with dementia" and "caregiver", which can be an emotional, disruptive process for each individual in the couple (Karner and Bobbitt-Zeher, 2005). It is thus important to identify ways of supporting dyads in retaining a positive sense of shared identity. Returning to the work of Johnson et al. (2017), facilitating interaction on a symbolic level through the use of photos, expressions, and gestures may support social engagement and connection between people with dementia and caregivers. This thesis suggests that technology may be a way of facilitating such interaction, with the SENSE-GARDEN being a promising solution for allowing individuals to easily store, access and engage with meaningful media content.

7.6.1. The role of technology in co-constructing identity

This thesis has focused on the co-construction of identity primarily through interpersonal relationships and shared meaningful experiences. However, it is important to note that these relationships and experiences are facilitated partly through technology i.e. the media contents used in SENSE-GARDEN. In the transactional model, technology falls under the broader component of "SENSE-GARDEN". However, further attention needs to be given to the role of technology in assessing how it contributes to the co-construction of identity.

Digital media is often discussed in terms of how we extend ourselves on online social platforms such as Facebook and Instagram. In her book on digital representation of self, Jill Walker Rettberg writes "technology can reflect back to us a version of who we are" (2014: 2). Whilst the context of the book is focused on how we represent ourselves on digital platforms, particularly through the use of social media, I think similar ideas can be applied here. The technology in SENSE-GARDEN is a means of portraying or "reflecting back" the identities of people with dementia through the use of film and photos, which seemed to be meaningful to them. For example, participants with dementia seeing themselves projected in the SENSE-GARDEN experienced feelings of joy, e.g. in response to the question "*What was it about SENSE-GARDEN that made you feel that way (happy)?*" : "It was the films I recognised myself in", and a sense of appreciation or recognition e.g. "I also like the photos. I liked to be remembered here in this house". Returning to Kitwood and Bredin's (1992) indicators of well-being, these participants displayed a sense of personal worth from having used SENSE-GARDEN. According to Kitwood and Bredin (1992), a sense of personal worth is the 'deepest' level of self-esteem (1992: 283). Thus, the findings in this study suggest that technology can beneficial to the promotion of a sense of self amongst people in later stages of dementia.

The findings in Papers III and IV also suggested that technology could be a means of providing moments for connection. Whilst technology is one of the tools through which people with dementia and caregivers engage with one another in SENSE-GARDEN, I argue that agency lies with the human participants in the transactional model – particularly the caregiver. As SENSE-GARDEN currently operates, it is the formal caregiver who has full control over what media contents are displayed during a session. As found in Paper IV, the formal caregivers often adapt the sessions based on their interactions and increased knowledge of the residents.

It should be noted that the original concept of SENSE-GARDEN was that the system would automatically adapt to the preference of the person as the sessions went on. The care professionals in Paper IV stressed the importance of technological improvements being made, so that this seamless automation of sessions could be achieved. If these improvements are made, the role of the technology would become more critical in not only facilitating sessions, but also creating meaningful experiences and co-constructing identities. As such, the transactional model would need to be amended to reflect this. As discussed in the introduction of this thesis, artificial intelligence technologies are sometimes perceived as a substitute for maintaining personhood (Berridge et al., 2021). Incorporating artificial intelligence into the SENSE-GARDEN would, on one hand, ease the preparation of sessions for caregivers. However, on the other hand, the caregivers' continuous process of learning and understanding of the person with dementia may be compromised if the technological player in the relationship would have a larger role in the individualization process of sessions. A trade-off between easing time consumptions with technology and taking time to learn about the person with dementia would need to be addressed.

7.7. Connecting through in-the-moment experiences

The findings of this PhD suggest that SENSE-GARDEN can create opportunities for meaningful experiences. It is arguably through these meaningful, in-the-moment experiences that identities are co-constructed. But how did this take place?

In terms of Deweyan philosophy, experience is considered as occurring continuously through interaction between an individual and their surrounding environment (Dewey, 1939). What constitutes as *an experience* among the continuity of lived experience is the individualizing quality that is attached to the particular experience e.g. a concert, a holiday, a wedding (Dewey, 1939). In the context of SENSE-GARDEN, we can refer to in-the-moment experiences that were described in the participants' accounts of their time using the intervention.

In these in-the-moment experiences, the role of non-verbal communication can be considered essential. Frequent examples given by participants in the studies included dancing and singing to music, which evoked strong emotional responses in caregivers. This non-verbal form of expression can be linked to the notion of embodied selfhood. In challenging the notion that the loss of cognitive function equates to a loss of self, Kontos (2005) recognises the body as a fundamental source of selfhood through which people can express themselves through movement and gestures, even for those with severe dementia. This holds relevance to this PhD, where the accounts of participants dancing and pointing towards photographs may be considered as expressions of selfhood. Holding further relevance to this PhD, work on embodied selfhood has also been linked to storytelling in the context of dementia care:

> "…embodied dimensions of storytelling is significant in that it models how individuals with dementia can make recognisably creative contributions despite the absence of sensical language" (Kontos et al., 2017: 188).

Throughout the papers and thesis, I have promoted the idea of caregivers *learning* about the life story of the person with dementia. Upon further reflection, I should have instead called for caregivers *co-constructing creative expression of identities* through the use of SENSE-GARDEN. This may alleviate the emphasis of there having to be a coherent autobiographical account of the individual that the caregiver must rely on in order to connect with the resident. It is important to promote the use of gesture and in-the-moment experiences, especially with people with moderate to advanced dementia. However, despite this, I still argue that care staff should be provided an opportunity to learn about the life story – or better yet, *stories* – of the person with dementia. By having background knowledge on the person with dementia, care staff may be more prepared in interpreting and responding to particular gestures and behaviours expressed by the resident.

7.8. "A bit strange and sore": Nostalgia and the potential for negative outcomes of reminiscence technologies

The discussion thus far has focused on positive outcomes of SENSE-GARDEN. However, it is important to address how SENSE-GARDEN and similar interventions may result in negative outcomes.

In some ways, highly individualized media content may be a double-edged sword. On one hand, it provides something that a person can relate to. The participants across Papers II-IV all emphasized the importance of SENSE-GARDEN being tailored to each individual as a means of providing an experience meaningful to them. On the other hand, however, individualized media comes with the attachment of personal memories which are recalled and reinterpreted in the present moment. For people with dementia and their families, these memories may serve as a reminder of a time when dementia had not made an impact on their lives. This can be seen in a quote from a wife of a participant with dementia, from Paper III:

> "You had a lot of nice pictures. It is a bit strange and sore to see pictures from when the kids were small. It was the time when everything was fine and good and safe…I thought the time I had then would always be with us"

Looking at the above quote through the lens of symbolic interactionism, it is clear to see how the past is symbolically reconstructed in the present (Mead, 1932; Maines, 2001). For this lady, seeing pictures of her and her husband's children at a young age reminded her of how life used to be for her family. "I thought the time…would always be with us" evokes a sense of loss, which may be related to the situation at the time of the interview whereby her husband had dementia and was living in a care home. Other participants in Paper III also spoke of emotional responses in reaction seeing photos and videos which took them back to previous experiences in their lives. Studies of other reminiscence technologies have found similar findings with regards to certain photographs evoking sadness amongst participants (Damianakis, 2010; Ryan et al., 2020). This raises the concern of whether these kinds of emotionally charged experiences should be elicited. The release of negative and/or mixed emotions is sometimes considered as being beneficial for people with dementia – as long as the caregiver is sensitive, ready to offer comfort to the person with dementia, and ready to stop the activity if needed (Swann, 2013). However, the elicitation of sadness amongst family members is also something that needs to be considered.

Another negative outcome to consider is that people with dementia using SENSE-GARDEN may feel that it is a test of their memory, and therefore they may feel pressured. During the interviews conducted in Paper IV, a care professional noted that the intervention took a "playful" approach and lacked formal structure and/or tests. Despite this, the care professionals in the same study noticed that family members sometimes became upset by the person with dementia not remembering certain names or facts from photographs. A resident at one test site had reportedly felt under pressure to "perform", or do well, whenever her husband joined the sessions. This issue has been reported in a similar study of digital reminiscence, in which participants with dementia felt that the conversation about the photographs had become a test of memory (Karlsson et al., 2017). It is therefore essential that the person facilitating SENSE-GARDEN prioritizes opportunities for in-the-moment experiences over conversations which turn to a test of memory. Drawing back to co-creativity for people with dementia, an approach such as the one taken in the *With All* project (Zeilig et al., 2019) serves as an example of how expectations can be removed, and how pressure may be alleviated.

7.9. SENSE-GARDEN: Is it worth the high cost and time investment?

Whilst this thesis has suggested that the SENSE-GARDEN can provide benefits in dementia care, the high cost of the solution has to be considered. One of the issues addressed in the literature review (Paper I) was that individualized technology can be expensive and time consuming. Unfortunately, the same can be said for the current version of SENSE-GARDEN. The final paper of the PhD aimed to address issues of time consumption and ease of use through discussion with the care professionals at each test site. Whilst they all liked the idea of SENSE-GARDEN, almost everyone agreed that the technology is not there yet.

A business plan for SENSE-GARDEN has proposed a target retail price for care institutions ranging from 25,000 Euros to 45,000 Euros, depending on the type of installation. Adaptation of an existing room (examples being the SENSE-GARDEN rooms in Belgium, Portugal, and Romania) would cost towards the lower end of this price range. However, a newly built self-standing structure (such as the SENSE-GARDEN in Norway) would cost approximately 45,000 Euros. Whilst SENSE-GARDEN is, to our knowledge, the first kind of technology that aims to provide immersive and personalized experiences to people with dementia and their caregivers, other types of individualized technologies may provide similar outcomes in terms of positive effects at a lower cost.

There are technologies aimed at providing interactive, meaningful activities through digital reminiscence. These are readily available at a much lower cost, or in some instances, completely free. For example, a digital reminiscence book called *Book of You* can be purchased for people with dementia and their family members at the low price of £25 (Book of You, 2021). The digital book can also be bought for licensed used by care organizations from £1295, which includes training for staff members in this price.

Another similar technology is the *Storii* app. *Storii* is free to use and allows families to create interactive, multimedia life biographies through the use of photos, music, videos, audio recordings and text (Storii, 2021). There are also priced options for care institutions to buy *(StoriiCare*) which start from 360 dollars a month. In addition to multimedia biographies, this contains an entire personalized care platform that includes the scheduling and logging of daily activities, the recording of care tasks and assessments, the creation of support plans, and connection with family members. An article suggests that care home staff find *StoriiCare* to be a useful tool, with a manager commenting:

> “As staff, we can now interact with a person who has dementia in a very meaningful way for them. We don’t have to use generic photographs for generic activities – it can be really specific and nowadays it’s got to be person-centred” (VanderWell, 2019:272).

Family members are also able to connect to the platform remotely and upload photos, videos and music for the person with dementia, meaning that care staff are able to learn about the person and provide person-centred care without adding to their busy workload (VanderWell, 2019). However, there is currently no research indicating the benefits of the app to residents with dementia.

SENSE-GARDEN is set apart from existing digital reminiscence technologies in the way that it is a dedicated, immersive space in which activities can take place. As seen in the interviews, the participants valued the SENSE-GARDEN space itself e.g.:

> “It is often the music and the light that comes into play. It's the design of the room, the fact that there are no sharp edges. No corners, it's carpeted. It is shielded from the rest of the world. One goes into something else, one forgets time.” (Paper III: 16)

In studying the experiences of spouses who had a partner with dementia living in long-term care, Førsund et al. (2016) found that opportunities for private interactions were key to facilitating the maintenance of relationships. In particular, the private room of the resident was appreciated as a place for couples to connect, as it provided space for interactions with one another. In a similar way, this thesis indicates that the SENSE-GARDEN is an important space in which family members can interact and connect with the person with dementia.

Furthermore, the integration of multisensory components such as olfactory stimuli add to an overall sense of immersion inside the room. Unfortunately, the different sensory components have overlooked in this thesis, perhaps due to the fact that specific sensory components were seldom spoken about during the interviews. It would have been insightful to give more focus to this area, especially given olfaction's link to emotional processing and autobiographical memory (Tischler and Clapp, 2020; D'Andrea, Tischler, and Dening, 2020). The inclusion of findings specific to non-technological aspects of the intervention, such as olfactory stimuli, may have provided further argument for why a solution such as SENSE-GARDEN is advantageous over app-based solutions.

In addition to cost, another issue is time consumption. The SENSE-GARDEN may be impractical to roll out to other care homes. As discussed in the introduction, issues such as time constraints amongst staff, perceived value of the intervention, and lack of motivation and energy amongst staff have recently been identified as barriers to implementing staff-led interventions into dementia care practice (Karrer et al., 2020; Kormelinck et al., 2020). Findings from Paper IV suggest that care professionals view the time investment of preparing and facilitating SENSE-GARDEN sessions as being worthwhile. Nevertheless, given that the SENSE-GARDEN intervention resulted in similar outcomes to studies identified in the literature review, further research needs to be undertaken to justify the high cost and time consumption.

However, perhaps a discussion needs to be had a higher level in terms of the care that ought to be delivered in care homes. In accepting that high quality care requires time investment, issues such as understaffing, lack of staff resources, and organisational issues need to be addressed.

7.10. Implications for future research

This thesis draws upon work that was conducted within the scope of the SENSE-GARDEN project, which ended in November 2020. However, the four test sites involved in the project have expressed the desire to continue using the SENSE-GARDEN currently installed at each facility with residents, even after the project's end. Conducting further research in the use of SENSE-GARDEN will provide an opportunity to build on the body of knowledge already acquired.

There are now numerous continuations of the SENSE-GARDEN. The SENSE-GARDEN Home project, which began in January 2021, is working on creating a portable SENSE-GARDEN that can be used in a variety of environments e.g. private home use as well as care environments. Another is to create a "smart" SENSE-GARDEN, in which artificial intelligence and machine learning will make a more seamless, personalized experience for users.

As a result of this doctoral research, I had planned to delve deeper into how narrative identities are shaped and co-constructed through digital media and art in the context of SENSE-GARDEN through a postdoctoral project. This could be achieved through exploring "in-the-moment" experiences within the SENSE-GARDEN. Keady and colleagues very recently published a new conceptual framework for studies that wish to explore a continuum of moments that can be used to contextualize and frame the lived experience of dementia (2020). Such a framework would be interesting to use with regards to the study of SENSE-GARDEN. It would also be timely, given recent recommendations that reminiscence activities for people with dementia should be evaluated from an 'in the moment' perspective (Woods et al., 2018). The framework was built upon six studies that all used creative, participatory approaches to conduct research on dementia, such as the co-production of digital-film-making, the compilation of life story books to aid biographical interviewing, and sensory ethnographic observations (Keady et al., 2020). By adopting a more creative and inclusive approach to future research on SENSE-GARDEN, perhaps the intervention could be evaluated in a way that manages to capture the perspectives of people with advanced dementia.

Whilst there are no plans for this postdoctoral project to take place anytime in the near future, it is important to acknowledge that another postdoctoral project has been granted funding for studying emotional experiences in SENSE-GARDEN in further detail. In drawing upon the theme of *Emotional Stimulation* identified in Paper II of this thesis, the project will aim to develop a deeper understanding of the experiences and emotional responses of people with dementia who use SENSE-GARDEN. This postdoctoral fellowship will be undertaken by another researcher.

Additionally, a small artistic research project on SENSE-GARDEN with myself as the project coordinator and lead applicant was granted funding from NTNU-SO funds to promote artistic development work at the university. This project, "Stories from SENSE-GARDEN: An exhibition of identity through art" would have involved workshops with MA Fine Art students inside a newly built SENSE-GARDEN room at the ImRo-Lab at NTNU. These workshops would have explored issues surrounding identity, ageing, and dementia by reflecting on findings from the SENSE-GARDEN project. Artwork created by the students (based on their reflections on the SENSE-GARDEN space, dementia, and identity) would have been curated into an exhibition in which members of the public could visit. Public perceptions towards SENSE-GARDEN would have also been collected and explored. However, due to complications caused by the COVID-19 pandemic, the project was never carried out.

Finally, given the promising findings during the UCD testing the of SENSE-GARDEN prototypes with people with mild cognitive impairment and early dementia (not reported in the thesis or the studies), future research could explore the use of SENSE-GARDEN for people with early dementia living in care homes. This would mean that with the progression of dementia, the intervention would perhaps be more tailored to the person in the later stages of the disease. This is something that could be explored further.

Overall, evidence from this thesis suggests that there is still a lack of opportunity for meaningful activities in care homes, despite global efforts to change this. Technology may be a solution for helping staff deliver such activities, but in order for this to be achievable, a co-creative, transdisciplinary approach to technology use must be adopted. Technology is a rapidly growing field. Devices, apps, virtual reality, and artificial intelligence are broadening the horizons of what is possible for dementia care. However, technological developments will not move forward if there continues to be little attention paid to the situational context in which the technology is to be used. Time consumption, costs, and training requirements are all factors that need to be assessed and appraised if technology is going to be increasingly used in dementia care.

7.11. Implications for practice

There is a clear potential for improving the quality of dementia care delivered in care homes. Policy makers are already emphasizing the need to shift towards more holistic approaches when delivering dementia care in nursing homes, where meaningful activities are integrated into daily routines in order to support and maintain the identity of residents. Such a shift challenges both researchers and care practices to identify ways of providing holistic, person-centred care for people with dementia in care homes. The work described in this thesis has provided several examples on how this may be done through the support of technological solutions. Such solutions can provide opportunities for care staff to learn more about residents with dementia, allowing them to connect on a more personal level.

Finally, in line with key messages from the *Lancet* Commission on Dementia Prevention, Intervention, and Care (Livingston et al., 2017), this thesis supports the claim that technological interventions have the potential to improve care delivery. However, it should not, as the commission states, be a replacement for social contact. This thesis demonstrates the value of other individuals in the facilitation and experience of technological interventions offered to people living with dementia, such as SENSE-GARDEN.

Chapter 8

Conclusions

This thesis has demonstrated how the narrative identity of people living with dementia can be preserved and shared through the use of an individualized, technological solution – SENSE-GARDEN. By shifting the focus away from the dementia and onto the person, opportunities for connection and meaningful experiences can be created.

SENSE-GARDEN is just one possible technological solution for supporting staff to facilitate meaningful activities in dementia care, but, to the extent of our knowledge, it is the first that aims to provide immersive, multisensory experiences based on the individual life story of the person with dementia. This thesis, and the SENSE-GARDEN project as a whole, has laid important foundations on which the future of technology in care can be built. By adopting a holistic approach to how the technology is used, and considering theoretical frameworks that may provide insight into how it is experienced, new technologies may be developed and implemented in a way that can benefit all users.

To conclude, it seems fitting to end this thesis with the quote on which it opened: “As individuals we are stories: we are composed and those compositions remain” (Aldridge, 2000). It is important to remember that the stories of people with dementia do not necessarily disappear in parallel with the progression of the disease. Instead, these stories can and ought to be shared, created, and enjoyed through interactions with others. In creating moments for these interactions, possibly through the use of technology, the identities of people with dementia will not only remain, but they will flourish.

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APPENDIX

Appendix A: Paper II Interview guide

1. What is your overall opinion about SENSE-GARDEN?
2. What do you like best about SENSE-GARDEN? And why?
3. Which part of parts do you remember best?
    - Do you understand why we made those?
4. Were the different parts of the SENSE-GARDEN east to understand?
    - Which ones were more difficult?
    - Why were these more difficult?
5. Will SENSE-GARDEN be able to add value to your life and/or work?
    - In what ways?
6. Can you think of ways to improve it?
7. Can you think of someone, or do you personally know someone, that could benefit from using the SENSE-GARDEN?
    - In what ways could they benefit?
8. [Directed only to professional (formal) caregivers] Do you believe you can use the SENSE-GARDEN in daily practice?
    - Would you require training?
    - What kind of training would you like? (prompts: demonstration of functionalities, classes, online tutorials, practicing with colleagues, etc.,)
9. Do you have any extra comments?

Appendix B: Paper III Interview guide

[adaptable to either single interview or group interview]

1. How would each of you describe your overall experience of using SENSE-GARDEN?
2. How did SENSE-GARDEN make you both feel?
    - What was it about SENSE-GARDEN that made you feel that way?
3. What did you like about SENSE-GARDEN? Why?
    - Prompts: ask about individual components of the SENSE-GARDEN
4. Was there anything you did not like about the SENSE-GARDEN? Why?
5. How did you feel about using SENSE-GARDEN together?
    - What did you talk about when using SENSE-GARDEN?
    - Were there any specific memories/events you talked about?
6. Does using SENSE-GARDEN affect your ability to communicate with one another?
    - In what ways?
    - Why do you think this is?
7. How does using SENSE-GARDEN compare to everyday activities?
8. Would you use SENSE-GARDEN again?
    - Why/why not?
    - How often would you like to visit SENSE-GARDEN?
9. [If the participant was in the control group and stopped the visits after 12 weeks]: How did you feel about having to stop the SENSE-GARDENS sessions?
    - [To the caregiver] Have you noticed any effects of changes in [the participant with dementia] since they stopped the SENSE-GARDEN sessions?
10. Do either of you have any other comments that you would like to add?

Appendix C: Paper IV Interview guide 2019

1. What were your initial reactions to seeing the SENSE-GARDEN for the first time?
2. Do the residents talk about the new SENSE-GARDEN space?
    - What were their initial reactions to seeing the physical structure of the SENSE-GARDEN in the care home?
3. Can you share an example of a positive experience you have had in the SENSE-GARDEN?
4. Have you had any negative experiences in the SENSE-GARDEN?
5. Have you learnt anything new about the residents as a result of using SENSE-GARDEN?
    - What do you think about the potential of SENSE-GARDEN being used to help staff to get to know residents better?
    - Do you think it can help new members of staff to get acquainted with the residents?
6. How does using the SENSE-GARDEN with a resident make you feel?
7. What do you think makes a SENSE-GARDEN visit “successful”? (Prompts below if needed)
    - Is it the conversation?
    - Is it the ability to recall memories?
8. How does using the SENSE-GARDEN with a resident fit into your daily working routine?
    - Do you see more benefits or difficulties to your work? Can you give examples?
9. How is using SENSE-GARDEN different to other leisure activities in the care home, such as, for example, group music sessions in the activity room?
10. How do you think the experience, or the space, could be made better?
11. Do you have any other comments?

Appendix D: Paper IV Interview guide 2021

1. Could you describe your overall experience of using SENSE-GARDEN?
2. Can you share an example of a positive experience you have had in the SENSE-GARDEN?
3. Have you had any negative experiences in the SENSE-GARDEN?
4. How did the residents react during the SENSE-GARDEN sessions?
5. Have you noticed any change in the residents' behaviour outside of the sessions?
6. Do the residents talk about the SENSE-GARDEN space outside of the sessions?
7. What is your approach to planning the SENSE-GARDEN sessions?
   - a. In what way were the family members involved
   - b. Prompt: ALMA questionnaire
   - c. Has the resident asked for specific media contents?
8. Have you been in a situation where a resident becomes upset by the media contents?
   - a. How do you handle the situation?
9. Have you learnt anything new about the residents as a result of using SENSE-GARDEN?
   - a. What do you think about the potential of SENSE-GARDEN being used to help staff to get to know residents better?
   - b. Do you think it can help new members of staff to get acquainted with the residents?
10. What results or outcomes would you like to see (or consider most important) during/after a session? (Prompts below if needed)
    - a. Improved conversation?
    - b. The ability to recall memories?
    - c. Other aspects?
11. How does using the SENSE-GARDEN with a resident make *you* feel?
12. How does using the SENSE-GARDEN with a resident fit into your daily working routine?
    - a. Do you see more benefits or difficulties to your work? Can you give examples?
13. How is using SENSE-GARDEN different or connected to other leisure activities in the care home?
14. Do you think SENSE-GARDEN could be used in care on a long-term basis?
15. How do you think the experience or the space could be made better?
16. Do you have any other comments?

Paper I

Review Article

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The use of technology in creating individualized, meaningful activities for people living with dementia: A systematic review

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Abstract

There is a growing interest in using technology to provide meaningful activities for people living with dementia. The aim of this systematic review was to identify and explore the different types of digital technologies used in creating individualized, meaningful activities for people living with dementia. From 1414 articles identified from searches in four databases, 29 articles were included in the review. The inclusion criteria were the study used digital technology to deliver an individually tailored activity to participants with dementia, the process of individualization was described, and findings relating to the mental, physical, social, and/or emotional well-being of the participant were reported. Data extracted from the included studies included participant demographics, aims, methods, and outcomes. The following information on the technology was also extracted: purpose, type, training, facilitation, and the individualization process. A narrative synthesis of the results grouped the various technologies into four main purposes: reminiscence/memory support, behavior management, stimulating engagement, and conversation/communication support. A broad range of technologies were studied, with varying methods of evaluation implemented to assess their effect. Overall, the use of technology in creating individualized, meaningful activities seems to be promising in terms of improving behavior and promoting relationships with others. Furthermore, most studies in this review involved the person with

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dementia in the individualization process of the technology, indicating that research in this area is adopting a more co-creative and inclusive approach. However, sample sizes of the included studies were small, and there was a lack of standardized outcome measures. Future studies should aim to build a more concrete evidence base by improving the methodological quality of research in this area. Findings from the review indicate that there is also a need for more evidence concerning the feasibility of implementing these technologies into care environments.

Keywords
dementia, technology, psychosocial, person-centered, systematic review

Introduction

Dementia is an umbrella term for various neurodegenerative syndromes that impact primarily memory, cognition, language, and behavior. There are currently around 50 million people living with dementia worldwide, and it is estimated that there are almost 10 million new cases of dementia each year (Prince et al., 2015). Given the increasing prevalence and incidence of dementia, the World Health Organization (WHO) has stressed the need to invest in research and cost-effective approaches to meet the needs of people living with dementia and their caregivers (WHO, 2015).

Psychosocial approaches to supporting those living with dementia include the use of meaningful activities to promote well-being. Previous literature that aims to define the term “meaningful activity” in the context of dementia care has often done so from the perspective of people with dementia, their family, and health-care professionals (Harmer & Orrell, 2008; Phinney et al., 2007). Focus is placed on values and beliefs that resonate with past roles, interests, and routines of the individual with dementia. Harmer and Orrell (2008) categorized activities considered to be “meaningful” into reminiscence, family and social, musical, and individual activities. This literature review focuses on the last of these activities, although the four types tend to overlap. Harmer and Orrell (2008) describe individual activities as being adapted to the preferences and capabilities of the person with dementia, and discuss the importance of relating these activities to the past lifestyle of the individual. This review uses the term “individualized” to emphasize that the fact that a process has taken place to adjust the activity to the specific preferences and abilities of the individual.

While work in this field has long focused on person-centered care (Brooker, 2003; Kitwood, 1997), findings from previous literature reviews concerning the individualization of activities for people with dementia appear to be mixed. Travers et al. (2016) recommend that individualized activities may be effective for behavioral and psychological symptoms of dementia, especially with regard to improving passivity and agitation, and increasing pleasure and interest. Subramaniam and Woods (2012) conducted a systematic literature review on the impact of individual reminiscence therapy for people with dementia. The authors suggest that conducting a life review with a person with dementia, in which a life storybook is produced, has a positive impact on cognition and well-being. They also suggest that personhood and well-being can be promoted using individualized reminiscence approaches that meet specific needs of the individual with dementia. Despite these suggestions, however, a recent Cochrane review found very little evidence for personally tailored activities being able to improve psychosocial outcomes for people living with dementia (Möhler et al., 2018). While offering personally tailored activities (such as listening to individualized music playlists or making puzzles from familiar photographs) to people with dementia in long-term care may slightly improve challenging behavior, effects on mood were uncertain, and the authors were unable to make recommendations about specific activities.

Constant advances in technology provide potential for designing new and innovative ways of meeting specific needs of individuals with dementia. In a very recent overview of technology and dementia, Astell et al. (2019) identified leisure and activity as one of the main domains of technology development within dementia care. The authors remark that technology—such as smartphones, tablets, wearables, robots, virtual reality, and artificial intelligence—is prompting thought on how care services can be better delivered to address the well-being of people with dementia. The authors also argue that the rapid pace of technology development requires a holistic view of dementia. In expanding the view of dementia beyond a narrow medical approach, technology may be used to empower people with dementia, supporting them to live a more meaningful life. For instance, a recent study suggested that the use of a social robot for hospital patients with dementia promoted a sense of self and facilitated social connection with others (Hung et al., 2019).

Arthur (2009) defines technologies as assemblies of practices and components put to use in order to fulfill a specific purpose. In recent years, there has been much work done on the use of various technologies for providing meaningful activities in dementia care. Digital technologies, such as mobile and tablet apps, have been suggested to enable collaborative explorations of life events by people with dementia and caregivers, encouraging the caregiver to reflect and learn more about the individual (Maiden et al., 2013). Purves et al. (2011) also comment on the role that multimedia technologies (e.g., digital life stories) have on conveying the narrative of people living with dementia, and the authors stress that further work needs to be done in understanding how these technologies can be used in everyday practice. In a review on touchscreen technology for people with dementia, Joddrell and Astell (2016) commented that the primary use of touchscreen technology has been to deliver assessments and screening tests, and they called for more focus on how this technology can be used to deliver independent activities for meaningful occupation.

To date, there are no literature reviews that provide an overview of the evidence on using technology to create individualized, meaningful activities for people with dementia. Furthermore, there is arguably a need to take qualitative and mixed-method studies into account in this area of research, especially given that meaningful activity within dementia care is often measured in subjective terms of enjoyment (Harmer & Orrell, 2008). While the importance of thorough quantitative meta-analyses remains, much can be learnt from qualitative and mixed-method research in addition to quantitative studies. The Cochrane Qualitative and Implementation Methods Group Guidance Series highlights the important role of qualitative and mixed-method reviews in understanding how interventions work and how they are implemented (Noyes et al., 2018). Therefore, this literature review will consider qualitative, quantitative, and mixed-methods research to acquire a comprehensive overview of the work that has been done on this topic.

The main purpose of this review is to answer the following research question: What are the different digital technologies used to create individualized activities for people with dementia, and how are these facilitated? For the purpose of this review, we define digital technologies as devices, systems, or applications that can be used to create, store, view and/or share information electronically. In order to further explore the findings from this question, the review will also answer the following secondary research questions: (a) How are these technologies individualized? and (b) What is known about the effects of these technologies on the well-being of people living with dementia?

Methods

This systematic review was conducted and reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al., 2009a).

Eligibility criteria

The SPIDER strategy (Sample, Phenomenon of Interest, Design, Evaluation, Research type) was used as a tool for shaping the search. SPIDER has been adapted from the PICO formulation (Population, Intervention, Comparison, Outcome) to be more suitable for qualitative and mixed methods research (Cooke et al., 2012). The SPIDER strategy for this review was as follows:

- Sample: people living with dementia.
- Phenomenon of interest: technology-based, meaningful activities tailored specifically for the person with dementia.
- Design: case study, observational study, randomized controlled trial, quasi-experimental study, questionnaire, interviews, and focus groups.
- Evaluation: outcomes related to the mental, physical, social and/or emotional well-being of the person with dementia.
- Research type: quantitative, qualitative, or mixed-method.

Only studies published in a peer reviewed journal and in English language were considered for review. In order to focus on more recent technologies, studies published before 2005 were not considered for review. Additionally, as another systematic review focusing on meaningful interventions for people living with dementia noted, person-centered care practices were not widely adopted until 2005 (Travers et al., 2016). Given that the scope of this review is to focus on individualized activities, it was deemed appropriate to limit the results to being published in 2005 or later.

Inclusion criteria. Studies were included if they met all of the following criteria: (a) uses digital technology to deliver an individually tailored activity to participants with dementia, (b) describes the process of individualization, and (c) reports on findings directly relating to the mental, physical, social, and/or emotional well-being of the person with dementia.

Exclusion criteria. Studies were excluded if they met any of the following criteria: (a) reports solely on the well-being of caregivers or (b) reports findings solely relating to the technology rather than the person with dementia. Literature reviews, study protocols, theoretical papers, conceptual papers, and position papers were also excluded from the review.

Information sources

Given the interdisciplinary nature of this topic, four databases were used for the search, with the aim of capturing as many potential articles as possible. The following databases were used: CINAHL, Embase, PubMed, and Scopus. A combination of Boolean operators and truncations were used. MeSH Terms were also used where applicable. Table 1 gives a summary of the search terms.

Search

Study selection. The selection of articles for review was conducted by the first author. All articles underwent a first screening after duplicates were removed. This consisted of titles and abstracts being screened against the inclusion and exclusion criteria. Included articles then underwent an assessment for eligibility, which involved a reading of the article in full. Additionally, backward citation searching and forward citation tracking was conducted on these articles. Articles from this additional search that met the inclusion criteria were included for review. Coauthors Kristin Taraldsen and J Artur Serrano independently checked the final selection of articles against the inclusion and exclusion criteria.There were no discrepancies, and therefore this final selection of articles was approved by all authors.

Data extraction and synthesis. Data relating to the study aims, design, demographics, data collection, methods, and findings were extracted from each article. Additionally, information on the purpose of technology studied, type of technology, media contents and services, the individualization process, environment of technology use, training on technology use, and facilitation of the intervention/activity was also extracted.

Due to the heterogeneity of the results and the novelty of this field of research, no meta-analysis was conducted. The application of technology for meaningful activities is still an emerging area of work, with many different approaches and devices being used. Therefore, results are presented through a narrative synthesis. Findings from the studies are summarized to answer each of the research questions in turn.

Results

Study selection

The initial search returned 1414 articles: 217 from PubMed, 507 from Scopus, 139 from CINAHL, and 551 from Embase. An overview of the study selection is shown in Figure 1.

Table 1. Summary of search terms.

Search	Terms
#1	dement* OR alzheimer's
#2	personal OR personalized OR personalised OR person-centred OR person-centered OR person-focused OR individualized OR individualised OR individualistic OR meaningful OR biographical OR autobiographical OR tailored
#3	technology OR virtual OR augmented OR media OR multimedia OR touchscreen OR iPad OR app OR mobile OR ICT OR tablet*
#4	#1 AND #2 AND #3

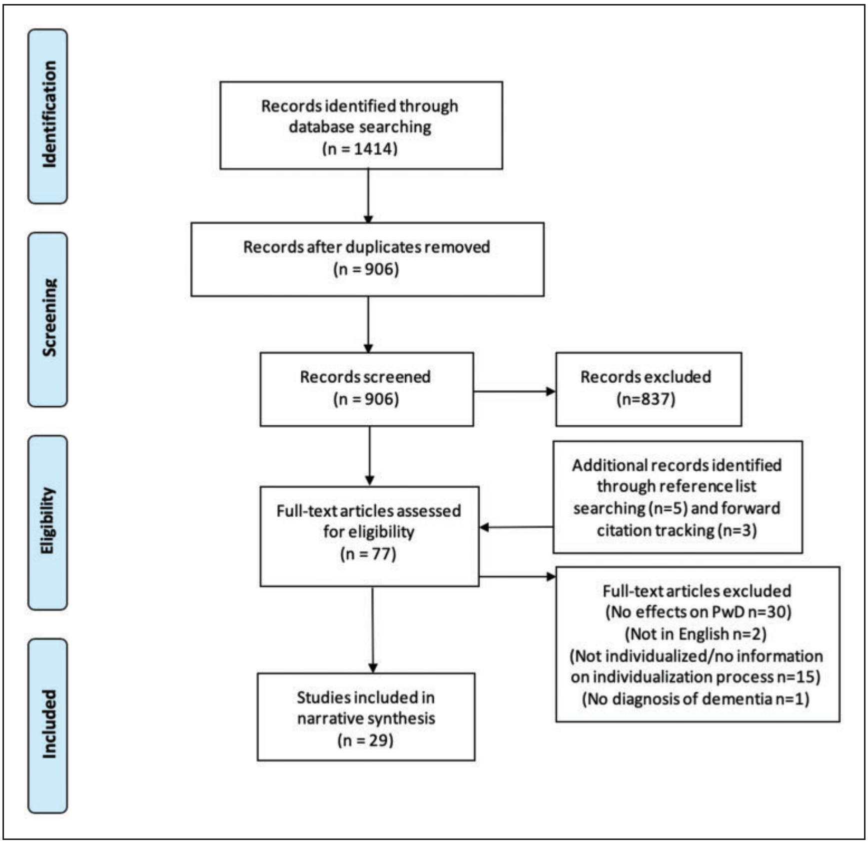

Figure 1. PRISMA flow diagram of study selection process. Adapted with permission from Moher et al. (2009b).

In short, 906 records were screened and 837 were excluded. Reference list checking and forward citation tracking was conducted on the remaining 69 articles to identify additional records. From these searches, 8 articles were identified, meaning that a total of 77 articles were assessed for eligibility. This assessment resulted in a total of 29 articles for review.

Study characteristics

Twenty-nine studies (reported in 29 separate articles) were included for review. From these studies, 12 were qualitative, 13 used mixed-methods, and 4 were quantitative. An overview of study characteristics is given in Table 2, which summarizes study design, participant information, aims of the study, interaction with technology, measures, and findings for each study.

The most commonly used study design was the case study (N = 12). Only two randomized trials were included. Other designs included field trials and explorative studies. A total of 231 participants were included across the 29 studies (ranging from 1 to 51, with a median of five participants per study). The mean age of participants ranged from 52 to 87. However, two studies only reported the age range of participants, and seven studies did not specify

Table 2. Study characteristics.

Author	Study design	Participants with dementia			Study aim(s)	Interaction with technology	Measures	Findings
		N	Mean age	Type and severity[a]				
Critten and Kucirkova (2017)	Case study	3	83.3	Mild to moderate dementia	Study the role of an individualized multimedia iPad app (Our Story) in the stimulation, preservation and sharing of special memories	Creation of multimedia story over 7 weeks	Interviews, field notes, observations	The app facilitated the elicitation, storage and sharing of special memories. All participants experienced positive feelings of confidence, empowerment and increased self-esteem
Damianakis et al. (2010)	Exploratory feasibility study	12	79.6	Early to advanced AD (N = 6), MCI (N = 6)	Observe participant responses to personalized multimedia biographies	Production of DVD biographies followed by weekly screenings for 6 months	Observations, interviews	Multimedia biographies stimulated reminiscence, evoked feelings of mostly joy but occasionally sadness, and stimulated social interactions
Davis and Shenk (2015)	Mixed-methods study	10	84.3	Late moderate dementia, mean FAST score 5.2	Compare effects of personalized and generic multimedia videos on engagement	Video screenings over 6 weeks	OME, language patterns from transcriptions using predefined codes	Slight preference for looking at personalized videos first. Generic videos produced wider range of conversational topics and phrasal patterns.
Davison et al. (2016)	Randomized, single-blinded cross-over study	11	86	Mild to severe dementia. Mean MMSE 16.2	Assess the effects of a personalized multimedia system (Memory Box) on agitation, depression and anxiety	Use of multimedia system for 4 weeks	CMAI; CSDD; RAID, interviews	Significant reduction in depression and anxiety scores. No significant change in agitation scores
De Leo et al. (2011)	Case study	1	80	AD, FAST Stage 4	Assess whether a slideshow of daily life moment pictures captured by a smart phone can support autobiographical memory	Use of smart phone for 4 weeks. DVD of recent events viewed once a week	Recent events memory recall test (non-standardized) and satisfaction questionnaire	DVD of daily life pictures helped the participant recall recent events significantly better
Ekström et al. (2015)	Case study	1	52	AD	Explore the effects of a personalized digital	Use of device over 2 weeks	Video recordings, interview	

(continued)

Table 2. Continued.

Author	Study design	Participants with dementia			Study aim(s)	Interaction with technology	Measures	Findings
		N	Mean age	Type and severitya				
					device application (GoTalk NOW) on communication			Application use increases interactive and communicative actions
Hashim et al. (2015)	Case study	1	74	Mild AD	To test a personalized digital memory book (myBook) for usability, functionality, reminiscence, and cognition	Weekly sessions over 8 weeks	Observations, evaluation form (non-standardized)	The participant felt the tool enhanced reminiscence. Observations indicated improvement in social interaction and communication
Hung et al. (2018)	Mixed-methods feasibility and acceptability study	4	Range 69–80	AD/Vascular/ Parkinson's Dementia	Explore the feasibility and acceptability of using an iPad Simulated Presence Therapy intervention	iPad simulated presence therapy over 2 weeks	Video ethnography, observations, semi-structured interviews with hospital staff	Four themes: (a) positive responses, (b) person-centered care, (c) video content, and (d) technical skills.
Karlsson et al. (2014)	Explorative multiple case study	7	Range 72–81	Alzheimer's disease	Explore the process of acceptance and integration of a digital photograph diary as a tool for remembrance of and conversations about daily life events	Use of digital photograph diary over 22 weeks	Interviews, observations, field notes, MMSE, PGCMS, Free recall memory index, recognition memory index	The digital photograph diary contributed to increased communication, promoted relationships, and was perceived as a stimulating joint activity
Karlsson et al. (2017)	Explorative study	7	77	Alzheimer's disease, Mean MMSE 22	Explore how sense of self and identity are manifested in narrations about recent events enabled by a digital photograph diary	Use of digital photograph diary over 3 months	Audio recorded communication sessions, observations, field notes	Two themes from discourse analysis: manifestations of sense of self and sense of self in relation to others. Digital photography diary supported communication
Kerssens et al. (2015)	Qualitative study	7	77	Dementia (N = 4), MCI (N = 3)	Test the usability, feasibility and adoption of a touchscreen computer intervention (The Companion)	Use of touchscreen computer intervention	Goal attainment, observations, interview	The Companion facilitated meaningful and positive engagement

(continued)

Table 2. Continued.

Author	Study design	Participants with dementia			Study aim(s)	Interaction with technology	Measures	Findings
		N	Mean age	Type and severity[a]				
						over an average of 31 days		
Khosla et al. (2014)	Field trial	4	–	–	Measure the impact of a personalized assistive robot on emotional engagement	Use of assistive robot over 6 months	Video recordings of interaction, activity data, emotional responses, quality of robot experience survey	The robot had positive impact on emotional well-being and provided sensory enrichment and social connectivity.
Khosla et al. (2016)	Longitudinal field trial	5	–	–	Evaluate the impact of a personalized assistive robot in the context of home-based dementia care	Use of assistive robot over 3–6 months	Observational videos, interactional data, quality of robot experience survey	Positive experience with the robot, improvement in sensory enrichment
Laird et al. (2018)	Quasi-experimental feasibility study	30	79	Early to moderate dementia	Measure the effect of technology-enabled reminiscence iPad app (InspireD) on mutuality, quality of carer and patient relationship and subjective well-being	Use of the iPad app over 12 weeks	Mutuality Scale, QCPR, WHO-5	Significant increases in mutuality, quality of carer and patient relationship, and subjective well-being
Massimi et al. (2008)	Pre/post-test single case study	1	84	AD, moderate	Assess whether a biographical ambient display (Biography Theatre) improves autobiographical memory and sense of identity	Use of ambient display over 1 month	GDS-30; GAS, AES-I; SIP-AD; TST; AMI; MMSE; IQCODE; custom interviews and questionnaires	Improvement in apathy and positive self-identity. No improvement in autobiographical memory, anxiety, depression and general cognition
McAllister et al. (2020)	Case study	3	82	Lewy body disease, AD,	To explore the use of a personalized iPad app		Field notes, focus groups and	Five themes: experienced and expected benefits of

(continued)

Table 2. Continued.

Author	Study design	Participants with dementia			Study aim(s)	Interaction with technology	Measures	Findings
		N	Mean age	Type and severity[a]				
				dementia non-specific, moderate to advanced	(Memory Keeper) with regard to barriers, facilitators, benefits and incorporation into care.	Use of app over 6-month trial period	individual interview	Memory Keeper; engagement of the person with dementia and their response to memory keeper; recruitment, media collection, set-up training and handover; use of memory keeper in long term care setting
Navarro et al. (2015)	Case study	1	70	AD, MMSE 17	Study the effect of an ambient display system (AnswerBoard) and mobile app (AnswerPad) on behavioral symptoms	Use of system over 16 weeks	NPI-Q; AES, caregiver diary, interviews	Use of systems had a positive effect in reducing challenging behaviors
Navarro et al. (2016)	Field study	2	N1 = "Over 70",	N2 = 73	AD, MMSE scores 17 and 21	Study the effectiveness of assisted cognition system (AnswerBoard/ AnswerPad) to support occupational therapy interventions	Use of system over 16 weeks	NPI-Q; AES
Use of systems had a positive effect in reducing challenging behaviors								
O'Connor et al. (2011)	Single-system ABA withdraw design	1	83	Vascular dementia, severe PAS = 21	To evaluate the effect of video-simulated presence for decreasing resistance to care	Video simulated presence for 14 days	Observations, adapted Positive Response Schedule	Significant reduction in resistance to care with the use of video simulated presence

(continued)

Table 2. Continued.

Author	Study design	Participants with dementia			Study aim(s)	Interaction with technology	Measures	Findings
		N	Mean age	Type and severity[a]				
Park et al. (2017)	Multi-site case study	7	–	Early stage dementia	Assess how digital storytelling affects quality of life in terms of relationships and self-identity	Seven-session workshop over 6 weeks	Observational field notes, audio recorded workshop sessions and interviews	Overall enjoyment of sessions, ability to share stories, enhance relationships, increase in communication and interaction
Peeters et al. (2016)	Formative evaluation	5	–	Early to severe dementia	Evaluate the use of a personalized music platform (Music ePartner)	Single time use of music platform	Observations, interview	Observed positive effects on memory recall, mood, and social interaction
Piasek et al. (2012)	Case study	1	87	Early-stage dementia	Explore whether SenseCam images can encourage meaningful discussions about recent memories and help maintain sense of identity	Use of SenseCam for 7 weeks. Viewing of images twice a week	Interview, observations, field notes, psychometric tests (not specified)	No change in psychometric measures, confusions about source of images, did not stimulate discussions
Ryan et al. (2018)	Qualitative study	15	78	–	To explore the impact of a personalized reminiscence program facilitated through an iPad app (InspireD)	Use of iPad app over 12 weeks	Semi-structured interviews	Six themes: usability, revisiting the past; home use; impact on the person with dementia; gains and abilities; impact on relationships
Samuelsson and Ekström (2019)	Dyad case studies	3	–	–	To understand how digital communication support may be used in interaction with people with dementia	Single time use of digital communication app	Video recordings	CIRCA and CIRCUS support conversation topics, personal photographs in CIRCUS are more engaging
Silva et al. (2017)	Single-blind randomized trial	51	73.7	Mild Alzheimer's disease	To assess the effects of wearable camera memory aid (SenseCam) on well-being compared to paper memory training program (Memo+) and written diary (control)	Use of SenseCam for 6 weeks. Images reviewed twice a week	GDS-30, IAFAI, WHOQOL-OLD	Significant reduction in depression with SenseCam and Memo+ compared to diary control condition

(continued)

Table 2. Continued.

Author	Study design	Participants with dementia			Study aim(s)	Interaction with technology	Measures	Findings
		N	Mean age	Type and severity[a]				
Subramaniam and Woods (2016)	Multiple case study	6	82.2	Mild to moderate dementia, CDR scores of 1 (N = 5) and 2 (N = 1)	To compare the use of a multimedia digital life storybook vs. conventional life storybook	Digital storybooks created over 7–10 weeks, DVD then given to participants for regular viewing	QOL-AD; AMI-E; GDS-12R; QCPR; Semi-structured interview	Five out of six participants showed improvement in quality of life and autobiographical memory after having the digital storybook for 4 weeks
Welsh et al. (2018)	Case study	11	–	Moderate to severe	To explore whether a personalized digital app (Ticket to Talk) can support communication between people with dementia and younger people	Use of digital app over 4 weeks across 6 visits	Interviews, workshop discussions	Three themes: promoting and managing reminiscence; starting and maintaining conversation; redistributing agency
Woodberry et al. (2014)	Within-subject longitudinal study	6	72	AD, mild to moderate, Addenbrooke's Cognitive Examination mean 70.8	To compare the effects of using a wearable camera vs. a written diary to aid retrospective recall of significant personal events	Use of wearable camera for 3.5 months	Memory recall tests, interview	Recall significantly more details of events in the camera condition for five out of six participants compared to the written diary condition
Yasuda et al. (2009)	ABCA design	15	77.3	AD, Mean MMSE 14.3	To assess whether personalized photo video obtain more attention compared to generic TV shows	Single event of viewing photo videos	Video recorded responses measured in terms of concentration and distraction scores	80% of participants showed more attention to personalized reminiscence photo video than other TV shows. Higher concentration scores for moderate and severe dementia participants

Note: Symbol "–" indicates not specified. AD: Alzheimer's Disease; MCI: Mild cognitive impairment; FAST: Functional Assessment Staging Tool; OME: Observational measure of engagement; CMAI: Cohen-Mansfield Agitation Inventory; CSDD: Cornell Scale for Depression in Dementia; RAID: Rating Anxiety in Dementia; MMSE: Mini-mental state examination; PGCMS: Philadelphia Geriatric Center Morale Scale; QCPR: Quality of the Caregiver Relationship questionnaire; WHO-5: World Health Organization Five Well-being Index; GDS-30: Geriatric Depression Scale-30; GAS: Goldberg Anxiety Scale; AES-I: Apathy Evaluation Scale-Informant; SIP-AD: Self-Image Profile-Adults; TST: Twenty Statements Test; AMI: Autobiographical Memory Interview; IQCODE; Informant Questionnaire of Cognitive Decline in the Elderly; NPI-Q; Neuropsychiatric Inventory Questionnaire; AES: Apathy Evaluation Scale; PAS: Psychogeriatric Assessment scales; IAFAI; Adults and Older Adults Functional Assessment Inventory; WHOQOL-OLD: World Health Organization Quality of Life-OLD module; CDR: Clinical Dementia Rating scale; QOL-AD: Quality of life Alzheimer's disease scale; AMI-E: Autobiographical Memory Interview extended version; GDS-12R: Geriatric Depression Scale (Residential).

[a] Type and severity as reported in the study.

age. The severity of dementia varied across the studies, with all stages being covered from mild to severe. Two studies included participants with mild cognitive impairment in addition to participants with more advanced dementia. The most common type of dementia was Alzheimer's disease (N = 14). There were inconsistencies in reporting participant demographics, with four studies failing to report either type or severity of dementia.

Most studies aimed to assess the impact of the technology-based activity on memory, communication or engagement. Some studies adopted a more exploratory approach and aimed to report any effects that the technology may have had on the person with dementia. Interviews and observations were the most popular tools for data collection, with thematic analysis and discourse analysis being used to draw findings. In quantitative and mixed-methods studies, there was a large variety of standardized measures used that focused on numerous domains (for details see Supplementary Material, Table S1). The studies were also greatly varied in terms of length of technology use, ranging from single-time use to use of the technology for six months. Across the 29 studies, the average time spent using the technology was seven weeks.

Synthesis of results

What are the different technologies used to create individualized, meaningful activities for people with dementia, and how are these facilitated? A wide array of technology, with varying media contents and services, has been explored for creating individualized, meaningful activities for people with dementia. This review categorized the technologies into four main purposes that all tackle common challenges people living with dementia face, namely: reminiscence/memory support, behavior management, stimulating engagement, and conversation/communication support. Table 3 gives an overview of the technologies studied with regard to their purpose, type, media contents and services, individualization process, environment of use, any training provided and the way in which the technology was facilitated in the study.

Environment, training, and facilitation. The majority of studies (N = 18) were conducted within the homes of participants, who were living in the community (Critten & Kucirkova, 2017; Damianakis et al., 2010; De Leo et al., 2011; Ekström et al., 2015; Hashim et al., 2015; Karlsson et al., 2014, 2017; Kerssens et al., 2015; Khosla et al., 2014, 2016; Laird et al., 2018; Massimi et al., 2008; Navarro et al., 2015, 2016; Piasek et al., 2012; Ryan et al., 2018; Samuelsson & Ekström, 2019; Welsh et al., 2018). Family members were often the facilitator of the technology use. In most studies, the presence of another person was required for the full facilitation of the intervention/activity. Whether it be family member, professional caregiver or therapist, it was deemed important that the technology was used as a joint activity. Even in the case where the person with dementia was encouraged to use the device or app independently, support from caregivers was available. Therefore, training of the technology was often given to both the person with dementia and their caregiver. Most studies were quite vague about the instructions given. However, a few studies described extensive training procedures (Davison et al., 2016; Kerssens et al., 2015; Laird et al., 2018). For example, in the study of the InspireD app (Laird et al., 2018), an IT assistant provided training to participants with dementia and their family members, who were living at home. In addition to this, participants also received reminiscence training.

There were a couple of cases where the person with dementia was trained individually. Davison et al. (2016) reported that each of the 11 participants (with mild to severe dementia)

Table 3. Overview of technology, individualization, and facilitation.

Purpose	Type	Study	Name	Media contents and services	Individualization process	Setting	Training	Facilitation
Reminiscence or memory support	Lifelogging: wearable camera devices	De Leo et al. (2011)	–	Photos taken on smartphone lanyard	Photos taken of everyday life at 5-minute intervals. Photos then saved to DVD	Home	Given to people with dementia and caregiver by researchers	People with dementia uses smartphone independently, then watches DVD of photos with caregiver
		Karlsson et al. (2014, 2017)	SenseCam/digital photograph diary	Photos taken by wearable camera, captions with geolocation	Wearable camera (SenseCam) takes photos of daily events. Photos then uploaded onto touchscreen computer (Digital photograph diary)	Home	Given to people with dementia and family member by researchers	People with dementia uses device, family uploads photos. They review photos together
		Piasek et al. (2012)	SenseCam	Photos taken by wearable camera	Wearable camera takes photos of daily events. Photos then reviewed on computer	Home	Given to people with dementia and family by researchers	People with dementia uses device, images reviewed with therapist
		Silva et al. (2017)				Hospital/clinic	Given to people with dementia by researchers	People with dementia uses device, images reviewed with neuropsychologist
		Woodberry et al. (2014)				–		People with dementia uses device, researcher or spouse uploads photos
	Digital app	Critten and Kucirkova (2017)	Our Story	Photos taken on iPad and found online, text captions, audio narration	Story captured in "conversational style" with people with dementia. People with dementia find own photos.	Home/club for people with dementia	Given to people with dementia by authors	Independent use by people with dementia (with researcher support if needed)
		Hashim et al. (2015)	myBook	Daily routine reminders, family photos, games	Caregivers supplied information and photos to authors	Home	Given to people with dementia and caregiver by authors	People with dementia and caregiver use together
		Laird et al. (2018)	InspireD	Photos, videos, music	People with dementia and family upload media contents with help of reminiscence trainer	Home	Given to people with dementia and family by IT assistant (+ reminiscence training)	People with dementia and family use together

(continued)

Table 3. Continued.

Purpose	Type	Study	Name	Media contents and services	Individualization process	Setting	Training	Facilitation
		Ryan et al. (2018)			People with dementia and family upload media contents to app		–	
		Peeters et al. (2016)	Music ePartner	Music with text captions and photos	Questionnaire filled in by people with dementia/ caregiver and given to authors	Day center	Given to people with dementia and caregiver by researcher	People with dementia and caregiver use together
	Multimedia biography (DVD/video-based)	Damianakis et al. (2010)	–	Photos, video, voice-over narration, music	Student collaboration with people with dementia and family using workbook	Home		People with dementia and family use together
		Park et al. (2017)	–	Photos, voice recordings, music, animation	People with dementia, Family and researcher	Community club	Given to people with dementia and family by authors	People with dementia and family use together guided by workshop facilitator
		Subramaniam and Woods (2016)	–	Photos, music, narration, video	Participatory design—people with dementia and Family, researcher as co-editor	Care home		Digital life book played on TV in people with dementia's room
		Yasuda et al. (2009)	–	Photos, narration, music	Caregivers provided photos to researchers	Hospital		People with dementia watched by him/herself
	Touchscreen device	Massimi et al. (2008)	Biography theatre	Photos, music, video, narration	Authors worked with people with dementia and family	Home	–	Independent use by people with dementia
Stimulate engagement	Social robot	Khosla et al. (2014, 2016)	–	Music, photo, social connectivity, games	Real-time individualization by robot capturing emotional responses	Home	–	Use by people with dementia and family
	PowerPoint	Davis and Shenk (2015)	–	Photos, music, video	Students used photos provided by family	Memory care unit	–	Facilitated by student volunteer
	Digital app	McAllister et al. (2020)	Memory Keeper	Family photos, music, video, book covers, themed images	Researcher collaboration with people with dementia and family	Long-term care facility	Given to family by researchers	People with dementia and family member use together
			Memory Box			Nursing home		

(continued)

Table 3. Continued.

Purpose	Type	Study	Name	Media contents and services	Individualization process	Setting	Training	Facilitation
Behavior management	Multimedia touchscreen device	Davison et al. (2016)		Movies, music, photos, video messages from family, family photos	Researcher collaboration with people with dementia and family		2.5 hours training given to people with dementia, staff, family by researchers	Main use by people with dementia, support from family and staff carers
		Kerssens et al. (2015)	The Companion	Photos, captions, music, reminders, messages	Life story interview with people with dementia and family	Home	Given to people with dementia and caregiver by expert in assistive technology	Use by people with dementia and family
		Navarro et al. (2015, 2016)	AnswerBoard/ AnswerPad	Reminders, personalized games	Researcher collaboration with caregiver	Home	–	Use by people with dementia with therapist
	Tablet with video only	Hung et al. (2018)	–	Video from family	Researcher collaboration with family	Hospital	–	Used by professional carer
		O'Connor et al. (2011)	–	Video from family	Family pre-recorded messages	Care home	Given by researchers	Used by professional carer
Communication/ conversation support	Digital app	Ekström et al. (2015)	GoTalk NOW	Photos, video, text captions, digitized and synthetic speech	Collaboration between people with dementia and speech therapist over 3 days	Home	Given to people with dementia and family member by researchers	Used by people with dementia and family
		Samuelsson and Ekström (2019)	CIRCUS	Photos, films, music, videos	Upload function on app	Home	Given by researchers to caregivers only	Used by people with dementia and professional caregiver
		Welsh et al. (2018)	Ticket to Talk	Photos, sounds, videos	Young person creates user profile with help from family. App provides prompts to invite young person to find out more about the people with dementia's life	Home/care home	–	Used by young person, people with dementia and family/carer

Note: Symbol "–" indicates not specified.

received 2 hours of individual training to use a personalized multimedia touchscreen device. This training utilized spaced retrieval learning principles and involved research staff demonstrating procedures and asking the participant to imitate them. Despite this training, however, some participants were unable to use the device due to cognitive or sensory impairment. Similarly, participants (with mild to moderate dementia) in the study of the OurStory iPad app were trained to use the app independently, however they experienced practical difficulties such as not being able to hold the device or being unable to use the keyboard (Critten & Kucirkova, 2017).

Facilitation ranged from professional caregivers having complete control of the technology (e.g., simulated presence on iPad apps in Hung et al., 2018; O'Connor et al., 2011), to joint use between people with dementia and family members (e.g., multimedia apps in Laird et al., 2018; Ryan et al., 2018, digital life storybooks in Critten & Kucirkova, 2017; Park et al., 2017, social robots in Khosla et al., 2014, 2016), and to more independent use by the person with dementia (e.g., Biography Theatre in Massimi et al., 2008). The most independently used devices were the lifelogging technologies. The SenseCam (Karlsson et al., 2014, 2017; Piasek et al., 2012; Silva et al., 2017; Woodberry et al., 2014) and the smartphone lanyard used by De Leo et al. (2011) were worn by the person with dementia during the day. However, in all studies of lifelogging technologies, support was needed from another individual to upload the photographs onto a DVD or computer. Reviewing the photographs then became a joint activity.

How are these technologies individualized? Most of the studies described the individualization process as a collaboration between the person with dementia, the family member, and often a researcher. While most studies were unclear on the length of time taken to individualize the technology, there were some that used several weeks for the process. For example, digital stories were created over a 6-week period in Park et al. (2017) and an average of 8.3 weeks in Subramaniam and Woods (2016).

Despite common collaboration between participants with dementia, family and researchers, approaches to individualizing the app/device still differed. Examples include structured workbooks (Damianakis et al., 2010), a chronological approach by listing major life chapters (Massimi et al., 2008), stories captured in a "conversational style" (Critten & Kucirkova, 2017), life story interview (Kerssens et al., 2015), questionnaire (Peeters et al., 2016), participatory design (Subramaniam & Woods, 2016), in-app prompts (Welsh et al., 2018), and participants uploading their own media content to apps (Laird et al., 2018; Ryan et al., 2018; Samuelsson & Ekström, 2019). The resonating theme among all these approaches is that of capturing the life story of the individual using photographs, music, and narratives (both textual and audio-recorded).

Several studies used theory to inform the individualization process. For instance, Positioning Theory (Harr & Van Langenhove, 1998) informed Karlsson et al.'s (2017) work on the SenseCam. The approach to the study was to understand narrations about recent events as being co-constructed between the person with dementia and their partner. Park et al. (2017) was influenced by Bruner's paradigm of narrative knowing and constructivism (Bruner, 2003). Damianakis et al. (2010) was informed by a framework that supports coherence of ego integrity and personhood during phases of impairment. Finally, Ryan et al.'s (2018) work on the InspireD app was underpinned by Kitwood's notion of person-centered care (Kitwood, 1997). These four studies that used theoretical foundations for narrative creation all reported positive effects on self-identity and/or engagement from qualitative methods including discourse analysis, interviews, observations and field notes.

What is known about the effects of these technologies on the well-being of people living with dementia? Overall, the evidence from the included studies suggest that individualized, digital technologies can have positive effects on the well-being of people living with dementia. Particularly promising areas of improvement include behavior and mood, sense of identity, and relationships and engagement with others. Specific domains of well-being are reported on in further detail below.

Memory. The impact of these technologies on memory was mixed, and methods to assess memory were varied. Based on observational and interview data, several studies found that personalized multimedia can stimulate reminiscence (Critten & Kucirkova, 2017; Damianakis et al., 2010; Hashim et al., 2015; Welsh et al., 2018). The use of formal tests on memory was scarce. Two studies used the Autobiographical Memory Interview (AMI) (Kopelman et al., 1989), including Subramaniam and Woods (2016) who found that the use of a digital life storybook improved autobiographical memory after using the storybook for four weeks. Contrastingly, the study of a personalized biographical ambient display did not improve AMI scores after one month of use (Massimi et al., 2008). Mixed results were also present in the study of lifelogging technologies. De Leo et al. (2011) and Woodberry et al. (2014) found that pictures taken by a wearable camera enabled the participants to recall significantly more details of recent events, as measured by non-standardized memory recall tests. However, a single case study of SenseCam conducted by Piasek et al. (2012) reported that the participant was confused about the source of images. Karlsson et al. (2017) also reported that there were certain situations where participants with Alzheimer's disease were unable to recall any information related to the event shown from SenseCam photographs.

Behavior and mood. Overall, the technologies included for review showed beneficial effects on behavior and mood. Furthermore, studies that focused on this domain were more consistent in using standardized outcome measures. The AnswerBoard (public ambient display) and AnswerPad (mobile phone app) devices were shown to have a positive effect in reducing challenging behaviors after 16 weeks of use, as indicated by decreased NPI-Q scores (Navarro et al., 2015, 2016). Another study on an ambient display system used the Apathy Evaluation Scale and found that the use of the system reduced the participant's apathy after one month of use (Massimi et al., 2008). A personalized multimedia system was shown to significantly reduce depression and anxiety after four weeks of use, as measured by the CSDD and RAID (Davison et al., 2016). Silva et al. (2017) found that the use of the SenseCam significantly reduced depression scores, using the Geriatric Depression Scale.

Studies focusing on simulated presence to reduce problematic behaviors had positive results. O'Connor et al. (2011) found that presenting residents with an iPad containing a video-recorded message from a family member for 14 days was able to significantly reduce resistance to care. Similarly, Hung et al. (2018) also tested iPad-facilitated video simulated presence for 14 days and found that hospital patients with dementia responded positively. As well as improving behavior, the iPad intervention also resulted in positive changes in the mood of all participants. However, the authors noted that video content with too many family members with multiple messages provoked anxiety, emphasizing the importance of acknowledging the individual needs of the person with dementia and being aware of possible over stimulation.

Self-identity. Results from the identified studies suggest that a sense of self can be preserved, even in later stages of dementia. Critten and Kucirkova (2017) found that the Our Story app gave participants confidence, empowerment and increased self-esteem. Karlsson et al. (2017) studied the SenseCam in relation to self and identity. From discourse analysis, the authors identified two key themes: manifestations of sense of self and self in relation to others. With regard to sense of self, the authors found that even if the participant could not relate to the event shown in the photograph, the material still stimulated conversation about personal experience. When the participants' partners had been involved in events captured by the SenseCam, narrating and remembering the event became a joint activity. However, it is important to note that some participants became stressed when the conversation became interrogative. The only study to use outcome measures for self-identity was Massimi et al. (2008) who used the Twenty Statements Test and the Self Image Profile (Adult). The authors found that use of the Biography Theatre for one month led to an improvement in positive self-identity. It is also important to note that studies which included the person with dementia in the individualization process of the technology empowered the individual to become more connected with their sense of self. For example, participants in a digital storytelling workshop enjoyed the process of creating and sharing their stories over a six-week period (Park et al., 2017).

Social relationships and engagement. Given the highly interactive nature of the technologies, many studies found improvements in relationships, communication and engagement. Social robots were identified as a way of facilitating engagement and interaction for people with dementia (Khosla et al., 2014, 2016). Personalized digital media was considered as a tool for starting conversations (Davis & Shenk, 2015; Karlsson et al., 2014; Samuelsson & Ekström, 2019; Yasuda et al., 2009), supporting interaction (Hashim et al., 2015; Park et al., 2017), and improving relationships between people with dementia and their caregivers (Karlsson et al., 2014; Laird et al., 2018; Park et al., 2017; Ryan et al., 2018). It was also reported that such media provided caregivers, and sometimes even family members, with new insights and heightened perspectives into the life of the person with dementia (Damianakis, 2010; Ryan et al., 2018; Samuelsson & Ekström, 2019). The majority of these findings were based on interview or observation data. However, Laird et al. (2018) used the Quality of Carer and Patient Relationship scale (Spruytte et al., 2002) and the Mutuality Scale (Archbold et al., 1990) to assess the effect of the InspireD app on the relationship between the person with dementia and their caregiver. Scores on both scales were significantly improved after 12 weeks of using the iPad app.

There were some cases where tensions in the relationship were reported. For example, Ekström et al. (2015) found that problems associated with dementia were foregrounded during joint interaction with a tablet computer. The person with dementia became dependent on their conversational partner to be able to use the technology. Similar issues were experienced with the SenseCam. The participant in Piasek et al.'s (2012) study of SenseCam relied on his wife while reviewing photographs together with a therapist. Participants in another SenseCam study were reportedly frustrated when they felt the conversation about the photographs had become a test of their memory (Karlsson et al., 2017).

Emotional well-being. Observations of interaction with technology were used to assess emotional reactions from the participants. Technologies that featured reminiscence activities or other autobiographical material provided participants with an enjoyable experience (Critten & Kucirkova; Damianakis et al., 2010; Hashim et al., 2015; Kerssens et al., 2015; Khosla et al., 2014, 2016; McAllister et al., 2020; Park et al., 2017; Peeters et al., 2016; Ryan et al., 2018; Samuelsson & Ekström, 2019; Subramaniam & Woods, 2016). However, due to the highly personal nature of these activities, there is a potential for sensitive topics to cause negative reactions. There were numerous reports of sadness being experienced, especially when personal photographs of those who had passed away were used (Damianakis, 2010; Ryan et al., 2018). In these cases, it is important to remember that emotions are highly complex. Damianakis et al. (2010) commented on the possibility of observing both happiness and sadness simultaneously in reaction to pictures of a deceased loved one. Furthermore, family members involved in the study felt that it was important to include photographs and stories of loved ones, even if they had passed away.

Discussion

Summary of evidence

This review has identified the varying types of digital technologies that are being used to create individualized, meaningful activities for people with dementia. Overall, the findings suggest the use of individualized technology to be promising in contributing to and advancing dementia care. Technology can be used to complement psychosocial approaches to care such as reminiscence therapy, simulated presence therapy, occupational therapy and life story work. Additionally, this review has demonstrated how theory-based knowledge may be used to complement technology-based activities in dementia care. Studies that used theoretical foundations for the individualization process of the technology all found positive impacts on a sense of self and/or engagement, suggesting that theory-based knowledge can be beneficial for technology development.

Findings from the review also indicate the amount of progress that has taken place in this field. Only 7 of the 29 included studies did not actively involve the person with dementia in the individualization process of the technology. This contrasts to a 2008 literature review on technology studies to meet the needs of people with dementia and their caregivers. Topo (2008) found that very few studies actively involved the person with dementia in using the technology. Studies identified in this review not only involved the person with dementia as users of the technology, but in most cases, they were involved in the individualization process, acting as co-creators of their own narratives. There was also a case where the individuals with dementia were involved in the development of the technology itself. The InspireD app was co-created by a User Development Group that consisted of six people with dementia working together with researchers (Laird et al., 2018; Ryan et al., 2018). Future work in this area should adopt a similar approach, involving people with dementia as co-creators from the onset of the technology development.

Opportunities afforded by technology. Findings from this review are in accordance with other literature reviews in this area, in terms of the benefits that technology can provide to people living with dementia. A systematic review of technology for reminiscence therapy found that using information and communication technologies for reminiscence therapy interventions has benefits such as providing access to rich multimedia materials, providing opportunities for social interaction, provision of memory support and ownership of conversations (Lazar et al., 2014). Similar results are resonated in this review, especially with regard to social interaction. Furthermore, the use of technology to preserve, share and explore the narrative of the person with dementia is consistent with earlier findings in this area (Maiden et al., 2013; Purves et al., 2011).

One particularly meaningful benefit of technology is that it provides a means of being able to access a wealth of images and other types of media. This can be very important, especially for those who may not have many photographs from their past. Participants using the OurStory iPad app found access to external images important (Critten & Kucirkova, 2017). This continuous and endless access to media also provides an opportunity to engage with not just the past, but also the present. Participants using the InspireD app were able to take pictures on the iPad and include them as part of their reminiscence program (Laird et al., 2018; Ryan et al., 2018). SenseCam captures everyday moments of daily life, enabling people to recollect upon recent events. The upload feature in CIRCUS (Samuelsson & Ekström, 2019) also allows participants to engage with media from recent events, if they wish to do so.

Technology also presents life histories in a new way, which can be beneficial for all individuals involved its use. Participants in the study of a digital life book were excited about seeing their life history: "I feel like I'm famous. I feel very excited," "I can't believe this, my mother will be proud of me . . . I feel like I'm being appreciated" (Subramaniam & Woods, 2016). Additionally, caregivers felt that technology provided a way of learning more about the life of the person with dementia (Damianakis et al., 2010; Ryan et al., 2018; Samuelsson & Ekström, 2019; Subramaniam & Woods, 2016). As Purves et al. (2011) suggest, technology can be a way of shaping an interactional environment in which narrative can be explored together: "With these technologies at our disposal, we not only have better ways to elicit and convey narratives... but we also have better ways to share these narratives with others, over time and across place" (p. 240). The technologies identified in this review provide examples of how this may be achieved.

Challenges going forward. The results from this review have raised some potential issues that could be faced when implementing individualized technologies into practice. Associated costs are an important issue. The Memory Box device (Davison et al., 2016) cost 12,000 U.S. dollars for four units. Installation of the Biography Theatre took an experienced technologist 30–40 hours over the course of one month (Massimi et al., 2008). In Laird et al.'s (2018) study of the InspireD app, which itself is free, the training sessions cost 2750 GBP per dyad.

Most studies were conducted in the homes of people with dementia, and this may be due to the fact that support from another individual was often needed in order to be able to use the technology. Care institutions such as nursing homes are often busy environments, in which one-to-one interaction may not always be possible due to time constraints. Additionally, home-dwelling individuals with dementia tend to be in more mild–moderate stages of dementia and therefore may be able to use the technology on a more independent level. This then raises the question of how practical it is to introduce such technology into care homes for individuals in more severe stages of dementia. Also, the issue of capacity was raised in Subramaniam and Wood's (2016) study of the digital life book. It was questioned whether members of staff could be expected to take on the role of coproducing the life stories together with the person with dementia.

Additionally, and maybe most importantly, there is a question of how well these technologies can be introduced to this vulnerable group, especially in later stages of dementia. Numerous participants across the studies experienced difficulties in being able to interact with the technology. Examples include physical issues with being able to hold the device or press buttons, issues with being able to see the screen, or difficulties with general operation of the technology. Piasek et al. (2012) witnessed a particular struggle with SenseCam in getting the participant, John, to remember that he was the one wearing the camera: "The SenseCam technology seemed confusing for someone with such severe memory impairments. It also seemed pointless to continuously explain what SenseCam is and that is was John who wore it." Even in studies where participants were aware of the SenseCam, they did not always respond positively to it. For example, one gentleman felt embarrassed by wearing the camera and felt it drew attention to him (Woodberry et al., 2014). These issues highlight the need to continue to develop awareness in potentially problematic areas such as physical limitations or sensory issues as well as self-consciousness or stigma. It is important that devices and technologies are developed with these issues in mind, so that they may be feasible for use by the target population.

Limitations

This is a relatively new field of research and new technologies are constantly being presented, meaning that the evidence on its impact and effectiveness is still somewhat limited. The findings from this review are limited by the small sample sizes of the included studies. Given the amount of time and effort required for individualizing technologies, especially when the identification and collection of personalized multimedia is involved, it is understandable that most studies had small sample sizes. Seven studies included only one participant. While these small case studies are valuable for providing rich, in-depth accounts, the findings are hard to generalize to a wider population. There is a clear need for studies with larger sample sizes with standardized outcome measures. Additionally, the time of use of the devices was highly varied among the studies. The use of the technology ranged from single-time use to six months.

Another limitation of this review is the lack of a quality appraisal of the included studies. Given the fact that the use of individualized technologies in dementia care is still an emerging field, we wanted to include a variety of studies in order to gain a broad overview of the topic. Most of the research in this area consists of small case studies, and excluding these studies based on their quality would have resulted in a limited understanding of how these technologies can be potentially used in dementia care. There is some level of quality of assurance, given the fact that only articles from peer-reviewed journals were included for review. However, there may be potential bias from studies where researchers acted as collaborators or co-editors in the individualization process. For example, participants in Critten and Kucirkova's (2017) study of the Our Story app enjoyed the process of reminiscing together with the first author and commented that the activity had brought back some 'happy times' that the participants were keen to share with the researcher at later interviews. Massimi et al. (2008) stated that a relationship had developed between the participant and the researcher in their role as "biographer." The authors state that this relationship shifted focus from the participant being "an old man with a bad memory" to being a human being. However, this is to be expected, given that participatory design and co-creative approaches are increasingly being adopted in dementia research. Once more knowledge exists in this area, there will be a need to critically evaluate the quality of the evidence.

Finally, a considerable number of articles had to be excluded for review due to lacking reports on the effects on the well-being of the person with dementia. This meant that other emerging technologies in this area were not commented on. It is important to be aware of other technologies beyond those included in this review, and how they can also create opportunities for the conveying of narrative. For example, virtual reality can be a means of recreating environments from the past (Hodge et al., 2018). Another example is a project called SENSE-GARDEN, which is developing multisensory spaces that combine music, film, pictures, and scent with innovative technology to create an immersive environment tailored specifically for the individual with dementia (Goodall et al., 2019).

Conclusion

Various technologies can add value to the individualization of meaningful activities in dementia care. This review highlights the need to focus on how these types of technologies could potentially be implemented into care practice, particularly in nursing home environments. Previous reviews of technology studies have raised issues that are still present today, with this review showing that studies are still highly varied in terms of design, sample sizes, methods of assessment, and the type of technology being used.

This review has also highlighted several important aspects to bear in mind when developing technologies for people with dementia. Findings suggest that people with dementia are able to learn how to use new technologies in more severe stages of dementia; however, support from caregivers is likely to still be needed. In order to further inform practice, future studies should assess time consumption, training requirements, costs, and long-term benefits. It is also important that technology is used as means to support people with dementia in fulfilling meaningful occupation, rather than as a means of interrogation. By developing technology in a user-friendly and user-conscious way, ideally with direct involvement of people with dementia, the right balance between support and empowerment can be identified.

To conclude, this review suggests that the use of individualized, digital technologies can have a positive impact on the well-being of people living with dementia. The included studies provide valuable information on how to individualize and facilitate the use of such technologies, which may serve as useful recommendations for implementing these technologies into practice and conducting future research. However, given the methodological limitations of research conducted in this area, more work is needed to strengthen the evidence base for using individualized, digital technologies in dementia care.

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Supplemental material

Supplemental material for this article is available online.

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Paper II

The Role of Adaptive Immersive Technology in Creating Personalised Environments for Emotional Connection and Preservation of Identity in Dementia Care

Insights from User Perspectives towards SENSE-GARDEN

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Abstract— **This paper presents early stage research on the development of an immersive, multisensory room for people living with dementia. Dementia is considered to be a public health priority on a global level. Our research addresses the challenge of meeting individual needs in dementia care, particularly in relation to social and emotional wellbeing. We draw upon findings from 52 interviews with users, including people with mild cognitive impairment, professional caregivers, and informal caregivers. These interviews were conducted to explore initial responses towards a personalised multisensory room called SENSE-GARDEN. Thematic analysis resulted in six themes: benefits for all, focus on the individual, past and present, emotional stimulation, shared experiences, and challenges to consider. This paper provides important theoretical considerations for the role of technology in not only the SENSE-GARDEN intervention, but in preserving the identities of people with dementia and providing opportunities for connection with others. Future work in this area should adopt an interdisciplinary approach to using technology in dementia care.**

Keywords-dementia; virtual environments; immersive technology; human computer interaction; interpersonal relationships

I. INTRODUCTION

This article builds upon a conference paper presented at the Fourth International Conference on Human and Social Analytics [1]. This extended version of the original paper offers detailed results from a preliminary study on a virtual adaptive environment for people with dementia.

Dementia is a syndromal term and can be caused by a variety of diseases, including neurodegenerative diseases. Memory, behaviour, and communicative abilities are often affected [2]. There are approximately 47 million people living with dementia worldwide [3]. With this number set to increase to 131.5 million by 2050, it is of the utmost importance to tackle dementia's progressive impact on the wellbeing of people living with this syndrome.

The World Health Organization has called for action on dementia, presenting it as a public health priority at a global level [2]. This action includes a call for research to identify ways of supporting the needs of people living with dementia, their caregivers, and the needs of society in the context of costs, understanding, and awareness.

In recent years, studies have identified numerous complex needs of people with dementia living in long-term care. These include the management of challenging behaviours, maintenance of social relationships, involvement of people with cognitive deficits in meaningful activities, and supporting the emotional needs of all [4][5].

Emotion-oriented approaches to care have been shown to be cost-effective ways of improving psychological wellbeing and social behaviour amongst people with dementia [6][7]. These nonpharmacological approaches are often person-centred, focusing on the social and emotional needs of the individual. Reminiscence rooms, virtual gardens and virtual reality forests are examples of how immersive technologies have been integrated in emotion-oriented approaches designed to create effective nonpharmacological interventions for people with dementia [8][9].

However, this area of study has called for further research in determining what works best for the individual [10]. It has recently been suggested that an individualised multisensory environment for people with dementia would be a highly beneficial intervention, especially if family members are included in the selection of stimuli [11]. Our research is in line with this suggestion, creating not only a personalised multisensory space and intervention, but one that also incorporates immersive technology, all with the inclusion of family members, friends, and professional care staff.

This paper presents early stage research on a multisensory room, SENSE-GARDEN, that is currently being developed as an adaptive, immersive environment integrating technology and multisensory stimulation for reminiscence in people living with mild to moderately severe dementia. We will first provide a brief overview of the project (Section II), followed by a description of the methodology used in research and development (Section III). We will then discuss the results of the interviews in relation to each of the six themes identified through thematic analysis (Section IV). In Section V, the results are summarised and discussed in relation to the role of technology in preserving the identity of the person with dementia and facilitating an environment in which relationships can be fostered. Finally, in Section VI, we conclude with final remarks, the next steps for SENSE-GARDEN, and suggestions for future research.

II. SENSE-GARDEN: AN OVERVIEW

SENSE-GARDEN is a psychosocial intervention that is being developed to create individualised reminiscence sessions for people living with dementia in residential care. The intervention combines the use of technology for reminiscence and multisensory stimulation, with human-to-human informational and emotional communication.

Prototypes of the SENSE-GARDEN room are currently being built across several countries in Europe, namely in Norway, Portugal and Romania, with an initial prototype already being tested in Belgium. These rooms are filled with individualised stimuli such as familiar music, soundscapes, imagery, films, and scents in order to stimulate memory and encourage active participation of the person with dementia in reminiscing activities. Particular emphasis is placed on using autobiographical content such as family photographs, music from childhood, and films of life events.

The use of large projection screens, scent dispensers, and surround sound systems will integrate the various multimedia of the room, creating an immersive environment. For example, high-definition imagery of a forest could be accompanied with the smell of pine trees and the sound of birds, to evoke a completely immersive sensation.

SENSE-GARDEN will expand on currently established sensory rooms, which are also known as ‘Snoezelen’ rooms. Deriving from the Dutch terms for ‘sniffing’ and ‘dozing’, Snoezelen was originally developed in the Netherlands as a therapy for individuals with learning difficulties [12].

SENSE-GARDEN presents an innovative approach to sensory rooms by utilising smart technologies that enable the space to adapt to the individual preferences and needs of the person with dementia. This focus on autobiographical content is achieved through the use of individual user profiles. Each profile has an associated media repository consisting of digital photographs, films, and music that holds significant meaning for the person with dementia.

Radio frequency identification (RFID) is used to allow the SENSE-GARDEN system to identify the user. Upon entering the room, the system automatically projects autobiographical multimedia from the person with dementia’s user profile.

The room is designed to be used by two main categories of users. The first is the person with dementia (PwD), who is also considered the primary user. The second is the caregiver, who will either be informal (family/friend) or formal (professional care staff). It is anticipated that together, the PwD-caregiver dyad will interact with the immersive environment to stimulate memory, conversation, sharing and engagement.

III. METHODOLOGICAL APPROACH

SENSE-GARDEN is a multidisciplinary project involving partners in Belgium, Norway, Portugal, and Romania. The consortium brings together multiple professions and competencies including technology development, architecture, care home management, health sciences and research.

There have been numerous calls to involve people with dementia in the process of designing assistive technologies [13][14]. Their contributions are thought to be of crucial importance, along with input from their caregivers [15]. More recently, user centred design has been recommended for the development and implementation of psychosocial interventions [16].

The SENSE-GARDEN project embraces a user centred design approach and is working co-creatively with user groups throughout all its phases. The aim of this preliminary research was to explore initial responses from user groups, so that their ideas and feedback may be integrated into the next phases of development of SENSE-GARDEN.

Thus far, 52 qualitative semi-structured interviews have been conducted with user groups across Belgium, Norway, Portugal, and Romania. The aims of these interviews were to collect responses and attitudes towards the SENSE-GARDEN room concept, and to identify challenges that may arise during the course of the project.

TABLE I. RESPONDENT INFORMATION

Country	**People with Mild Cognitive Impairment**				**Informal Caregivers**				**Formal Caregivers**			
	N	Mean Age	Gender		N	Mean Age	Gender		N	Mean Age	Gender	
			Male	Female			Male	Female			Male	Female
Belgium	3	89.6	2	1	6	57	1	5	4	31.5	1	3
Norway	4	84	0	4	4	59.3	0	4	4	38.8	1	3
Portugal	3	79.7	0	3	3	55.7	0	3	3	44.3	0	3
Romania	6	67.2	3	3	6	50.7	0	6	6	42.7	2	4
Total	**16**	**77.9**	**5**	**11**	**19**	**55.3**	**1**	**18**	**17**	**39.4**	**4**	**13**

The specific research questions for this study were as follows: (1) What are the users' attitudes towards the concept of SENSE-GARDEN? (2) What benefits, if any, do users think SENSE-GARDEN could provide in the care of people living with dementia?

In order to answer these research questions, the interview was designed in a way that allowed for an in-depth exploration of the users' beliefs surrounding SENSE-GARDEN. The interview was semi-structured with open-ended questions and lasted for approximately 30 minutes. Interview questions focused on the overall concept of SENSE-GARDEN, the individual components of the intervention, and potential benefits.

The respondents included 16 people living with a diagnosis of mild cognitive impairment, 19 informal caregivers, and 17 professional caregivers. Table 1 gives an overview of the respondent information.

In order to conduct an in-depth exploration of the ideas and perspectives given by the users, data was analysed using thematic analysis. Thematic analysis is a qualitative method in which prevalent patterns of ideas and responses are identified amongst data. The analysis procedure for this study undertook the following phases, given by Braun and Clarke [17]:

1) Familiarisation with the data: All the data was thoroughly read and re-read, along with notating initial ideas and interpretations of the dataset.

2) Coding: The ideas were used to generate codes, which identify interesting features across the data. In this study, data was manually coded in an inductive manner, meaning that the codes and themes were developed directly from the content of the data, rather than being developed by pre-existing ideas.

3) Searching for themes: The codes were used to search for themes, which represent patterned responses or meanings across the data.

4) Reviewing themes: The themes were reviewed to ensure that they accurately represent the views of the users and the view from the entire dataset.

5) Defining and naming themes: The essence of each theme was identified, along with its relevance to the research questions.

6) Producing the report: Finally, the themes were considered in their relationship to one another, and a narrative about the dataset was created. This narrative is supported by direct quotes from the dataset.

In order to stay true to the 'voice' of the users, codes and themes were constantly checked back against original data. Braun and Clarke [17] emphasise the importance of flexibility in thematic analysis and identify the process as one of continuous reflection on the reading, shaping, and checking of data and themes.

IV. RESULTS

Six themes were identified through the thematic analysis: *(A)* Benefits for All, *(B)* Focus on the Individual *(C)* Past and Present, *(D)* Emotional Stimulation, *(E)* Shared Experiences, and *(F)* Challenges to Consider. A thematic map is shown in Figure 1 to provide a visual summary of all six themes and their respective subthemes.

This thematic map also demonstrates the interactive nature of the themes and their relationship to one another. Numerous subthemes falling under different main themes are related to each other. For example, the subtheme of 'stimulating emotional memory' (under the theme of Emotional Stimulation) can be connected to the subtheme of 'avoiding negative memories' (under the theme of challenges to consider). In this way, all the themes presented provide an overarching narrative of the users' beliefs, views, and attitudes towards SENSE-GARDEN and the technology within it.

The following subsections will discuss each of the six themes in turn. The full dataset from the interviews has been made available online, along with the interview guide, and coding from thematic analysis [18].

A. Benefits for All

There was a resounding view from all users that SENSE-GARDEN may be able to provide benefit in some way. These benefits were grouped into five subthemes: benefits for the person with dementia, benefits for the family, benefits for professional caregivers, benefits in practice, and benefits beyond dementia care.

Benefits for the person with dementia. All users believed that SENSE-GARDEN has the potential to provide numerous benefits for people living with dementia. These benefits included improvements in memory, mood and overall quality of life: "Stimulating memory and improving quality of life, the person with dementia and caregivers can enjoy life more"..., "This can enrich their [people with dementia] everyday life"...,"I am sure this will be of value.

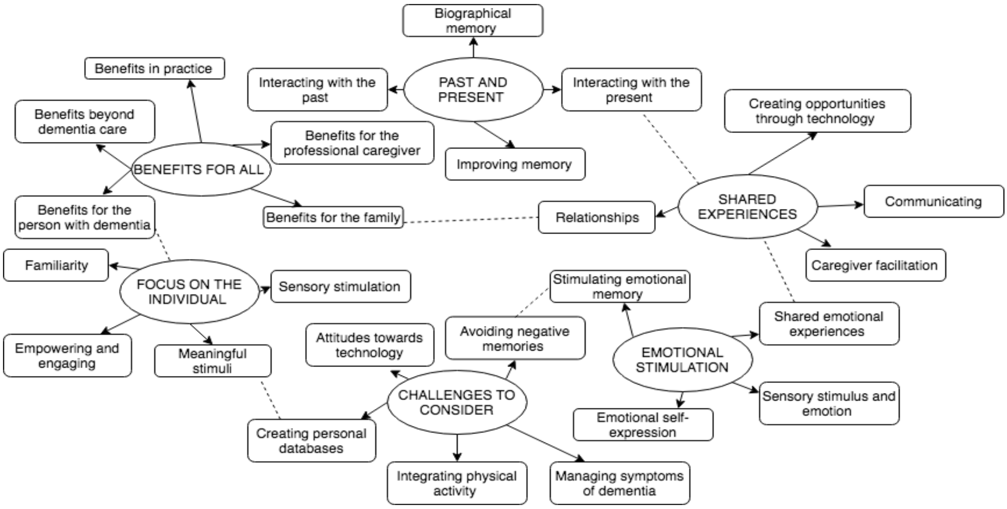

Figure 1. Thematic map of themes and subthemes identified across the dataset.

The person with dementia gets a good experience every day. In this we have faith”. One person with mild cognitive impairment discussed the role of the intervention in tackling issues of helplessness that are associated with not only dementia, but illness in general: “When ill, it is like you are closed in a dark place you cannot leave by yourself. SENSE-GARDEN can help you out”.

Benefits for the family. Many of the caregivers, both informal and formal, commented on SENSE-GARDEN being able to provide ways for the family to strengthen relationships with loved ones who have dementia: “It’s hard to be a relative, so little competence, dialogue is difficult. This [SENSE-GARDEN] is a great tool for having a nice time together”.

Benefits for the professional. Formal caregivers considered SENSE-GARDEN as a tool for getting to know people with dementia better. The highly personalised nature of the intervention means that staff have the opportunity to gain insight into the resident’s life in a way that is perhaps not possible in day-to-day care: “The advantage is that you can have full focus on the patient, being able to be alone with him or her. We get to know the patient better. It creates security.”..., “This will also mean that the staff become better acquainted with the person with dementia”. Another caregiver commented as follows: “It’s good for the staff to see the person with dementia in another way”. These comments go to suggest that digital media can create opportunities for learning more about individuals with dementia, which could be especially important for people in later stages of dementia, who may not be able to coherently express themselves.

Benefits in practice. As well as presenting individual benefits, users believed that SENSE-GARDEN could benefit the healthcare system in terms of cost and practice: “Why has nobody thought of this before? Many of these things should have already been at the nursing home even if one does not have a SENSE-GARDEN”..., “May become important in terms of reducing the cost of dementia care over time”.

Benefits beyond dementia care. There was a consensus across the respondents that SENSE-GARDEN could also provide benefits to people living without dementia: “It is always good to go back to childhood and youth, for all of us. No need to be a person with dementia”.

The users’ positive outlook on SENSE-GARDEN captures a range of benefits that not only apply to the person with dementia, but also to caregivers and care practice as a whole. Future studies on SENSE-GARDEN will need to incorporate outcome measures that evaluate these various aspects.

B. Focus on the Individual

The key concept of SENSE-GARDEN is creating an environment in which the person with dementia is the central focus. The users not only valued this focus on the person with dementia, but they also offered their suggestions on to how best create an individualised environment. These suggestions are grouped into the following subthemes: familiarity, meaningful stimuli, sensory stimulation, and empowering and engaging.

Familiarity. With the SENSE-GARDEN being a new and unfamiliar concept, both informal and formal caregivers stressed the importance of providing a familiar surrounding for the person with dementia: “A familiar environment, familiar objects to touch, is mandatory”..., “At least for the first sessions, the SENSE-GARDEN room must include familiar items, besides the personal records used for projection and music".

Meaningful stimuli. Users believed that the stimuli used in SENSE-GARDEN should have significant meaning for the person with dementia: "Family photo album, with photos from important emotional occasions"..., "Meaning from one's own trips. You must remember a trip, but also the reason you went on that trip, the scope".

Sensory stimulation. There was an overall positive attitude towards SENSE-GARDEN's proposed methods of sensory stimulation. Users commented on the ability for such stimulation to trigger memories and improve mood: "Imagine what scent can bring forth, the idea of what this can do, it's gorgeous". There were also numerous suggestions for SENSE-GARDEN to broaden its current plans for sensory stimuli, such as including tactile elements: "Maybe something more for the sense of touch. When you see a mountain and smell the fern tree, why not touch a fern tree branch?".

Empowering and engaging. SENSE-GARDEN was perceived as an opportunity for people with dementia to actively engage and express themselves: "The person with dementia has to be reassured that life has not come to an end when diagnosed with dementia, and reality is not limited by the walls of the bedroom. They still have things to show and share with us all".

The suggestions given by the users imply that whilst the technology and media within the SENSE-GARDEN needs to be individualized, there are additional ways in which individualisation can be achieved. This is through caregiver facilitation, tactile stimuli, and the physical design of the room. All of these factors will need to be taken into consideration throughout the development of the intervention.

C. *Past and Present*

Given that SENSE-GARDEN borrows techniques from reminiscence therapy, it is of no surprise that discussion regarding memories arose during the interviews. However, the users identified links between interaction with the past and with the present, as well as the impression of overall improvement of memory in general. Therefore, the subthemes are: interacting with the past, interacting with the present, and improving memory over sessions.

Interacting with the past. In discussing the benefits of SENSE-GARDEN, all respondents believed that the individualised nature of the virtual environment could trigger autobiographical memories. This was linked to helping people with dementia connect with their past: "Personal videos and photos are important. You resonate with your past".

Improving memories over sessions. As well as stimulating memories of the past, respondents also believed that memory could be strengthened over the course of the SENSE-GARDEN sessions. Some users suggested using visual markers in the SENSE-GARDEN components in order to trigger memory in consequent sessions: "Using memory anchors will improve experience and stimulate reality connection". An example of this would be to use a recent photograph of a familiar place that holds significant meaning for the person with dementia. The same photograph could then be presented to the user in the next SENSE-GARDEN session to see if they remember the meaning connected to that picture.

Interacting with the present. There was a suggestion that even if the person with dementia does not have the capacity for long term memory of the sessions, the individual could still benefit from the 'in-the-moment' experience of SENSE-GARDEN: "They probably do not remember afterwards, but think about being happy one hour every day. That's a good benefit". Respondents also considered interaction with the past an activity for strengthening self-identity in the present moment: "Nowadays we forget who we are. SENSE-GARDEN will help us all relive forgotten events and identities".

This symbiotic relationship between past and present has been much discussed in regards to selfhood. Surr [19] adopts a socio-biographical approach to explain how people with dementia use their past in the context of telling their life story to others, in order to maintain a sense of self in the present. Technology may have much to offer in this maintenance of self, ideas of which will be given in detail in the discussion section of this paper.

D. *Emotional Stimulation*

Whilst emotion was a prominent topic amongst all of the themes, the comments from the users proved emotion to be highly complex. It was therefore decided to include a more detailed discussion of emotion. The subthemes are as follows: sensory stimulus and emotion, stimulating emotional memory, emotional self-expression, and shared emotional experiences.

Sensory stimulus and emotion. The users believed that stimulating the senses through imagery and music could stimulate positive emotions in the person with dementia: "One connects so much to music, there are a lot of emotions"..., "Stimulating senses brings joy and memories".

Stimulating emotional memory. The users focused primarily on familiar music in being able to stimulate emotional memory in the person with dementia. "Just three notes will bring back that special moment if music is connected to that moment"....,"When we hear a song, we think of something and then we will be happy".

Emotional self-expression. Individuals with dementia are capable of experiencing and expressing a wide range of emotions, even in later stages of the disease [6][20]. Building upon the idea of sensory stimulation triggering emotional memories, the users also believed that SENSE-GARDEN could enable people with dementia to express themselves in ways that transcend typical verbal communication: "Some people stop talking, but they can sing". Furthermore, they believed that people may be able to experience a heightened state of feeling through the intervention: "SENSE-GARDEN is an intermediary space, between the memories and the here and now, a space we can all access and we can remember how to feel, by one's self and together, without shame or fear".

Shared emotional experiences Finally, the discussion of emotion went beyond individual feelings. The users expressed the value of SENSE-GARDEN in being able to help people connect with one another: “Sharing the experience is most important for reconnecting”. One person with mild cognitive impairment also highlighted the importance of how these shared experiences should be shaped: “The therapist is very important and can instil peace and wellbeing. A special emotional environment must be created for SENSE-GARDEN to work.” The idea of creating a “special emotional environment” goes to suggest that it is not the intervention alone that can provide benefits to the relationships, but it is also the individuals present who can shape the experience of SENSE-GARDEN.

This theme has demonstrated the intricate nature of emotions, and how they can be manifested through the stimulation of the senses, through the remembrance of past events, and through our relationships with others.

E. Shared Experiences

SENSE-GARDEN is designed to be a joint experience between the person with dementia and their caregiver. As discussed in the previous subtheme, the users expressed the importance of sharing the experience together. This current theme goes beyond that of emotions and discusses the shared experience in relation to the following subthemes: caregiver facilitation, relationships, communicating, and creating opportunities through technology.

Caregiver facilitation. Many users believed that carefully planned facilitation of SENSE-GARDEN is required for the intervention to work. Particular stress was placed on the importance of being accompanied by a familiar individual: “We must have people accompany us- internal people we know”. Users also believed that effective facilitation could shape a positive environment in which the benefits of the intervention could be maximised: “The caregiver must be well trained and possess good communication skills...to be able to support and fructify the person with dementia’s gains in terms of cognitive and behavioural improvements”.

Relationships. Respondents believed that SENSE-GARDEN could improve understanding and relationships between people with dementia and their caregivers- both formal and informal. There was a sense of the intervention being able to ‘restore’ what dementia had taken away from the relationship, such as self-identify and communication: “Family and friends can be with the patient as they were before”. SENSE-GARDEN was considered a catalyst for fostering relationships and providing opportunities for self-expression and understanding between people with dementia and their families. This improvement in relationships was considered important in easing caregiver burden: “Improving relationships with family members and staff, easing caregiver burden on the staff and family”.

Communicating. During the interviews, discussions turned to benefits of creative activity in dementia care. In particular, there were strong references to the ability of visual media and music to provide alternative forms of communication beyond that of verbal means. Users believed that the inclusion of music and visual imagery in SENSE-GARDEN would be able to provide tools for sharing information: “Being able to tell stories, if one has lost the language, pictures and movies can tell things.” Users also believed that SENSE-GARDEN may be able to play a role in triggering conversation topics: “If I visit, there are always dead moments. This will help to get the life back into the conversations.”

Creating opportunities through technology. Users with mild cognitive impairment displayed a sense of exploration and adventure when discussing the components of SENSE-GARDEN. The use of virtual environments was perceived as providing ways of visiting new places and experiencing an outdoor environment: “Maybe a place you never went to, but you want to see”. One user was particularly impressed with a component of SENSE-GARDEN called “Life Road”, which allows the person with dementia to cycle on a stationary bike in front of a film of a familiar place: “We are afraid to ride outside so this option is great. To be safe on a bike.” This technology was also considered to provide opportunities for individuals to see places that they can no longer visit: “My mother wants to see her old street again, but we can’t do it. With this she can visit again”.

These quotes from the users have highlighted the amount of work that goes into creating meaningful experiences for people with dementia. However, with the right kind of facilitation, SENSE-GARDEN may be able to provide these experiences for not only people with dementia, but also for their caregivers.

F. Challenges to Consider

This final theme is perhaps one of the most important in going forward with the SENSE-GARDEN project. The users raised important issues to be aware of when preparing and implementing the SENSE-GARDEN intervention. These concerns are given in the following subthemes: avoiding negative memories, creating personal databases, integrating physical activity, managing symptoms of dementia, and attitudes towards technology.

Avoiding negative memories. Many users emphasised the importance of avoiding stimuli that could evoke negative emotions, such as photographs of relatives who have passed away, for example: “It is necessary to note that there are memories that are not good, and that it is necessary to have very careful prior fieldwork”.

Creating personal databases. The main purpose of SENSE-GARDEN is to create experiences that are tailored to the individual with dementia and their past. However, users suggested that there might be challenges in collecting necessary information to achieve this. Issues included the lack of information from family and friends, but potential solutions were also offered by the users: “How you create a database for a lonely person- general triggers in an exploratory approach”..., “The reduced availability of family and friends can be a hindrance. The process of collecting personal data can be eased by using a questionnaire developed for the future SENSE-GARDEN users”. A formal caregiver also raised the issue of collecting visual imagery: “We have to see who has videos and films because in this rural area only a few had them”.

Integrating physical activity. Whilst many of the respondents emphasised the importance of physical health, issues in implementing physical activity were discussed. One user had a concern regarding the use of a stationary bike for the "Life Road" component of SENSE-GARDEN: "One should reassess the issues of physical activity. For example, bicycles must be those where the person rests and pedals almost lying down".

Managing symptoms of dementia. As in any intervention for people with dementia, it is important to consider how symptoms will be managed and prevented during the sessions: "The person conducting the SENSE-GARDEN session will be essential and must have backup for interventions when disturbed behaviours occur. You don't know how the person will react, even if what you show was a best experience for him". Other issues relating to hallucinations and medication were also raised.

Attitudes towards technology. There was quite a strong sense among the respondents that technology should be hidden during the SENSE-GARDEN sessions: "The experience will be richer when the technology is hidden"..., "The room must be very tempting, persuading- all technology must be hidden". These comments could be interpreted in two ways. Firstly, technology should be hidden to create a more realistic, immersive environment. Contrastingly, it could be that users were referring to the potential reservations that some people have against technology. Some users explicitly expressed negative attitudes towards technology: "Many beware technology". There were also respondents who preferred experiences in natural environments compared to virtual scenarios: "I'd prefer to walk the person with dementia in a real park"…, "SENSE-GARDEN must be just an intermediary step to outdoor and social activities."

This theme has highlighted that whilst the users see many potential benefits for SENSE-GARDEN, they are also aware of the challenges that lay ahead. This affirms the inclusion of not only caregivers, but also people with cognitive impairment in the development of interventions, and the value of adopting a user centred design in interventional research.

V. DISCUSSION

The findings from these user interviews have covered a large variety of ideas regarding the SENSE-GARDEN intervention. Firstly, the respondents were persistent in their beliefs that the environment, the facilitation of the intervention, and the stimuli all need to be tailored to the individual with dementia visiting the SENSE-GARDEN. It should be acknowledged that the task of individualisation is not an easy feat. As human beings, we are all individualistic by nature, with different tastes, preferences, and desires. Adding the constantly fluctuating progression of dementia to this individuality makes it a difficult task in designing technology for these users [21][22]. This is something that the SENSE-GARDEN project will have to tackle through rigorous work and collaboration with users, technology developers, and researchers of various disciplines.

Secondly, the respondents also emphasised the importance of interaction between the SENSE-GARDEN stimuli, the person with dementia, and the caregiver. The respondents` numerous ideas regarding this interaction can be taken forward into a theoretical consideration of technology and its role within SENSE-GARDEN.

A. *Technology as the Storyteller: The Potential of Digital Media in Preserving Narrative Identity*

Dementia's impact on memory, behaviour and communicative abilities can have detrimental implications for a person's identity. However, there is evidence to suggest that individuals may preserve a sense of self to some extent, even in more severe stages of dementia [19][23]. In this study, there was an overall sense of the immersive environment being able to stimulate autobiographical memory, which was valued as important for preserving a sense of identity. The perspectives of respondents are in agreement with previous research on virtual environments for people with dementia. Siraraya and Ang [24] describe the virtual world as a 'memory sanctuary', in which selfhood and relationships are maintained.

In order to understand how technology and media may be able to preserve identity, we have first to consider what identity means to people with dementia and how it can be shaped by other individuals. The role of others should not be underestimated in maintaining the identity of the person with dementia. In discussing the needs of people with dementia, Kitwood [25] stresses the importance of others in the maintenance of personhood. Westius, Kallenberg, and Norburg [26] present the notion of 'intertwined narrative' in which the life story of the person with dementia is integrated with the narrative of their family carer. Thus, if the person with dementia should become unable to independently recall their story, the intertwined narrative of the caring relationship may provide the opportunity for the maintenance of self.

Earlier literature presents similar ideas. Mills [27] suggests that people with dementia bestow their life stories to another, therefore continuing their sense of identity. Mills states that in this sense, the narrative of the individual never disappears, regardless of the inevitable fading of the person's memory.

One way of preserving this narrative is through the use of digital life books. Digital storytelling, an activity in which technology is used to create innovative forms of narrative, has been shown to educate nursing home staff about the person with dementia [28]. This is especially important for people with dementia living in care homes with little or no family, a challenge mentioned by one of the users included in the present study. Technology and personalised media contents may be the answer to not only preserving, but also sharing that individual's life story with care staff.

SENSE-GARDEN could potentially offer a method for assisting professional caregivers, family and friends in preserving the life story of the person with dementia. Furthermore, the technology of SENSE-GARDEN goes beyond the "life book" concept by offering an entire environment shaped around a person's life. It offers the opportunity for individuals to become completely immersed in their past. The next section will discuss the technology's place in the overall environment.

B. Beyond Physical Space: Creating 'Emotional' Environments through a Transactional Relationship

The respondents emphasised the significance of creating an environment in which the person with dementia and their caregiver could share an emotional experience together. Here, respondents applied meaning beyond the physical space to include emotional and social factors that contribute to the experience of space. In this sense, it is important to have a holistic understanding of what constitutes as an 'environment'.

There is growing acknowledgement of the environment being defined as more than just a physical space. According to literature, an environment is composed of psychosocial elements as well as physical factors [29]. In considering how an environment can shape social interaction, Freund's concept of space is particularly relevant. He writes "space is not merely a place in which social interaction occurs, it structures such interaction" [30].

The way in which an environment simultaneously influences the behaviour of individuals and interpersonal relationships, and yet is shaped by those persons, can be referred to as the transactional relationship. The notion of 'transaction' was firstly used in this context by the philosopher John Dewey, who asserted "Everything that exists in far as it is known and knowable is in interaction with other things. It is associated, as well as solitary, single." [31]. In the context of SENSE-GARDEN, it could be said that a transactional relationship exists between the various technologies (the intervention environment), the person with dementia, and the caregiver. This transactional relationship is conceptualised visually in Figure 2. The figure highlights the numerous interactions that take place between SENSE-GARDEN and its users.

To understand the transactional relationship as a whole, one must consider the individual interactions that take place between each of the three components:

Person with dementia and SENSE-GARDEN stimuli: The SENSE-GARDEN stimuli has a direct effect on the person with dementia, e.g., the system plays a song that evokes a positive reaction in the person with dementia. The SENSE-GARDEN, in turn, will also be influenced by the reactions of the person with dementia. Feedback will enable the system to learn more about the user with each session and therefore, future visits to the SENSE-GARDEN will become increasingly personalised.

Caregiver and SENSE-GARDEN stimuli: The SENSE-GARDEN stimuli may also have an effect on the caregiver. For example, a familiar song might hold significant meaning for an informal caregiver, as well as the person with dementia. In this way, the caregiver may experience their own emotional reaction towards particular stimuli. Alternatively, the caregiver may be indirectly affected by the stimuli through emotional contagion. Emotional contagion refers to the process of an individual's emotional state becoming triggered by emotions displayed in another person [32]. In the context of SENSE-GARDEN, the caregiver's emotions may be shaped in response to the reactions of the person with dementia. The caregiver will also be able to configure the SENSE-GARDEN environment based on these reactions, e.g., they can choose to immediately stop a video if it prompts negative behaviour in the person with dementia.

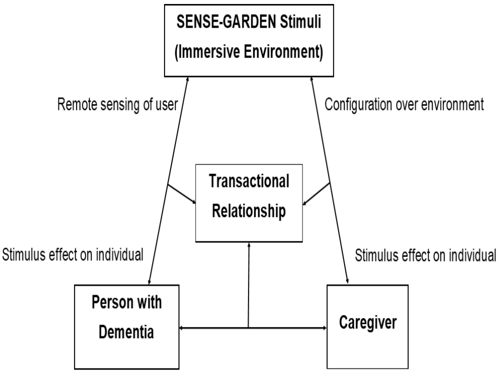

Figure 2. Conceptual model of the transactional relationship that takes place between the person with dementia, caregiver and the SENSE-GARDEN stimuli during the intervention

Person with dementia and caregiver: The interpersonal relationship between the person with dementia and the caregiver will shape the entire SENSE-GARDEN experience. For example, if the person with dementia and the caregiver are spouses with a close relationship, they might spend the SENSE-GARDEN session reminiscing on shared moments from their past. However, if the session is taking place between a person with dementia and a new professional caregiver who is not so acquainted with the individual, then their session may involve SENSE-GARDEN providing prompts for the caregiver in order for them to ask questions about the person with dementia's life.

Applying this theoretical frame to the SENSE-GARDEN environment may provide insight into how the intervention works. It will not be possible to gain a full insight into the effects of SENSE-GARDEN without studying the numerous components of the environment. Later literature on emotion echoes Dewey's view, suggesting a need to study the complex relationship between person and environment, for emotions cannot be comprehended by one or the other alone [33].

These ideas can be linked to current thoughts on the nature of technology design, which has been described as "deeply contextual" [22]. Therefore, incorporating the study of context, environment and relationships seems appropriate for both dementia studies and technology development. The interaction between environment and the people within it is vital. How does SENSE-GARDEN, and technology as a whole, fit into this interaction? What role does it play? Going forward, research should adopt a holistic approach to evaluating technology, considering the wider context in which the technology is situated.

VI. CONCLUSION AND FUTURE WORK

This paper has demonstrated the value and usefulness of including user groups in the development of not only innovative technologies, but also of interventions for dementia care. Viewing a project through the lens of the user can offer contrasting perspectives with fresh insight into solutions. In the present study, the user interviews yielded valuable insights for the progression of the SENSE-GARDEN project.

The users' value for the relationships within the SENSE-GARDEN suggests that the social and emotional aspects of virtual environments should not be underestimated. This view is supported by previous literature which has called for more research on social interaction in dementia care settings [34]. The results highlight the significance users find in fostering relationships through means of self-identity and emotional relationships. A focus on social and emotional interactions between technology, users, and interpersonal relationships could provide very fruitful results in the context of dementia care. This research provides rationale for the study of emotional engagement and interaction not only in the SENSE-GARDEN project, but also in the wider context of assistive technologies.

The next steps for SENSE-GARDEN include a focus on this emotional aspect. The full trials, planned for summer 2019, will adopt a mixed-methods approach to studying the intervention. Whilst qualitative methods capture rich personal accounts of user experiences, it is important to recognise the value of quantitative measures. Therefore, physiological data will be collected in addition to data from questionnaires, interviews and observation measures. The Empatica E4 wristband [35] will be used to collect information on heart rate and electrodermal activity (EDA). These measures will be assessed during the SENSE-GARDEN visits, as a reaction to different stimuli. Combining this data with qualitative accounts of the SENSE-GARDEN experience will provide a stronger overview of the processes that occur within the intervention.

This research also provides rationale for theoretical work on the role of technology for people with dementia. Firstly, ways of meeting individual needs need to be identified. Respondents stressed the importance of familiarity for the person with dementia, and they raised issues regarding the identification of individual preferences and behaviours.

Secondly, the role of technology as an active contributor to environments, and interactions within those environments, should not go unnoticed. This paper has discussed the SENSE-GARDEN technology in the context of a transactional relationship, but other theories may apply.

Finally, this paper demonstrates the highly interdisciplinary nature of this topic. The users' comments have formed a piece of work that lays at the intersection of human centred design, technology, psychology, sociology, and arguably the creative arts. Future work within dementia care can benefit from incorporating knowledge from these various disciplines.

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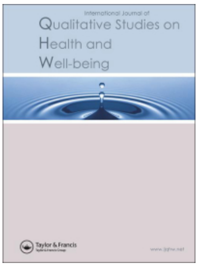
Paper III



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Supporting identity and relationships amongst people with dementia through the use of technology: a qualitative interview study

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Supporting identity and relationships amongst people with dementia through the use of technology: a qualitative interview study

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ABSTRACT
Meaningful activities in dementia care can promote the co-construction of narrative identity in caregiving relationships, helping to preserve the sense of self in people with dementia.
Purpose: Informed by symbolic interactionism and Deweyan transactionalism, the aim of this study was to develop a transactional model of how narrative identity and relationships are promoted through the use of a new technological solution, SENSE-GARDEN, that uses digital technologies and multisensory stimuli to facilitate individualized, meaningful activities.
Method: We conducted a qualitative interview study to explore the experiences of people with moderate to advanced dementia and their caregivers in Norway and Portugal. After using SENSE-GARDEN for 12–16 weeks, 20 participants (7 persons with dementia and 13 caregivers) were interviewed. The interviews were analysed using reflexive thematic analysis.
Results: Three themes were generated: openness, learning, and connection. Findings suggest that SENSE-GARDEN can stimulate emotional experiences, preserve narrative identity, and foster interpersonal relationships. These findings are illustrated through a transactional model.
Conclusion: This study highlights the complex multitude of factors affecting person-environment interactions in which narrative identity and relationships are constructed. To better understand these factors, future work should adopt a holistic approach to studying new methods of creating meaningful activities in dementia care.

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Dementia; technology; narrative; identity; relationships; symbolic interactionism; reflexive thematic analysis; qualitative research methods

Introduction

Common forms of dementia, such as Alzheimer's Disease, primarily affect memory, language, and behaviour. These impacts can lead to difficulties in communicating and socializing with others, which means people living with dementia often experience stigmatization as a result of behaving in a way that deviates from social norms (Mukadam & Livingston, 2012). The stigma surrounding dementia is characterized by negative perceptions of the disease, particularly with regard to the loss of self. For instance, as Beard et al. (2009) note, one dominant story that has been portrayed about people with dementia is that their talk is meaningless, their recollections are of little importance, and their memories are defective. However, the importance of challenging these perceptions and advocating positive attitudes towards dementia, in both social and scientific contexts, is becoming increasingly recognized (Swaffer, 2014; Zeilig, 2014; Dementia Engagement and Empowerment Project, 2014; Brotherhood et al., 2017). Discourse on dementia is shifting away from a reductionist biomedical perspective, that portrays the disease primarily in terms of loss, towards a more holistic perspective that considers the person with dementia not as a "sufferer" but as an individual who can be supported to cope and potentially live well with the condition (Beard et al., 2009; Kitwood, 1997; Swaffer, 2014). According to sociological perspectives, the loss of self that is experienced by people with dementia has much to do with the attitudes of others, rather than being caused solely by the disease itself (Sabat & Harré, 1992; Surr, 2006). As such, the way in which people with dementia experience social interactions in care impacts not only their sense of self but also their state of psychological well-being (Clare et al., 2008; Lee, Boltz, Lee & Algase, 2017).

Recently, international policymakers have suggested that people with dementia often receive suboptimal care, and there is a need to understand how to deliver high-quality care particularly to those in later stages of the disease (OECD Policy Brief, 2018; World Dementia Council, 2018). This echoes previous research that has voiced these issues, with Baldwin (2008) labelling care homes as places in which residents with dementia "are essentially warehoused until death". Baldwin (2008) also called for the development of services that encourage opportunities for

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expression and co-construction of narrative in care institutions. The role of others has been well established in maintaining a sense of identity amongst people living with dementia (Kitwood, 1997; Mills, 1997; Surr, 2006), and as such, there is a need to consider how care homes can be places in which others are given the tools and opportunities to co-construct the narratives of residents with dementia. In Norway, the Government acknowledges the lack of meaningful activities for people living with dementia, and states that future care services need to be oriented towards the individual's wishes, interests, and habits (Norwegian Ministry of Health and Care Services, 2015).

Technologies for reminiscence

Technology has much to offer in supporting, facilitating, and creating new possibilities for meaningful activities in dementia care that promote a sense of identity. Digital technologies, such as mobile and tablet apps, can support collaborative explorations of life events by people with dementia and caregivers, encouraging the caregiver to reflect and learn more about the individual (Maiden et al., 2013). These technologies can also be used as a means of conveying the narrative of people living with dementia. Purves et al. (2011) suggest that the use of photographs, films, and music can bring history to life, extending the reach of stories to others, not only to the person with dementia.

With the rapid development of technological solutions for care, there has been an increasing amount of reminiscence technologies developed for people living with dementia. One popular area of study is the use of digital life books, which are often mobile or tablet apps that combine music, photographs, videos, and narration to create personalized content for people with dementia and their family members (Critten & Kucirkova, 2019; Hashim et al., 2015; Laird et al., 2018; Ryan et al., 2018). Studies of digital life books suggest that they can encourage the delivery of person-centred care amongst staff and improve quality of life and autobiographical memory in people with dementia (Subramaniam & Woods, 2016). Even in later stages of dementia, digital story apps can help to support a sense of self-identity and empowerment amongst individuals (Critten & Kucirkova, 2019; Park et al., 2017).

These types of apps are also becoming readily accessible on a commercial level. For instance, *Book of You* is a digital reminiscence book that can be purchased for individuals with dementia and their family members (Book of You, 2021). *Book of You* is also available for care organizations to buy, which includes not only the digital books for residents, but training for staff members. Another example is *Storii*, a free online resource that allows families to create an interactive, multimedia life biography with the use of photos, music, videos, audio recordings and text (Storri, 2021).

Whilst digital apps and multimedia biographies have been shown to be effective in dementia care, more immersive approaches to life story work are currently being explored. For example, virtual reality can be a means of providing individuals with dementia the opportunity to interact with locations and events when it is no longer possible to do so in-person. For instance, Hodge et al. (2018) explored the use of virtual reality experiences for people with dementia, designing various environments including a personalized virtual reality experience of a concert venue for one couple in particular wherein the wife had dementia. Participants were able to engage in new experiences, which served as a talking point amongst couples. However, the authors identified potential barriers to use such as some participants feeling "silly" whilst wearing the headset and the headset being too heavy to wear. Additionally, whilst caregivers expressed that they enjoyed watching their relatives interact with the virtual environment, they wished they could have joined them in some way.

The importance of providing technologies that can be used as a joint activity is supported by research in this field. Laird et al. (2018) found that a reminiscence iPad app (InspireD) significantly improved the quality of carer and patient relationship as well as mutuality and subjective well-being amongst people with dementia and their family members. Other studies suggest that personalized digital media can be used as a tool for starting conversations and supporting interaction (Davis and Shenk, 2015; Hashim et al., 2015; Samuelsson & Ekström, 2019). As such, it is important to identify ways of creating an immersive environment whilst still providing the opportunity for social interaction. Furthermore, it has been suggested that providing dedicated spaces in nursing homes for private interaction is vital for maintaining relationships and enabling connections between spouses with partners living with dementia in long-term care (Førsund & Ytrehus, 2018). Therefore, providing not just the technology but a space in which residents, family, and staff can share private and meaningful interactions may result in benefits for all users.

SENSE-GARDEN

The SENSE-GARDEN is a novel, technological solution used to deliver an individualized intervention (i.e., the SENSE-GARDEN intervention) to people with moderate to severe dementia. It was developed as part of an interdisciplinary EU project (SENSE-GARDEN, 2021) that aimed to create individualized, immersive spaces for people living with dementia in Belgium, Norway, Portugal, and Romania. A SENSE-GARDEN is a room built inside of a dementia care environment (i.e., care home or hospital) that combines immersive technologies, digital media, and multisensory stimuli to create environments personalized to the life story of the person with dementia. The concept builds upon techniques from reminiscence therapy, in which the individual is encouraged to remember and reflect upon people, places, and events from their lives (Butler, 1963). By using digital technologies to present familiar music, photographs, films and scents within an immersive environment, it is hoped that the SENSE-GARDEN can provide staff and residents with dementia new opportunities to engage with the life story of the individual.

Whilst there has been research on the combination of digital and multisensory environments (see Moyle et al., 2018 *Virtual Reality Forest*, for example), there has been little work conducted on creating immersive, multisensory environments tailored to the life story of the individual with dementia. To date, *Snoezelen* has been the most widely used approach to using immersive, sensory stimulation with people living with dementia (Pinto et al., 2020). Deriving from the Dutch terms *snuffelen* (to seek and explore) and *doezelen* (to relax), *Snoezelen* multisensory environments offer a choice of olfactory, auditory, visual and/or tactile stimuli to individuals so that they may explore the stimuli whilst being in a state of relaxation (Baker et al., 2001). However, *Snoezelen* environments are not used for reminiscence purposes. SENSE-GARDEN has a different approach in that it aims at engaging the person with dementia in reminiscence activity through the use of personalized stimuli that is based on the life story of the individual. The use of innovative technology means that the stimuli can be adjusted to the individual, and thus, every SENSE-GARDEN session is unique to each user. Through presenting personalized content in a multisensory way, the person with dementia is immersed in their own life story.

Previous studies on SENSE-GARDEN have included the exploration of initial user perspectives towards the overall concept (Goodall et al., 2019a) and care staff experiences of the space in a Norwegian care home (Goodall, Taraldsen, Granbo et al., 2020). However, the experiences of people with dementia and their family members have yet to be explored. Additionally, although digital technologies are being increasingly used in an individualized manner to complement approaches such as life story work and reminiscence therapy for people living with dementia (Goodall, Taraldsen, Serrano et al., 2020), most of the work has been conducted in the homes of people with dementia. There is a need to investigate the use of technology in long-term residential care, also for people living with moderate to severe dementia.

Aims

The primary aim of this study is to create a transactional model of how narrative identity and relationships are promoted through the use of SENSE-GARDEN. We will address the following research questions: 1) What are the experiences of people with dementia and their caregivers with the new technological intervention, SENSE-GARDEN?, 2) How are narrative identities constructed and shared using SENSE-GARDEN?, and 3) How does SENSE-GARDEN facilitate interactions and communication between people with dementia and caregivers?

Theoretical positioning: symbolic interactionism and Deweyan transactionalism

Symbolic Interactionism

The SENSE-GARDEN a) uses meaningful stimuli significant to the individual and b) aims to facilitate meaningful experiences in the present moment. Therefore, this study draws upon symbolic interactionism for the ways in which it considers how individuals interact with one another reciprocally to form meaning (Blumer, 1986). Deriving from George Mead's (1934) belief that an individual's sense of self is developed through social interaction with others, symbolic interactionism is a theory that seeks to explain social behaviour in terms of the way people reciprocally interact with each other through symbols. Symbols —such as language, signs, and gestures—may hold different meanings for different people and, as such, will influence how an interaction is interpreted and experienced. The theory was refined and developed by Mead's student, Herbert Blumer, who described three key premises on which symbolic interactionism is built (Blumer, 1986, p. 2). First, the ways in which an individual behaves towards objects and other individuals is based on personal meanings that the individual has given to them. Second, the meaning of these objects is based on the social interaction that the individual has with others and with society as a whole. Third, these meanings are handled in, and modified through, an interpretive process. In other words, our meaning of the world around us constantly changes through the influence of social interactions and personal experiences.

Previous work in this area has also used symbolic interactionism to provide insights into interpersonal relationships, communication, and couple well-being in dementia care (Hayes et al., 2009; McGovern, 2010; Walmsley & McCormack, 2014). Johnson et al. (2017) used a symbolic interactionist perspective to outline the ways in which caregivers can communicate with people living with advanced dementia. The authors suggest that by interacting with the individual with dementia on a symbolic level, e.g., using photos, expressions and gestures, powerful connections can be made.

Transactionalism

Given the complexity of the SENSE-GARDEN space, the multi-dimensional nature of narratives, and the intricacy of interpersonal relationships, it is important to go beyond interactions between persons and also consider the wider environment as a whole. As such, this study is also informed by Dewey's transactional theory, which is concerned with the dynamic nature of person-environment experiences. He writes, "Everything that exists in far as it is known and knowable is in interaction with other things. It is associated, as well as solitary, single." (Dewey, 1929, p. 175). In other words, individual components of an environment interact with each other in ways that form an overall relationship. In the context of this study, it could be insightful to consider the ways in which the users within SENSE-GARDEN not only reciprocally interact with one another but also with the multisensory stimuli and digital media surrounding them.

One field in which Deweyan transactional perspectives is being increasingly used is that of occupational science (Garrison, 2002; Cutchin, 2004; Dickie et al., 2006; Cutchin & Dickie, 2012; Lavelley, 2017). In adopting Dewey's holistic approach to person–environment interactions, scholars in this area consider client and practitioner as reflexive social selves (Cutchin, 2004), and imply that occupational practice has much to benefit from considering how occupation is a mode through which individuals function in their "complex totality" (Dickie et al., 2006).

To date, and to our knowledge, the only research on dementia that explicitly refers to Dewey's transactional theory is a study on the unfolding transactions of assistive technology use amongst people living with dementia and their significant others (Rosenberg & Nygård, 2012). Findings suggested that assistive technology use was influenced by a number of factors including the choice of problem that the technology was meant to address, the user's experiences and views of the situation, views on how and when the technology should be used, and—most prominently—the view of the individual who had the most power in the decision-making. From these insights, the authors concluded that flexibility and a process-oriented approach are key issues when introducing and prescribing assistive technology to people with dementia (Rosenberg & Nygård, 2012). By applying this theory to the context of SENSE-GARDEN use, future implications may be made for the facilitation and evaluation of similar interventions and technological solutions in dementia care.

Furthermore, theories such as transactionalism have been recognized as useful in the transdisciplinary development of assistive technologies, including technologies for people with dementia. Boger et al. (2017) suggest that dynamic and transactional philosophies that acknowledge the complexity of an individual's interaction with their environment can help transdisciplinary collaborators in creating technologies that complement the needs, preferences, abilities, and resources of users.

Methods

Study design

This study adopted a qualitative interview study design and was part of the SENSE-GARDEN multisite trial (Goodall et al., 2019b). The trial was suspended in March 2020 due to the coronavirus pandemic, and as such, we only included persons with dementia and caregivers who had finished their time in the SENSE-GARDEN study at the time of suspension. Participants had visited the SENSE-GARDEN 2–3 times per week for 16 weeks or 2–3 times per week for 12 weeks. After these visits, 20 participants (7 people with dementia and 13 caregivers) were interviewed. A mixture of individual interviews and group interviews was used, meaning that there were 16 interviews in total (12 individual interviews and 4 group interviews).

Qualitative research is focused not on finding truth but is instead focused on meaning and meaning-making, in which the stories of participants and phenomena can be portrayed (Braun & Clarke, 2019). This resonates with the theory in which this study is rooted, with Deweyan philosophy aiming to seek meaning and knowledge that may make the world a better place. As Cutchin and Dickie (2013) comment, Dewey's transactional perspective may not solve problems theoretically or practically, but it offers a method of inquiry that can be used to make a better world (p. 9). In adopting a transactional perspective, this study approaches the participants' reflections and interpretations of their experiences within SENSE-GARDEN in a way that may inform how interventions of this kind can be best optimized to improve the lives of people living with dementia.

Settings

Two care homes were involved in this study, located in Norway and Portugal. Care home 1 was a municipality-based care home for the elderly, located in a remote town on the west coast of Norway which has a population of less than 10,000 inhabitants. The facility provides residents with daily care, a communal dining area and a day centre where individuals can participate in leisure activities such as group singing. Care home 2 was a care facility belonging to a large, non-profit organization. The care facility is based in one of Portugal's largest cities, with a population of over half a million people. The organization has over 20 care facilities in this city, and each facility operates according to a humanitarian goal through focusing on promoting resident quality of life. The SENSE-GARDEN space at each care home is shown in Figure 1.

Participants

A total of 12 dyads were included in this interview study, with each dyad consisting of one person with dementia and a caregiver. The relationships between dyads in Norway were familial or spousal. The relationships between dyads in Portugal consisted of two familial relationships, three close friendships, and four professional caregiving relationships. Due to the unavailability of informal caregivers, four residents had only formal caregivers (care staff at the facility) accompanying them to the sessions.

The persons with dementia were recruited by managerial staff at the two care facilities if they were aged 55 or more and living with dementia in stage 2 (moderate) or stage 3 (severe) according to the Clinical Dementia Rating scale (CDR) (Hughes et al., 1982). Demographics of the participants are shown in Table I. Pseudonymisation was used to process personal data. The generated codes include two initial letters designating the country, a letter for type of participant (person with dementia or caregiver) and a sequential number. The mean age of the 12 participants with dementia was 84.1 years, and most had moderate dementia according to the CDR scale (N = 10).

Intervention

The SENSE-GARDEN intervention is a psychosocial intervention that provides individualized, meaningful activities to people with moderate to severe dementia within a multisensory environment (the SENSE-GARDEN space). The SENSE-GARDEN consists of numerous components and activities (shown in Figure 2) including an interactive game designed to improve balance and physical activity, a stationary bike placed in front of a film of a known place, old films, a touchscreen device with family photographs, a scent dispensary system which dispenses familiar scents, a large-screen projection of scenic imagery, and surround sound music and soundscapes.

The SENSE-GARDEN intervention is facilitated by a member of care staff at the care home (who is referred to as a formal caregiver). The formal caregiver encourages the person with dementia to interact with

Figure 1. SENSE-GARDEN space in care home 1, Norway (left) and care home 2, Portugal (right).

Table I. Overview of participants.

Dyad number	Care home	PWD participant code	Age	Type of dementia	CDR Level	SG Use (weeks)	Caregiver participant code	Relationship
1	1	NOp01	94	Unspecified	2	16	NOic01	Mother-daughter
2	1	NOp02	83	Unspecified	2	12	NOic02	Husband-wife
3	1	NOp03	79	Alzheimer's Disease	2	12	NOic03	Father-daughter
4	2	PTp01	88	Dementia with Lewy Bodies and Parkinson's	2	12	PTic01	Close family friends for a considerable amount of years
5	2	PTp03	71	Vascular Dementia	2	16	PTfc03	Care home staff
6	2	PTp04	89	Dementia with Parkinson's	2	16	PTic04	Close friends
7	2	PTp05	81	Unspecified	2	16	PTfc05	Care home staff
8	2	PTp06	69	Alcohol-related dementia	3	12	PTic06	Close friends
9	2	PTp07	77	Unspecified	2	12	PTfc07	Care home staff
10	2	PTp08	92	Unspecified	2	16	PTic08	Father-Daughter
11	2	PTp09	97	Unspecified	2	16	PTic09	Aunt-niece
12	2	PTp10	89	Dementia with Parkinson's	3	12	PTfc10	Care home staff

PWD: Person with dementia; ic: Informal caregiver (family/friend); fc: formal caregiver (professional care staff); NO: Norway; PT: Portugal; CDR: Clinical Dementia Rating Scale; SG: SENSE-GARDEN

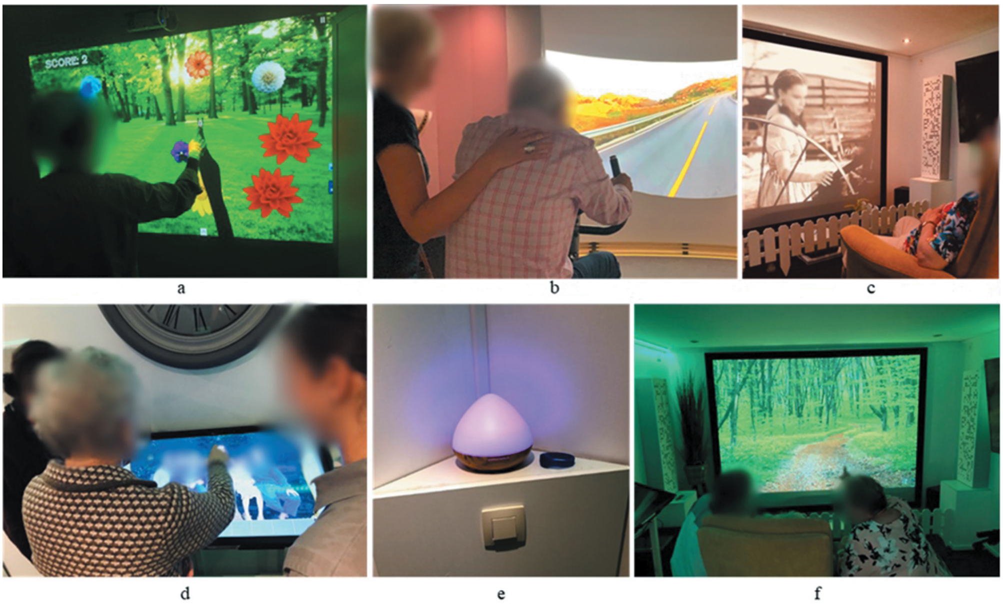

Figure 2. Activities within the SENSE-GARDEN: Move to improve (a); Life road (b); Films of my life (c); Memory lane (d); Scent to memories (e); Reality wall (f).

the various activities within the SENSE-GARDEN space. Family members (informal caregivers) may also join the sessions, engaging in the various activities together with the person with dementia and the formal caregiver.

The preparation and facilitation of SENSE-GARDEN sessions is undertaken by the formal caregiver. To ensure that the intervention is individualized to the person with dementia, the first step in preparing the SENSE-GARDEN sessions involves working with the family of the person, who are asked to provide information about the life story of the individual along with photographs and videos that could be used. The collated information and media are used to create a user profile for the person with dementia, designated as the "Arts of Life Memory Album" (ALMA). Formal caregivers involved in the project have reported that the process of creating a profile takes approximately an hour for each resident.

The next step in preparing the sessions involves using the contents of the ALMA to create media flows, which are sequences of photos, videos, and music that can be used for the activities carried out during the SENSE-GARDEN sessions. This is done using a tablet app developed by the SENSE-GARDEN technical team. Formal caregivers have reported that this process takes approximately 15 minutes for each media flow. This same app is also used in the facilitation of the sessions, with the formal caregiver using it to control the contents used for each session. Each session is intended to last between 30 and 60 minutes.

In addition, the caregiver is asked to use the app to register the feedback of the person with dementia, for example, how the individual responded to the media contents used in the session. This feedback is used to improve the selection of media contents for subsequent SENSE-GARDEN sessions. When planning future sessions, the app should automatically prioritize content that has been assigned positive feedback on the displayed list of available content, so that the formal caregiver can easily access the content that is most enjoyed by the resident. Depending on time availability, the wishes of the resident, and new knowledge gained about resident through the sessions, the formal caregiver can choose to create new sessions with updated media contents or use previously made media flows used in earlier sessions.

Prior to the study, care staff received written instructions and video tutorials on how to prepare and conduct sessions using the aforementioned SENSE-GARDEN app. During the study, the care staff used an online helpdesk to report any technical issues they encountered. These issues were addressed by the project's technical team, who were able to offer support as needed.

Data collection

A total of 16 interviews (12 individual interviews and 4 group interviews) were conducted with 7 residents with dementia and 13 caregivers across the two care facilities between December 2019 and May 2020. An overview of these interviews is shown in Table II.

Table II. Overview of interviews.

Dyad	Interview	Interview type	Participants	Interviewer(s)
1	1	Individual	PwD	SG Facilitator
	2	Individual	ICG	SG Facilitator
2	3	Individual	PwD	SG Facilitator
	4	Individual	ICG	SG Facilitator
3	5	Individual	PwD	SG Facilitator
	6	Individual	ICG	SG Facilitator
4	7	Group	PwD, ICG	Researcher + SG Facilitator
5	8	Individual	PwD	Researcher + SG Facilitator
	9	Individual	FCG[a]	Researcher + SG Facilitator
6	10	Group	PwD, ICG	Researcher + SG Facilitator
7	11	Group*	FCG, FCG**	Researcher + SG Facilitator
8	12	Individual*	ICG	Researcher + SG Facilitator
9	13	Group	PwD, FCG	Researcher + SG Facilitator
10	14	Individual*	ICG	Researcher
11	15	Individual*	ICG	Researcher + SG Facilitator
12	16	Individual*	FCG[a]	Researcher

PwD: Person with dementia; ICG: Informal caregiver; FCG: Formal caregiver; SG Facilitator: SENSE-GARDEN Facilitator

[a]The caregiver did not join any SENSE-GARDEN sessions

*Interview had to be conducted over the phone due to the coronavirus pandemic. It was not possible to interview the PwD in the dyad during this time.

**The PwD in this case had become seriously ill at the end of the study and it was not possible to conduct an interview with him. Another member of care staff who had helped facilitate some SENSE-GARDEN sessions with the resident joined the interview.

Interviews were semi-structured and conducted in a conversational style (see Supplementary Material for Interview Guide). The interviews in Norway were conducted by a member of staff at the care home who joined the SENSE-GARDEN project in August 2019. This member of staff, who has a background in nursing, had been facilitating all of the SENSE-GARDEN sessions at the care home. The interviews in Portugal were conducted by two individuals who both joined the project before the start of the trials, which commenced in August 2019. The first is researcher and co-author LA, who has a background in sociology. The second is a psychologist recruited for the SENSE-GARDEN project. She had been facilitating most of the SENSE-GARDEN sessions in Portugal, along with members of staff at the care home.

Where possible, both the person with dementia and the informal caregiver were interviewed. In Norway, all interviews were conducted on an individual basis- one with the person with dementia, and the other with the informal caregiver. In Portugal, a mix of individual and group interviews were used. Additionally, two formal caregivers in Portugal did not join for SENSE-GARDEN sessions but were still interviewed. In these two interviews, the guide was adapted to ask questions about their perceptions of SENSE-GARDEN in general, and what effects—if any—they had noticed on the person with dementia.

After the onset of the coronavirus pandemic, it was no longer possible to conduct interviews in-person. There were a remainder of 5 dyads to be interviewed, and we were able to reach the caregivers in each dyad by phone to conduct telephone interviews. However, it was not possible to interview the person with dementia in the dyad.

All interviews, with the exception of one, were audio recorded, transcribed, and then translated into English for analysis. The one interview that was not recorded was a telephone interview with an informal caregiver (PTic08), who requested that the conversation was not recorded. In this instance, the interviewer took note of the participant's answers.

Ethics and consent

Each test site followed ethical guidelines in accordance with their national regulations. In Norway, the study was approved by the Regional Committee for Medical and Health Research Ethics (REK nord reference 10015). Ethical approval from a formal ethics review committee was not required for this kind of intervention study in Portugal. However, the study followed the principles of the Declaration of Helsinki.

Written informed consent was given by the participants. If the participant lacked capacity to consent, consent was gained through proxy. The current study adhered to national regulations concerning consent to research. Norway's Health Research Act (Lovdata, 2008) states that in the case that a person does not have the capacity to provide consent, the person's next-of-kin shall have authority to grant consent. The act also states that people who lack the capacity to give consent may only be included in research if a) the potential risks or disadvantages are insignificant; b) the individual involved is not averse to it; and c) there is reason to assume that the results of the research may be of use to the person concerned or other people with the same disorder or disease. Similarly, Portugal's legislation concerning clinical trials ("Aprova a Lei da Investigação Clínica," 2014) states that if a person is incapable of providing consent, consent must be provided by the person's legal guardian. Legislation also states that a person without capacity to provide consent may only participate in the study if the intervention is designed to prevent the disease, to provide rehabilitation, and to prevent any foreseeable risk related to the disease, as well as the degree of suffering caused by the disease. Given the SENSE-GARDEN's aim to improve the well-being of people with moderate/advanced dementia, it was considered ethically sound to conduct the study with people who may not have the capacity to provide consent. In both sites, the guardian or legal representative was the informal caregiver, with whom the participant with dementia was close to prior to the study. Thus, it was expected that the informal caregiver would have decided whether or not to agree to the study based on the interests of the person with dementia.

Despite informed consent being provided by proxy, the participants with dementia could still refuse to participate. Before each SENSE-GARDEN session, the professional facilitating the session would approach the resident, greet them, and ask if the participant would like to join them to the SENSE-GARDEN to take a look at some photos and play some music. The professional caregiver would then decide whether or not to take the resident to the SENSE-GARDEN, based on the resident's response and behaviour. This could be considered in line with Dewing's (2007) guidelines for ongoing consent monitoring, in which ensuring initial consent is revisited and re-established on every occasion throughout the study. Additionally, the sessions could be stopped at any time. If the participants showed any sign of distress or discomfort during the session, the session would be immediately stopped. To ensure the well-being of participants, all SENSE-GARDEN sessions were facilitated by care professionals with experience of working with people with dementia. In Norway, sessions were conducted by a nurse who has 14 years of experience caring for people with dementia. In Portugal, sessions were conducted by two psychologists who have 8 and 4 years of experience in dementia care, respectively, and an occupational therapist who has 17 years of experience.

The interviews were conducted by the professionals who had been facilitating the SENSE-GARDEN sessions, as to provide the participants a sense of familiarity during the interview. Professionals received an interview guide from the first author of the study, as well as advice on how to conduct the interview. The interviewers were also able to contact the first author if they needed further help with the interviews. No interviews were conducted with residents with dementia during the COVID-19 pandemic.

Analysis

Reflexive thematic analysis (Braun & Clarke, 2006, 2019; Braun et al., 2019) was used to analyse the interview transcripts. The aim of reflective thematic analysis (RTA) is to generate themes that reflect a pattern of shared meaning around a central organizing concept. In RTA, researcher subjectivity and reflexivity are used as resources (Braun et al., 2019). The following six steps (as outlined by Braun & Clarke, 2006, 2019) were taken:

1. Familiarization with data

The first author compiled the transcripts from the two sites into NVivo 12 (QSR International, 1999). In order to get a sense of the data, the transcripts were read repeatedly, and initial ideas and reflections were noted down.

2. Generating codes

Reflexive thematic analysis allows for varying approaches to coding. In the present study, Fereday and Muir-Cochrane (2006) hybrid approach of deductive and inductive coding was used. This approach integrates theory-driven (deductive) codes with data-driven (inductive) codes. In this case, Deweyan philosophy and symbolic interactionism were used to inform the development of the codebook for deductive coding. This was done by using the key principles and ideas behind transactionalism and symbolic interactionism to develop codes a priori that would be relevant to the research questions and the context of the SENSE-GARDEN intervention. Table III demonstrates the development of the theory-driven codes, giving the theoretical foundation and definition for each code.

Three coders (GG, LA, JAS) independently read the transcripts and performed deductive coding using the initial codebook of theory-driven codes. The use of multiple coders in RTA is to develop a more nuanced understanding of the data through collaboration (Braun & Clarke, 2019). Additionally, qualitative analysis can be enhanced by including multiple coders with varying backgrounds (Berends & Johnston, 2005). The coders in this study have a background in music psychology (coder 1), sociology (coder 2), and care and assistive technologies (coder 3). Once coding was complete, the coded transcripts were shared amongst the coders, who then discussed their impressions of the data, as well as their suggestions for inductive codes, based on the data.

As a result of discussion, two deductive codes (temporal focus and shared identity) were removed from the codebook. This was based on the fact that they were seldom used in the coding amongst the three coders and, after discussion, the coders felt they did not accurately represent the participants' views and experiences of SENSE-GARDEN. As Braun and Clarke (2019) state, reflexive thematic analysis should be a flexible process that values the importance of deep reflection on, and engagement with, the data. Therefore, in order to be true to the dataset, the decision was made to remove the codes.

Table III. Development of deductive codes.

Code name	Theoretical foundation for code	Code definition
Temporal focus	Building on the work of Mead, symbolic interactionists believe that the past is symbolically reconstructed in the present, and assigned new meaning based on an anticipated future (Mead, 1932; Maines, 2001). Given the SENSE-GARDEN's focus on the life story of the person with dementia, it is important to understand how the participants refer to past, present, and future as a result of interacting with personally significant media.	Referring to past, present, and/or future
Shared identity	Symbolic interactionists believe that meaning, emotions, and pasts can be shared between individuals through joint interaction (Mattley, 2002). As such, social—or shared—identities can be co-constructed as a result of these interactions and shared values. The code "shared identity" is to reflect on how dyads in the study—particularly familial dyads—may feel that their identity is shared based on the meaning they assign to their experiences.	Referring to identity as co-constructed between two or more people
Meaning	People assign meanings to objects, places, events, others etc. and these meanings are constantly reinterpreted as a result of interaction with these objects etc. (Blumer, 1986). The meaning that an individual has attributed to the world around them may influence how they experience the SENSE-GARDEN intervention.	Attributing meaning to media contents, object, place, event, or memory
Interpersonal relationships	Given that symbolic interactionism concerns how behaviour is shaped through interaction with others, the exploration of how participants perceive and describe their relationships with others may provide insight into how these relationships are experienced in the context of SENSE-GARDEN.	Referring to relationships with other individuals
Behaviour and actions	Symbolic interactionism concerns human behaviour and how it is shaped through social interaction. The way that participants perceive and interpret their own behaviours and the behaviours of others, as well as how they interpret their interactions, will contribute to the overall understanding of experiences within SENSE-GARDEN.	Referring to verbal and/or non-verbal behaviours and actions
Space and aesthetics	Transactionalism emphasizes that human experience is shaped through an individual's interaction with their environment (Dewey, 1934). Understanding the participants' awareness and perceptions of their surrounding environment is therefore vital to making sense of their experiences both in and outside of SENSE-GARDEN.	Referring to SENSE-GARDEN space or space of other environments
Emotions	Both Dewey and Mead viewed emotion as embedded in social interaction (Ward & Throop, 1989). According to a symbolic interactionist perspective, emotions are not only experienced and reflected upon in response to situations, but the ways in which they are expressed—or not expressed—can shape social interactions and relationships (Mattley, 2002). Exploring how the participants experience and make sense of their emotions, as well as the emotions of others, may provide insight into the relationships they hold with one another.	Referring to both positive and/or negative emotions and feelings

The inductive codes suggested by each coder were merged to form three inductive codes (see Figure 3). As a result of discussion, two deductive codes (temporal focus and shared identity) were removed from the codebook. A final version of the codebook is shown in Table IV. The entire dataset was once again coded in NVivo according to this new version of the codebook. This was conducted by GG.

PwD: Person with dementia

3. Generating initial themes

Initial themes were generated by GG, who used that to identify patterns across the dataset. She collated the codes, along with the coded excerpts of data, into potential themes through careful reflection on the dataset and the research questions. Braun and Clarke (2006) note the importance of this phase of analysis being conducted at the broader level of themes, in which codes may be discarded, combined to create themes, or become themes of their own. As such, themes and subthemes were identified across different codes. For example, excerpts of data coded for "Emotions", "Behaviour and Actions", or "Interpersonal Relationships" were interconnected by the prevalence of communication, which later became a subtheme under the theme "Openness".

4. Reviewing themes

The reviewing of themes took place through a joint discussion amongst authors. GG consulted with the other two coders to ensure that these themes reflected the dataset as a whole, as well as being representative of the participants on an individual level. A thematic map was made to aid the process of reviewing themes, as well as to gain insight into how the themes interlink with one another and form an overall narrative about the data.

5. Defining and naming themes

This process involves refining the specifics of each theme and the overall story the analysis tells. This was again done in a collaborative manner between co-authors.

6. Producing the report

The report was produced primarily by GG. The aim was to provide the reader with a sense of the story about the data that was generated by the authors, using direct quotes from the participants to support the portrayal of this story. The final report was approved by all co-authors.

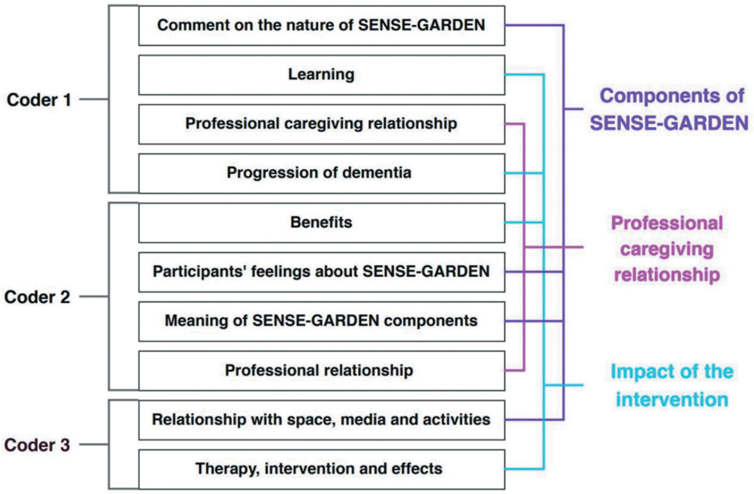

Figure 3. Generating inductive codes.

Results

Three themes were generated from reflexive thematic analysis: openness, learning, and connecting. An overview of these themes and their respective subthemes is shown in Figure 4. The first theme, "openness", reflects the way in which participants felt encouraged to be more open with one another while using SENSE-GARDEN. The second theme, "learning", reflects the way in which caregivers felt that their knowledge of the person with dementia had improved through the use of SENSE-GARDEN and thus wanted to apply similar techniques to optimize the care environment in general. The third theme, "connecting", captures the various ways in which participants felt connected to one another while using the SENSE-GARDEN. The thematic map also illustrates the interactive and interdependent nature between the three themes. For instance, in order to facilitate openness, there must be an opportunity for the resident and the caregiver to connect with one another. However, this connection will be hindered if the caregiver has limited knowledge on the person with dementia. As such, learning is required. In order for learning to take place, the caregiver should have an open attitude towards the person with dementia, encouraging them to be expressive and engaged.

Openness

The theme "openness" reports on the participants' overall belief that the SENSE-GARDEN encourages those who use it to become more open with one another. This theme has four subthemes: 1) "communication" reporting on how SENSE-GARDEN provided benefits in terms of communicative abilities, 2) "engagement" reporting on how participants actively engaged with the activities and media contents within the SENSE-GARDEN, 3) "expressing emotions" relating to how SENSE-GARDEN not only evoked emotional reactions but how these emotions were expressed and interpreted by participants, and 4) "behaviour" relating to how caregivers noticed a change in behaviour amongst the residents during and after using SENSE-GARDEN.

Communication

Both people with dementia and caregivers spoke about openness in terms of communication, particularly with being able to talk freely. One gentleman with dementia, who used to be a teacher, was adamant in his opinion that the SENSE-GARDEN encouraged people to talk more openly:

> "It was an open forum, you could talk about everything. It must be like that you know. It must be so that one can open up a bit, then you get people talking too. There was openness to talk about everything, and that was definitely the meaning I guess … I think it's really good that people get to talk a little, and then you get it out." NOp02

As well as opening up inside the SENSE-GARDEN, benefits in communication were also observed outside of the SENSE-GARDEN sessions:

> "I generally think it has become easier to talk to her even when she is not in the SENSE-GARDEN. She is more sharp and able to hold the thread of the conversation better than she did before. She doesn't ask the same question again. If I switch topic and then come back to the previous conversation, she manages to remember what we talked about 3 minutes ago." NOic01

Table IV. Final codebook.

Code name	Definition	Description	Example
Meaning	Meaning is attributed to a place, event, media, or memory	The participant talks about the meaning/significance of media (music, photographs etc.), places (e.g., hometown), events or memories	"I know that Fátima* is very important to her, and the religious part touches her a lot"
Interpersonal relationships	Discusses interpersonal relationships with other individuals	Interpersonal relationships with other individuals (living or deceased, inside and/or outside of SENSE-GARDEN). The emotional and/or social nature of the relationship may be discussed	"I've learned more about appreciating our 60 years of life and all of the 21,000 days we have had. Most of them have been happy. It has not been said that we have never quarrelled, but we have never gone to bed as enemies. We have taught ourselves to pay attention to each other"
Behaviour and Actions	Interaction (verbal and/or non-verbal)	May refer to gestures, body language, facial expressions as well as verbal communication. Can refer to interaction either inside or outside of SENSE-GARDEN	I generally think it has become easier to talk to her even when she is not in the SENSE-GARDEN. She is more sharp and able to hold the thread of the conversation better than she did before.
Space and aesthetics	Participant discusses space and/or comments on aesthetics	Can refer to the SENSE-GARDEN space, or space of other environments (e.g., other areas of the care facility)	"It's the design of the room, the fact that there are no sharp edges, no corners, it's carpeted. It is shielded from the rest of the world. One goes into something else, one forgets time."
Emotions	Emotions are discussed	Emotions experienced either inside or outside SENSE-GARDEN are discussed. The nature of the emotion can be mixed (does not have to be only positive or negative).	"I even cried while playing the children's song. it was a powerful experience … it was strong for me when my mother sang along to these songs. I think my mom is happy when she is here, happy and bright at heart."
Professional caregiving relationship	Discusses the care given to the PwD by the professional caregiver	Refers to how professional caregiver interacts with the PwD, how they facilitate the SENSE-GARDEN session or the caregiving relationship outside of sessions	"I do not believe all the caregivers have become involved in his life situation and there is always a reason why they are angry or sad. I think the staff misinterprets the user. One must find the reason why the user is the way he is."
Impact of the intervention	Discusses benefits or issues as a result of the SENSE-GARDEN intervention	Refers to either immediate or long-term effects (both positive and negative) of the intervention on the person with dementia and/or caregivers	"I generally think it has become easier to talk to her even when she is not in the sensory garden. she is more sharp and able to hold the thread of the conversation better than she did before. She doesn't ask the same question again. if I switch topic and then comes back to the previous conversation the topic, she manages to remember what we talk about 3 minutes ago. It has become much easier to talk to her now on the phone. It is probably the change that I think I have seen."
Components of SENSE-GARDEN	Discusses aspects of the SENSE-GARDEN	Refers to activities, media and/or technology within the SENSE-GARDEN space	"It was especially the pictures combined with the music I liked the best. The family pictures I liked a lot. It is so wonderful, and it is accurate that I want to burst with enthusiasm. Quite phenomenal."

* Fátima is a Portuguese town that's home to the "Sanctuary of Fátima", a well-known Catholic pilgrimage destination.

The SENSE-GARDEN itself was also talked about outside of the sessions, facilitating communication between care home residents. For example, the wife of one participant commented on how her husband would tell the other residents in the care home about his visits to the SENSE-GARDEN:

> "He (NOp02) … was interested in telling the other residents about his stay in the sensory room and he also liked to tell the family. He was shining like the sun." NOic02

The lady also commented that her husband "was shining like the sun", suggesting that not only was he talking about SENSE-GARDEN but he was doing so in a way that conveyed his enjoyment of being inside the space.

Engagement

Caregivers noticed that the participants with dementia were willing to participate in the SENSE-GARDEN sessions and engage with the activities inside the space. As such, they became more open through this engagement:

> "Yes, he participated and … showed a lot of interest . . . Then it wasn't so isolated, I mean, in his little world . . . he is more open." PTfc03

Even in the case where memory was notably impaired, one caregiver noticed that the person with dementia still managed to engage with the music despite having a suggested lack of self-awareness. The quote below suggests a symbiosis between past and present, with the person with dementia engaging in the present moment (i.e., singing along to the music) whilst simultaneously returning to the past:

> "I realized that even though [PTp06] didn't know who she was, deep down, she felt the music, she felt good, as if she remembered that place. And then I also saw that when she started singing … There was a very interesting interaction … She sang and it seemed that … she went back to the past." PTic06

Participants with dementia also expressed their desire to engage with the stimuli inside SENSE-GARDEN, with music being particularly popular:

> "Without the music everything would have been boring. I think it was very important. There is something going on inside, one knows it in the whole body. I want to sing and dance." NOp01

Expressing Emotions

From the transcripts, it was clear that SENSE-GARDEN had an effect on the emotional state of participants. Accounts of various emotional experiences encountered within the SENSE-GARDEN were prominent throughout the interviews. The caregivers offered thoughtful and reflective interpretations of how the participants with dementia experienced the intervention:

> "I thought she was much more open … it's not just the memory, it's an opening to this part of feeling that she closes to protect herself." PTic01

The above quote illustrates a sense of openness in terms of experiencing and expressing feelings. It also highlights how emotions are not only connected to memories but to the self as a whole, beyond that of the ability to recall or recollect information.

Participants with dementia also expressed positive emotions experienced within the SENSE-GARDEN:

> "It was especially the pictures combined with the music I liked the best. The family pictures I liked a lot. It is so wonderful and it is accurate that I want to burst with enthusiasm. quite phenomenal." NOp01

Again, the "bursting" with enthusiasm resonates with the theme of openness in a particularly strong manner. The caregivers also experienced strong emotional experiences, particularly in reaction to seeing the person with dementia sing. Their interpretation of this

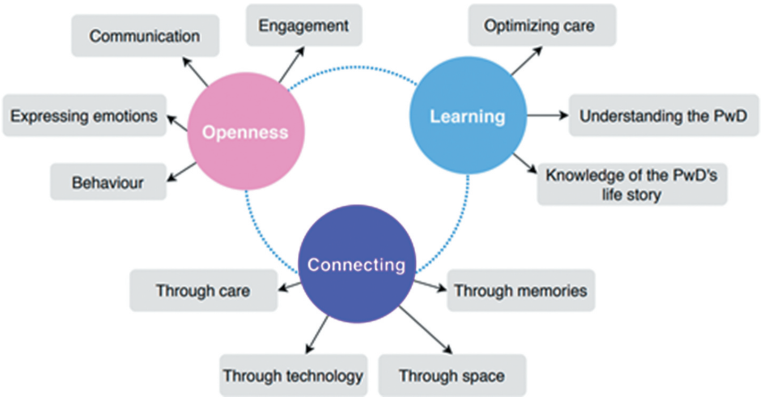

Figure 4. Thematic map of themes generated through reflexive thematic analysis.

gesture was loaded with meaning—the action of singing reminded the caregivers that their family members could still engage in the present moment:

> "I even cried while playing the children's song. It was a powerful experience. There were several songs we sang when I was little. it was strong for me when my mother sang along to these songs." NOic01

> "I had my throat many times [wanting to cry] … Because she remembered, because she sang." PTic01

Additionally, the above quotes illustrate the complex nature of emotions, that is, being happy but wanting to cry. This mixture of emotions was also associated with the media contents shown inside the sessions. The participants often spoke about pictures and videos of the past. The association with these pictures had a new meaning when being recollected in the present, as they served as a reminder of a time before dementia had made an impact on their lives:

> "You had a lot of nice pictures. It is a bit strange and sore to see pictures from when the kids were small. It was the time when everything was fine and good and safe. You put the kids to bed in the evening and they were happy and fell asleep well. I thought the time I had then would always be with us." NOic02

> "It is positive because it brings up a lot of memories that he has really forgotten or displaced. He had so much inside as that he has closed inside him, something that the SENSE-GARDEN now has opened. Both with joy and some sorrow." NOic03

One participant with dementia stated that he became emotional when watching a video of a ferry trip to Nordkapp—somewhere he had been numerous times in his life. In sharing his experience of watching the video, it is clear to see that he held strong emotional attachment to this memory, and he felt comfortable in being able to express his feelings both in the session and again in the interview:

> "Fabulous, the first trip was by ferry and up to Nordkapp. I remember that trip very well, I became emotional and cried a lot." NOp03

In some instances, sessions included the use of photographs containing family members who had passed away. One woman expressed that she felt sad as a result of seeing her father upset by nostalgia attached to the pictures:

> "I get sensitive when being in the SENSE-GARDEN. I felt joy and a bit of sadness. I got sad when I saw what grief [NOp03] is carrying. He remembers more when he looked at pictures, fond memories of the family he lost." NOic03

The above quotes illustrate that whilst the SENSE-GARDEN is successful in provoking memories, it also provokes a sense of nostalgia attached to these memories. As such, a mixture of emotions is experienced. The quotes also emphasize the social nature of emotions—how they can be shared, interpreted, and expressed in relation to others. The openness inside the SENSE-GARDEN seems to prompt a level of vulnerability amongst participants, which allows for a free expression of emotions, without fear of judgement.

Behaviour

Openness was also experienced with regard to verbal and non-verbal behaviours. Caregivers noticed positive changes in the behaviour of participants with dementia after attending the SENSE-GARDEN sessions. One informal caregiver felt that her friend with dementia had returned to how she used to be 15 years ago as a result of using SENSE-GARDEN:

> "It's like night and day, it's the [PTp01] of old times, 15 years ago. There were activities that she … in these years, in recent times, in recent years that she had never done again and now she did." PTic01

A member of care staff commented on how a resident with dementia became less aggressive after the SENSE-GARDEN sessions, indicating the possibility for the staff member to interact with the resident in a different way:

> "She used to spend more time gesturing, more aggressive, talking aggressively and now she is not, she is calmer, she is different." PTfc07

However, when the intervention period ended and the visits to SENSE-GARDEN had stopped, caregivers noticed a negative change in behaviour. Caregivers commented that residents were disappointment when the intervention came to an end, and that they wanted to continue sessions. For example, the wife of one participant stated:

> "He looks blank. He had the SENSE-GARDEN to look forward to. I notice that he falls into himself … he becomes more confined when he does not receive stimuli. When I ask him how he is doing, he blames his back. But I think he blames his back when he doesn't feel so good." NOic02

The notion of "he falls into himself" indicates a kind of closing, opposite to the openness which has been apparent throughout this theme. This indicates the importance of maintaining individualized activities in dementia care in helping residents to maintain positive behaviours that can help them connect with others.

Learning

The theme "learning" refers to the ways in which visits to SENSE-GARDEN improved knowledge on the person with dementia in terms of knowing their life story, and also in terms of understanding them in everyday interactions. This theme has three subthemes: 1) "optimizing care" reporting on how caregivers believed that SENSE-GARDEN, or similar activities offered in the intervention, should be incorporated into regular care within the care home, 2) "understanding the person with dementia" reporting on how spending one-on-one time with the person with dementia improved not just the caregivers' biographical knowledge of the resident, but also their understanding of the person's behaviour, and 3) "knowledge of the person with dementia's life story" relating to how using the SENSE-GARDEN can shed more light on the life story of the resident for both family caregivers and professional caregivers.

Optimizing care

Insights from SENSE-GARDEN experience led caregivers—both in Norway and Portugal—to reflect on how the usual care environment, beyond the project intervention, could be improved. Participants felt that the residents' living environment should incorporate personalized items such as pictures and movies, in order to promote their well-being. For example, the daughter of a participant commented:

> "The walls of the care home should have been wallpapered by pictures. Now I have made photo albums for her, but I think the best thing is to have it on the wall. A good thing would be to have photos on the tv in the care home. I think the older ones would like that." NOic01

One lady noted how the care environment itself was a contributing factor to the progression of her husband's dementia:

> "His illness is aggravated by sitting in a care home. He makes bad thoughts after moving into the nursing home." NOic02

Others felt that SENSE-GARDEN should be integrated into all care homes, specifying that a care home should be a place in which residents should be valued:

> "I really liked it, I think it was very good, very positive, I think this work is worthwhile, should be put in every residence. For me, I think that residences are not a place where people are there … handing them over … it is not a warehouse. At the end of people's lives, people have to have dignity, be happy and die well. Be valued." PTic04

These quotes highlight a visible need for enhancing the quality of the care environment in both settings.

Understanding the person with dementia

During the interviews, there were criticisms from family caregivers towards the care that their loved one receives. One wife of a participant felt that her husband was given the opportunity to engage with activities and gain a sense of achievement in SENSE-GARDEN, which is something he does not have an opportunity to do in normal care:

> "He does not have the same opportunity in the nursing home, that he can master something [as he does in SENSE-GARDEN]. No one expects anything from him." NOic02

The lady also says no one expects anything from her husband, which resonates with the misperception of people with dementia as being passive sufferers of the disease. However, in SENSE-GARDEN, the formal caregiver empowered her husband, as he expressed during his interview: "I was encouraged to tell" (NOp02). Similarly, the daughter of another participant felt that the staff at the care home did not take the time to understand her father:

> "He had so much … closed inside him, something that the SENSE-GARDEN now has opened … It doesn't seem like everyone understands it. I do not believe all the caregivers have become involved in his life situation and there is always a reason why he is angry or sad. I think the staff misinterprets [NOp03]. One must find the reason why he is the way he is." NOic03

In contrast, caregivers felt that spending time with the person with dementia inside the SENSE-GARDEN led to an improved understanding of the individual. As such, this provided benefits for both individuals in the caregiving relationship:

> "I started to know [PTp04] better … Sometimes, we don't understand why there are certain reactions … . I think it was very important for us to get to know each other better, I understand what [PTp04] likes most, how [PTp04] works in terms of connections with people. [PTp04] accepts me better now than she accepted me before … When I know that [PTp04] smiles I am happy and that is true. When I know that [PTp04] is bored and sad, I also wonder what can I do, what is going on? … I think that [PTp04] also felt more confident about telling me things, therefore, a greater opening. I think it was positive for both sides." PTic04

Looking at these results from a symbolic interactionist perspective emphasizes the importance of social interaction in the maintenance of identity and relationships. By learning to interact with the resident through the use of activities that provide meaning to the resident's everyday life—as opposed to only providing basic care—staff may understand the person with dementia in a way that provides benefits to the caregiving relationship.

Knowledge of the person with dementia's life story

The technology inside of SENSE-GARDEN provides the opportunity to interact with the life story of the person with dementia in a readily accessible and sustainable manner. Engaging with the media contents based on the life story of the person with dementia provided the opportunity for the caregiver to get to know the individual better. A touching account from the wife of a participant with dementia suggests that the SENSE-GARDEN can provide new knowledge on the person with dementia, even in spousal relationships:

> “The experience itself has probably caused me to open my eyes to small things that I have not noticed before. Things I had no idea meant anything to him, with us having gone further into ourselves. And I learned more about appreciating our 60 years of life and all of the 21,000 days we have had. Most of them have been happy. It has not been said that we have never quarreled, but we never went to bed as enemies. We have taught us to pay attention to each other.” NOic02

This new knowledge is particularly important for professional caregivers, who may not know as much about the resident compared to a close friend or family member. One member of staff mentioned she had done some research on topics she knew were of interest to a resident, and found that this prompted the resident to share more of his life story with her as the sessions went on:

> “As the sessions went by, he added information … he was talking about the picnics that he had with the wife, with the children, with the mother-in-law … And I think this middle part [of the sessions] was more significant than the initial part.” Formal caregiver who facilitated sessions with PTp05

The caregiver commented that later sessions were more significant compared to the initial ones, and this could be due to the increased amount of knowledge gained on the life story of the resident. However, whilst the SENSE-GARDEN can help staff engage with the life story of the person with dementia, it is important to acknowledge the amount of time and effort it takes to collect media and prepare sessions. One staff member mentioned the difficulty of planning sessions:

> … about the preparation of the sessions, it is difficult to have a planned drawing [organization of the sessions], for example, for 30 sessions. The meaning of this [SENSE-GARDEN intervention] is to always be changed, created.” PTfc05

Connecting

The theme “connecting” encapsulates how connections are made between individuals through using SENSE-GARDEN together. This theme has four subthemes: 1) “through care” reporting on how the formal caregivers facilitated sessions in a way that enhanced the caregiver-resident relationship and the overall SENSE-GARDEN experience, 2) “through technology” reporting on how the technology used in SENSE-GARDEN prompted conversation and connected participants to their own sense of identity, 3) “through space” reporting on how participants considered the SENSE-GARDEN space as one in which they felt safe and connected, and 4) “through memories” reporting on how participants connected through talking about memories that were triggered and shared during the sessions, and how these memories remained intact after the sessions.

Through care

The informal caregivers perceived the SENSE-GARDEN as a positive experience partly due to the way in which sessions were facilitated by the formal caregivers. Informal caregivers in both Norway and Portugal commented on the facilitation style, which was perceived as comforting, safe, and respectful. The informal caregivers also felt the care provided by the formal caregivers was a factor in the residents wanting to return to the SENSE-GARDEN for subsequent sessions:

> “Another thing I have been thinking about is that you, [formal caregiver], have a comfortable attitude, you make my mother feel safe and respected. Not everyone is as good at meeting people as openly as you do.” NOic01

> “The person he was waiting to see was [the formal caregiver], because he knew that during that time she was going to be with him and that she was going to be doing something that gave him pleasure, that he liked.” PTfc05

One niece of a resident with dementia commented on how the facilitation style from the formal caregiver resulted in the SENSE-GARDEN session feeling like a family gathering:

> “Also, the way [the formal caregiver] conducted the approaches and the conversation, I think it was all very natural, it seems that we were a family there. (Laughs). [The formal caregiver] already knew some stories, things from other sessions … I think we were a family, that we were there watching a family album.” PTic09

These quotes indicate that meaningful care staff-resident interactions can be fostered inside the SENSE-GARDEN, which can then influence the caregiving relationship outside the SENSE-GARDEN sessions.

Through technology

The digital technologies and media contents used in the SENSE-GARDEN sessions were thought to facilitate connection and communication between the participants. Even in the case where memory was impaired, the contents of SENSE-GARDEN provided conversation topics and aided the flow of conversation. One participant with dementia also spoke about how he was encouraged to share his life story when being inside the SENSE-GARDEN:

> "The SENSE-GARDEN is great for getting people to tell and say things. And that is important … then things come out more. I was encouraged to tell." NOp02

Additionally, a sense of connection was identified not only between individuals but also to a sense of self amongst the participants with dementia:

> "I think she sees things here that calm her heart … They are memories. It's her story." PTfc07

The technology was used as a way of portraying the life story of the residents back to the participants, and as such, it was something that they were able to connect to. One man with Alzheimer's disease expressed that he felt a lot of happiness as a result of recognizing himself in the media contents:

> *Interviewer* How did SENSE-GARDEN make you feel?
>
> *NOp03* A lot of happiness.
>
> *Interviewer* What was it about SENSE-GARDEN that made you feel that way?
>
> *NOp03* It was the films that I recognized me in."
>
> The above quotes suggest that the use of digital technologies to convey personalized media contents can be useful in promoting a sense of self, even in the moderate stage of dementia.

Through space

Overall, the participants were positive towards the physical aspects and aesthetics of the SENSE-GARDEN room. They also spoke about the ways in which the space harnessed an energy in which they could connect with others:

> "It is the energy inside the sensory garden, good energy. One feels safe, very safe frames. It has to do with light, and the colors and people in it." NOic03

Others spoke about how they felt transported inside the space:

> "It may well be that it is quiet, the colors have a lot to say. It is often the music and the light that comes into play. It's the design of the room, the fact that there are no sharp edges. No corners, it's carpeted. It is shielded from the rest of the world. One goes into something else, one forgets time." NOic01

> "Those forests that [facilitator] showed us and we were running. (Laughs) In the middle of that forest, wasn't it? With that running water, a spring. All of this transports us to our imagination, our childish part. I'm very romantic (Laughs) Here it makes me dream, this space … PTic04

This quote illustrates how connection is made to not only other individuals in the room but also to the part of one's self that is perhaps not connected to so often, that is, the "childish" part. Additionally, the caregivers spoke of the SENSE-GARDEN space being a part of the person with dementia:

> "It's his moment, his space." PTfc05

> "I felt that she was in her space, that she felt that space as if it were hers, it was of her … PTic06

These remarks resonate strongly with Dewey's notion of "human-as-organism-in-environment", in which an individual is fundamentally at one with their surrounding (Dewey, 1929). Furthermore, the quotes reflect a metaphysical understanding of space, one which goes beyond physical features.

Through memories

Whilst memories were often triggered by the digital media contents shown in the SENSE-GARDEN, the participants expressed the significance of the memories themselves. The participants' remarks resonated with symbolic interactionist perspective that memories—and the emotions and meanings attached to these memories—can be shared through social interaction. For example, one caregiver reflected on how she felt that "people are made" through the joint recollection and conservation of memories:

> "That's [sharing memories are] how people are made. I like to talk about things I've experienced together. The pictures are a trigger of the memory and conversation. I think if I have been on a holiday trip, it is nice to look at the pictures with the family and talk about them later." NOic01

Again, benefits of the intervention were seen beyond the SENSE-GARDEN room. Memories that were triggered in the SENSE-GARDEN appeared to be lasting beyond the session and were able to help communication between caregivers and residents:

> "When I was talking about a cousin of his, I forgot what he was called. Suddenly my husband remembered his name." NOic02

Similarly, the niece of a participant noticed that her aunt was able to remember aspects of what they spoke about during the sessions. In this case, the niece had expressed her concerns over her aunt being potentially upset by bringing up memories of the family, which had experienced problems in the past. However, her concerns were eased when she noticed her aunt "was fine":

> "Afterwards, when we finished the session sometimes I spent a little bit of time with her, or in the other days that I would go there and then I would talk to her a little bit about [their family]. I brought up the subject and noticed that she was fine … I noticed she remembered things well and spoke well, it was neither pity nor nostalgia. She spoke as if it had been a fact of her life and that was it." PTic09

Another caregiver explained how her close family-friend became more connected to her family through the remembrance of family members and songs:

> "I have the notion that she began to give and gave much more appreciation to this Christmas … because she remembered and spoke to my brothers, my husband and my cousin … so the people who went there … she remembered the names of those people and their loved ones, and they promised to come and see her now." PTic01

Additionally, it is not only the memories of the person with dementia that provides connection, but it is also the ways in which other individuals consider the person that have an impact. In a rather touching remark, one lady with dementia commented on how she liked to be remembered by others:

"I also liked the photos and to be remembered here in this house" PTp04

This quote illustrates the important role of others in constructing narrative identity amongst people with dementia. For this participant, the role of others in "remembering" her was important to her. Through being remembered by others, and through the sharing of photos and stories, this sense of narrative identity can be sustained even when the person progresses into more moderate and advanced stages of dementia.

Discussion

Overall, the findings suggest that an individualized technological intervention such as SENSE-GARDEN has a promising impact on facilitating meaningful activities in dementia care, particularly with regard to stimulating emotional experiences, preserving a sense of narrative identity, and improving interpersonal relationships—both on a familial and professional level. The findings are consistent with previous studies that implemented meaningful activities tailored to people with dementia in care homes which found that staff are encouraged to see the unique personhood of the individual (Broome et al., 2017: Figueiredo et al., 2013; Fritsch et al., 2009; Helgesen et al., 2020; Kuosa et al., 2015). This can improve the caregiving interaction, resulting in benefits for both staff and resident (Figueiredo et al., 2013; Helgesen et al., 2020).

This study also holds relevance to recent calls for the study of technology use in dementia care. For instance, a fairly recent Lancet commission on dementia prevention, intervention and care called for the use of technology in helping to improve care delivery (Livingston et al., 2017). Similarly, the World Dementia Council (2018) called for exploration into how new technology can be used as a means of connecting with others. The findings from this study indicate the potential of using a new technology combined with multisensory stimuli, such as SENSE-GARDEN, to provide a way for caregivers to connect with people with dementia. To gain insights into how this connection takes place, the results are discussed in relation to symbolic interactionism and Deweyan concept of transactional relationships.

Symbolic interactions within SENSE-GARDEN

The findings suggest that the SENSE-GARDEN intervention is loaded with meanings constructed through the use of media contents to provide multisensory stimuli, through emotional reactions during the sessions, and through conversation and gestures. Similar to how Johnson et al. (2017) found that using symbols provides opportunities for making powerful connections in dementia caregiving relationships, this study also found that connections can be facilitated through the use of symbolic interactions aided by multisensory stimulation, for example, dancing, singing, looking at photographs and watching films. These connections can have a particularly strong impact when facilitated between residents and care staff, who may not much prior knowledge on the person with dementia. Other work in this area has also found that sensory stimulation in dementia care can be a way of creating mutual relations between staff and residents (Lykkeslet et al., 2014).

The findings from this study found that music in particular prompted meaningful interactions between caregivers and participants with dementia. The residents' desire to dance and sing could be interpreted as means of expressing their identities beyond verbal means. This can have important implications for people with advanced dementia, who may no longer have the capability to communicate verbally. For example, in one interview where a caregiver was speaking about a piece of music used in the sessions, the resident who had difficulties with verbal expression started humming the song. By doing this, she was able to engage in the conversation that was taking place.

The caregivers' accounts of being touched by the ways in which the residents engaged with the music suggests a deeper connection to the individual was made. This is in agreement with other studies on music and dementia. McDermott et al. (2014) suggest that individual preference of music is preserved throughout the progression of dementia. Thus, the authors stress the importance of care personnel learning each resident's musical history in order to promote musical and interpersonal connectedness, helping to maintain a sense of identity and quality of life (McDermott et al., 2014).

A transactional model of narrative identity and relationships within SENSE-GARDEN

The findings from this study highlight the dynamic nature of interactions between not only people but also between person and environment. The ways in which the participants described their experiences inside the SENSE-GARDEN space reflects Deweyan philosophy in the sense that space was referred to as more than just being physical. For example, in recalling their experiences from inside the space, participants spoke about feeling an "energy" or feeling "transported". This resonates with Peter Freund's argument that "space is not merely a place in which social interaction occurs, it structures such interaction" (Freund, 2001, p. 694).

Furthermore, from the interviews, a clear interplay between past and present is distinguished. The idea that SENSE-GARDEN provokes reminiscence of past events and simultaneously prompts expression, communication and reflection in the present moment resonates with Deweyan philosophy. According to Dewey, there is no fixed self. Experience is temporally continuous, with past, present, and future being integrated with one another (Dewey, 1957). This is in line with more recent literature in this area. Edelman writes "Every perception, is some degree an act of creation, and every act of memory is to some degree an act of imagination" (Edelman, 2006, p. 123). Similarly, Rosenfield claims that "Recollection is a kind of perception … and every context will alter the nature of what is recalled" (Rosenfield, 1988, p. 89).

In the context of SENSE-GARDEN, the media contents trigger memories which are recalled and reflected upon in the present moment, loaded with new meanings and emotional connotations. For example, the participants often spoke of joy, mixed feelings or nostalgia when looking at old photographs. In this way, memories become stories that convey emotional importance (Wright-St Clair & Smythe, 2013). As Dewey writes, "the past is recalled not because of itself but because of what it adds to the present (Dewey, 1957, p. 2). The SENSE-GARDEN is arguably a means of recalling the past to create meaningful experiences in the present.

In an attempt to make sense of these experiences within SENSE-GARDEN, a transactional model of how narrative identity and relationships are fostered through the use of the intervention has been created. The model, presented in Figure 5, considers the multiple factors that contribute to preserving and promoting narrative identity, of which instantiations will differ from person to person. For example, a person with dementia who lacks the ability to communicate verbally will need the opportunity for alternative methods of expression. In order to provide such an opportunity, the caregiver will need knowledge about the person with dementia's life history and personal preferences in order to identify what kind of media contents could be useful in stimulating memories and prompting engagement and expression. Again, this media contents will differ from person to person, being dependent on the meaning that the person with dementia holds towards memories, events, and people in their lives. This personal knowledge can be hard to gain in the normal care setting during usual daily routines, especially when caring for residents with advanced dementia. However, through using the SENSE-GARDEN with the resident in a meaningful way (i.e., facilitating it in a way that encourages engagement from the resident), the caregiver has the opportunity to increase their understanding of the resident, which may benefit the caregiving relationship in terms of reciprocity and understanding. The caregiver can then plan and prepare future sessions using the new knowledge that they may have gained on the resident through previous sessions. This shows that flexibility in terms of individualization and facilitation is key in order for the intervention to be efficient.

The model also includes the factors that contribute to fostering relationships, such as reciprocity between the participant with dementia and the caregiver. However, this reciprocity is only achieved if the caregiver connects with the resident on a meaningful level, looking beyond the diagnosis of dementia. This meaningful connection will then, in turn, encourage the person with dementia to be more expressive and open with the caregiver. Similarly, Figueiredo et al. (2013) suggest that if caregivers provide opportunities to empower residents with dementia in long-term care, this may produce a "virtuous cycle" in which the well-being of the resident is improved, and, in turn, a sense of well-being and achievement is reinforced in caregivers.

The findings also suggest that meaning, which contributes to narrative identity and relationships, is generated in a constant flux between the SENSE-GARDEN environment and the participants inside the space. This resonates strongly with work conducted on transactional theory and occupational science. According to Dickie et al. (2006), who draw upon Deweyan philosophy to reflect on meaning-making in occupational science, meaning should be understood as flowing from the aesthetic, imaginative, creative and emotional modes of the transaction, not only in terms of the function of a transaction and its outcomes. Therefore, the influence of symbolic interactionism is also integrated into the model:

- *Meaning attributed to memories/media by PwD* refers to how the person with dementia holds meaning for the photographs, films and music within SENSE-GARDEN, and their associated memories.
- *Meaning attributed to PwD by caregiver* refers to caregiver's perception and attitude towards the person with dementia, which are shaped through facilitating the sessions and learning more about the resident as an individual.
- *Meaning formed through interpersonal interaction* refers to how meaning is constructed through

joint interaction between the person with dementia and the caregiver. This interaction is facilitated through the opportunity for expression, understanding, and reciprocity—all of which the participants experienced whilst using SENSE-GARDEN.

Situating SENSE-GARDEN amongst similar technological solutions

The outcomes of this study draw similarities to studies on other kinds of reminiscence technologies. We found that SENSE-GARDEN can stimulate emotional experiences, help preserve narrative identity, and foster interpersonal relationships between people with dementia and their caregivers. Similarly, studies of the digital multimedia apps have found that they are useful for increasing a sense of identity, prompting conversation, and supporting social interaction amongst people with dementia (Critten & Kucirkova, 2019; Park et al., 2017; Samuelsson & Ekström, 2019; Subramaniam & Woods, 2016). Personalized music playlists, which require considerably less effort to configure, have also been shown to improve communication and evoke positive emotions amongst people with dementia (Huber et al., 2020; Long, 2017). Thus, with results being so similar to cheaper and more accessible technologies, one may question whether the cost of an expensive solution such as SENSE-GARDEN can be justified. One argument is that SENSE-GARDEN is not just a technological solution, but a space. Participants expressed that they enjoyed being inside the SENSE-GARDEN space. SENSE-GARDEN may also overcome barriers previously experienced in studies of other types of reminiscence technologies. For example, it could be easier to engage with media inside a space, compared to holding, using and/or viewing content on a touchscreen device (Critten & Kucirkova, 2019; Davison et al., 2016: Hashim et al., 2015). SENSE-GARDEN presents media on large walls, therefore not requiring the person with dementia to control any part of the technology. Nevertheless, further work should consider the cost-effectiveness of SENSE-GARDEN.

Furthermore, if this intervention is to be delivered on a long-term basis in the future, factors such as sustainability and scalability need to be considered. Issues such as time constraints amongst staff, perceived value of the intervention, and lack of motivation and energy amongst staff have recently been identified as barriers to implementing staff-led interventions into dementia care practice (Karrer et al., 2020; Kormelinck et al., 2020). With SENSE-GARDEN requiring a large time investment from staff in terms of preparing and facilitating sessions with individual

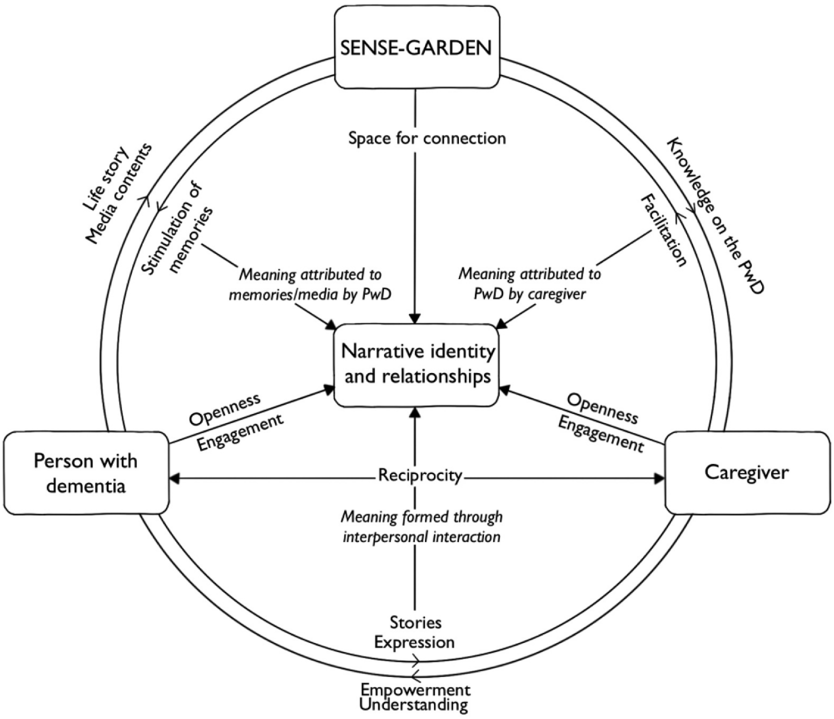

Figure 5. Transactional model of narrative identity and relationships facilitated through SENSE-GARDEN.

residents, there is a risk that this intervention asks "too much" of staff members. In order to deliver this intervention at scale and ensure its continued use, multiple strategies on the use of SENSE-GARDEN could be explored. Alternative options may include: offering group sessions; using "generic" media content over personalized individual sessions; training additional personnel in the facility such as assistants and volunteers; creating pre-loaded media storage relating to specific themes, places, or eras that would be provided to the care facilities together with the SENSE-GARDEN solution. All these could be potential options for alleviating time pressure from what is already a fast-paced and busy environment. Whilst the strength of SENSE-GARDEN appears to be the meaningful interactions it facilitates between residents and caregivers, these interactions will be short-lived if the intervention cannot be scaled up and sustained in the long term. As Hirt et al. (2021) suggest in their study of nurse-led intervention in long-term dementia care, nurses should have the option of adjusting an intervention after it has been implemented. Whilst the options listed above may be useful to staff, it is ultimately the decision of nurses and other care professionals to integrate SENSE-GARDEN into their facilities in the way that they see best working for them.

Limitations

This is a rather small study, based on a novel intervention. Therefore, the findings lack generalizability to other care homes. However, the knowledge generated from the findings may be applicable within a broader perspective of technology use beyond SENSE-GARDEN, as well as within the facilitation of meaningful activities in care.

Data collection was limited in two ways. First, the impact of the coronavirus pandemic hindered the way in which some interviews were conducted. Five interviews had to be conducted over the phone, which meant a lack of visual cues and expressions may have resulted in a less natural conversation. However, there is thought to be no significant differences between transcripts from telephone and face-to-face interviews (Sturges & Hanrahan, 2004). More importantly, the impact of the pandemic meant that five of the participants with dementia were not able to be interviewed. Second, there was a potential for bias during data collection. The interviews were conducted by the facilitators of the SENSE-GARDEN sessions. This would have most likely had an influence on how the participants chose to answer. Here, it is important to address researcher reflexivity. In being aware of and critical towards one's own positionality within a study, a researcher should explicitly address the effect that this position may have on the research process and outcome (Berger, 2015; Dowling, 2006). Due to the relationships that formed between residents, informal caregivers, and facilitators over the course of the intervention, the data generated during the interviews may be less credible compared to having the interviews conducted by someone else with no connection to the intervention. However, given that the participants with dementia had moderate to severe dementia, we decided that the interviewer should be somebody who is familiar to the participants. Had another individual independent of the intervention conducted the interview, the conversational nature of the interviews would have been hindered and the participants may not have felt as comfortable. The advantage of having the facilitator conduct the interview was the fact that they could make the participants feel at ease, and also refer back to moments experienced together in the SENSE-GARDEN space as prompts during the interview. It is also important to note that the SENSE-GARDEN facilitators were not involved in the analysis of the transcripts or writing of this paper. The only interviewer who was involved with the analytic process was researcher and co-author LA who has a background in sociology and qualitative methods.

The analysis of data is also limited, mainly due to the fact that the transcripts were translated to English. Therefore, these transcripts lack the nuance of the quotes in their original language. However, the authors consist of one native English speaker, one native Norwegian speaker and two native Portuguese speakers. Together, the authors tried to ensure that the transcripts reflected what the participants were expressing in their original language.

Finally, the study of transactional relationships within the SENSE-GARDEN would have been enhanced with study of "in-the-moment" experiences. The analysis is based on reflections and interpretations of experiences already lived within the SENSE-GARDEN. Having included an observational element in situ would have provided further insight into the dynamic processes that take place within the intervention.

Ethical considerations

Due to challenges concerning consent, participation, and safety, people with dementia are often excluded from many areas of research (Rivett, 2017). However, it is important that people with dementia are given opportunities to participate in research—especially individuals with moderate to advanced dementia. In the current study, careful considerations were made in the planning of the study to ensure the safety and well-being of the participants, as well as ensuring that their willingness to attend the SENSE-GARDEN sessions was respected. Information was given to residents and their informal caregivers before each step of the study by care professionals who had been involved with the planning and development of the intervention. Clear communication between researchers, care professionals, informal caregivers, and residents meant that all participants were kept well informed on the study and researchers were kept informed on any issues that had arisen. Most importantly, care professionals were able to continuously assess consent and willingness to participate by interacting with the residents before and after each SENSE-GARDEN session. Having built up a relationship over the 12–16 study period, the professionals were also able to assess whether or not the residents were willing to participate in an interview.

Another important consideration is the use of photographs in this article. The recording of photos and videos was included in the consent, along with the scientific and public dissemination of these materials. However, given the fact that consent was provided by proxy, it is important to address the ethical implications of using photographs. We felt the need to include the photos as a means of portraying the SENSE-GARDEN and its sessions in a way that words could not. However, the faces of the participants (as well as faces of individuals in photographs) have been blurred to respect the privacy of the participants.

Going forward, it is important to reflect upon the use of SENSE-GARDEN in the context of day-to-day use, outside of a research study, and what impact this may have on residents. An intervention that focuses so heavily on a person's past memories is bound to evoke emotions that are not always positive. This has been the case in research of this nature, where including photographs of loved ones who have passed away in digital life stories has caused sadness amongst participants (Damianakis et al., 2010; Ryan et al., 2018). There may also be instances in which emotions are mixed. Whilst Swann (2013) acknowledges that the release any emotions can be good for the person with dementia, she also suggests that staff facilitating reminiscence activities should be sensitive to the emotions of residents, ready to offer comfort if needed, and ready to stop the activity if necessary.

Implications for future research and practice

Future research on technology use in dementia care should adopt a holistic approach to considering not only the effect of the technology but also considering the situational context in which it is to be used. Technology design for dementia care, as Jiancaro, Jaglal and Mihailidis argue, is "deeply contextual" (2017: 576). This study has shown the benefit of integrating theoretical perspectives into exploring how technology may be used in care, particularly with regard to facilitating meaningful activities that promote narrative identity and relationships. Similar to Rosenberg and Nygård's (2012) transactional approach to assistive technology use, our findings suggest that the use of technology for meaningful activities is complex and requires flexibility in order to be used efficiently. In the context of SENSE-GARDEN, possibilities for integrating partial automation into the creation and adaptation of the sessions is currently being explored. As one of the caregivers stated, it is difficult to prepare sessions manually. Furthermore, it is time-consuming to put together user profiles at the initial stage of preparing the sessions (approximately one hour per resident). If SENSE-GARDEN is to be used in everyday practice with multiple residents, there needs to be way of reducing the time taken to prepare sessions. Introducing this automated component may support caregivers in being able to prepare and facilitate sessions more easily and with less time constraints. Additionally, staff members should not be expected to have to manage any issues with the system themselves. Ensuring technical support is provided as needed by suppliers of the SENSE-GARDEN service, outside of a research context, is essential if the technology is to be used on a day-to-day basis.

Furthermore, the similarities between remarks made by caregivers in both Portugal and Norway, particularly regarding the lack of opportunities for residents to engage in meaningful activities, provokes an important question of whether there is still a serious lack of offer of such activities to people with moderate to advanced dementia on an international level. This study has shown how a technological solution such as SENSE-GARDEN can support care staff in providing meaningful activities, but more work needs to be done on how feasible it is to implement an intervention of this kind into a regular care routine within these environments. As mentioned by a member of staff in the present study, it is difficult to plan large numbers of SENSE-GARDEN sessions for one resident, especially when the contents of the session will need to be continuously adapted based on new information they receive from the resident. In order for an intervention such as SENSE-GARDEN to be used on a long-term basis, factors such as costs, time consumption, and staff resources and training, need to be considered.

Conclusion

To conclude, there is promising potential for the use of technology for facilitating activities that may help construct narrative identities and promote interpersonal relationships within dementia care. Care residencies should incorporate the knowledge of residents into everyday activities in order to provide high-quality care, and the SENSE-GARDEN is an example of a tool that can be used to support this incorporation. A transactional perspective has illustrated the complex nature of the SENSE-GARDEN, and of person–environment interactions in general. In understanding the multiple factors that characterize the transactional relationships that take place through an intervention, implications for implementing and facilitating such intervention may be appreciated and assessed. These interactions—or transactions—need to be explored from a holistic approach. Whilst the technology offered by SENSE-GARDEN can be used for creating opportunities to engage with the life story of people with dementia, it is ultimately the relationships and interactions between people happening inside the space that gives meaning to the experience.

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Data availability statement

The data that support the findings of this study are openly available in Zenodo at https://doi.org/10.5281/zenodo.4081468

Supplementary mateials

Supplemental data for this article can be accessed here.

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