

Design for Everyday Sounds in Dementia

Citation for published version (APA):

Houben, M. (2022). *Design for Everyday Sounds in Dementia*. [Phd Thesis 1 (Research TU/e / Graduation TU/e), Industrial Design]. Eindhoven University of Technology.

Document status and date:

Published: 01/11/2022

Document Version:

Publisher's PDF, also known as Version of Record (includes final page, issue and volume numbers)

Please check the document version of this publication:

- A submitted manuscript is the version of the article upon submission and before peer-review. There can be important differences between the submitted version and the official published version of record. People interested in the research are advised to contact the author for the final version of the publication, or visit the DOI to the publisher's website.
- The final author version and the galley proof are versions of the publication after peer review.
- The final published version features the final layout of the paper including the volume, issue and page numbers.

[Link to publication](#)

General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal.

If the publication is distributed under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license above, please follow below link for the End User Agreement:

www.tue.nl/taverne

Take down policy

If you believe that this document breaches copyright please contact us at:

openaccess@tue.nl

providing details and we will investigate your claim.

Design for Everyday Sounds in Dementia

Doctoral Dissertation

by

Maarten Houben

A catalogue record is available from the Eindhoven University of Technology Library

ISBN: 978-90-386-5584-0

The research represented in this doctoral thesis was part of the 'Everyday Sounds of Dementia' project, funded by ZonMw in the Create Health Program, under project number 443001122.

© Maarten Houben, 2022

All rights reserved. No part of this document may be photocopied, reproduced, stored, in a retrieval system, or transmitted, in any form or by any means whether, electronic, mechanical, or otherwise without the prior written permission of the author.

Design for Everyday Sounds in Dementia

PROEFSCHRIFT

ter verkrijging van de graad van doctor aan de Technische Universiteit
Eindhoven, op gezag van de rector magnificus prof.dr.ir. F.P.T. Baaijens,
voor een commissie aangewezen door het College voor Promoties, in het
openbaar te verdedigen op dinsdag 1 november 2022 om 11:00 uur

door

Maarten Houben

geboren te Genk, België

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

Voorzitter:	prof.dr.ir. A.C. Brombacher
1e Promotor:	prof.dr.ir. J.H. Eggen
2e Promotor:	prof.dr. I.M.B. Bongers (Universiteit van Tilburg)
Copromotor:	dr.ir. R.G.A. Brankaert
Leden:	prof.dr. A.J. Astell (University of Toronto) prof.dr. D.M. Frohlich (University of Surrey) prof.dr. W.A. IJsselsteijn
Adviseur:	dr. G. Kenning (University of New South Wales)

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

Table of Contents

TABLE OF CONTENTS	6
INTRODUCTION	9
1.1 Dementia	10
1.2 Technology and Dementia	14
1.3 Music and Dementia	15
1.4 Everyday Sounds in Dementia	16
1.5 Design for and with People with Dementia	17
1.6 Research Objectives and Thesis Outline	18
1.7 References	21
EXPLORE	31
FOREGROUNDING EVERYDAY SOUNDS IN DEMENTIA	33
2.1 Introduction	34
2.2 State-of-the-art	36
2.3 Method	38
2.4 Results	44
2.5 Discussion	53
2.6 Conclusion	57
2.7 Acknowledgments	57
2.8 References	57
DESIGN	63
CO-CREATING PERSONAL AUDIO CONTENT WITH PEOPLE WITH DEMENTIA AND THEIR RELATIVES	67
3.1 Introduction	68
3.2 Background	69
3.3 Research Setup	71
3.4 Life Story Soundboard	73
3.5 Iterative Approach in Personalizing Everyday Sounds	75
3.6 Personalizing Sounds to Meaningful Past Experiences	79
3.7 Relative as Support and Collective Memory	81
3.8 Discussion	83
3.9 Conclusion	85
3.10 References	85
DESIGNING FOR EVERYDAY SOUNDS AT HOME WITH PEOPLE WITH DEMENTIA AND THEIR PARTNERS	89
4.1 Introduction	90
4.2 Background	92
4.3 Study Design	94
4.4 Stage 1: Exploring Personal Everyday Sounds at Home	98
4.5 Stage 2: Interactions with Everyday Sounds	103
4.6 Stage 3: Design for Home Environment	108
4.7 Discussion	114
4.8 Conclusion	117
4.9 Acknowledgments	118
4.10 References	118

EVALUATE	127
THE PERSPECTIVES OF PROFESSIONAL CAREGIVERS ON IMPLEMENTING AUDIO-BASED TECHNOLOGY IN RESIDENTIAL DEMENTIA CARE	131
5.1 Introduction	132
5.2 Materials and Methods	134
5.3 Results	140
5.4 Discussion	148
5.5 Conclusions	152
5.6 References	152
THE ROLE OF EVERYDAY SOUNDS IN ADVANCED DEMENTIA CARE	159
6.1 Introduction	160
6.2 Related Work	161
6.3 Method	164
6.4 Results	170
6.5 Discussion	179
6.6 Conclusion	183
6.7 Acknowledgments	183
6.8 References	183
REFLECT	189
DISCUSSION	191
7.1 Summary of Findings	192
7.2 Everyday Sounds as Open-Ended Cues.....	193
7.3 Tangible Interactions with Everyday Sounds	199
7.4 Enriching Everyday Experiences in Dementia	206
7.5 The Role of the Design Researcher	209
7.6 Conclusion of Discussion	213
7.7 References	214
CONCLUSION.....	223
8.1 Introduction	224
8.2 Research Conclusions.....	225
8.3 Future Directions.....	227
8.4 Concluding Remarks	230
8.5 References	231
SUMMARY	234
SAMENVATTING.....	236
PUBLICATIONS.....	240
CURRICULUM VITAE	244
ACKNOWLEDGEMENTS.....	246

“The sounds we associate with certain rooms: speaking personally, what always comes first to my mind are the sounds when I was a boy, the noises my mother made in the kitchen. They made me feel happy. If I was in the front room, I always knew my mother was at home because I could hear her banging about with pots and pans.” (Peter Zumthor, [128], p.29)

1

Introduction

Over the years, there has been a vast number of studies demonstrating the positive effects of music on people with dementia. However, the impact of non-musical or everyday sounds in dementia has been insufficiently researched. The quote (left) by Peter Zumthor illustrates the potential of everyday sounds in evoking meaningful experiences which could benefit people with dementia. This thesis explores how everyday sounds can enrich the lived experiences of people with dementia through interactions with technologies. This chapter provides a brief overview of the lived experiences of dementia and the potential of everyday sounds and technology to address the psychological and emotional needs of people with dementia. Furthermore, this chapter elaborates on the research through design approach adopted in this thesis and formulates the research objectives and thesis outline.

1.1 DEMENTIA

Dementia is a global societal challenge as more than 55 million people worldwide live with dementia [125]. The number of people with dementia is growing rapidly and is expected to keep rising in the coming years due to the aging of the world's population [4]. There is currently no pharmacologic treatment available to stop the progression of dementia despite progress being made in clinical trial testing [38]. Dementia is an umbrella term encompassing a range of progressive neurodegenerative diseases that affect the brain and result in decreased cognitive functioning. Alzheimer's disease is the most prevalent cause of dementia as it approximately accounts for 60% to 80% of all reported dementia cases, followed by cerebrovascular disease (5% to 10%), Lewy body disease (5%), and frontotemporal lobar degeneration (3% in population 65 and older) [4]. This thesis will only focus on people with Alzheimer's disease and cerebrovascular dementia, who are further referred to as people with dementia.

1.1.1 *Lived Experiences of People with Dementia*

Being diagnosed with dementia has a significant impact on a person's everyday life. Dementia negatively affects the general quality of life, resulting in various behavioral and psychological symptoms such as anxiety, stress, and depression [27]. Short-term memory loss is an early indication of dementia, as people have difficulties recalling recent events, conversations, or names [3]. At an early diagnosis of dementia, people are still highly engaged in everyday social life and try to integrate their impairment within society [111]. However, people in the early stages of dementia often lack hope or motivation to adjust to the disease as they must cope with being aware of their diagnosis [35]. Feelings of insecurity and low self-esteem due to this awareness lead to avoidance or withdrawal from social interactions [55]. Over time, the disease progresses as symptoms become more severe and impact the ability of the person to actively participate in social life or complete activities of daily living, such as household chores, cooking, or personal hygiene [88]. People in advanced stages of dementia can experience clinical complications that negatively affect body functioning, such as eating problems or agitation [89]. Aphasia is also a common symptom of advanced dementia, as language impairment increases with the severity of dementia [37]. Furthermore, people in the later stages of dementia can display apathy or a lack of interest in daily activities, which is negatively associated with quality of life [94].

The diagnosis of dementia has long been associated with a loss of self and identity [13], and people with dementia were often identified as passive recipients of care and as

lacking interest or active contributions in social situations [113]. As a result, people with dementia have often been depersonalized and identified by their diseases, referred to as ‘demented’, ‘senile’, or ‘sufferers’. Being treated as such negatively affects people with dementia as they keep implicit memories of these experiences despite their impaired memory [102]. For example, people with dementia expressed how they lack influence in making decisions that impact their personal health or social life [1]. However, people with dementia can still express their identity or selfhood, which is often mistaken for memory [13]. Therefore, cognitive impairment does not imply a loss of selfhood, as people with dementia maintain selfhood by making social connections and embodied interactions such as bodily movement, eye gazing, or gestural communication [73]. For example, people with dementia are still able to perceive or appreciate humor and contribute to humorous situations [14]. Therefore, it is important not to view people with dementia by their clinical symptoms but as unique individuals with vastly different subjective experiences of dementia based on their personality and life experiences [72]. Furthermore, there is a moral incentive to ensure people with dementia are being heard as part of their human rights [32]. This thesis adopts this socially inclusive perspective by addressing the lived experiences of dementia, focusing on ability and empowerment, and involving people with dementia as active contributors in research. Similarly, the language used to describe dementia also influences how people with dementia are viewed by society or how they feel about themselves [40]. Therefore, the use of words matters, and the term *people with dementia* is used in this thesis.

1.1.2 Informal Care at Home

Dementia does not only impact the person who is diagnosed but also affects the family and partners. The majority of people with dementia prefers to age in place at home as long as possible before moving to a care home [114]. However, people with dementia require more support over time in activities of daily living, such as cooking, dressing, personal hygiene, and household chores [88]. A large part of these care tasks often falls on the partners or relatives who provide informal care for their loved one with dementia, which can be burdensome and physically demanding as they also need to maintain their personal health, household, and family life [31]. Informal caregivers also experience psychological distress as they must cope emotionally with the declining health condition of the person with dementia [96]. Informal caregivers experience this coping as an ongoing iterative process of grief as their loved one with dementia is gradually changing by the condition [71]. As such, informal caregiving drastically impacts the emotional relationship between couples as their bond evolves in a care relationship between a caregiver and a recipient of care [52]. However, even though

informal care for dementia is broadly perceived as emotionally draining, some couples can still experience growth or renewed commitments by reinforcing and reflecting on their enduring bond [84].

To enable people with dementia to live independently at home, there is a global need for professional support strategies and home care services [129]. Informal caregivers rely on assistance from professional home care services, such as personal counseling on coping with dementia, assistance with routine care or household tasks, and social and recreational activities provided at home [30]. People with mid to early-stage dementia living at home go to daycare centers multiple times per week where they participate in social or recreational activities, which also offers much-needed respite and moments of rest for informal caregivers [83].

At a certain point in time, people with dementia move from their homes to residential care, often when informal caregivers can no longer manage the increasing care needs [67]. During these transitions from home to formal care, difficulties can arise as informal caregivers experience a loss of control and their loved one with dementia struggles to adjust to a new home [7]. Informal caregivers and relatives often feel guilty or conflicted about institutionalizing their loved ones and experience a sense of loss or grief [110]. Furthermore, family members and partners can feel disconnected from their relatives with dementia living in residential care settings due to a lack of communication and contact with the professional care staff [19]. As these examples illustrate the impact of dementia on relatives, friends, and family, this thesis also values and considers the needs and well-being of informal caregivers together with the perspectives of their loved ones with dementia.

1.1.3 Residential Care Facilities

The experiences of people with dementia and their relatives are also affected by their interactions with professional caregivers who are trained professionals in providing assistance and care. Dementia care facilities or care homes face a continuously increasing demand straining existing care systems [3]. Therefore, professional caregivers who work in care homes and provide care to people with dementia are under time pressure and required to perform their job under restrictive efficiency requirements, resulting in less time spent caring for and socializing with residents [85]. While recreational and social events can provide enjoyment to some extent, there are still many reported cases of loneliness and depression among dementia care home residents [113]. The lack of social contact correlates with higher incidences of behaviors relating to

the unmet psychosocial needs of people with dementia, such as anxiety, apathy, or aggression towards their social surroundings [41].

As a result, there is a need for non-pharmacological interventions as cost-effective alternatives to improve the quality of life of people with dementia [95]. Certain non-pharmacological interventions aim to address specific unmet needs such as discomfort, loneliness, or boredom through activities tailored to the remaining abilities and preferences of the person with dementia and offer social contact and sensory stimulation [33,34]. Such interventions are referred to as 'meaningful activities' that are characterized by stimulating active participation from care home residents, addressing their personal background and preferences, and providing a sense of social belonging and inclusion [82]. Meaningful activities stimulate active engagement, interest, and positive emotions in people with dementia through engaging with stimuli, their environment, and the people present [34]. These activities are often part of scheduled recreational programs to address anxiety, depression, or boredom in the form of activities provided by the care staff [24], such as reminiscence activities [124], art therapy [28], or music sessions [107].

To address the personal needs of people with dementia, person-centered care has become a widely adopted approach in dementia care practice to support the psychosocial well-being of care home residents by putting their values, needs, and social circumstances at the center of the care delivery process [23]. Person-centered care focuses on the remaining capabilities of people with dementia by acknowledging selfhood and identity and recognizing them as individuals with unique lived experiences [72]. Professional caregivers actively engage in social interactions with people with dementia during everyday care tasks and develop interpersonal relationships to better support the individual needs and unique experiences of the person with dementia [49]. Establishing an equal partnership in care between the caregiver and resident can empower residents to handle aspects of care themselves or acknowledge them as experts of their own experiences [109]. These person-centered approaches reduce agitation among the residents [29], while better relationships between residents and staff also lead to a positive work atmosphere and decrease emotional workload for care professionals [87]. However, tools and resources for providing person-centered care are often lacking [5]. To improve the quality of care for people living with dementia in residential care, the needs and struggles of care professionals need to be addressed. This thesis aims to contribute to the quality of life of people with dementia in residential care

by primarily focusing on the lived experiences of dementia and by including the perspectives of the professional caregivers.

1.2 TECHNOLOGY AND DEMENTIA

As there is currently no cure for dementia, research has been increasingly exploring the role of technology in supporting the well-being of people with dementia. Initially, research on technology for dementia mainly focused on offering relief and support for physical and cognitive disabilities caused by dementia by assisting in activities of daily living [15]. These technologies are often aimed to enable people with dementia and their informal caregivers to live independently at home [74]. Common examples of such assistive technologies include: GPS-trackers to enable safe wandering [121]; devices that prompt calendar reminders [100] or grocery lists [127]; and applications that provide cognitive assistance during household chores such as cooking [123] or personal hygiene routines such as handwashing [86]. Over the years, a large number of assistive technologies have expanded beyond mainly addressing the physical and cognitive needs of people with dementia as research has argued how the experiences, preferences, and impact on the everyday life of the person with dementia should be considered as well [16].

The field of human-computer interaction (HCI) that studies the interactions between people and technology is increasingly exploring the role of technology in supporting the quality of life of people with dementia [22]. Researchers in HCI have proposed alternative strategies to broaden the scope of assistive technologies by foregrounding novel perspectives on design and technology that focus on individual potential and possibility and address the full range of lived experiences of the person with dementia [90]. These emergent critical views on dementia in HCI highlight how interactive technologies can tap into the remaining abilities of individuals with dementia, address their specific psychosocial needs and enrich the lived experiences of dementia through physical and embodied interactions [76]. For example, design and digital technologies that evoke the reflection of past life experiences or social interactions with others can support people with dementia in maintaining a sense of self and expressing personal identity [120].

A large body of work in HCI on dementia explores how technologies that offer multisensory stimuli utilize the full range of senses and abilities of people with dementia to support meaningful activities. For example, technologies can be used for recreational purposes and provide stimulation such as arousal, enjoyment, or pleasure [76]. Digital

media such as images or videos are commonly used in meaningful activities such as reminiscence therapy to evoke memories and conversations with caregivers or relatives [51,77]. Therefore, there is an extensive body of research on technologies that provide media experiences in dementia care, such as virtual reality [64], ambient or public displays [50,104,117], and touchscreens [57]. A large body of work heavily relies on visual stimulation within this research context, such as videos [39] or images [8,46]. This thesis aims to contribute to this body of knowledge by further expanding the scope of sound-based technologies to offer a meaningful activity for people with dementia.

1.3 MUSIC AND DEMENTIA

Music has been widely used to offer meaningful activity and contribute to the well-being of people with dementia at home [75] and in care home environments [97]. Over the years, researchers have investigated and identified many benefits of music for people with dementia, such as advantageous physiological, psychological, cognitive, and emotional effects [11,54,97,107]. Music therapy can reduce distress or agitation in people with dementia [54,56] and result in positive changes in mood as people with dementia express enjoyment, appear relaxed, increase eye contact or engage in conversations [65]. Furthermore, collective engagement with music during group sessions provides opportunities for people with dementia to feel a sense of social belonging and mutual connection [54]. For example, background music or singing by caregivers can reduce agitated behavior during morning care tasks and increase the personal and social relationship between the care home staff and the clients with dementia [56]. In addition to music listening, people with dementia can also actively engage in music-making by using instruments [97], as the implicit musical memory functions needed to play an instrument are relatively spared from impairment [10]. Interactions with music can also increase physical activity by using the preserved sensorimotor capabilities of the individual with dementia, such as dancing, singing, or expressive body movement [79].

Music can provide meaningful ‘in the moment’ experiences that focus on the abilities and embodied sensory experiences of people with dementia [45]. Research has argued how person-centered approaches in music-based therapies increase ongoing engagement by using music that the person with dementia enjoyed before the diagnosis [60]. Exploring the musical history of the person with dementia evokes memories and deep positive feelings associated with a specific song as people with dementia recall past experiences in the here and now [68,75]. For example, research has shown how personal music from early adulthood is best recollected by the person with dementia and is

effective in evoking reminiscence or emotional reactions [98]. As such, music can stimulate and enhance the sense of self as listening to familiar music is a process that involves remembering as a meaningful activity or reflection on personal identity [12].

Motivated by the beneficial effects of music, there is an increasing interest in technology for facilitating music therapy for people with dementia [36]. Research has explored how to make music accessible for people with dementia at home who can no longer use traditional music players such as a radio or cd player. These research efforts resulted in developing various music players accessible for people with dementia enabling them to listen to personal music at home independently [92,116,122]. In addition, research shows how adapted musical instruments can allow people with dementia to actively participate in music sessions in care facilities without the difficulties of manually operating a traditional musical instrument [36,48,70,91]. Furthermore, music pillows [80] or collaborative interfaces [48,81] can provide shared music activities between people with dementia and their caregivers. However, compared to the extensive body of research on music and dementia, there has been little research on non-musical or everyday sounds.

1.4 EVERYDAY SOUNDS IN DEMENTIA

Our sonic environment exists of a rich collection of everyday sounds that often go unnoticed yet influence our behavior, movement, and emotions [9]. These arrays of everyday sounds perceived in our day-to-day surroundings are called soundscapes [105]. Whereas the sonic environment refers to the physical sounds present in a space, a soundscape is defined as a perceptual construct that not only describes an acoustic setting but also how these sounds are perceived and experienced by the listener [66]. People can have vastly different interpretations of sound-producing events based on auditory memory, problem-solving abilities, or other unconscious factors [53]. In addition, the perception of soundscapes is strongly influenced by the listener's attitude, expectations, and socio-cultural background [25].

Whereas annoying or unpleasant soundscapes can have adverse health effects, enjoyable or pleasant everyday sounds can positively influence our feelings, emotions, and environment appraisal [6]. Based on the potential benefits of sound on health and well-being, there has been an increasing interest in investigating the effect of the acoustic environment of care facilities on residents and care staff [2]. These works have highlighted the need to reduce unwanted noise [115] and provide acoustic comfort to improve the well-being of the residents and care staff [43]. Acoustic guidelines for dementia care homes also suggest adding familiar or pleasant sounds to provide

appropriate sensory stimulation [61]. For example, nature soundscapes such as forest or beach sounds that are perceived as pleasant reduce stress and provide relaxation for people with profound intellectual disabilities [18].

These research efforts on sound and dementia have further increased the interest in applying soundscapes as non-pharmacological support to relieve stress and agitation among care home residents [78,112,119]. Professional caregivers have expressed the potential for everyday sounds in reducing unrest or anxiety in residents with dementia by providing feelings of safety or creating soothing atmospheres [17,44]. However, additional sounds in care homes should not interfere with existing care routines, yet signal or compliment activities, for example cueing cafeteria sounds during eating activities [42]. Furthermore, the sonic environment in care homes provides novel opportunities to socially connect residents through sound [58]. The perception of soundscapes is a social process grounded in the interactions between people and their environment [101]. So as sound travels through care home spaces, it shapes social relations and connects residents through their collective perception and engagement with sound [59].

However, there exists a gap of knowledge on how listening to everyday sounds can shape and improve the unique lived experiences of people with dementia. Similar to listening to music, engaging with non-musical sounds in our environment can trigger reminiscence or recollections of particular places or periods in time as familiar sounds are being re-experienced [106]. Despite the potential benefits of everyday sounds in influencing emotions and evoking strong associations [26,81], there remains little to no work on technologies that facilitate everyday sounds to support the social and emotional needs of people with dementia. This thesis will focus on the lived experiences evoked by everyday sounds and how these experiences benefit people with dementia, their loved ones, and caregivers.

1.5 DESIGN FOR AND WITH PEOPLE WITH DEMENTIA

Person-centered and accessible technologies are required to facilitate meaningful experiences with everyday sounds in the day-to-day context of people with dementia and their caregivers. Therefore, this thesis adopts a research through design approach [126] in exploring the role of technology in facilitating meaningful engagement with everyday sounds for people with dementia. Research through design methods are widely adopted in HCI, in which research is conducted through the development and evaluation of novel design artifacts as physical embodiments of theory, ideas, or

opportunities [126]. In a design-oriented research approach, the design artifact is not the primary output, but a means to generate new knowledge, and the design activities are part of the research process [47]. Within this landscape of design research, participatory designs involve the user as a partner in collaboration with the design researcher [103]. Participatory design approaches empower the end-users of technology to express their values, preferences, and everyday contexts in the design process [108].

There has been an increasing interest in designing for people with dementia and including them in participatory approaches [21,63,99]. Inclusive and personalized participatory design approaches can offer insight into the lived experiences of dementia and how design can support the needs, values, and social context of people with dementia [120]. These approaches aim to empower people with dementia to make active contributions as collaborators or co-creators during the research activities as experts of their own experiences [99]. Personalized design approaches that make use of remaining abilities allow people with dementia to voice their preferences, thoughts, and opinions through unique forms of expression [20,63]. In addition, research activities set up as pleasant social activities can provide reciprocal engagements during which people with dementia can experience immediate benefits from participating [69]. For example, activities that involve creative expression through art or music provide playfulness and stimulate participation in people with dementia to act as co-creators in the design process [118]. Furthermore, allowing room for playfulness and social engagement provides opportunities to directly connect with the person with dementia and their caregivers and provide feelings of acknowledgment [93]. Socially connecting with people with dementia enables the designer or researcher to interpret implicit responses and establish feelings of trust [62].

The research presented in this thesis adopts a research through design approach to focus on the individual experience of dementia by closely involving people with dementia and people from their immediate living environment, such as professional caregivers and family members.

1.6 RESEARCH OBJECTIVES AND THESIS OUTLINE

This thesis addresses the following main research question: *how can everyday sounds enrich the lived experiences of dementia?* The research question was divided into three sub-questions to address the full range of lived experiences in dementia and involve both formal and informal caregivers:

RQ1: What are the experiences of people with dementia evoked by everyday sounds?

RQ2: How can we design for meaningful experiences with everyday sounds to support people with dementia and their caregivers?

RQ3: How can interventions that facilitate meaningful experiences with everyday sounds be integrated into dementia care practice?

These three sub-questions aim to feed the overall objective of creating an understanding of how everyday sounds can support people with dementia in different stages of the progression of the condition by involving their extended care networks such as informal caregivers and professional caregivers. To address these sub-questions, this thesis is divided into four sections to *explore, design, evaluate* and *reflect* how everyday sounds can be meaningful for people with dementia (see Figure 1.1).

1.6.1 Section 1: Explore

Section 1 provides an initial exploration in gaining insights into the unique experiences of people with dementia while listening to everyday sounds and the social interactions that emerged from these experiences. *Chapter 2* reports on a series of explorative workshops with people in the early to mid-stages of dementia in a daycare facility. The workshop participants engaged with a design artifact, namely the Dementia Soundboard, to interactively explore multilayered soundscapes composed of everyday sounds while sharing their responses, preferences, and stories in a group setting.

1.6.2 Section 2: Design

Section 2 of this thesis reports on a one-year co-design study with four care dyads to design for personal everyday sounds at home for people with dementia aging in place supported by their informal caregiver. *Chapter 3* describes the first part of the co-design study, in which the care dyads co-created personal sets of everyday sounds related to meaningful memories, life experiences, stories, or personal preferences. *Chapter 4* covers the second part of the co-design study in which the care dyads were involved in designing an accessible sound player for listening to their everyday sounds identified in *Chapter 3* to explore how everyday sounds facilitated by technology can support meaningful activity at home.

1.6.3 Section 3: Evaluate

To further explore the lived experiences of people in later stages of dementia, *Section 3* focuses on evaluating the role of technology that facilitates everyday sounds in existing care practices. This section covers the field deployment of Vita: an interactive sound cushion in two residential care facilities. *Chapter 5* reports on the participatory workshops with professional caregivers who reflected on using audio-based technology in everyday care by envisioning and discussing the potential benefits of Vita in the care home. *Chapter 6* reports on the field study of Vita in two residential care facilities to capture the lived experiences of people with advanced stages of dementia and the care staff engaging with everyday sounds in a care home.

1.6.4 Section 4: Reflect

Finally, *Section 4* of this thesis discusses the value of everyday sounds and technology for people with dementia and their caregivers. *Chapter 7* connects the insights from the studies in the previous chapters and formulates the general contributions of this thesis on how technology that provides meaningful engagement with everyday sounds can support the emotional and social well-being of people with dementia. Lastly, *Chapter 8* presents the research conclusions and sets out avenues for future work.

SECTION I: EXPLORE	Chapter 2 <i>Foregrounding Everyday Sounds in Dementia</i>	
SECTION II: DESIGN	Chapter 3 <i>Co-Creating Personal Audio Content with People with Dementia and Their Relatives</i>	Chapter 4 <i>Designing for Everyday Sounds at Home with People with Dementia and their Partners</i>
SECTION III: EVALUATE	Chapter 5 <i>The Perspectives of Professional Caregivers on Implementing Audio-Based Technology in Residential Dementia Care</i>	Chapter 6 <i>The Role of Everyday Sounds in Advanced Dementia Care</i>
SECTION IV: REFLECT	Chapter 7 <i>Discussion</i>	Chapter 8 <i>Conclusion</i>

Figure 1.1: This thesis is divided into four sections to *explore*, *design*, *evaluate* and *reflect* how everyday sounds facilitated through technology can benefit people with dementia and their social surroundings.

1.7 REFERENCES

- [1] Mari S Aaltonen, Anne Martin-Matthews, Jutta M Pulkki, Päivi Eskola, and Outi H Jolanki. 2021. Experiences of people with memory disorders and their spouse carers on influencing formal care: “They ask my wife questions that they should ask me.” *Dementia* (February 2021), 1471301221994300. DOI:<https://doi.org/10.1177/1471301221994300>
- [2] Francesco Aletta, Tara Vander Mynsbrugge, Dominique Van de Velde, Patricia De Vriendt, Pieter Thomas, Karlo Filipan, Dick Botteldooren, and Paul Devos. 2018. Awareness of ‘sound’ in nursing homes: A large-scale soundscape survey in Flanders (Belgium). *Building Acoustics* 25, 1 (March 2018), 43–59. DOI:<https://doi.org/10.1177/1351010X17748113>
- [3] Alzheimer Association. 2019. 2019 Alzheimer’s disease facts and figures. *Alzheimer’s & Dementia* 15, 3 (March 2019), 321–387. DOI:<https://doi.org/10.1016/j.jalz.2019.01.010>
- [4] Alzheimer’s Association. 2022. 2022 Alzheimer’s disease facts and figures. DOI:<https://doi.org/10.1002/alz.12638>
- [5] Katrina Anderson and Annaliese Blair. 2021. What have staff got to do with it? Untangling complex relationships between residential aged care staff, the quality of care they provide, and the quality of life of people with dementia. *Arch Gerontol Geriatr* (2021), 104378. DOI:<https://doi.org/https://doi.org/10.1016/j.arcgher.2021.104378>
- [6] Tjeerd C. Andringa and J. Jolie L. Lanser. 2013. How pleasant sounds promote and annoying sounds impede health: A cognitive approach. *Int J Environ Res Public Health* 10, 4 (April 2013), 1439–1461. DOI:<https://doi.org/10.3390/ijerph10041439>
- [7] Jessica Ashbourne, Veronique Boscart, Samantha Meyer, Catherine E Tong, and Paul Stolee. 2021. Health care transitions for persons living with dementia and their caregivers. *BMC Geriatr* 21, 1 (2021), 285. DOI:<https://doi.org/10.1186/s12877-021-02235-5>
- [8] Arlene J. Astell, Maggie P. Ellis, Norman Alm, Richard Dye, and Gary Gowans. 2010. Stimulating People with Dementia to Reminisce Using Personal and Generic Photographs. *Int. J. Comput. Healthc.* 1, 2 (2010), 177–198. DOI:<https://doi.org/10.1504/IJCH.2010.037461>
- [9] Jean-François Augoyard. 2006. *Sonic experience: a guide to everyday sounds*. McGill-Queen’s Press.
- [10] Ameer Baird and Séverine Samson. 2009. Memory for Music in Alzheimer’s Disease: Unforgettable? *Neuropsychol Rev* 19, 1 (May 2009), 85–101. DOI:<https://doi.org/10.1007/s11065-009-9085-2>
- [11] Ameer Baird and Séverine Samson. 2015. Music and dementia. In *Progress in Brain Research*, Eckart Altenmüller, Stanley Finger and François Boller (eds.). Elsevier, 207–235. DOI:<https://doi.org/10.1016/bs.pbr.2014.11.028>
- [12] Ameer Baird and William Forde Thompson. 2018. The Impact of Music on the Self in Dementia. *J Alzheimers Dis* 61, 3 (May 2018), 827–841. DOI:<https://doi.org/10.3233/JAD-170737>
- [13] Anne Davis Basting. 2003. Looking back from loss: views of the self in Alzheimer’s disease. *J Aging Stud* 17, 1 (February 2003), 87–99. DOI:[https://doi.org/10.1016/S0890-4065\(02\)00092-0](https://doi.org/10.1016/S0890-4065(02)00092-0)
- [14] Gudrun Baumgartner and Karl-Heinz Renner. 2019. Humor in the elderly with dementia: Development and initial validation of a behavioral observation system. *Current Psychology* (November 2019), 1–14. DOI:<https://doi.org/10.1007/s12144-019-00455-y>
- [15] Ashok J. Bharucha, Vivek Anand, Jodi Forlizzi, Mary Amanda Dew, Charles F. Reynolds, Scott Stevens, and Howard Wactlar. 2009. Intelligent Assistive Technology Applications to Dementia Care: Current Capabilities, Limitations, and Future Challenges. *Am J Geriatr Psychiatry* 17, 2 (February 2009), 88–104. DOI:<https://doi.org/10.1097/JGP.0b013e318187dd e5>
- [16] Stephanie Blackman, Claudine Matlo, Charisse Bobrovitskiy, Ashley Waldoch, Mei Lan Fang, Piper Jackson, Alex Mihailidis, Louise Nygård, Arlene Astell, and Andrew Sixsmith. 2016. Ambient Assisted Living Technologies for Aging Well: A Scoping Review. *Journal of Intelligent Systems* 25, 1 (January 2016), 55. DOI:<https://doi.org/10.1515/jisys-2014-0136>
- [17] Kirsten A. van den Bosch, Tjeerd C. Andringa, Deniz Başkent, and Carla Vlaskamp. 2016. The Role of Sound in Residential Facilities for People With Profound Intellectual and Multiple Disabilities. *J Policy Pract Intellect Disabil* 13, 1 (March 2016), 61–68. DOI:<https://doi.org/10.1111/jppi.12147>
- [18] Kirsten A. van den Bosch, Tjeerd C. Andringa, Wolter Peterson, Wied A. J. M. Ruijsenaars, and Carla Vlaskamp. 2017. A comparison of natural and non-natural soundscapes on people with severe or profound intellectual and multiple disabilities. *J Intellect Dev Disabil* 42, 3 (July 2017), 301–307. DOI:<https://doi.org/10.3109/13668250.2016.1250251>
- [19] Marguerite Bramble, Wendy Moyle, and Margaret McAllister. 2009. Seeking connection: family care experiences following long-term

- dementia care placement. *J Clin Nurs* 18, 22 (2009), 3188–3125.
- [20] Rita Maldonado Branco, Joana Quental, and Óscar Ribeiro. 2017. Personalised participation: an approach to involve people with dementia and their families in a participatory design project. *CoDesign* 13, 2 (2017), 127–143. DOI:<https://doi.org/10.1080/15710882.2017.1310903>
- [21] Rens Brankaert. 2016. Design for dementia : a design-driven living lab approach to involve people with dementia and their context. Eindhoven University of Technology, Eindhoven.
- [22] Rens Brankaert and Gail Kenning (Eds.). 2020. HCl and Design in the Context of Dementia. Springer International Publishing, Cham. DOI:<https://doi.org/10.1007/978-3-030-32835-1>
- [23] Dawn Brooker. 2003. What is person-centred care in dementia? *Rev Clin Gerontol* 13, 03 (August 2003), 215–222. DOI:<https://doi.org/10.1017/S095925980400108X>
- [24] Dawn J Brooker, Rosemary J Woolley, and David Lee. 2007. Enriching opportunities for people living with dementia in nursing homes: An evaluation of a multi-level activity-based model of care. *Aging Ment Health* 11, 4 (July 2007), 361–370. DOI:<https://doi.org/10.1080/13607860600963679>
- [25] Bennett M. Brooks, Brigitte Schulte-Fortkamp, Kay S. Voigt, and Alex U. Case. 2014. Exploring our sonic environment through soundscape research & theory. *Acoust. Today* 10, 1 (2014), 30–40.
- [26] Sarah Campbell, David Frohlich, Norman Alm, and Adam Vaughan. 2019. Sentimental Audio Memories: Exploring the Emotion and Meaning of Everyday Sounds. In *Dementia Lab 2019. Making Design Work: Engaging with Dementia in Context*. D-Lab 2019., Rens Brankaert and Wijnand IJsselsteijn (eds.). Springer, Cham, 73–81. DOI:https://doi.org/10.1007/978-3-030-33540-3_7
- [27] Joaquim Cerejeira, Luísa Lagarto, and Elizabeta Mukaetova-Ladinska. 2012. Behavioral and Psychological Symptoms of Dementia. *Front Neurol* 3, (2012), 73. DOI:<https://doi.org/10.3389/fneur.2012.00073>
- [28] Bree Chancellor, Angel Duncan, and Anjan Chatterjee. 2014. Art Therapy for Alzheimer’s Disease and Other Dementias. *Journal of Alzheimer’s Disease* 39, 1 (January 2014), 1–11. DOI:<https://doi.org/10.3233/JAD-131295>
- [29] Lynn Chenoweth, Madeleine T King, Yun Hee Jeon, Henry Brodaty, Jane Stein-Parbury, Richard Norman, Marion Haas, and Georgina Luscombe. 2009. Caring for Aged Dementia Care Resident Study (CADRES) of person-centred care, dementia-care mapping, and usual care in dementia: a cluster-randomised trial. *Lancet Neurol* 8, 4 (April 2009), 317–325. DOI:[https://doi.org/10.1016/S1474-4422\(09\)70045-6](https://doi.org/10.1016/S1474-4422(09)70045-6)
- [30] Helen Chester, Paul Clarkson, Linda Davies, Caroline Sutcliffe, Sue Davies, Alexandra Feast, Jane Hughes, and David Challis. 2018. People with dementia and carer preferences for home support services in early-stage dementia. *Aging Ment Health* 22, 2 (2018), 270–279. DOI:<https://doi.org/10.1080/13607863.2016.1247424>
- [31] C.-Y. Chiao, H.-S. Wu, and C.-Y. Hsiao. 2015. Caregiver burden for informal caregivers of patients with dementia: A systematic review. *Int Nurs Rev* 62, 3 (2015), 340–350. DOI:<https://doi.org/https://doi.org/10.1111/inr.12194>
- [32] Shaan Chopra, Emma Dixon, Kausalya Ganesh, Alisha Pradhan, Mary L. Radnofsky, and Amanda Lazar. 2021. Designing for and with People with Dementia Using a Human Rights-Based Approach. In *Extended Abstracts of the 2021 CHI Conference on Human Factors in Computing Systems (CHI EA ’21)*, Association for Computing Machinery, New York, NY, USA. DOI:<https://doi.org/10.1145/3411763.3443434>
- [33] Jiska Cohen-Mansfield. 2013. Nonpharmacologic Treatment of Behavioral Disorders in Dementia. *Curr Treat Options Neurol* 15, 6 (2013), 765–785. DOI:<https://doi.org/10.1007/s11940-013-0257-2>
- [34] Jiska Cohen-Mansfield, Maha Dakheel-Ali, and Marcia S Marx. 2009. Engagement in persons with dementia: the concept and its measurement. *Am J Geriatr Psychiatry* 17, 4 (April 2009), 299–307. DOI:<https://doi.org/10.1097/JGP.0b013e31818f3a52>
- [35] Valerie T Cotter, Elizabeth W Gonzalez, Kathleen Fisher, and Kathy C Richards. 2017. Influence of hope, social support, and self-esteem in early stage dementia. *Dementia* 17, 2 (November 2017), 214–224. DOI:<https://doi.org/10.1177/1471301217741744>
- [36] Barbara J Crowe and Robin Rio. 2004. Implications of Technology in Music Therapy Practice and Research for Music Therapy Education: A Review of Literature. *J Music Ther* 41, 4 (2004), 282–320. DOI:<https://doi.org/10.1093/jmt/41.4.282>
- [37] Jeffrey L. Cummings, Frank D. Benson, Mary Ann Hill, and Stephen Read. 1985. Aphasia in dementia of the Alzheimer type. *Neurology* 35, 3 (March 1985), 394–397. DOI:<https://doi.org/10.1212/wnl.35.3.394>
- [38] Jeffrey Cummings, Garam Lee, Kate Zhong, Jorge Fonseca, and Kazem Taghva. 2021. Alzheimer’s

- disease drug development pipeline: 2021. *Alzheimer's & Dementia: Translational Research & Clinical Interventions* 7, 1 (2021), e12179. DOI:<https://doi.org/https://doi.org/10.1002/trc2.12179>
- [39] Boyd H. Davis and Dena Shenk. 2015. Beyond Reminiscence: Using Generic Video to Elicit Conversational Language. *American Journal of Alzheimer's Disease & Other Dementias* 30, 1 (February 2015), 61–68. DOI:<https://doi.org/10.1177/1533317514534759>
- [40] DEEP. 2014. Dementia words matter: Guidelines on language about dementia.
- [41] Abhilash K Desai and George T Grossberg. 2001. Recognition and Management of Behavioral Disturbances in Dementia. *Prim Care Companion J Clin Psychiatry* 3, 3 (June 2001), 93–109. DOI:<https://doi.org/10.4088/pcc.v03n0301>
- [42] Paul Devos, Francesco Aletta, Pieter Thomas, Karlo Filipan, Mirko Petrovic, Dick Botteldooren, Tara Vander Mynsbrugge, Dominique Van de Velde, and Patricia De Vriendt. 2018. Soundscape design for management of behavioral disorders: a pilot study among nursing home residents with dementia. In *Impact of noise control engineering: proceedings of Inter-Noise 2018*, Institute of Noise Control Engineering of the United States of America, 8.
- [43] Paul Devos, Francesco Aletta, Pieter Thomas, Tara Vander Mynsbrugge, Mirko Petrovic, Dominique de Velde, Patricia De Vriendt, and Dick Botteldooren. 2020. Application of a Prediction Model for Ambient Noise Levels and Acoustical Capacity for Living Rooms in Nursing Homes Hosting Older People with Dementia. *Applied Sciences* 10, (2020).
- [44] Paul Devos, Francesco Aletta, Pieter Thomas, Mirko Petrovic, Tara Vander Mynsbrugge, Dominique Van de Velde, Patricia De Vriendt, and Dick Botteldooren. 2019. Designing Supportive Soundscapes for Nursing Home Residents with Dementia. *Int J Environ Res Public Health* 16, 24 (December 2019), 4904. DOI:<https://doi.org/10.3390/ijerph16244904>
- [45] Robyn Dowlen, John Keady, Christine Milligan, Caroline Swarbrick, Nick Ponsillo, Lucy Geddes, and Bob Riley. 2021. In the moment with music: an exploration of the embodied and sensory experiences of people living with dementia during improvised music-making. *Ageing Soc* (2021), 1–23. DOI:<https://doi.org/10.1017/S0144686X21000210>
- [46] James Edmeads and Ouassama Metatla. 2019. Designing for Reminiscence with People with Dementia. In *Extended Abstracts of the 2019 CHI Conference on Human Factors in Computing Systems - CHI '19*, ACM Press, New York, New York, USA, 1–6. DOI:<https://doi.org/10.1145/3290607.3313059>
- [47] Daniel Fallman. 2007. Why Research-Oriented Design Isn't Design-Oriented Research: On the Tensions Between Design and Research in an Implicit Design Discipline. *Knowledge, Technology & Policy* 20, 3 (October 2007), 193–200. DOI:<https://doi.org/10.1007/s12130-007-9022-8>
- [48] Stu Favilla and Sonja Pedell. 2013. Touch Screen Ensemble Music: Collaborative Interaction for Older People with Dementia. In *Proceedings of the 25th Australian Computer-Human Interaction Conference on Augmentation, Application, Innovation, Collaboration - OzCHI '13*, ACM Press, New York, New York, USA, 481–484. DOI:<https://doi.org/10.1145/2541016.2541088>
- [49] Sam Fazio, Douglas Pace, Janice Flinger, and Beth Kallmyer. 2018. The Fundamentals of Person-Centered Care for Individuals With Dementia. *Gerontologist* 58, suppl_1 (January 2018), S10–S19. DOI:<https://doi.org/10.1093/geront/gnx122>
- [50] Yuan Feng, Suihui Yu, Dirk van de Mortel, Emilia Barakova, Jun Hu, and Matthias Rauterberg. 2019. LiveNature: Ambient Display and Social Robot-Facilitated Multi-Sensory Engagement for People with Dementia. In *Proceedings of the 2019 on Designing Interactive Systems Conference - DIS '19*, ACM Press, New York, New York, USA, 1321–1333. DOI:<https://doi.org/10.1145/3322276.3322331>
- [51] David M. Frohlich, Emily Corrigan-Kavanagh, Sarah Campbell, Theopisti Chrysanthaki, Paula Castro, Isabela Zaine, and Maria da Graça Campos Pimentel. 2020. Assistive Media for Well-being. In *HCI and Design in the Context of Dementia*, Rens Brankaert and Gail Kenning (eds.). Springer International Publishing, Cham, 189–205. DOI:https://doi.org/10.1007/978-3-030-32835-1_12
- [52] Mary Galvin. 2016. Supporting positive interactions within dementia relationships of care. PhD Thesis, University College Cork.
- [53] William W. Gaver. 1993. How Do We Hear in the World? Explorations in Ecological Acoustics. *Ecological Psychology* 5, 4 (1993), 285–313. DOI:https://doi.org/10.1207/s15326969ecoo504_2
- [54] Karen Gold. 2014. But does it do any good? Measuring the impact of music therapy on people with advanced dementia: (Innovative practice). *Dementia (London)* 13, 2 (2014), 258–264. DOI:<https://doi.org/10.1177/1471301213494512>
- [55] Sylwia Górska, Kirsty Forsyth, and Donald Maciver. 2017. Living With Dementia: A Meta-synthesis of Qualitative Research on the Lived

- Experience. *Gerontologist* 58, 3 (2017), e180–e196.
DOI:<https://doi.org/10.1093/geront/gnw195>
- [56] Eva Götell, Steven Brown, and Sirkka-Liisa Ekman. 2009. The influence of caregiver singing and background music on vocally expressed emotions and moods in dementia care. *Int J Nurs Stud* 46, 4 (May 2009), 422–430. DOI:<https://doi.org/10.1016/j.ijnurstu.2007.11.001>
- [57] Gary Gowans and Jim Campbell. 2004. CIRCA (Computer Interactive Reminiscence and Conversation Aid): The Collaborative Research Process in Context Challenge. In *Futureground - DRS International Conference 2004*, Melbourne, Australia. Retrieved from <https://dl.designresearchsociety.org/drs-conference-papers/drs2004/researchpapers/34>
- [58] Megan E. Graham. 2018. Re-socialising sound: investigating sound, selfhood and intersubjectivity among people living with dementia in long-term care. *Sound Studies* 5, 2 (December 2018), 175–190. DOI:<https://doi.org/10.1080/20551940.2018.1551051>
- [59] Megan E Graham. 2020. Long-term care as contested acoustical space: Exploring resident relationships and identities in sound. *Building Acoustics* 27, 1 (2020), 61–73. DOI:<https://doi.org/10.1177/1351010X19890478>
- [60] Katherine Hackett, Steven R. Sabat, and Tania Giovannetti. 2021. A person-centered framework for designing music-based therapeutic studies in dementia: current barriers and a path forward. *Aging Ment Health* 0, 0 (2021), 1–10. DOI:<https://doi.org/10.1080/13607863.2021.1931029>
- [61] Michael James Hayne and Richard Fleming. 2014. Acoustic design guidelines for dementia care facilities. In *Proceedings of 43rd International Congress on Noise Control Engineering: Internoise 2014*, Australia: Australian Acoustical Society, 1–10.
- [62] Niels Hendriks, Liesbeth Huybrechts, Karin Slegers, and Andrea Wilkinson. 2018. Valuing implicit decision-making in participatory design: A relational approach in design with people with dementia. *Design Studies* 59, 58–76. DOI:<https://doi.org/10.1016/j.destud.2018.06.001>
- [63] Niels Hendriks, Karin Slegers, and Pieter Duysburgh. 2015. Codesign with people living with cognitive or sensory impairments: a case for method stories and uniqueness. *CoDesign* 11, 1 (January 2015), 70–82. DOI:<https://doi.org/10.1080/15710882.2015.1020316>
- [64] James Hodge, Madeline Balaam, Sandra Hastings, and Kellie Morrissey. 2018. Exploring the Design of Tailored Virtual Reality Experiences for People with Dementia. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems (CHI '18)*, ACM Press, New York, New York, USA, Paper 514, 1–13. DOI:<https://doi.org/10.1145/3173574.3174088>
- [65] Emily S. Ihara, Catherine J. Tompkins, Megumi Inoue, and Sonya Sonneman. 2019. Results from a person-centered music intervention for individuals living with dementia. *Geriatr Gerontol Int* 19, 1 (January 2019), 30–34. DOI:<https://doi.org/10.1111/ggi.13563>
- [66] ISO. 2014. 12913-1:2014 Acoustics — Soundscape — Part 1: Definition and conceptual framework. International Organization for Standardization, Geneva.
- [67] Ursula M. Kellett. 1999. Transition in care: Family carers' experience of nursing home placement. *J Adv Nurs* 29, 6 (June 1999), 1474–1481. DOI:<https://doi.org/10.1046/j.1365-2648.1999.01035.x>
- [68] Lisa Kelly and Bill Ahessy. 2021. Reminiscence-Focused Music Therapy to Promote Positive Mood and Engagement and Shared Interaction for People Living With Dementia. *Voices: A World Forum for Music Therapy* 21, 2 SE-Research (June 2021). DOI:<https://doi.org/10.15845/voices.v21i2.3139>
- [69] Gail Kenning. 2020. Reciprocal Design. In *HCI and Design in the Context of Dementia*, Rens Brankaert and Gail Kenning (eds.). Springer International Publishing, Cham, 17–32. DOI:https://doi.org/10.1007/978-3-030-32835-1_2
- [70] Gail Kenning, Alon Ilisar, Rens Brankaert, and Mark Evans. 2019. Improvisation and Reciprocal Design: Soundplay for Dementia. In *Dementia Lab 2019. Making Design Work: Engaging with Dementia in Context*. D-Lab 2019. Springer, Cham, 82–91. DOI:https://doi.org/10.1007/978-3-030-33540-3_8
- [71] Gail Kenning and Cathy Treadaway. 2018. Designing for Dementia: Iterative Grief and Transitional Objects. *Design Issues* 34, 1 (January 2018), 42–53. DOI:https://doi.org/10.1162/DESI_a_00475
- [72] Tom Kitwood. 1997. The experience of dementia. *Aging Ment Health* 1, 1 (1997), 13–22. DOI:<https://doi.org/10.1080/13607869757344>
- [73] Pia C. Kontos. 2004. Ethnographic reflections on selfhood, embodiment and Alzheimer's disease. *Ageing Soc* 24, 6 (November 2004), 829–849. DOI:<https://doi.org/10.1017/S0144686X04002375>
- [74] L Koumakis, C Chatzaki, E Kazantzaki, E Maniadi, and M Tsiknakis. 2019. Dementia Care Frameworks and Assistive Technologies for Their Implementation: A Review. *IEEE Rev Biomed Eng* 12, (2019), 4–18. DOI:<https://doi.org/10.1109/RBME.2019.2892614>
- [75] Danica Kulibert, Alexandria Ebert, Sharayah

- Preman, and Susan H McFadden. 2018. In-home use of personalized music for persons with dementia. *Dementia* 18, 7–8 (March 2018), 2971–2984.
DOI:<https://doi.org/10.1177/1471301218763185>
- [76] Amanda Lazar, Caroline Edasis, and Anne Marie Piper. 2017. A Critical Lens on Dementia and Design in HCI. In Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems (CHI '17), ACM Press, New York, New York, USA, 2175–2188.
DOI:<https://doi.org/10.1145/3025453.3025522>
- [77] Amanda Lazar, Hilaire Thompson, and George Demiris. 2014. A systematic review of the use of technology for reminiscence therapy. *Health Educ Behav* 41, 1 Suppl (October 2014), 51S–61S.
DOI:<https://doi.org/10.1177/1090198114537067>
- [78] Ruslan Leontjevas. 2021. Soundscape in nursing homes as a treatment strategy for challenging behavior in dementia? *Int Psychogeriatr* 33, 6 (2021), 553–556.
DOI:<https://doi.org/10.1017/S1041610220003348>
- [79] Micheline Lesaffre, Bart Moens, and Frank Desmet. 2017. Monitoring music and movement interaction in people with dementia. In *The Routledge Companion to embodied music interaction*. Routledge, 294–303.
- [80] Helle Nystrup Lund, Lars Rye Bertelsen, and Lars Ole Bonde. 2016. Sound and music interventions in psychiatry at Aalborg University Hospital. *SoundEffects - An Interdisciplinary Journal of Sound and Sound Experience* 6, 1 (November 2016), 48–68.
DOI:<https://doi.org/10.7146/se.v6i1.24912>
- [81] Tom Luyten, Susy Braun, Susan van Hooren, and Luc de Witte. 2018. How groups of nursing home residents respond to “the CRDL”: a pilot study. *J Enabling Technol* 12, 4 (December 2018), 145–154.
DOI:<https://doi.org/10.1108/JET-05-2018-0025>
- [82] William E Mansbach, Ryan A Mace, Kristen M Clark, and Isabella M Firth. 2017. Meaningful Activity for Long-Term Care Residents With Dementia: A Comparison of Activities and Raters. *Gerontologist* 57, 3 (June 2017), 461–468.
DOI:<https://doi.org/10.1093/geront/gnv694>
- [83] Lena Måvall and Bo Malmberg. 2007. Day care for persons with dementia: An alternative for whom? *Dementia* 6, 1 (February 2007), 27–43.
DOI:<https://doi.org/10.1177/1471301207075627>
- [84] Justine McGovern. 2011. Couple meaning-making and dementia: challenges to the deficit model. *J Gerontol Soc Work* 54, 7 (October 2011), 678–690.
DOI:<https://doi.org/10.1080/01634372.2011.593021>
- [85] May Helen Midtbust, Rigmor Einang Alnes, Eva Gjengedal, and Else Lykkeslet. 2018. Perceived barriers and facilitators in providing palliative care for people with severe dementia: the healthcare professionals’ experiences. *BMC Health Serv Res* 18, 1 (2018), 709.
DOI:<https://doi.org/10.1186/s12913-018-3515-x>
- [86] Alex Mihailidis, Jennifer N Boger, Tammy Craig, and Jesse Hoey. 2008. The COACH prompting system to assist older adults with dementia through handwashing: An efficacy study. *BMC Geriatr* 8, 1 (December 2008), 28.
DOI:<https://doi.org/10.1186/1471-2318-8-28>
- [87] Evonne Miller, Nicole Devlin, Laurie Buys, and Geraldine Donoghue. 2020. The happiness initiative: Changing organizational culture to make ‘brilliance’ mainstream in aged care. *Journal of Management & Organization* 26, 3 (2020), 296–308.
DOI:<https://doi.org/10.1017/jmo.2019.59>
- [88] Eneida Mioshi, Christopher M. Kipps, and John R. Hodges. 2009. Activities of Daily Living in Behavioral Variant Frontotemporal Dementia: Differences in Caregiver and Performance-based Assessments. *Alzheimer Dis Assoc Disord* 23, 1 (January 2009), 70–76.
DOI:<https://doi.org/10.1097/WAD.0b013e318182d293>
- [89] Susan L. Mitchell, Joan M. Teno, Dan K. Kiely, Michele L. Shaffer, Richard N. Jones, Holly G. Prigerson, Ladislav Volicer, Jane L. Givens, and Mary Beth Hamel. 2009. The clinical course of advanced dementia. *New England Journal of Medicine* 361, 16 (2009), 1529–1538.
DOI:<https://doi.org/10.1056/NEJMoa0902234>
- [90] Kellie Morrissey, John McCarthy, and Nadia Pantidi. 2017. The Value of Experience-Centred Design Approaches in Dementia Research Contexts. In Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems (CHI '17), ACM Press, New York, New York, USA, 1326–1338.
DOI:<https://doi.org/10.1145/3025453.3025527>
- [91] Kellie Morrissey, Gavin Wood, David Green, Nadia Pantidi, and John McCarthy. 2016. ‘I’m a rambler, I’m a gambler, I’m a long way from home’: The Place of Props, Music, and Design in Dementia Care. In Proceedings of the 2016 ACM Conference on Designing Interactive Systems - DIS '16, ACM Press, New York, New York, USA, 1008–1020.
DOI:<https://doi.org/10.1145/2901790.2901798>
- [92] Alexander Müller-Rakow and Rahel Flechtner. 2017. Designing Interactive Music Systems with and for People with Dementia. *Design Journal* 20, sup1 (July 2017), S2207.
DOI:<https://doi.org/10.1080/14606925.2017.1352736>
- [93] S. Neves, A. Macdonald, M. Poole, and K. Harrison Denning. 2021. Participatory Co-design: Approaches to Enable People Living with Challenging Health Conditions to Participate in Design Research. In *Perspectives on Design and*

- Digital Communication II: Research, Innovations and Best Practices, Nuno Martins, Daniel Brandão and Fernando Moreira da Silva (eds.). Springer International Publishing, Cham, 193–216. DOI:https://doi.org/10.1007/978-3-030-75867-7_13
- [94] Johanna M H Nijsten, Ruslan Leontjevas, Martin Smalbrugge, Raymond T C M Koopmans, and Debby L Gerritsen. 2019. Apathy and health-related quality of life in nursing home residents. *Quality of Life Research* 28, 3 (2019), 751–759. DOI:<https://doi.org/10.1007/s1136-018-2041-y>
- [95] Javier Olazarán, Barry Reisberg, Linda Clare, Isabel Cruz, Jordi Peña-Casanova, Teodoro del Ser, Bob Woods, Cornelia Beck, Stefanie Auer, Claudia Lai, Aimee Spector, Sam Fazio, John Bond, Miia Kivipelto, Henry Brodaty, José Manuel Rojo, Helen Collins, Linda Teri, Mary Mittelman, Martin Orrell, Howard H. Feldman, and Ruben Muñoz. 2010. Nonpharmacological Therapies in Alzheimer’s Disease: A Systematic Review of Efficacy. *Dement Geriatr Cogn Disord* 30, 2 (2010), 161–178. DOI:<https://doi.org/10.1159/000316119>
- [96] Michelle Putnam, Joseph G Pickard, Carroll Rodriguez, and Erin Shear. 2010. Stakeholder Perspectives on Policies to Support Family Caregivers of Older Adults With Dementia. *J Fam Soc Work* 13, 2 (March 2010), 173–190. DOI:<https://doi.org/10.1080/10522150903487479>
- [97] Alfredo Raglio, Stefania Filippi, Daniele Bellandi, and Marco Stramba-Badiale. 2014. Global music approach to persons with dementia: evidence and practice. *Clin Interv Aging* 9, (2014), 1669–1676. DOI:<https://doi.org/10.2147/CIA.S71388>
- [98] Chirag B. Rao, John C. Peatfield, Keith P. W. J. McAdam, Andrew J. Nunn, and Dimana P. Georgieva. 2021. A Focus on the Reminiscence Bump to Personalize Music Playlists for Dementia. *J Multidiscip Healthc* 14, (August 2021), 2195–2204. DOI:<https://doi.org/10.2147/JMDH.S312725>
- [99] Paul A. Rodgers. 2018. Co-designing with people living with dementia. *CoDesign* 14, 3 (2018), 188–202. DOI:<https://doi.org/10.1080/15710882.2017.1282527>
- [100] Kasper Rodil, Chatrine Elisabeth Larsen, Christoffer Caesar Faelled, Emil Færch Skov, Thomas Gustafsen, Antonia Krummheuer, and Matthias Rehm. 2020. Spending Time: Co-Designing a Personalized Calendar at the Care Center. In *Proceedings of the 11th Nordic Conference on Human-Computer Interaction: Shaping Experiences, Shaping Society (NordiCHI ’20)*, Association for Computing Machinery, New York, NY, USA. DOI:<https://doi.org/10.1145/3419249.3420144>
- [101] Jøran Rudi. 2013. Soundscape as social construct. EMS-network conference 2013 January (2013), 1–5.
- [102] Steven R Sabat. 2006. Implicit memory and people with Alzheimer’s disease: Implication for caregiving. *Am J Alzheimers Dis Other Dement* 21, 1 (2006), 11–14.
- [103] Elizabeth B.-N. Sanders and Pieter Jan Stappers. 2008. Co-creation and the new landscapes of design. *CoDesign* 4, 1 (March 2008), 5–18. DOI:<https://doi.org/10.1080/15710880701875068>
- [104] Corina Sas, Nigel Davies, Sarah Clinch, Peter Shaw, Mateusz Mikusz, Madeleine Steeds, and Lukas Nohrer. 2020. Supporting Stimulation Needs in Dementia Care through Wall-Sized Displays. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems (CHI ’20)*, Association for Computing Machinery, New York, NY, USA, 1–16. DOI:<https://doi.org/10.1145/3313831.3376361>
- [105] Raymond Murray Schafer. 1993. *The Soundscape: Our Sonic Environment and the Tuning of the World*. Simon and Schuster.
- [106] Jennifer Schine. 2010. Movement, Memory & the Senses in Soundscape Studies. *Canadian Acoustics* 38, 3 (May 2010), 100–101.
- [107] Mahsa Soufneyestani, Arshia Khan, and Mina Sufneyestani. 2021. Impacts of Music Intervention on Dementia: A Review Using Meta-Narrative Method and Agenda for Future Research. *Neurol Int* 13, 1 (2021), 1–17. DOI:<https://doi.org/10.3390/neurolint3010001>
- [108] Clay Spinuzzi. 2005. The methodology of participatory design. *Tech Commun* 52, 2 (May 2005), 163–174. Retrieved from <http://www.ingentaconnect.com/content/stc/tc/2005/00000052/00000002/art00005>
- [109] Marjorie Splaine Wiggins. 2008. The partnership care delivery model: an examination of the core concept and the need for a new model of care. *J Nurs Manag* 16, 5 (July 2008), 629–638. DOI:<https://doi.org/10.1111/j.1365-2834.2008.00900.x>
- [110] Tamara L Statz, Colleen M Peterson, Robyn W Birkeland, Hayley R McCarron, Jessica M Finlay, Christina E Rosebush, Zachary G Baker, and Joseph E Gaugler. 2021. “We moved her too soon”: Navigating guilt among adult child and spousal caregivers of persons living with dementia following a move into residential long-term care. *Couple and Family Psychology: Research and Practice* (May 2021). DOI:<https://doi.org/http://dx.doi.org/10.1037/cfp0000150>
- [111] Els Steeman, Bernadette Dierckx De Casterlé, Jan Godderis, and Mieke Grypdonck. 2006. Living with early-stage dementia: A review of qualitative studies. *J Adv Nurs* 54, 6 (2006), 722–738.
- [112] Arezoo Talebzadeh, Andrea Iaboni, Paul Devos,

- Dick Botteldooren, Dominique Van de Velde, and Patricia de vriendt. 2020. Randomized Clinical Trial in Soundscape Research. In *Inter-Noise 2020*.
- [113] Kristine Theurer, W. Ben Mortenson, Robyn Stone, Melinda Suto, Virpi Timonen, and Julia Rozanova. 2015. The need for a social revolution in residential care. *J Aging Stud* 35, (December 2015), 201–210. DOI:<https://doi.org/10.1016/J.JAGING.2015.08.011>
- [114] Theresa Thoma-Lürken, Michel H C Bleijlevens, Monique A S Lexis, Luc P de Witte, and Jan P H Hamers. 2018. Facilitating aging in place: A qualitative study of practical problems preventing people with dementia from living at home. *Geriatr Nurs (Minneapolis)* 39, 1 (2018), 29–38. DOI:<https://doi.org/https://doi.org/10.1016/j.gerinurse.2017.05.003>
- [115] Pieter Thomas, Francesco Aletta, Karlo Filipan, Tara Vander Mynsbrugge, Lieven De Geetere, Arne Dijkmans, Dick Botteldooren, Mirko Petrovic, Dominique Van de Velde, Patricia De Vriendt, and Paul Devos. 2020. Noise environments in nursing homes: An overview of the literature and a case study in Flanders with quantitative and qualitative methods. *Applied Acoustics* 159, (2020), 107103. DOI:<https://doi.org/https://doi.org/10.1016/j.apacoust.2019.107103>
- [116] Myrte Thoolen, Rens Brankaert, and Yuan Lu. 2019. Sentic: A Tailored Interface Design for People with Dementia to Access Music. In *Companion Publication of the 2019 on Designing Interactive Systems Conference 2019 Companion - DIS '19 Companion*, ACM Press, New York, New York, USA, 57–60. DOI:<https://doi.org/10.1145/3301019.3325152>
- [117] Myrte Thoolen, Rens Brankaert, and Yuan Lu. 2020. AmbientEcho: Exploring Interactive Media Experiences in the Context of Residential Dementia Care. In *Proceedings of the 2020 ACM Designing Interactive Systems Conference (DIS '20)*, Association for Computing Machinery, New York, NY, USA, 1495–1508. DOI:<https://doi.org/10.1145/3357236.3395432>
- [118] Emmanuel Tsekleves, Amanda F Bingley, Maria A Luján Escalante, and Adrian Gradinar. 2018. Engaging people with dementia in designing playful and creative practices: Co-design or co-creation? *Dementia* 19, 3 (August 2018), 915–931. DOI:<https://doi.org/10.1177/1471301218791692>
- [119] Frédéric Voisin. 2019. Designing Virtual Soundscapes for Alzheimer's Disease Care. In *Conference: 14th International Symposium on Computer Music and Multidisciplinary Research*.
- [120] Jayne Wallace, Anja Thieme, Gavin Wood, Guy Schofield, and Patrick Olivier. 2012. Enabling self, intimacy and a sense of home in dementia: An Enquiry into Design in a Hospital Setting. In *Proceedings of the 2012 ACM annual conference on Human Factors in Computing Systems - CHI '12*, ACM Press, New York, New York, USA, 2629. DOI:<https://doi.org/10.1145/2207676.2208654>
- [121] Lin Wan, Claudia Müller, Volker Wulf, and David Randall. 2014. Addressing the subtleties in dementia care: Pre-study & evaluation of a GPS monitoring system. In *Conference on Human Factors in Computing Systems - Proceedings*, ACM Press, New York, New York, USA, 3987–3996. DOI:<https://doi.org/10.1145/2556288.2557307>
- [122] Rik Wesselink, Marike Hettinga, Geke Ludden, and Berry Eggen. 2020. Unforgetting Music: Exploring the role of music in the daily lives of people with dementia living at home. In *Proceedings of the 6th International Conference on Design4Health, Lab4Living*, Sheffield Hallam University, Amsterdam, 721–728.
- [123] Dennis Wolf, Daniel Besserer, Karolina Sejunaite, Matthias Riepe, and Enrico Rukzio. 2018. CARE: An Augmented Reality Support System for Dementia Patients. In *The 31st Annual ACM Symposium on User Interface Software and Technology Adjunct Proceedings (UIST '18 Adjunct)*, Association for Computing Machinery, New York, NY, USA, 42–44. DOI:<https://doi.org/10.1145/3266037.3266095>
- [124] Bob Woods, Laura O'Philbin, Emma M. Farrell, Aimee E. Spector, and Martin Orrell. 2018. Reminiscence therapy for dementia. *Cochrane Database of Systematic Reviews* 3 (March 2018). DOI:<https://doi.org/10.1002/14651858.CD00120.pub3>
- [125] World Health Organization. 2021. Global status report on the public health response to dementia. Geneva: World Health Organization (2021), 251. Retrieved May 23, 2022 from <https://digitalcommons.fiu.edu/cgi/viewcontent.cgi?article=1962&context=srhrefports>
- [126] John Zimmerman, Jodi Forlizzi, and Shelley Evenson. 2007. Research through design as a method for interaction design research in HCI. In *Proceedings of the SIGCHI conference on Human factors in computing systems - CHI '07*, ACM Press, New York, New York, USA, 493. DOI:<https://doi.org/10.1145/1240624.1240704>
- [127] Tamara Zubatiy, Kayci L Vickers, Niharika Mathur, and Elizabeth D Mynatt. 2021. Empowering Dyads of Older Adults With Mild Cognitive Impairment and Their Care Partners Using Conversational Agents. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems*. Association for Computing Machinery, New York, NY, USA.

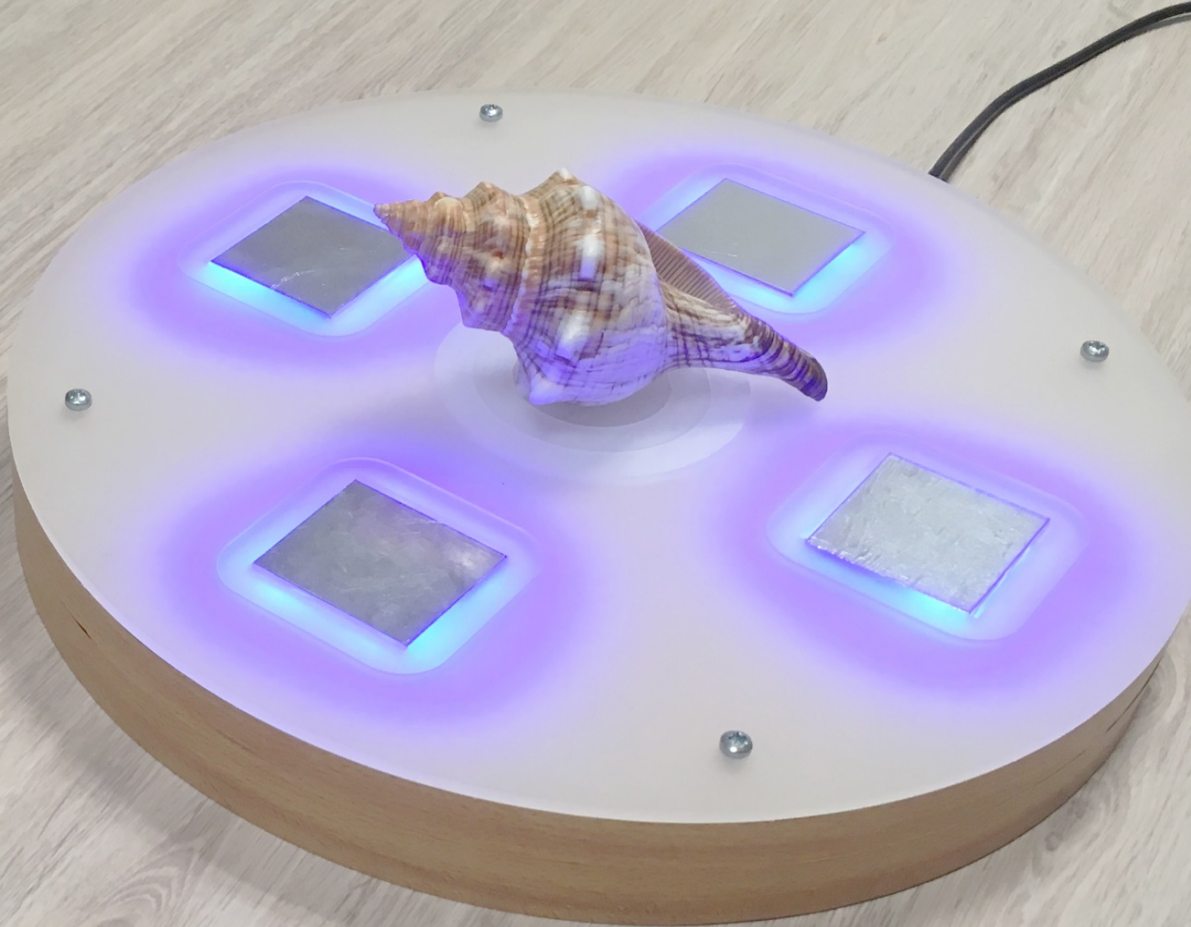
DOI:<https://doi.org/10.1145/3411764.3445124>
[128] Peter Zumthor. 2006. *Atmospheres: Architectural Environments. Surrounding Objects*. Birkhäuser.

[129] 2017. *Global action plan on the public health response to dementia 2017- 2025*. World Health Organization, Geneva.

I

EXPLORE

As there is a scarcity of research on the lived experiences of everyday sounds in the context of dementia, this first section provides an initial exploration into how people with dementia experience and engage with everyday sounds. Using a participatory approach that provides social engagement, this section reports implications for design on how everyday sounds can facilitate meaningful activity for people with dementia.



2

Foregrounding Everyday Sounds in Dementia

There has been an increased interest in researching the beneficial effects of everyday sounds, other than music on people with dementia. However, to turn this potential into concrete design applications, a qualitative understanding of how people engage with sound is needed. This chapter presents the outcomes of three workshops, exploring the personal experiences evoked by soundscapes of people in early to mid-stages of dementia. Using the Dementia Soundboard, we provide key insights into how sounds from everyday life triggered personal associations, memories of the past, emotional responses, and the sharing of experiences. Furthermore, we identified several design considerations and practical insights for sound-based technologies in the context of dementia care. This chapter sets out a path for further design-research explorations and development of concrete sound-based interventions, for enriching the everyday lives of people with dementia.

This chapter is a reproduction of the paper published as:

Maarten Houben, Rens Brankaert, Saskia Bakker, Gail Kenning, Inge Bongers, and Berry Eggen. 2019. Foregrounding Everyday Sounds in Dementia. In Proceedings of the 2019 on Designing Interactive Systems Conference (DIS '19). Association for Computing Machinery, New York, NY, USA, 71–83. <https://doi.org/10.1145/3322276.3322287>

(Best Paper Award)

2.1 INTRODUCTION

Dementia is increasingly the subject of research in HCI, exploring how interaction design can contribute to the everyday lives of people with dementia. Currently, this research is shifting the focus from remediating deficits in cognitive and physical abilities, to addressing individuals' potential and experience of dementia [34,42,47]. In this context, there exists a large body of work exploring the role of music in providing meaningful activities, that enrich social and daily life in care facilities [5,6,23,26,48,52]. Music has been proven to be beneficial for people with dementia as it can relieve stress and boredom [52], stimulate reminiscence [5], encourage physical movement [45], facilitate social interactions [23] and act as a stimulus for exploring and maintaining identity [7]. Music is however only a small part of the broad spectrum of sounds we consciously or unconsciously perceive in our surroundings. Everyday sounds, other than music, support human beings in their everyday lives by facilitating communication, providing contextual information, building expectations, and cueing behaviors [8,21]. Over the years we develop strong and personal associations with our auditory surroundings [59], which are not only linked to time and space but also deeply embedded within our physical and social surroundings [54]. For these reasons, there is a growing interest in studying the role of everyday sounds in the lives of people with dementia [10,11,16,19,28,30].



Figure 2.1. Placing the everyday object (e.g. seashell) on the Dementia Soundboard triggered the corresponding soundscape (e.g. beach). By touching the surrounding touchpads, each layer (e.g. beach_children) could be activated or deactivated.

While demonstrating the beneficial effects of everyday sounds on mood and behavior, (e.g. [11]), related research investigates the overall psychological and physiological symptoms. However, dementia affects cognitive and physical abilities in such a way that each person's experience is different [38], and so individual experiences need to be considered. The qualitative understandings of how people with dementia individually engage with sound are currently still under-researched. Therefore, by building on the successes of music therapy [6,52], we can identify new design considerations and increase the scope for meaningful sound-based interventions in the care context. For example, as people with dementia can relive past experiences by listening to music from their youth [5], everyday sounds from a person's home environment might evoke childhood memories, create a sense of familiarity and comfort, and trigger social interactions [36].

Design artifacts are known to be a successful means for triggering personal opinions, thoughts and reflections for people with dementia [12,61]. So, to gain qualitative insight into the personal experiences evoked by everyday sounds, we employed a research-oriented design approach [22]. This chapter presents the findings of an exploratory study consisting of three interactive workshops, where people in early to mid-stages of dementia listened and interacted with various soundscapes through a design artifact, namely the *Dementia Soundboard* (see Figure 2.1). In this study we found 1) key insights into the personal experiences of people with dementia when listening to everyday sounds, and 2) how social interactions play a role in these experiences. The study outcomes contribute to existing literature by providing innovative insights into how everyday sounds triggered personal associations, memories or a re-experiencing of the past, emotionally loaded responses and sharing of experiences. Furthermore, we offer considerations for the design and implementation of sound-based interventions in the context of dementia care, and practical insights based on our experience of designing sound for dementia. The research in this chapter sets the stage for new design-research explorations and the development of sound-based technologies to enrich the everyday lives of people living with dementia.

2.2 STATE-OF-THE-ART

2.2.1 *Everyday Sounds and Dementia*

The impact of music on people with dementia has been extensively studied, however, the experiences of everyday sounds are surprisingly under-researched in the field of design. Over the years, the acoustics of care facilities have received little attention but have been shown to be a source of stress and agitation for residents [30]. This research originated from a similar concern about the influence of the auditory environment on people with cognitive disabilities in general [3,10]. Existing research, in the field of psychology, primarily focused on how everyday sounds impact mood by looking at changes of emotional states, e.g. [2,11], or can be used to remediate perceived behavioral disorders, e.g. [19]. Similarly, research has demonstrated that everyday sounds, when perceived as enjoyable or pleasant, can positively influence mood and behavior of people with cognitive disabilities in general [10,11,16,19]. For instance, everyday sounds used in therapy sessions can reduce agitation and provide relief from stress for people with dementia [16]. In addition, everyday sounds can be applied to create a sense of place and structure, providing a feeling of safety within a care environment [10].

Care practitioners suggest that, in order to leverage these positive effects, everyday sounds could be integrated into the daily activity pattern of the care facility [19]. But, care practitioners thought that involving people with dementia in the process was not feasible due to their limited cognitive abilities [1,10,19]. While practitioners can provide insight into how everyday sounds can be integrated into the routines of the care staff, this still leaves a gap in knowledge on how people with dementia personally experience and engage with sound.

2.2.2 *Personal Experiences of Dementia*

Understandings about people with dementia have shifted from seeing them as a homogeneous patient group to individuals, each with having different and unique personal experiences of dementia [38]. This view is fundamental to person-centered care (PCC) [15] which is currently regarded as the primary approach in dementia care [24]. PCC emphasizes the role of care practitioners in building personal relations with people with dementia in order to support their individual experience [39]. Parallels can be drawn with the field of HCI, and the role of technology in the lives of people with dementia. Initially, the research scope was limited to assistive technologies to overcome cognitive and physical disabilities as a result of dementia [9]. However current literature [34,42,47,48,61] focusses on the personal experiences of dementia and explores the role

of design in this respect. This approach does not aim to replace assistive design but offers a new perspective [47]. The power of design is that it can engage with the personal experiences of people with dementia through designed artifacts that elicit reflections on personal relations, beliefs, values and thoughts [61]. In this context, there is an increasing interest in research, design and the evaluation of immersive multisensorial technologies that address and enrich personal experience e.g. [34,46,53,60]. This related work has mainly focused on visual aspects but has emphasized the potential of sound. However, to implement this potential successfully into design artifacts or applications for dementia care, knowledge about the personal experiences of everyday sounds is needed. Therefore, the research presented in this chapter aims to actively involve people with dementia in the design process.

2.2.3 Involving People with Dementia in Design

Participatory design approaches have primarily relied on the cognitive abilities of participants, such as the communication of thought and ability to work with abstraction. But, these approaches are difficult for people with dementia to engage with [32]. Exploring inclusive approaches to actively engage people with dementia in participatory design has been a growing area of research, e.g. [12,31,33,55,56]. Participatory sessions that center around creativity and expression minimize the burden of participants by providing meaningful activity in a comfortable, enjoyable and social setting [37]. Furthermore, by establishing an informal and pleasurable atmosphere, designers can develop social connectedness and equal-power relations [24]. These relations enable facilitators of participatory sessions to observe and value reactions, responses, and actions that may seem insignificant in other circumstances, but have specific meaning and provide insights into the responses, personality and social background of participants [31].

2.2.3.1 Embodied Interaction Using Tools, Props, and Materials

Researchers have attended to creative activities in care facilities, that involved people with dementia actively engaging in creating art or making music, offering pleasure and enjoyable social interactions, and stimulating self-esteem [17]. Extensive field studies (e.g. [41]) of such activities have provided valuable insights for designers on how to empower people with dementia by providing tools that enable different ways of self-expression beyond verbal communication [43]. People with dementia can meaningfully interact and communicate non-verbally using their bodies through movement, making gestures, singing and laughing [42].

Similarly, everyday objects frequently serve as stimuli in reminiscence therapy sessions [62]. By introducing playful tangible objects, people with dementia can engage in forms of participation such as holding, feeling and smelling [57]. These multisensorial stimuli offer cues for remembering past experiences and triggering emotional responses that are strongly associated with those experiences [58]. Similarly, in music therapy sessions, props and physical objects play an important role in facilitating connectedness between participants by acts of giving, passing along and moving together [48]. Therefore, when working with sound in the context of dementia, other senses such as touch also need to be considered.

2.3 METHOD

This study consisted of three workshops, to explore the personal experiences and social interactions of people with dementia when listening to everyday sounds. The workshops centered around a tangible design artifact, namely the *Dementia Soundboard* which provided meaningful activity by stimulating social engagement [37]. This setting aimed to actively engage participants in the discovery and exploration of everyday sounds and to encourage them in sharing their thoughts, feelings, and memories in a comfortable group setting. As each experience is different, social interactions such as sharing, comparing, listening and reacting to each other were strongly encouraged. Researchers did not only observe but also interacted with participants to perceive and value their verbal and physical expressions [31].

2.3.1 *Setting and Participants*

In total, eleven people in early to mid-stages of dementia participated in the workshops (see Table 2.1). Each workshop involved a maximum of four participants, accompanied by a care practitioner from the care organization, who was familiar with the participants. The care practitioner recruited the participants and the following inclusion criteria were adhered to: 1) participant is diagnosed with dementia caused by Alzheimer's Disease (frontotemporal lobar degeneration and Lewy bodies were excluded from this study); 2) participant is in early to mid-stages of dementia, indicated by the care organization; 3) participant still lives at home and visits the care facility several days per week; 4) participant has no severe visual and auditory processing disorders; 5) participant has sufficient physical abilities to participate in the workshop; 6) participant is willing to participate in a group workshop.

The facilitator (F) maintained the flow of the different steps of the workshops and initiated the group discussions. A research assistant (RA) was present to assist with practical issues, such as handing props and adjusting the volume of the soundscapes. The RA also took observational fieldnotes during the workshops. The care practitioner (CP) supported the facilitator with the workshop flow and safeguarded the participants. The RA and the CP did not actively participate in the workshop but they did occasionally interact with the participants.

PN	Session	Age	M/F	Dementia stage*
P1	1	77	male	early
P2	1	73	female	early
P3	1	66	female	early
P4	1	64	female	early
P5	2	69	female	early
P6	2	67	female	early
P7	2	86	female	early
P8	2	72	female	early
P9	3	81	male	moderate
P10	3	87	male	moderate
P11	3	87	male	moderate

Table 2.1. In total 11 participants in early to mid-stages of dementia participated in this study, divided over three workshops. (*as indicated by the care organization)

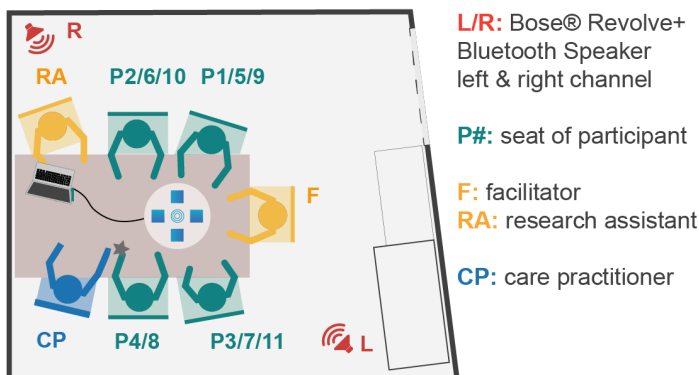


Figure 2.2 The participants were seated in reach of the soundboard, with 2 Bluetooth speakers (Bose Revolve+) positioned diagonally across the space.

2.3.1.1 *Activity Set at Daycare Facility*

The workshops were conducted at a daycare facility in Eindhoven, the Netherlands. The participants visit the facility several days per week, but are still living at home with an informal caregiver (e.g. spouse). The daycare facility delivers a secure and safe environment for data collection, as the participants are familiar with the setting and in some cases know each other. The intimate group setting (see Figure 2.2) afforded an informal and friendly ambiance for reducing possible experiences of social pressure, embarrassment or awkwardness. Furthermore, this setting gave the opportunity for participants to remain passive if desired, for instance by watching or listening to other participants. The space where the workshop took place was selected for its favorable acoustics, low ambient noise (e.g. air conditioning), and minimal sources of distraction for the participants.

2.3.2 **Workshop: Procedure and Props**

2.3.2.1 *Soundscapes of Everyday Sounds*

In each workshop, four soundscapes [49] were assessed, each representing a collection of sounds which can be perceived in a specific everyday environment. Two soundscapes depicted a natural setting, i.e. *beach* and *forest*, and the other two non-natural settings, namely *city*, and *home*. These settings were selected due to the likelihood of provoking meaningful reactions, assuming most participants would be familiar with these everyday sounds. Each soundscape was made up out of 4 separate sound layers, to give the participants 'building blocks' of everyday sounds to explore and interact with. The four layers are largely based on the notion of *soundscape ecology* [50], a theoretical approach for describing the entirety of sounds in a specific landscape. The three main components *anthrophony*, *biophony*, and *geophony* [51], were respectively translated into a *human*, *animal*, and a *water* and *background* layer (see Table 2.2). High-quality recordings for the layers were then carefully selected and retrieved from an online database [63]. The individual sound layers were mixed so that when activated together, it would produce a harmonious soundscape. Prior to the workshops, the overall perception of the soundscapes, regarding volume, mixing and quality of the used recordings was assessed by students, sound experts, and a group of twelve researchers with experience in working with people with dementia. Their comments were taken into account in the final mixing process of the soundscapes.

Soundscape/ Layer	Beach	Forest	City	Home
Human	Children	Footsteps	Market	Kitchen
Animal	Gulls	Birds	Pigeons	Cat
Water	Waves	Creek	Fountain	Thunder
Background	Wind	Trees	Traffic	Fireplace

Table 2.2. Each soundscape was made up out of four layers of everyday sounds. In the text, the layers are referenced as *soundscape_layer*, e.g. *beach_gulls*.

2.3.2.2 *Everyday Objects*

In a pilot workshop, prior to this research, the authors worked with caregivers and stakeholders of people with dementia to explore the opportunities of everyday sounds. It became apparent that not everyone engaged with everyday ambient sounds and that some people had little interest in exploring or recalling sounds. This informed the research study as it suggested there was a risk of disengagement and incomprehensibility for people with dementia, who have difficulty with understanding abstract concepts. Therefore to make the abstract concept of everyday sounds more tangible, each soundscape was represented by an everyday object [25] (see Figure 2.1). The main criterion for selecting the objects was the relatability to one of the sounds of the corresponding soundscape. Therefore *beach*, *forest*, *city*, and *home* were respectively represented by a *seashell*, *tree leaf*, *small bell*, and a *coffee mug*. A second criterion was the affordance for familiar handlings or actions, such as holding a seashell to your ear, rippling tree leaves, ringing the bell and drinking from a mug. A third criterion was the rigidity of the objects, in order to withstand rough handling or dropping. Therefore, we used a paper *tree leaf*, as a real leaf would easily degenerate or break.

2.3.2.3 *Dementia Soundboard*

Each soundscape was triggered and explored through a design artifact, more specifically by the *Dementia Soundboard* (see Figure 2.1). The soundboard served as a physical means with which to support the workshop. The interaction design needed to be minimal and easy to understand. When placed upon the soundboard, the everyday objects (recognized by an RFID reader) automatically triggered the corresponding soundscape, with all four layers activated at once. The Arduino in the soundboard was connected to a Processing sketch running on a laptop, which played the soundscapes through two connected Bluetooth speakers (see Figure 2.2). Participants could then

deactivate or reactivate each layer by tapping one of the four touchpads. Blue LEDs provided visual feedback on the state of each layer so that the presence of a sound could always be associated with an illuminated touchpad. The touchpads were intentionally not labeled to avoid distraction or influence of the participants' interpretation of the everyday sounds. Lastly, the circular symmetrical design lends itself to be used in a group setting, as there are no hierarchical differences and the board can be easily moved around the table.

2.3.2.4 Workshop Procedure

Before the start of the workshops, the facilitator and the research assistant introduced themselves to the participants, and engaged in informal small talk over a cup of coffee to establish a comfortable and safe setting. Following the introductions, the participants were extensively briefed about the aim and procedure of the workshop. Lastly, the participants were reminded of their rights to withdraw their participation at any point during the workshop.

The workshop itself was structured into three consecutively steps that are repeated for each soundscape: 1) *familiarizing*, 2) *listening* and 3) *exploring*. At each step, the facilitator observed the reactions of the participants and invited them accordingly to share opinions, likes or dislikes, stories or feelings evoked by everyday sounds. During *step 1: familiarizing*, one of the everyday objects was passed along to the participants. Such a relatively straightforward exercise served as an icebreaker, to offer a sense of comfort in the workshop setting and to reduce potential feelings of being socially awkward or embarrassed. The goal of *step 2: listening* was to listen to the soundscape with all four layers on. The facilitator would ask a participant, alternating for each soundscape, to place the object onto the soundboard, resulting in the corresponding soundscape being played. After a first listen, the group discussion was initiated by the facilitator. The research assistant then lowered the volume, so the soundscapes could still be heard but did not disturb the discussion. Lastly, *step 3: exploring* aimed to explore the separate layers of the soundscape. The facilitator explained how the layers could be turned on or off with the touchpads. Each participant was then invited to explore the soundscape, by selecting the layers they preferred the most. At the end of each workshop, the participants were debriefed and asked about their overall experiences of the workshop. Afterwards, the care practitioner who attended the workshops provided feedback in a semi-structured exit interview with the facilitator.

2.3.3 *Ethics*

This research was approved by the Ethics Review Board of Tilburg School of Social and Behavioral Sciences (EC-2018.70). All participants were able to give consent for participating themselves, and all informal caregivers (e.g. spouse) were informed about the study by the care practitioner. Participating in this study required only a small time investment of approximately an hour and a half. The workshops were organized to replace a regular activity at the daycare facility. Therefore, the activity was less obtrusive and did not cost extra time for both participants and care staff. During the workshops, the physical and mental burden was minimized by employing a participatory approach [37] that provided social engagement and meaningful activity. By establishing this informal ambiance, we also aimed to offset the perceived time burden of the participants. A familiar care practitioner of the daycare facility was always present to function as a gatekeeper. The gatekeeper decided continuously whether participating was still suitable for the involved participants. The informed consent was thus not considered as a one-time affirmation, but as a continuous dialogue between the researchers, the care practitioner and the participants [18,20].

2.3.4 *Data Collection and Qualitative Analysis*

The data gathered in this study consisted of: 1) participant information such as name, age, gender and stage of dementia; 2) audio recordings of the workshops; 3) video recordings of the workshops; 4) reflective fieldnotes of the facilitator; 5) observational fieldnotes of the research assistant; 6) audio recording of the exit interview with the care practitioner; 7) photographic documentation; and 8) digitally logged interactions of the soundboard.

The audio recordings of the three workshops and the exit interview with the care practitioner were transcribed verbatim by the researcher. The transcriptions of the workshops were combined with log files from the soundboard, in order to distinguish what sounds were played at the time. The video footage (see Figure 2.3) was muted and tagged with notes indicating bodily expressions in terms of intensity, such as yawning or being surprised, and frequency, such as reoccurring gestures. All the data was then aggregated and analyzed in ATLAS.ti by thematic analysis using an inductive approach [13]. As all participants were Dutch, the quotes used in this chapter were translated to English after the analysis.



Figure 2.3. Screenshot of the video recordings, providing a clear overview of the setting to monitor bodily responses.

2.4 RESULTS

2.4.1 Making Personal Associations

The initial responses of the participants to the everyday sounds were attempts to recognize and identify what they had heard. These responses varied considerably among the participants. For instance, when listening to *beach*, participants [P3, P5, P6-7, P11] instantly recognized *beach_waves*, while others [P1-2, P4] heard mainly *beach_gulls* and described the overall soundscape as: “A big flock of birds passing by!” [P2]. Three participants [P3, P6, P11] also clearly recognized *beach_children* in combination with *beach_waves* and remarked how this reminded them of “A very busy beach, you can hear all those children...” [P3] These different personal associations became a topic of discussion, with the participants expressing and comparing what they had heard.

2.4.1.1 Association Beyond Recognition

Associations made with the everyday sounds were not fixed, as these were also influenced by interactions with other participants. For instance, *home_cat* was for most participants [P1-2, P5-8] difficult to recognize at first. It received little to no attention, with participants perceiving it as unpleasant and resembling the “snoring of a man” [P6] or “scraping of a [metal] wire” [P7]. After one of the participants had recognized *home_cat* [P3, P6], the others responded differently, such as laughing together when they suddenly heard a ‘meow’: “Ha-ha, yes a cat, yes... purring... Then they have a good time, you can hear it!” [P2]

Additionally, participants [P1-8, P10-11] mistook everyday sounds for other sounds. For instance, P1-2 did not notice the soundscape had changed from *beach* to *forest*, and associated *forest_trees* with *beach_waves*. However, it is important not to consider this a ‘wrong’ answer, as it still elicited meaningful associations and emotions. The facilitator did not correct P2, leaving her to continue telling her story about going to the beach: “*Yes at the beach... we’d go walking, and we brought a lot of stuff with us... to make [sand]castles.*” P11 associated *forest_footsteps* with “*walking through freshly fallen snow,*” which elicited memories of how the river in his local town “*was often frozen during the winter.*” Rather than identifying the correct sounds, building meaningful associations with everyday sounds was key in eliciting participant responses.

2.4.1.2 Associations through Personal Experiences from the Past

Participants needed to be familiar with the sounds to build meaningful associations, as P1 expressed: “*I never had a cat, so I do not know the sound.*” Participants [P1-4, P6, P9-11] related the everyday sounds to their own experiences. P4 associated *beach* with a memorable moment she once experienced on holiday:

“I immediately think of a situation I once experienced [...] A very large colony [...] more than two hundred thousand seabirds [...] and then you heard the waves knocking against rocks, I heard that here too, and that was indeed a cacophony of sound... that was very beautiful!” [P4]

Through this association, P4 recognized *beach_children* as birds, as she remarked: “*I have the idea you also listen from your own experience because those children on the beach were birds for me.*” The influence of past experiences in making associations was also illustrated by P9 who recognized *forest_footsteps* as “*Some device... it’s an overtone, and it indicates that I’m working with that device,*” or recognized *home_thunder* as: “*Well if the car starts in the garage, you get this sound.*” P9 further explained that he had worked in a timber factory, where he used to operate heavy machinery that always produced a lot of noise. These examples offered insight into how participants during the workshop perceived and associated sounds through their personal experiences.

2.4.1.3 Relating to Everyday Physical and Social Surroundings

Participants [P3-7, P9] related sounds to their home environment, as P3 mentioned: “*I always sleep with the window open, and then I wake up with bird songs.*” Furthermore, P6 stated how *city_traffic* did not bother her, as she lives in a place which is “*not very busy but [...] where occasionally cars come by. And then, as the youth [passes by], you hear*

'boom boom boom!' Participants also mentioned loved-ones such as spouse [P6-7], children [P1, P3, P6] and family [P7, P9, P11]. For instance, P11 started to chuckle in himself upon hearing *beach_children*. When he was asked why he started to laugh, P11 stated:

"It reminds me of someone who is teaching his mother-in-law... (bursts out into laughter) ... of someone who is teaching his mother-in-law how to swim [...] Ha-ha... a bit disrespectful... because she's just such a lovely woman!"

These personal associations offered cues for the participants to relate to aspects of their everyday life which they considered valuable, such as their home or family.

2.4.2 Reliving Past Experiences

The soundscapes proved to be powerful in stimulating reminiscence [14,62] and experiences from the participants' past. Participants shared rich descriptions of memories that were explicitly triggered by the soundscapes.

2.4.2.1 Childhood Memories

The everyday sounds elicited numerous childhood memories from the participants [P1, P3, P5-7, P10]. For instance, *home_fireplace* reminded P6 of: *"lighting a campfire... then you heard that too!"* This cued P6 to further elaborate on her childhood by telling stories of how she spent more time playing with boys than with girls, partially because she grew up in a household with three brothers: *"Yes I was always among the boys ... we made campfires, build huts ... we were always outside."* For P10 who is in a mid-stage of dementia, *forest* triggered a specific memory from when he, as a child, was on his way to church and encountered a tree that was fully covered with birds:

"Back in the days, when we were heading to church, we always walked by under a tree, and that were trees like those we just heard, and they always created these beautiful sounds [...], but they were with so many birds, and they always sat together in one tree, and the chaplain and the pastor were not so happy with that. The leaves came down very quickly, and so they actually destroyed the shape of the tree, I remember that, but otherwise nothing, but at least it was clear that the owner of the tree and... the birds, they were not happy about that..." [P10]

P10 experienced a sense of empowerment and self-fulfillment in how he was still able to recall this encounter, which as a child had left a big impression on him:

“Nice [I am] still able... I can still remember that! ... Yes, I still remember it very clearly, as a child I already found it impressive that so many birds were sitting together...”

By reliving childhood memories, the participants experienced a sense of enjoyment in the present as well. When listening to *beach_wind*, P7 described a joyful moment she once experienced on the seaside boulevard:

“Storm! ... That’s nice to walk through ... I still have photos of this, my friend and I, we used to wear these lacquer raincoats, and we had them on, and then we were simply pushed forward by the wind in our backs. Yes, that was lovely! Those are nice memories, I’ve also been young you know!” [P7]

2.4.2.2 Meaningful Experiences from the Past

Several participants [P4, P6-7, P10-11] described thoroughly memories of meaningful and unique moments they once experienced and had left an impression on them. For P11, *forest_birds* stirred a memory with remarkable detail, of an encounter with an Austrian, who in his workplace had a large number of birds:

“Yes, I am just thinking about something that I have ever experienced. It was in Austria, and there was a cobbler with a half-open workshop sitting there making shoes, and there were all these cages with finches in them, and if they... yes [when] they started singing, then that cobbler knew exactly which finch was [singing], because they have a so-called beat, end of a certain tone, and then it was so [...] This was about ten years ago.” [P11]

2.4.2.3 Anecdotes about Loved Ones

The soundscapes evoked memories that were strongly linked to relatives and loved ones [P3, P6-7, P10-11]. Whereas P4 did not recognize *beach_children*, P3 immediately thought of an overcrowded beach on holiday:

“When I went to the beach with the kids, I always had a balloon with helium attached to the back of their shorts ... [because if] you turned around, she would be gone... Yes, but then [with the balloon] I thought ‘ok she is over there!’”

Similarly, when listening to *home_kitchen*, P7 started to share an amusing anecdote, through which she elaborated on her loving and playful relationship with her husband:

“Oh, I would say to my husband: ‘What are we having for dinner tonight?’ and he said: ‘I don’t know, you have to prepare the food!’ ‘No!’ I said: ‘There’s nothing in the house, you have to go out to do the shopping!’ He has to do the shopping himself, and then he can also decide what food he wants! Ha-ha! Our children were always laughing at us!” [P7]

This re-experiencing of emotionally loaded memories from the past provided the participants with a sense of enjoyment in the present. Sounds that evoked detailed memories in particular were overall experienced as “pleasant” [P4]. This was prompted by reliving the memories that were evoked by the sounds: “*I do not think it’s a bad sound. Because I’m thinking about the trees again with the pastor*” [P10]. The act of being able to recall memories in itself elicited a sense of achievement and self-acknowledgment. This was also mentioned during the exit-interviews by the participants who expressed how they enjoyed the workshop, as they felt pleasure in reminiscing, and “*recalling nice memories*” [P6].

2.4.3 Engaging in Emotional Experiences

The analysis identified how all participants engaged in emotionally loaded experiences, that were evoked explicitly by everyday sounds.

2.4.3.1 Enjoyment and Pleasure

When listening to the everyday sounds, participants [P1-8, P10] each expressed a feeling of enjoyment and appreciated the aesthetic qualities of the everyday sounds at one point during the workshop. The vibrant *forest_birds* evoked several [P2, P6-8, P10] joyful responses: “*Birds! (Laughs), beautiful! Yes, that is nice yes.*” [P8], or “*He really wants to be heard! Marvelous, really!*” [P7] Furthermore, P1 expressed his fondness of *home_thunder*: “*But I myself find thunder always enjoying to listen to, that is if you are sitting someplace dry of course!*”

2.4.3.2 Relief from Stress

During the workshops, the participants indicated how everyday sounds could create atmospheres that provide a sense of relief and tranquility. For example, *home_fireplace* had a “*meditative*” effect on P3 that could make her “*completely calm*”. As P7 leaned back in her chair and closed her eyes, she remarked: “*Well nice, nice and quiet, you can easily*

turn away. You can sleep well with this. If I sit back with my eyes closed, I think oh... (laughs)... nice yes.” The soundscapes, with all four sound layers on, were in general experienced as too chaotic and participants [P1, P3-4, P6-7] stressed the importance of how sound should provide relief from disordered thoughts and worries: “And then I notice that I just get the quiet sounds out of it. Rest in here (points to head). That’s just clear to me.” [P4]

2.4.3.3 Coming Alive in a Group Setting

Participants P2 and P8, who were less engaged and more introvert than others, suddenly displayed increased forms of active participation. When listening to the *forest_birds*, P2 suddenly started glancing around and smiling, as she suddenly was fully immersed in the soundscape. While explaining, P2 was heavily mimicking the movement of the *forest_birds*, to emphasize how she enjoyed the way the sound was scattered around the space: “I sometimes get a little bit of jitters, so I go up there, with all those birds [...] I just love it! How everything flies up there!”

Similarly, P8 was also more passively involved in the workshop, as it was difficult for her at times to verbally express herself. When the facilitator asked her a question, several times she turned to the care practitioner and murmured something indistinctly. After the group had recognized *home_cat*, there was a brief moment of silence, which P8 suddenly interrupted upon hearing a short ‘meow’: “Oh ha-ha, there he is! Hehe!” (starts laughing out loud) While verbally expressing herself seemed difficult during the first half of the workshop, this sudden response was spontaneous and indicated that she recognized and enjoyed the sound.



Figure 2.4. P7 (left) bursting in laughter after acting silly.

P7 was fully engaged during the whole workshop, sharing memories and anecdotes from her past, and providing the group with her own opinion and preferences. While exploring the soundboard, she triggered *forest_creek*, and upon hearing the sound of water running, she looked surprised [RA] and began to act silly by intentionally overreacting to the sound (see Figure 2.4). Afterwards she started laughing intensely together with the others [P5-6, P8, CP] and smiled at the facilitator [RA]. This was a moment for her to not take the workshop too seriously, by enjoying herself and the group in an act of silliness.

These responses indicate how listening to everyday sounds in itself can be a joyful and pleasant experience, which affords opportunities for pleasure, relief, excitement, and silliness.

2.4.4 *Sharing of Experiences*

Upon hearing the soundscapes, the participants as an initial response engaged in a 'guessing game', in which they discussed and compared with each other what they thought they had heard, and searched for the acknowledgment of others. This resulted in an informal atmosphere, which allowed for teasing, making jokes and acting silly:

P2: "You can hear [purring of cats] when they are having a good time."

P1: (looks at P2) "Well, then you should start already!"

P2: "What did you say?! Oh, you!" (laughing back to P1)

This atmosphere provided a safe and comfortable setting in which the participants felt encouraged to share their own opinions, preferences, experiences, and memories with the group, as observed by F, RA, and CP. Participants also verbally responded to each other's stories [P6-7, P10-11], rather than only reacting to the soundscapes. In these cases, the everyday sounds served as a conversation starter and stimulated social connectedness, as participants were engaged in each other's stories and memories.

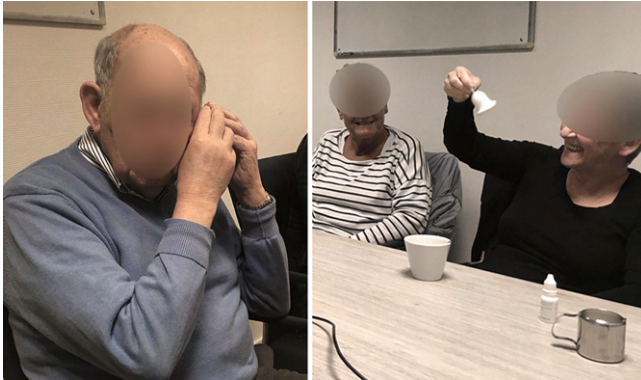


Figure 2.5. Playful objects, such as a seashell (left) and a small bell (right) introduced each soundscape to the participants.

In addition to verbal forms of expression, participants [P1-4, P6-8, P11] expressed their thoughts and emotions to each other through bodily responses, e.g., smiling, frowning, or making gestures. While listening to each other, participants provided signs of acknowledgment and validation, such as nodding along. For participants who had difficulty in verbally expressing themselves, bodily responses became a way of participating in the conversation by smiling or laughing along with the group [P2, P5, P8]. Participants made gestures for expressing sounds, such as mimicking ringing a bell [P1-4] (see Figure 2.5), releasing pigeons [P7], or tapping fingers on the table [P2-3]. By doing this, the participants easily connected and engaged in an embodied way that was comprehensible to all.

2.4.5 Use of Props: Dementia Soundboard and Objects

The everyday objects (see Figure 2.5) introduced the soundscapes and the general setting of the workshop in a way that was “*approachable*” [CP] and easy for the participants: “*Yes, it’s just a leaf of a tree... and I’ve seen a lot of it in my life. (Laughs)*” [P10]. Participants made associations that were similar to the corresponding soundscapes, such as relating the *seashell* to a beach [P1-9, P11]. These associations were considered “*a first chat*” [CP], which established and explained the format of the group discussions.

In contrast to our expectations, attention to the objects completely disappeared when placed upon the soundboard: “*I do not know whether people at some point also associated the sound with the object [...] that didn’t matter anymore.*” [CP] For instance, after associating the *leaf* with “*nature*” and “*trees*”, P1-2 still associated *forest* with *beach*.

Moreover, during *step 2: listening* and *step 3: exploring* with the object placed on the soundboard, there was no mention of it at all.



Figure 2.6. The Dementia Soundboard was a tangible interface by which the participants could interact with the soundscapes.

2.4.5.1 *Tangible and Comprehensible Interactions with Sound*

There was a substantial difference in how each of the participants interacted with the soundboard. P3-4 were very keen on using the soundboard for discovering the hidden sounds and creating their own preferred soundscape: “*That’s my sound!*” [P4]. For them, it felt like they were playing a game of exploring and guessing all the different sounds: “*now you can play!*” [P3], as shown in Figure 2.6. Other participants [P2, P5-10] were less spontaneous and needed to be asked by the facilitator whether they wanted to turn a layer of sound on or off. Nevertheless, they did seem to understand the concept of the touchpads with the LED feedback. Only for P9 and P10, the operating of the soundboard seemed unclear as they had confused the RFID reader for the objects as one of the touchpads. When interest in interacting fell, the facilitator or care practitioner interacted with the soundboard to adapt the soundscapes. Although interaction by the participants with the soundboard waned at times, it proved to be a tangible medium to adapt the everyday sounds in a way that was understandable. Participants could either explore the soundscapes themselves or witness someone else turn a sound on or off. Every interaction became a visible event that refocused the attention of participants, as they expected a change in the soundscape that was played at the time.

2.4.5.2 Thinking About Outcome and Potential Applications

The presence of a real design artifact triggered feedback about the research and potential outcomes of it. The participants considered the *Dementia Soundboard* as a finished product or application. They appreciated the modern and simple aesthetics of the soundboard and displayed interest in the technical working: “*How did you manage that?*” [P1]. During the exit interviews, participants [P1-4, P6, P11] spontaneously began discussing the potential of sound-based applications and the effects of music and sound in general:

“Yes, I am trying to understand what the system is that you are working with, and I think you will indeed have a nice and beautiful experience with it.” [P11]

P3-4 stressed the importance of modifying the soundscapes to personal preferences, and even suggested the idea of creating a soundscape yourself: “*Because imagine that there are more levels in it [...] then you could assemble your own forest [soundscape]*” [P3]. The personal aspect of sound prompted a discussion concerning the social context in which potential sound-based applications could or should be set. P3-4 expressed their preference for listening unaccompanied with headphones in all “*peace and quietness*” while P1-2 considered that “*asocial*” and remarked that when in group settings, it is more enjoyable to listen together, as this creates a friendly and sociable ambiance. These examples illustrate the creative attitude and engagement of the participants towards the soundboard.

2.5 DISCUSSION

The above findings contribute to existing research on sound and dementia by describing extensively how everyday sounds triggered personal associations, memories of the past, emotional responses, and sharing of participant experiences. We will further discuss the implications of these results for design research, and outline practical insights and considerations for the development of sound-based technologies for people living with dementia.

During the workshops, generic everyday sounds evoked numerous personal and emotional participant responses. The participants recognized everyday sounds through their own lived experiences, by associating sound to their personal background, past experiences, social network, and everyday physical surroundings. This aligns with research which investigated differences between generic and personal photographs and

demonstrated how personal content could be confronting if, for example, family members are not recognized [27]. Generic content, on the other hand, is more likely to prompt longer stories, as the focus shifts away from giving the ‘correct’ answer such as naming people, places, and events, to reliving the memory itself [4]. Similarly, the workshops outcomes indicated how meaningful associations were of high value in evoking responses, whether or not the association was ‘correct’. Everyday sounds offer universal cues for making personal unjudged associations and reliving past experiences, that are not explicitly bound to the details of a specific time or place.

Our results demonstrated how everyday sounds stimulated reminiscence [62], by evoking memories that were strongly linked to specific sounds people had experienced in the past. These findings contribute to the large body of work demonstrating the beneficial effects of reminiscence therapy for people with dementia [4,14,27,40,44,62]. Facilitators of these activities employ different types of media, such as music, images or video to prompt memories [44]. The results of this study indicate that everyday sounds can do the same. Furthermore, the immersive character of sound adds value to the experience, by letting participants relive their memories and express emotions in the present [57].

By doing so in a group setting, the sharing of personal stories and memories in itself becomes a collective in-the-moment experience [14]. The exploration of adaptable soundscapes of everyday sounds enabled pleasurable social interactions and opportunities for expressing emotions and receiving acknowledgment of others. Everyday sounds functioned as a conversation starter and stimulated social connectedness, as participants engaged further in meaningful interactions with each other. The emotional experiences evoked by sound are thus not only individual but also situated in social activities and contexts [42].

2.5.1 Design Considerations for Sound-Based Interventions

2.5.1.1 Personal Experience

Generalized statements about how people with dementia experience sound should be carefully considered. For instance, research suggests that mechanical sounds result in feeling unsafe and experiencing discomfort [3]. During the workshops however, one participant made several associations with mechanical sounds from a factory. This evoked strong personal responses, as he had spent a long time working in a timber factory and still had many meaningful memories from this significant period of his life. This example stresses the need for addressing personal experiences and engaging

individually, rather than looking for overall group responses in terms of changes in behavior and mood.

This individual approach is fundamental to person-centered care [15], which is built upon the notions of personhood and supportive social relations [24]. Therefore we can link the experience of sound to current research in HCI, exploring ways how design can provide insight into personhood of people with dementia [28,42,61]. In this study, everyday sounds elicited deeply held memories, values, beliefs and facilitated meaningful and enjoyable social interactions with other residents and care practitioners. Conversating about associations made with personal life offered opportunities for exploring and recognizing identity [61]. Therefore, everyday sounds can be used as a powerful tool for developing creative approaches that encourage the recognition of identity, and stimulate social connection in future design proposals and research projects.

2.5.1.2 Adaptable to Social Contexts

The responses evoked from the participants were strongly influenced by the social interactions and contexts in which they were observed. Therefore, consideration is needed for the different social contexts in which sound-based design proposals are applied. During the first workshop, two participants remarked that they would like to listen to everyday sounds on their own, while the other two participants argued that would be asocial. Therefore, the ability to dynamically adapt sound to different social contexts must be further explored. This again accounts for individual responses and preferences, and reinforces the importance of not treating people with dementia as a homogenous group.

2.5.1.3 Meaningful Activity in Care Environment

The workshops were organized as one of the activities at a dementia daycare facility. This provided direct insight into how sound-based interventions can be integrated in this context. The attending care practitioner remarked that this activity could fit within the current program of the daycare facility. The activity in itself does continuously facilitate conversations between participants and the care practitioner. The use of generic everyday sounds to evoke strong personal responses offers a meaningful activity [37] through which caregivers can build supportive relations with their clients [39]. As everyday sounds offer cues for triggering unexpected stories and topics, this also releases part of the burden of the care practitioner in preparing and facilitating time and cost consuming activities [40].

The interaction design of the *Dementia Soundboard*, using tangible objects and touchpads, enabled live selection of sound content. Aside from personal preferences, soundscapes could be instantly modified to the participant's current responses, mood, and behavior. Furthermore, the soundboard added a playful element, as some participants considered the activity as a game, or a pleasant voyage of discovery, which was different from the activities they usually participate in.

2.5.2 Practical Insights for Sound Design for Dementia

Based on our experience of designing and evaluating everyday sounds with people living with dementia, we offer practical insights for sound-based applications.

2.5.2.1 Tranquility and Moments of Silence

The soundscapes were in general perceived as overwhelming and chaotic. This was remarked upon by both the research assistant and the attending care practitioner. The participants stressed multiple times how they preferred calmness and tranquility. This was confirmed by the reactions to the individual layers of everyday sounds, which elicited more verbal and non-verbal responses compared to when all four layers were played at once. Furthermore, it was essential to allow for silence and to provide moments of relief and rest. The *familiarizing* step (where the object was passed along, and no sound is played) served as a 'palate cleanser' before the next soundscape was triggered. This offered moments of silence and rest for the participants during the workshops.

2.5.2.2 Quality of Reproducing Everyday Sounds

Participants had remarked that several sounds did not sound quite the same as those they had built associations with. This can be attributed to the artificial aspect of reproducing sounds electronically (e.g. 'uncanny valley of sound' [29]), as it can never sound as how the participants had experienced it in reality. Furthermore, to ensure all the participants heard the soundscapes clearly, the audio files were played at high volume. For sounds that in real life are rather quiet, such as *home_cat*, this created an unrealistic distorted effect. This raises considerations for producing sound more authentically through mechanically actuating materials, rather than using electronic loudspeakers [35].

2.6 CONCLUSION

In conclusion, this chapter has provided new knowledge on the personal experiences evoked by everyday sounds for people in early to mid-stages of dementia. We have offered practical insights into sound design and have outlined design considerations for sound-based technologies in dementia care. We cannot overgeneralize sound associations, as each individual perceives this differently through their own experience. Furthermore, the emotional experiences evoked by sound have to be considered within social context and activity. As the scope of this research is limited to people in early to mid-stages of dementia, more research is necessary to gain an understanding of the relation between sound and people in a later stage of dementia. In essence, we aim to raise awareness of the role of sound in the care context and to demonstrate how sound is a powerful tool for caregivers and designers to engage with people with dementia.

2.7 ACKNOWLEDGMENTS

We would like to thank ZonMw for funding the ‘Everyday Sounds of Dementia’ project in the Create Health program, Archipel care organization, Betty Jansen and Jolien ter Brugge for their assistance in facilitating the workshops, and especially the participants of the workshops.

2.8 REFERENCES

- [1] Francesco Aletta, Tara Vander Mynsbrugge, Dominique Van de Velde, Patricia De Vriendt, Pieter Thomas, Karlo Filipan, Dick Botteldooren, and Paul Devos. 2018. Awareness of ‘sound’ in nursing homes: A large-scale soundscape survey in Flanders (Belgium). *Build. Acoust.* 25, 1 (March 2018), 43–59. DOI:<https://doi.org/10.1177/1351010X17748113>
- [2] Tjeerd C. Andringa and Kirsten A. van den Bosch. 2013. Core affect and soundscape assessment: fore- and background soundscape design for quality of life. In *Proceedings of Internoise 2013 - 42nd International Congress on Noise Control Engineering: Noise Control for Quality of Life*, 2273–2282.
- [3] Tjeerd C. Andringa and J. Jolie L. Lanser. 2013. How pleasant sounds promote and annoying sounds impede health: A cognitive approach. *Int. J. Environ. Res. Public Health* 10, 4 (April 2013), 1439–1461. DOI: <https://doi.org/10.3390/ijerph10041439>
- [4] Arlene J. Astell, Maggie P. Ellis, Norman Alm, Richard Dye, and Gary Gowans. 2010. Stimulating People with Dementia to Reminisce Using Personal and Generic Photographs. *Int. J. Comput. Heal.* 1, 2 (2010), 177–198. DOI: <https://doi.org/10.1504/IJCIH.2010.037461>
- [5] Ameer Baird and Séverine Samson. 2009. Memory for Music in Alzheimer’s Disease: Unforgettable? *Neuropsychol. Rev.* 19, 1 (May 2009), 85–101. DOI: <https://doi.org/10.1007/s11065-009-9085-2>
- [6] Ameer Baird and Séverine Samson. 2015. Music and dementia. In *Progress in Brain Research*, Eckart Altenmüller, Stanley Finger and François Boller (eds.). Elsevier, 207–235. DOI: <https://doi.org/10.1016/bs.pbr.2014.11.028>
- [7] Ameer Baird and William Forde Thompson. 2018. The Impact of Music on the Self in Dementia. *J. Alzheimers. Dis.* 61, 3 (May 2018), 827–841. DOI: <https://doi.org/10.3233/JAD-170737>
- [8] Saskia Bakker, Elise van den Hoven, and Berry Eggen. 2012. Knowing by ear: leveraging human attention abilities in interaction design. *J. Multimodal User Interfaces* 5, 3–4 (February 2012), 197–209. DOI:

- <https://doi.org/10.1007/s12193-011-0062-8>
- [9] Ashok J. Bharucha, Vivek Anand, Jodi Forlizzi, Mary Amanda Dew, Charles F. Reynolds, Scott Stevens, and Howard Wactlar. 2009. Intelligent Assistive Technology Applications to Dementia Care: Current Capabilities, Limitations, and Future Challenges. *Am. J. Geriatr. Psychiatry* 17, 2 (February 2009), 88–104. DOI:<https://doi.org/10.1097/JGP.0b013e318187dd e5>
- [10] Kirsten A. van den Bosch, Tjeerd C. Andringa, Deniz Başkent, and Carla Vlaskamp. 2016. The Role of Sound in Residential Facilities for People With Profound Intellectual and Multiple Disabilities. *J. Policy Pract. Intellect. Disabil.* 13, 1 (March 2016), 61–68. DOI:<https://doi.org/10.1111/jppi.12147>
- [11] Kirsten A. van den Bosch, Tjeerd C. Andringa, Wolter Peterson, Wied A. J. J. M. Ruijsenaars, and Carla Vlaskamp. 2017. A comparison of natural and non-natural soundscapes on people with severe or profound intellectual and multiple disabilities. *J. Intellect. Dev. Disabil.* 42, 3 (July 2017), 301–307. DOI: <https://doi.org/10.3109/13668250.2016.1250251>
- [12] Rita Maldonado Branco, Joana Quental, and Óscar Ribeiro. 2017. Personalised participation: an approach to involve people with dementia and their families in a participatory design project. *CoDesign* 13, 2 (2017), 127–143. DOI: <https://doi.org/10.1080/15710882.2017.1310903>
- [13] Virginia Braun and Victoria Clarke. 2006. Using thematic analysis in psychology. *Qual. Res. Psychol.* 3, 2 (January 2006), 77–101. DOI: <https://doi.org/10.1191/1478088706qp0630a>
- [14] D. Brooker and L. Duce. 2000. Wellbeing and activity in dementia: A comparison of group reminiscence therapy, structured goal-directed group activity and unstructured time. *Aging Ment. Health* 4, 4 (November 2000), 354–358. DOI: <https://doi.org/10.1080/713649967>
- [15] Dawn Brooker. 2003. What is person-centred care in dementia? *Rev. Clin. Gerontol.* 13, 03 (August 2003), 215–222. DOI: <https://doi.org/10.1017/S095925980400108X>
- [16] Caroline Bulsara, Karla Seaman, and Silke Steuxner. 2016. Using sound therapy to ease agitation amongst persons with dementia: a pilot study. *Aust. Nurs. Midwifery J.* 23, 7 (2016), 38–39.
- [17] Bree Chancellor, Angel Duncan, and Anjan Chatterjee. 2014. Art Therapy for Alzheimer’s Disease and Other Dementias. *J. Alzheimer’s Dis.* 39, 1 (January 2014), 1–11. DOI: <https://doi.org/10.3233/JAD-131295>
- [18] Tim Coughlan, Kerstin Leder Mackley, Michael Brown, Sarah Martindale, Stephan Schlögl, Becky Mallaband, John Arnott, Jettie Hoonhout, Dalila Szostak, Robin Brewer, Erika Poole, Antti Pirhonen, Val Mitchell, Sarah Pink, and Nicolas Hine. 2013. Current issues and future directions in methods for studying technology in the home. *PsychNology J.* 11, 2 (2013), 159–184.
- [19] Paul Devos, Francesco Aletta, Pieter Thomas, Karlo Filipan, Mirko Petrovic, Dick Botteldooren, Tara Vander Mynsbrugge, Dominique Van de Velde, and Patricia De Vriendt. 2018. Soundscape design for management of behavioral disorders: a pilot study among nursing home residents with dementia. In *Impact of noise control engineering : proceedings of Inter-Noise 2018*, 8.
- [20] Jan Dewing. 2007. Participatory research: A method for process consent with persons who have dementia. *Dementia* 6, 1 (February 2007), 11–25. DOI: <https://doi.org/10.1177/1471301207075625>
- [21] Berry Eggen. 2016. Interactive Soundscapes of the Future Everyday Life. In *Peripheral interaction: challenges and opportunities for HCI in the periphery of attention*. 239–251. DOI:https://doi.org/10.1007/978-3-319-29523-7_11
- [22] Daniel Fallman. 2007. Why Research-Oriented Design Isn’t Design-Oriented Research: On the Tensions Between Design and Research in an Implicit Design Discipline. *Knowledge, Technol. Policy* 20, 3 (October 2007), 193–200. DOI: <https://doi.org/10.1007/s12130-007-9022-8>
- [23] Stu Favilla and Sonja Pedell. 2013. Touch Screen Ensemble Music: Collaborative Interaction for Older People with Dementia. In *Proceedings of the 25th Australian Computer-Human Interaction Conference on Augmentation, Application, Innovation, Collaboration - OzCHI ’13*, 481–484. DOI: <https://doi.org/10.1145/2541016.2541088>
- [24] Sam Fazio, Douglas Pace, Janice Flinner, and Beth Kallmyer. 2018. The Fundamentals of Person-Centered Care for Individuals With Dementia. *Gerontologist* 58, suppl_1 (January 2018), S10–S19. DOI:<https://doi.org/10.1093/geront/gnx122>
- [25] Bill Gaver, Tony Dunne, and Elena Pacenti. 1999. Design: Cultural probes. *Interactions* 6, 1 (January 1999), 21–29. DOI: <https://doi.org/10.1145/291224.291235>
- [26] Karen Gold. 2014. But does it do any good? Measuring the impact of music therapy on people with advanced dementia: (Innovative practice). *Dementia* 13, 2 (2014), 258–264. DOI: <https://doi.org/10.1177/1471301213494512>
- [27] Gary Gowans, Jim Campbell, Norm Alm, Richard Dye, Arlene Astell, and Maggie Ellis. 2004. Designing a multimedia conversation aid for reminiscence therapy in dementia care environments. In *Extended abstracts of the 2004 conference on Human factors and computing*

- systems - CHI '04, 825–836. DOI: <https://doi.org/10.1145/985921.985943>
- [28] Megan E. Graham. 2018. Re-socialising sound: investigating sound, selfhood and intersubjectivity among people living with dementia in long-term care. *Sound Stud.* (December 2018), 1–16. DOI: <https://doi.org/10.1080/20551940.2018.1551051>
- [29] Mark Grimshaw. 2009. The audio Uncanny Valley: Sound, fear and the horror game. In *Games Computing and Creative Technologies: Conference Papers (Peer-Reviewed). Paper 9.* (2009), 21–26.
- [30] Michael James Hayne and Richard Fleming. 2014. Acoustic design guidelines for dementia care facilities. In *Proceedings of 43rd International Congress on Noise Control Engineering: Internoise 2014*, 1–10.
- [31] Niels Hendriks, Liesbeth Huybrechts, Karin Slegers, and Andrea Wilkinson. 2018. Valuing implicit decision-making in participatory design: A relational approach in design with people with dementia. *Design Studies* 59, 58–76. DOI: <https://doi.org/10.1016/j.destud.2018.06.001>
- [32] Niels Hendriks, Liesbeth Huybrechts, Andrea Wilkinson, and Karin Slegers. 2014. Challenges in doing participatory design with people with dementia. In *Proceedings of the 13th Participatory Design Conference on Short Papers, Industry Cases, Workshop Descriptions, Doctoral Consortium papers, and Keynote abstracts - PDC '14 - volume 2 (PDC '14)*, 33–36. DOI: <https://doi.org/10.1145/2662155.2662196>
- [33] Niels Hendriks, Karin Slegers, and Pieter Duysburgh. 2015. Codesign with people living with cognitive or sensory impairments: a case for method stories and uniqueness. *CoDesign* 11, 1 (January 2015), 70–82. DOI: <https://doi.org/10.1080/15710882.2015.1020316>
- [34] James Hodge, Madeline Balaam, Sandra Hastings, and Kellie Morrissey. 2018. Exploring the Design of Tailored Virtual Reality Experiences for People with Dementia. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems (CHI '18), Paper 514*, 1–13. DOI: <https://doi.org/10.1145/3173574.3174088>
- [35] Maarten Houben, Benjamin Deneff, Matthias Mattelaer, Sandy Claes, and Andrew Vande Moere. 2017. The Meaningful Integration of Interactive Media in Architecture. In *Proceedings of the 2017 ACM Conference Companion Publication on Designing Interactive Systems (DIS '17 Companion)*, 187–191. DOI: <https://doi.org/10.1145/3064857.3079143>
- [36] Emily S. Ihara, Catherine J. Tompkins, Megumi Inoue, and Sonya Sonneman. 2019. Results from a person-centered music intervention for individuals living with dementia. *Geriatr. Gerontol. Int.* 19, 1 (January 2019), 30–34. DOI: <https://doi.org/10.1111/ggi.13563>
- [37] Gail Kenning. 2018. Reciprocal design: inclusive design approaches for people with late stage dementia. *Des. Heal.* 2, 1 (January 2018), 142–162. DOI: <https://doi.org/10.1080/24735132.2018.1453638>
- [38] Tom Kitwood. 1997. The experience of dementia. *Aging Ment. Heal.* 1, 1 (1997), 13–22. DOI: <https://doi.org/10.1080/13607869757344>
- [39] Tom Kitwood. 1997. *Dementia reconsidered: The person comes first.* Open University Press, London.
- [40] Noriaki Kuwahara, Shinji Abe, Kiyoshi Yasuda, and Kazuhiro Kuwabara. 2006. Networked reminiscence therapy for individuals with dementia by using photo and video sharing. In *Proceedings of the 8th international ACM SIGACCESS conference on Computers and accessibility - Assets '06*, 125–132. DOI: <https://doi.org/10.1145/1168987.1169010>
- [41] Amanda Lazar, Raymundo Cornejo, Caroline Edasis, and Anne Marie Piper. 2016. Designing for the Third Hand. In *Proceedings of the 2016 ACM Conference on Designing Interactive Systems - DIS '16*, 1047–1058. DOI: <https://doi.org/10.1145/2901790.2901854>
- [42] Amanda Lazar, Caroline Edasis, and Anne Marie Piper. 2017. A Critical Lens on Dementia and Design in HCI. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems (CHI '17)*, 2175–2188. DOI: <https://doi.org/10.1145/3025453.3025522>
- [43] Amanda Lazar, Jessica L. Feuston, Caroline Edasis, and Anne Marie Piper. 2018. Making as Expression: Informing Design with People with Complex Communication Needs through Art Therapy. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems - CHI '18, Paper 351*, 1–16. DOI: <https://doi.org/10.1145/3173574.3173925>
- [44] Amanda Lazar, Hilaire Thompson, and George Demiris. 2014. A systematic review of the use of technology for reminiscence therapy. *Health Educ. Behav.* 41, 1 Suppl (October 2014), 51S–61S. DOI: <https://doi.org/10.1177/1090198114537067>
- [45] Micheline Lesaffre, Bart Moens, and Frank Desmet. 2017. Monitoring music and movement interaction in people with dementia. In *The Routledge Companion to embodied music interaction.* Routledge, 294–303.
- [46] Tom Luyten, Susy Braun, Gaston Jamin, Susan van Hooren, and Luc de Witte. 2017. How nursing home residents with dementia respond to the interactive art installation 'VENSTER': a pilot study. *Disabil. Rehabil. Assist. Technol.* (August 2017), 1–8. DOI: <https://doi.org/10.1080/17483107.2017.1290701>

- [47] Kellie Morrissey, John McCarthy, and Nadia Pantidi. 2017. The Value of Experience-Centred Design Approaches in Dementia Research Contexts. In Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems (CHI '17), 1326–1338. DOI: <https://doi.org/10.1145/3025453.3025527>
- [48] Kellie Morrissey, Gavin Wood, David Green, Nadia Pantidi, and John McCarthy. 2016. “I’m a rambler, I’m a gambler, I’m a long way from home.” In Proceedings of the 2016 ACM Conference on Designing Interactive Systems - DIS '16, 1008–1020. DOI: <https://doi.org/10.1145/2901790.2901798>
- [49] Raymond Murray Schafer. 1977. The soundscape: Our sonic environment and the tuning of the world. Vancouver Destin. Books (1977).
- [50] Bryan C. Pijanowski, Almo Farina, Stuart H. Gage, Sarah L. Dumyahn, and Bernie L. Krause. 2011. What is soundscape ecology? An introduction and overview of an emerging new science. *Landsc. Ecol.* 26, 9 (May 2011), 1213–1232. DOI: <https://doi.org/10.1007/s10978-011-9600-8>
- [51] Bryan C. Pijanowski, Luis J. Villanueva-Rivera, Sarah L. Dumyahn, Almo Farina, Bernie L. Krause, Brian M. Napolitano, Stuart H. Gage, and Nadia Pieretti. 2011. Soundscape Ecology: The Science of Sound in the Landscape. *Bioscience* 61, 3 (May 2011), 203–216. DOI: <https://doi.org/10.1525/bio.2011.61.3.6>
- [52] Alfredo Raglio, Stefania Filippi, Daniele Bellandi, and Marco Stramba-Badiale. 2014. Global music approach to persons with dementia: evidence and practice. *Clin. Interv. Aging* 9, (2014), 1669–1676. DOI: <https://doi.org/10.2147/CIA.S71388>
- [53] Kimberly Johanna Schelle, Carolina Gomez Naranjo, Martijn ten Bhömer, Oscar Tomico, and Stephan Wensveen. 2015. Tactile Dialogues: Personalization of Vibrotactile Behavior to Trigger Interpersonal Communication. In Proceedings of the Ninth International Conference on Tangible, Embedded, and Embodied Interaction - TEI '14, 637–642. DOI: <https://doi.org/10.1145/2677199.2687894>
- [54] Jennifer Schine. 2010. Movement, Memory & the Senses in Soundscape Studies. *Can. Acoust.* 38, 3 (May 2010), 100–101.
- [55] Sandra Suijkerbuijk, Rens Brankaert, Yvonne A.W. De Kort, Liselore J.A.E. Snaphaan, and Elke Den Ouden. 2015. Seeing the first-person perspective in dementia: A qualitative personal evaluation game to evaluate assistive technology for people affected by dementia in the home context. *Interacting with Computers* 27, 47–59. DOI: <https://doi.org/10.1093/iwc/iwu038>
- [56] Cathy Treadaway and Gail Kenning. 2016. Sensor e-textiles: person centered co-design for people with late stage dementia. *Work. with Older People* 20, 2 (June 2016), 76–85. DOI: <https://doi.org/10.1108/WWOP-09-2015-0022>
- [57] Cathy Treadaway, Gail Kenning, and Steve Coleman. 2014. Designing for positive emotions: Ludic artifacts to support wellbeing for people with dementia. In Colours of care: 9th Design and emotion conference.
- [58] Cathy Treadaway, Gail Kenning, David Prytherch, and Jac Fennell. 2016. LAUGH: Designing to enhance positive emotion for people living with dementia. In Celebration and Contemplation (Proceedings of Design and Emotion International Conference 2016, 27-30 September), 37–44.
- [59] Barry Truax. 2001. Acoustic communication. Greenwood Publishing Group.
- [60] Carlijn Valk, Xu Lin, Loe Fijes, Matthias Rauterberg, and Jun Hu. 2017. Closer to Nature - Interactive Installation Design for Elderly with Dementia. In Proceedings of the 3rd International Conference on Information and Communication Technologies for Ageing Well and e-Health, 228–235. DOI: <https://doi.org/10.5220/0006378502280235>
- [61] Jayne Wallace, Peter C. Wright, John McCarthy, David Philip Green, James Thomas, and Patrick Olivier. 2013. A design-led inquiry into personhood in dementia. In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems - CHI '13, 2617–2626. DOI: <https://doi.org/10.1145/2470654.2481363>
- [62] Bob Woods, Laura O’Philbin, Emma M. Farrell, Aimee E. Spector, and Martin Orrell. 2018. Reminiscence therapy for dementia. *Cochrane Database Syst. Rev.* 3 (March 2018). DOI: <https://doi.org/10.1002/14651858.CD00120.pub3>
- [63] BBC Sound Effects - Research & Education Space. Retrieved January 9, 2019 from <http://bbcsfx.acropolis.org.uk/>

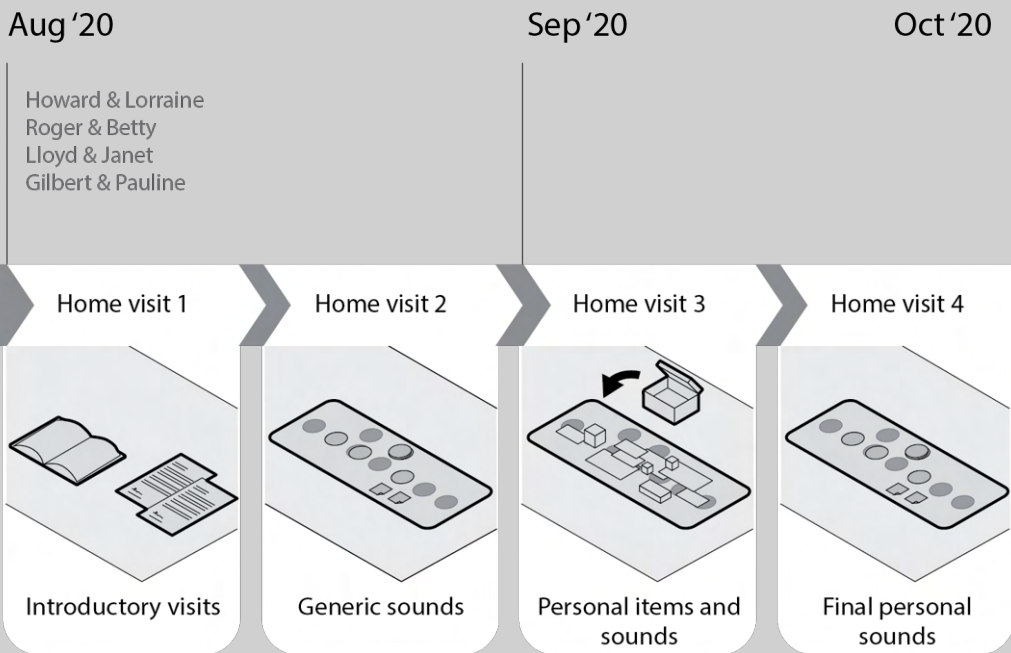
II

DESIGN

Section 2 builds further on the insights from the workshop study with the Dementia Soundboard presented in Chapter 2 by exploring how we can design for meaningful experiences with everyday sounds. This section reports a one-year co-design study that involved four couples consisting of a person with dementia and a relative. This study aimed to identify personal everyday sounds and explore how technology can facilitate engagement with these personal sounds in the everyday home context.

Chapter 3 reports the first part of the longitudinal co-design study in which the couples co-created personal collections of everyday sounds that evoked meaningful responses. The participants were introduced to the study setup and aim during the first home visit. Over two months, three co-design sessions were held as visits at the participants' home. The participants interacted with a new design artefact, namely the Life Story Soundboard which offered more flexibility than the Dementia Soundboard used in Chapter 2 to iterate a generic set of everyday sounds into a collection of highly personal sounds.

Chapter 3: Co-Creating Personal Audio Content with People with Dementia and Their Relatives



Chapter 4 reports the second part of the longitudinal co-design study in which we continued with three couples to co-design an accessible audio player to experience their personal sounds as outcome from Chapter 3. Similarly, four home visits were held over five months to involve the couples to have a say in all stages of the design process of the accessible audio player. The outcome of these co-design sessions was the Tumbler that we evaluated during the final home visit.

Chapter 4: Designing for Everyday Sounds at Home with People with Dementia and their Partners

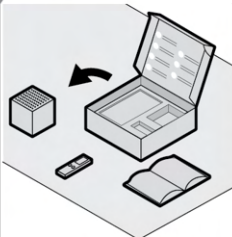
Mar '21

Howard & Lorraine
Roger & Betty
Lloyd & Janet

Apr '21

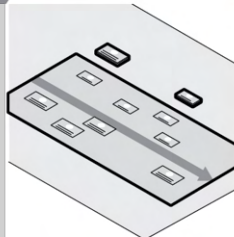
Aug '21

Home visit 1



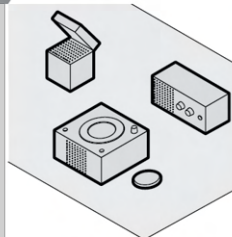
Sound probes

Home visit 2



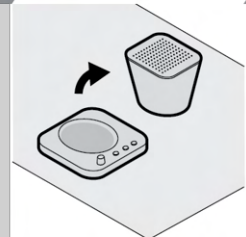
Mapping activities

Home visit 3



Mockup players

Home visit 4



Tumbler evaluation

Studententijd

Waar doet het je
aan denken?

Wil ik niet horen

Thuis
fwiet

Swim les
huur. nu
Kendmeester
Kraag quality drink

Vakantie
vroem

Waar doet het je

aan denken?
aan denken
aan denken
aan denken

Uitgaan
klap

Beste speler
vindt in elke
by hand van
Klaarheid

3

Co-Creating Personal Audio Content with People with Dementia and Their Relatives

Familiar everyday sounds can evoke autobiographical memories and personal stories from people with dementia. However, there is a lack of participatory approaches to explore, select and curate personal audio content. More insight is needed into how everyday sounds that prompt individual memories and reflections for people with dementia can be identified. This chapter presents our study in which four care dyads consisting of a person with dementia and their relative co-created personalized sets of everyday sounds. The dyads participated in three iterative sessions during which they played and categorized everyday sounds using the Life Story Soundboard. Based on the participants' responses, we elaborate on our process of tailoring sound content to the personal background and life experiences of people with dementia and their relatives. Our results show how personal audio content should match meaningful past experiences of the person with dementia and how the relative can provide collective memories of shared life experiences. We conclude how the selection of meaningful everyday sounds requires a dialogical approach and a tangible platform to explore shared experiences in the here and now.

This chapter is a reproduction of the paper currently in submission:
Maarten Houben, Rens Brankaert, Gail Kenning, Inge Bongers, and Berry Eggen.
Co-Creating Personal Audio Content with People with Dementia and Their Relatives.

3.1 INTRODUCTION

Dementia is an umbrella term for various progressive conditions and diseases that significantly impact everyday life [23]. As the condition progresses, people with dementia increasingly experience physical, cognitive, and emotional difficulties, resulting in feelings of insecurity or struggles to engage in everyday social life [15]. Therefore, design researchers are increasingly exploring how technology and design can support the social needs of people with dementia, for example, by facilitating communication and social activities with relatives [3]. These research efforts have resulted in a substantial increase in digital media applications to provide reminiscence, social interactions, or emotional experiences for people with dementia [12]. A common example is music therapy, where people with dementia can listen to music and reminisce in a social setting to reduce stress or agitation and improve the overall quality of life [31].

Currently, researchers are also exploring the beneficial effects of non-musical or everyday sounds to expand the scope of sound-based interventions for people with dementia [5,19]. Initial research has demonstrated the potential of everyday sounds as effective cues to support storytelling and facilitate social interactions by eliciting meaningful open-ended associations [19]. Everyday sounds can provide evocative cues and meaningful recollections from ordinary or everyday life experiences from the past and the present [5]. For example, beach sounds can bring back memories of past holidays.

However, identifying relevant everyday sounds that can prompt reminiscence and memories can be challenging as gathering personal content is often primarily reliant on input from relatives [1]. Furthermore, there is a risk that the collected audio content may not match the experiences of the person with dementia. Therefore, more insights are needed into how everyday sounds can be identified and personalized for people with dementia to support social and meaningful activity with their informal caregivers or relatives.

This chapter investigated how people with dementia and their relatives can select and identify meaningful everyday sounds that prompt reminiscence and social activity. Four care dyads consisting of a person with dementia and a relative participated in three iterative co-creation sessions in which they played, evaluated, and categorized everyday sounds that represented meaningful events or memories from past or present everyday life. We facilitated these sessions with the Life Story Soundboard as a tangible design

artefact that enabled the participants to play and categorize everyday sounds according to meaning and preference. We contribute to existing literature on music therapy and reminiscence in dementia by elaborating on how people with dementia can be involved in co-creating personal audio content.

3.2 BACKGROUND

3.2.1 *Design for Social Activity in Dementia*

Technologies for people with dementia have expanded beyond assistive technologies and healthcare applications, supporting all aspects of living with the condition, such as maintaining function, leisure and daytime activities, and supporting care provision [2]. This development is reflected in the increasing body of design research to improve the wellbeing of people with dementia by addressing selfhood and identity through focusing on reminiscence and creating social engagement with loved ones [29]. By sharing narratives about past life experiences, people with dementia can engage in meaningful conversations with their partners or caregivers who provide attention and acknowledgement as listeners [11]. Furthermore, storytelling is a collaborative activity beyond sharing cohesive verbal narratives as the person with dementia re-enacts or performs their story through embodied forms of communication to the listener, such as gestures or eye contact [20].

Life story books provide tangible prompts that evoke autobiographical memories to support social and person-centered activities in dementia care [10]. Personal digital media related to meaningful life events can support people with dementia in reconstructing their life stories during social activities [8]. Therefore, digital storytelling effectively supports memory and communication for people with dementia by increasing self-confidence and facilitating self-expression. However, such studies often focus on visual cues such as photographs or videos [27]. While recent works have also shown the potential of generic everyday sounds as open-ended cues to evoke memories [5,19], the personalization of everyday sounds to represent life stories is not yet explored in current literature.

3.2.2 *Personalization of Meaningful Audio Content*

Studies on music and dementia have highlighted how familiar music can evoke personal memories associated with a specific song [21]. Especially music from the teenage years successfully prompts recognition and reminiscence in people with dementia [26]. Therefore, personalized music interventions that address preference and music history

have an increased and ongoing impact on the wellbeing of people with dementia [17]. However, accessing music or curating personal playlists can be complicated for people with dementia. Therefore, the caregivers often select music for people with dementia based on biographical information such as known musical preferences, cultural background, or age group [13].

Initial research on everyday sounds and dementia explored how informal caregivers can identify meaningful ambient sounds related to shared memories and recollections for the person with dementia [5]. However, other work highlighted how people with dementia can actively select and adapt generic soundscapes according to their preferences and personal experience [19]. This chapter aims to build on this work by exploring how people with dementia and their caregivers can be actively involved in co-creating personal audio content that reflects their personal stories and experiences.

3.2.3 Co-Creation with People with Dementia and Their Partners

People with dementia can still have a say in decisions that affect them and actively participate in design activities that promote self-esteem and impact identity [28]. Participatory, creative, and arts-based activities can provide playfulness and stimulation to enable people with dementia to contribute to the design process as co-creators [32]. Furthermore, playful and creative approaches allow researchers to engage and communicate with the person with dementia directly, supported by the caregivers who provide feelings of security and acknowledgement [24].

These approaches highlight how predefined protocols are not necessarily well-suited in catering to the diverse range of needs of people with dementia [18]. Instead, designers require empathy to relate and adjust to the individual experiences of a person living with dementia [30]. Adopting a personalized approach in participatory design allows for design researchers to attend to the unique abilities that remain in the person with dementia [3]. Therefore, *design for one* approaches where a design is based on the specific needs of one individual with dementia allow for a level of personalization that offer rich understandings of the participants' unique characteristics and personal context [16].

3.3 RESEARCH SETUP

The co-creation sessions were organized as home visits by an adult daycare center. We involved four care dyads, each consisting of a person with dementia and their relative (see Table 3.1). We adopted a parallel *design for one* approach for each dyad [16] and conducted three iterative co-creation sessions together with their relative, facilitated by the first author and a professional caregiver from the daycare center.

Table 3.1: We recruited four care dyads consisting of a participant with dementia and a relative.

Participant with dementia	Age	Alzheimer stage	Relative (informal caregiver)	Relation with participant	Age
<i>Howard</i>	88	Mid	<i>Lorraine</i>	Howard's Wife	87
<i>Roger</i>	76	Mid	<i>Betty</i>	Roger's Wife	75
<i>Gilbert</i>	90	Mid	<i>Pauline</i>	Gilbert's Daughter	61
<i>Lloyd</i>	80	Early	<i>Janet</i>	Lloyd's Wife	79

3.3.1 Participants and Research Setting

First, two professional caregivers from the daycare center selected and recruited four eligible participants in this study based on the following selection criteria:

- the participant has early to moderate dementia caused by Alzheimer's disease;
- the participant lives at home and visits the daycare center;
- the participant has no severe hearing impairment;
- the participant is able to participate in the co-creation sessions;
- the participant is willing to participate and interested in sound and music.

For each participant with dementia, we recruited a relative who provided informal care at home, of which three relatives were the spouse and one was the daughter. Both professional caregivers were acquainted with all participants, but each were assigned two to divide the workload. The professional caregivers assisted the researcher during the co-creation sessions and engaged in conversations with the dyads during the sessions. The co-creation sessions took place in the living room of the participants with dementia and the relative (see Figure 3.1). The researcher and a professional caregiver were seated across from the dyads and provided instructions to guide the activity. While the participants interacted with the Life Story Soundboard, the researcher played the sounds using a laptop to simulate the technological properties of the board as we

adopted a 'Wizard of Oz' approach [22], to simulate of the technological properties of the soundboard to convey the experience of using it.

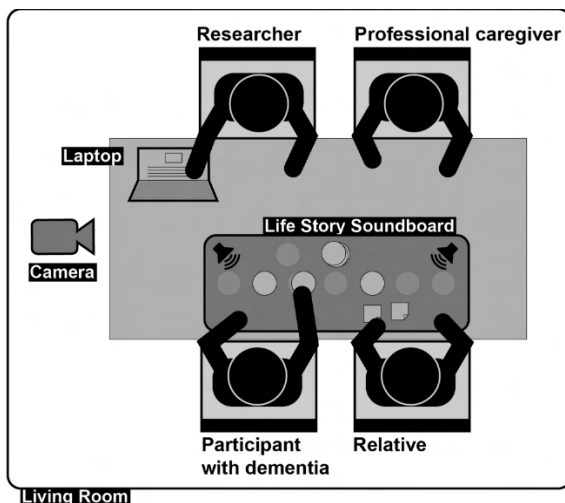


Figure 3.1: The co-creation sessions took place at the participants' homes who interacted with the Life Story Soundboard at the table in the living room.

3.3.2 Ethics

The University Ethics Review Board approved this research (RP-134) and we gained informed consent from the participant with dementia and the relative who were the legally authorized representative of each participant. We held introductory visits to get the participants acquainted with the researcher and build an initial trust relationship during an informal conversation. The researcher explained the study and presented an information booklet explaining the research aim, activities, time investment, and benefits. The informed consent was a *process* [9] as the researcher actively responded to in-context actions of the participants and communicated with the caregivers and participants continuously whether participating was still suitable. The home environment provided a safe environment for the data collection, supporting a familiar and non-intimidating setting [6]. The participants were pseudonymized for analysis and presentation in this chapter.

3.4 LIFE STORY SOUNDBOARD

We developed the Life Story Soundboard (see Figure 3.2) as a tangible interface to engage the person with dementia and their relative in playing and categorizing everyday sounds. The Life Story Soundboard was inspired by research on storyboards to support people with dementia and their caregiver to organize biographical media content, such as photos, videos, and music, according to meaningful aspects of a person's life story [8]. This approach is similar to the use of the Dementia Soundboard to play immersive soundscapes triggered by corresponding everyday objects as a way of engaging participants in the process of listening and identifying meaningful everyday sound [19].



Figure 3.2: The participants played and categorized everyday sounds by placing the corresponding sound disks on the Life Story Soundboard as the sounds were played through the speakers.

The everyday sounds were represented by a sound disk that contained an image related to the sound and a word that phonetically described it (e.g., ‘meow’). The participants could play each sound by placing the corresponding disk on one of the seven categories on the Life Story Soundboard that resembled key aspects of past life experiences: *childhood*, *student years*, *work*, *home*, *vacation*, *going out*, and *dreams* (see Figure 3.3). These categories were not intended to map the sounds on a specific period or place but as additional cues or open-ended themes for discussion and associating sounds.

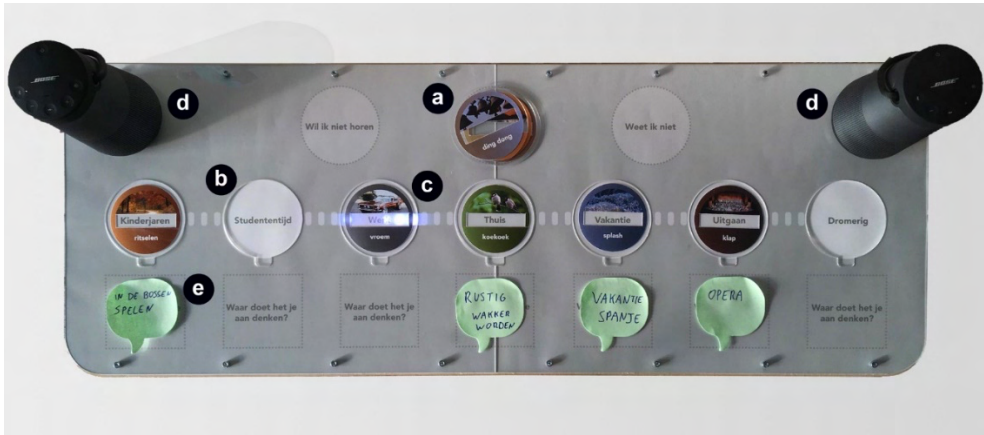


Figure 3.3: The Life Story Soundboard was a tangible interface to play and categorize everyday sounds.

First, the person with dementia was invited to pick a sound disk from a pile of stacked disks at the top of the soundboard (see Figure 3.3: a) to look at the picture and share any associations the word or image might have evoked. Next, the participants played the everyday sound by placing the sound disk on the Life Story Soundboard on a specific category (see Figure 3.3: b) based on their association with the word and image on the disk. The LEDs under each white circle with a category would light up when the sound disk was placed (see Figure 3.3: c) as the sound was played on the speakers on the board in a continuous loop (see Figure 3.3: d). The participants were given time to listen, and the researcher asked questions based on the participants' initial reactions and initiated a conversation to further explore the evoked associations and memories. After listening to each sound, the relative was provided with post-its to make annotations of the conversation to add on the allocated space below the category (see Figure 3.3: e). If the participants did not like a sound, they could discard the disk on a separate category named 'Do not want to hear' on top of the board. This procedure was repeated for all sound disks. The middle part of the disk was transparent, so the categories on the soundboard remained visible, and the disks could be stacked upon each other when multiple sounds fitted the same category.

3.5 ITERATIVE APPROACH IN PERSONALIZING EVERYDAY SOUNDS

We conducted three co-creation sessions for every person with dementia together with their relative and professional caregiver (see Figure 3.4). Each co-creation session lasted for approximately one hour to one and a half-hour, and the time between each session ranged from one to two weeks. In this section, we describe our iterative approach in using each session's outcome as input for the next session.

3.5.1 *Session 1: Generic Set of Everyday Sounds*

In the first session, all participants were presented with the same set of preselected sounds based on research by [19] to evoke initial personal associations: 1) *seaside*, 2) *birdsongs*, 3) *pets*, 4) *evening campfire*, 5) *walking in forest*, 6) *city square*, 7) *audience concert*, and 8) *car engine*. A previous study revealed how multilayered soundscapes are overwhelming for people with dementia, while single layered soundscapes were experienced as pleasant [19]. Therefore, we provided sets of single everyday sounds that were composed in the moment. First, generic sounds offered a first experience of listening to everyday sounds to sensitize the participants of the potential benefits of sound and explore their initial responses. After the session, the researcher watched the video recordings and noted the remarks and responses of the participants to the generic sounds. Next, the researcher discarded sounds that elicited no meaningful responses and selected new high-quality sound recordings from open-source online sound libraries linked to particular personal associations and memories that emerged during the first session. This resulted in a first unique set of everyday sounds to be evaluated during the second session. At the end of the first session, the relative and person with dementia were given an assignment for the second session to collect personal items such as pictures, objects, or souvenirs in a 'sound box' related to the stories and memories that emerged during the first session. The participants could keep the written post-it notes while collecting the personal items so the items were related to the sounds and stories discussed in the first session.



Figure 3.4: The iterative personalization process started from the same set of sounds for all dyads and resulted in different personalized sets based on the participants’ unique responses and input during the sessions.

3.5.2 Session 2: Personal Items and Sounds

The collected personal items were used to play the personal sounds prepared by the researcher in the second session and to further explore the participants’ backstories and past. The participants with dementia were asked to in turn present one of the personal items from their sound box and place it on the soundboard on a category that corresponded with their associated memory (see Figure 3.5). Next, the researcher played a personal sound related to the object or memory that he prepared for the session. For

example, *Betty* and *Roger* shared stories of their vacations to Spain in the first session and presented holiday pictures in the second session, after which the researcher played beach sounds with Spanish chatter in the background. If the researcher had no relevant sounds available or there was a mismatch between a sound or an object, the participant could still present it and the sound was played later in the session. The researcher made notes of the memories or associations that emerged during the sessions.



Figure 3.5: During the second session, the participants presented their personal items from the sound box (left) and listened to their personal everyday sounds by placing them on the Life Story Soundboard (right).

After the second session, the researcher iterated each participant's personal everyday sounds based on their responses by discarding sounds that were not enjoyed and searching for new sounds related to new stories, associations or more detailed descriptions that emerged during the second session. To prevent that the personal items might distract from the sounds during the third session, the researcher created unique sound disks for the participants' personal everyday sounds (see Figure 3.6).



Figure 3.6: The sound disks for the third session were personalized based on the outcome of the second session, such as the radar tower from *Howard's* pictures from his work to represent the harbor sounds.

3.5.3 Session 3: Evaluating the Second Iteration of Personal Sounds

By using the personalized disks on the Life Story Soundboard, the participants could experience their personal sounds and provide feedback while the researcher asked open-ended questions (see Figure 3.7). After the session, the researcher interviewed the professional caregivers about their experiences in general of all sessions during a short semi-structured exit interview.

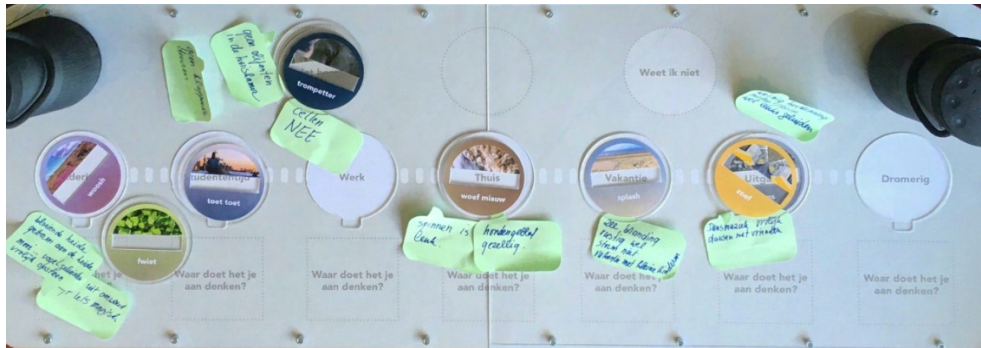


Figure 3.7: The participants explored and evaluated their personal sound sets during the third session using personalized sound disks.

3.5.4 Analysis of Iterative Process

All sessions were recorded on video, and the exit interviews were recorded on audio. All recordings were transcribed verbatim, and the transcriptions of the sessions were expanded into field texts by adding notes of nonverbal responses recorded by the video observations. To analyze the iterative process of personalizing everyday sounds, the first author conducted a theoretical or deductive thematic analysis on the field texts and interviews transcripts [4]. The researcher classified statements from all co-creation sessions and participants using codes regarding 1) responses to the everyday sounds and 2) observed interactions and communication between the participants and the relatives. The codes were iterated with the second author, and the final set of themes were further refined in consultation with all co-authors resulting in two main themes: 'Personalizing sounds to meaningful past experiences' and 'Relative as support and collective memory' that are further discussed in the following sections.

3.6 PERSONALIZING SOUNDS TO MEANINGFUL PAST EXPERIENCES

3.6.1 *Linking Sounds to Past Experiences*

The participants linked the everyday sounds to various topics such as nature, family, hobbies, work, home or vacation related to their past experiences. In this section, we discuss the responses of *Roger* to illustrate how the sounds were personalized to match the previous life experiences of the participants.

Roger mentioned many times during the sessions that he was a professional train driver at the national railways (“*I was a train driver for 40 years*”). Therefore, the researcher collected sound recordings of a train ride from the national railways that were played to *Roger* during the second session. However, *Roger* did not recognize these sounds at first, as he explained:

“Oh on the train! Oh that [sound] doesn’t do anything to me! You don’t hear that [the passenger cabin] anymore when the doors are closed!” (Roger, session 2)

These sounds were recorded in a passenger cabin of a train and did not match his recollection of driving a train. In response, the researcher played different sounds recorded in a train driver’s cabin that included auditory signals for train drivers, such as a bell that indicates the train needs to slow down. These sounds could evoke a spontaneous reaction as *Roger* immediately recognized the sounds and started laughing:

The researcher plays a bell sound from the train driver’s cabin and Roger suddenly starts to laugh and points with his index finger to the Life Story Soundboard and says: ‘That’s this! Haha! [...] That it [the train] stops.’ (Observation, Roger, session 2)

Later in the third session, *Roger* confirmed these responses and elaborated on the meaning of these sounds by further reminiscing about his experiences as a train driver:

“The dead man’s switch! You have to stand on some sort of pedal, and then you have to hold on, and when you let go of it, the train stops! Every once in a while, a bell rings, so then you take your foot off and on it again. And if you don’t, you

hear it two more times, and then it does (imitates sound), and then the train stops. I did it for 40 years and really enjoyed it!” (Roger, session 3)

This example of *Roger* illustrates how sounds that match his perceived reality can evoke recognition and familiarity. *Roger’s* professional caregiver present at the sessions acknowledged later in the interview how the personalized train driver sounds were able to evoke stronger associations from *Roger* than the sounds recorded in the passenger cabin of a modern train as it resembled his own experiences:

“He’s going back to his time as a train driver, [...] He recognized train sounds from that time faster than the sounds from current modern trains.” (Interview, Roger’s professional caregiver)

In contrast, all participants also indicated if certain sounds did not match their recollections and elaborated more in detail on their memory by clarifying how it did sound like. For example, *Lloyd* explained in the second session why the recording of a marching band did not match his recollections of when he played in a drum band in his teenage years:

“No, no... No, because that drum band only played one or two marches, and then the trumpets came in” (Lloyd, session 2)

These examples illustrate how sounds linked to past experiences could evoke recognition and familiarity, or could spark more detailed accounts of their recollections.

3.6.2 The Emotional Value of Stories and Memories

The associations and stories evoked by the sounds offered emotional experiences for the participants by recollecting memories in the moment. The example of *Roger* above indicated how reminiscing offered positive emotions, such as laughing, smiling, and acting playfully. Similarly, *Lloyd* explicitly stated how the memories evoked by the everyday sounds were more meaningful than the sound itself:

“Not the sound itself, but it reminds me of those things [...] Gives me some joy, nice to hear! [...] It’s more about the memories of the sound.” (Lloyd, session 3)

The everyday sounds could also evoke mixed feelings by reminding participants of emotionally difficult experiences in their lives. During the first session, *Gilbert* explained

how he worked as a justice officer and transported delinquents. Based on these stories, the researcher collected sounds related to prison, such as jingling keys. While *Gilbert* proudly presented his epaulettes and old handcuffs during the second session, he did not enjoy the corresponding sounds due to the associated memory:

“A terrible sound! [...] People deprived of their liberty and locked up, the only place where I’ve ever heard this was when you walk through jail.” (Gilbert, session 2)

Nevertheless, this experience was meaningful as *Gilbert* expressed he loved his job for many years and elaborated on the more challenging aspects of his work. Therefore, expressing these mixed feelings are also a way of sharing and processing difficult past experiences that shape a person’s identity:

“When children who did nothing wrong but had problems at home were placed in the same institution as criminals, I would be furious!” (Gilbert, session 2)

Therefore, the personalization of sound content should address the specific associations and meaning evoked by the sound to address a wide range of emotional experiences.

3.7 RELATIVE AS SUPPORT AND COLLECTIVE MEMORY

3.7.1 *Tapping into the Shared Memories of Relatives*

The relatives supported the participants with dementia during the sessions by acknowledging them and confirming their responses. Furthermore, the relatives expanded on the participants’ responses and provided detailed descriptions of shared memories. This section discusses the sessions with *Gilbert* and his daughter *Pauline* to illustrate how the relatives can provide rich insights in their shared experiences. During the first session, *Gilbert* indicated he recognized the *car engine* sounds by imitating the sounds out loud. *Pauline* confirmed the responses of *Gilbert* and was pleased that her father was able to recognize the sounds. This example illustrates how a positive focus on ability can support social relations by acknowledging and validating the responses of loved ones:

Gilbert: ‘That engine, it started to do, whaam whaam’

Pauline: ‘But this is something else? This is a familiar sound!’

Gilbert: ‘Yes that is the race track in Zandvoort!’

Pauline points at Gilbert: 'Haha! Exactly!'
(*Observation, Gilbert, session 2*)

Pauline also explicitly stated how she and *Gilbert* have collective memories that they can still share. These stories from family members can offer insight into potential memories and experiences for collecting meaningful audio content. *Pauline* recalled a recent memory of a holiday with her sister and *Gilbert* to Berlin and told how *Gilbert* was truly amazed by the subways rushing in and out the metro station. In response to *Pauline's* story, the researcher collected sound recordings of a subway station for the third session. Upon playing these sounds, *Gilbert* was able to recall and share his account of this shared memory:

Gilbert hears the subway doors closing, points his finger upwards, and says: "There it closes! And now yuuuup!" Gilbert imitates the sound of a departing metro and moves his hand upwards, looks ahead and makes another sign with finger and says: "There's another one coming!" (*Observation, session 3*)

The sounds played during the sessions served as additional cues to support the dyads in reminiscing together, as the participants with dementia expressed their reactions to the sounds, and the relatives acknowledged their recollections of shared memories.

3.7.2 Balancing Different Perspectives

All relatives at some point interrupted or spoke for the participants with dementia who needed more time to express their thoughts or find their words. These interruptions or corrections would distract the participants and make them lose track of the story they were telling. The professional caregiver present at the session with *Howard* explained in the exit interview how informal caregivers tend to react in this manner because they try to compensate for lost abilities and skills of their partners:

"She corrects him very often and tries to keep him in the here and now. These actions often come from what partners miss as they feel their partner slipping away [...] But then you also see the irritation arising in the person with dementia, who is constantly corrected." (*Interview, Howard's professional caregiver*)

While the relatives can offer rich and insightful contributions, this quote illustrates the difficulty and sensitivity of balancing the perspectives of the participants and their relatives in ensuring all voices are heard and respected.

3.8 DISCUSSION

With the iterative approach facilitated by the Life Story Soundboard, we personalized the same set of everyday sounds for all participants, resulting in four unique and personal sound sets (see Figure 3.4). While the first session introduced the participants to everyday sounds, the second session opened up the conversation and further explored the shared lived experiences and sounds associated with these events. In the last session, the personal sounds could be experienced by the participants who shared their accounts of past life experiences. We further discuss how the selection of meaningful everyday sounds requires a dialogical approach by exploring shared experiences in the moment with relatives or caregivers and providing a tangible platform for curating personal sound content.

3.8.1 Adopting a Dialogical Approach

Our results indicated how the appropriateness of everyday sounds depends on the participants' specific and individual lived experiences. Recordings that closely resembled previously experienced sounds in everyday life could evoke spontaneous recognition and a familiar association similar to how people with dementia are likely to recognize music from their teenage years [26]. The process of identifying sounds from everyday life was a journey into the participants' past life experiences, values, and history before their diagnosis of dementia that added meaning to their present experiences. While positive memories could provide pleasure or excitement to the participants, emotionally difficult experiences could also result in mixed feelings such as nostalgia. Therefore, the personalization of audio content should also address a full range of different emotions and experiences that represent a person's life story.

The *design for one* [16] approach offered space and flexibility to personalize the sounds and cater to each participant's uniqueness. This level of personalization required an iterative process where the responses of the person with dementia could be explored, captured, and considered for the next iteration. To act upon these responses, researchers or designers need to interpret the results and unexpected contributions of people with dementia [3]. During the sessions, the researcher acted in the moment and improvised by playing specific sounds in response to a story or reaction expressed by the

participants with dementia, such as *Roger's* train driver sounds. Therefore, this iterative approach was a 'dialogic composition' with an ongoing interchange between the researcher and the participant with dementia that evolved by exploring responses and emotional expressions to sound [7]. We recognize the researcher's influence on the sessions' outcomes and position the person with dementia as a co-creator in the design study [32]. Therefore, the final sets of everyday sounds resulted from the dialogical collaboration between the researcher and the dyads through mutual listening, conversation, and learning.

3.8.2 Exploring Shared Experiences In-The-Moment

The co-creation sessions demonstrated how the involved dyads all had a collective memory as the relatives uncovered meaningful memories for the person with dementia. Family members are often consulted to collect materials for delivering reminiscence to the person with dementia [8]. Similarly, the personal items were mostly collected by the relative, but helped to uncover past experiences or memories embedded in these objects to identify related or associated sounds. Therefore, the relative can act in a supportive role and give rich recollections of their shared life. The professional caregiver and design researcher should act as mediators to carefully divide attention between participants and relatives by actively listening to both and keeping their feelings and sensitive situation in mind.

Engaging with everyday sounds offered a shared activity for the duos that involved reminiscence and storytelling. Sharing memories benefits the person with dementia, as storytelling in social settings gives feelings of encouragement and achievement [25]. Social activities offered to people with dementia and their relatives tend to be locked into the past to provide a sense of connection with themselves, built on shared histories and events. This focus on the past often comes from the relative's need to be reassured when the person with dementia engages with a memory or recollection that reaffirms their connection and past experiences. However, using sounds to prompt associations gives a sense of a memory and reduces the focus on the exactness of remembering events, places, or people. We suggest using everyday sounds to provide open-ended associations to enable the person with dementia to reconstruct these past experiences as their present selves and share reflections on a lived life with loved ones.

3.8.3 A Tangible Platform for Curating Personal Sound Content

The evaluation of sound content is challenging as sounds are intangible and emerge or disappear over time [14]. The Life Story Soundboard provided a tangible interface as

visual support in selecting and evaluating audio content for the participants and relatives. For example, the participants could pick up, organize, or discard the sound disks to engage with the everyday sounds as a shared activity with the relative. The Life Story Soundboard offered different roles where the person with dementia played and categorized sounds, and the relative was in a supportive role by making notes and providing additional insights into their shared memories.

The participants actively contributed to the sessions by voicing their opinions or expressing emotional responses while engaging with the soundboard. Therefore, our findings build further on previous research on how interactive design artefacts can engage participants with dementia in the process of listening and identifying meaningful everyday sounds [19]. We contribute to this work by demonstrating how design artefacts should offer flexibility and personalization to tailor sound-based experiences to the unique preferences, needs, and life history of people with dementia. Therefore, the curation of meaningful audio content requires a platform that provides an accessible and tangible interface, allows for shared activity between the person with dementia and the relative, and offers personalized participation to address the uniqueness of each person with dementia.

3.9 CONCLUSION

The co-creation sessions resulted in personalized sets of everyday sounds to evoke recollections of past experiences and a lived life for people with dementia and their relatives. We have highlighted how a dialogical approach can enable the selection of audio content based on life experiences, values, and stories to enable people with dementia to connect to themselves through open-ended engagement with sound. Furthermore, we argue how dyadic interventions should focus on shared experiences in the moment. We aim to motivate future research to explore how personal everyday sounds can provide meaningful activity for people with dementia and their loved ones, focusing on life review, reflection, and social engagement.

3.10 REFERENCES

- [1] Sérgio Alves, Filipa Brito, Andreia Cordeiro, Luís Carriço, and Tiago Guerreiro. 2019. Designing Personalized Therapy Tools for People with Dementia. In Proceedings of the 16th International Web for All Conference (W4A '19), Association for Computing Machinery, New York, NY, USA. DOI:<https://doi.org/10.1145/3315002.3317571>
- [2] Arlene J. Astell, Nicole Bouranis, Jesse Hoey, Allison Lindauer, Alex Mihailidis, Chris Nugent, and Julie M. Robillard. 2019. Technology and Dementia: The Future is Now. *Dement Geriatr Cogn Disord* 47, 3 (2019), 131-139. DOI:<https://doi.org/10.1159/000497800>
- [3] Rita Maldonado Branco, Joana Quental, and Oscar Ribeiro. 2017. Personalised participation:

- an approach to involve people with dementia and their families in a participatory design project. *CoDesign* 13, 2 (2017), 127–143. DOI:<https://doi.org/10.1080/15710882.2017.1310903>
- [4] Virginia Braun and Victoria Clarke. 2006. Using thematic analysis in psychology. *Qual Res Psychol* 3, 2 (January 2006), 77–101. DOI:<https://doi.org/10.1191/1478088706qp0630a>
- [5] Sarah Campbell, David Frohlich, Norman Alm, and Adam Vaughan. 2019. Sentimental Audio Memories: Exploring the Emotion and Meaning of Everyday Sounds. In *Dementia Lab 2019. Making Design Work: Engaging with Dementia in Context. D-Lab 2019.*, Rens Brankaert and Wijnand IJsselstein (eds.). Springer, Cham, 73–81. DOI:https://doi.org/10.1007/978-3-030-33540-3_7
- [6] Daphne Sze Ki Cheung, Shuk Kwan Tang, Ken Hok Man Ho, Cindy Jones, Mimi Mun Yee Tse, Rick Yiu Cho Kwan, Kit Ying Chan, and Vico Chung Lim Chiang. 2021. Strategies to engage people with dementia and their informal caregivers in dyadic intervention: A scoping review. *Geriatr Nurs (Minneap)* 42, 2 (2021), 412–420. DOI:<https://doi.org/https://doi.org/10.1016/j.gerinurse.2021.02.002>
- [7] Chris J. H. Cook. 2021. Trevurr: A dialogic composition on dementia, auraldiversity and companion listening. *Organised Sound* 26, 2 (2021), 230–239. DOI:<https://doi.org/10.1017/S1355771821000273>
- [8] Masashi Crete-Nishihata, Ronald M. Baecker, Michael Massimi, Deborah Ptak, Rachelle Campigotto, Liam D. Kaufman, Adam M. Brickman, Gary R. Turner, Joshua R. Steinerman, and Sandra E. Black. 2012. Reconstructing the Past: Personal Memory Technologies Are Not Just Personal and Not Just for Memory. *Hum Comput Interact* 27, 1–2 (April 2012), 92–123. DOI:<https://doi.org/10.1080/07370024.2012.656062>
- [9] Jan Dewing. 2007. Participatory research: A method for process consent with persons who have dementia. *Dementia* 6, 1 (February 2007), 11–25. DOI:<https://doi.org/10.1177/1471301207075625>
- [10] Teuntje R. Elfrink, Sytse U. Zuidema, Miriam Kunz, and Gerben J. Westerhof. 2018. Life story books for people with dementia: a systematic review. *Int Psychogeriatr* 30, 12 (2018), 1797–1811. DOI:<https://doi.org/10.1017/S1041610218000376>
- [11] Deborah I. Fels and Arlene J. Astell. 2011. Storytelling as a Model of Conversation for People With Dementia and Caregivers. *Am J Alzheimers Dis Other Demen* 26, 7 (November 2011), 535–541. DOI:<https://doi.org/10.1177/1533317511429324>
- [12] David M. Frohlich, Emily Corrigan-Kavanagh, Sarah Campbell, Theopisti Chrysanthaki, Paula Castro, Isabela Zaine, and Maria da Graça Campos Pimentel. 2020. Assistive Media for Well-being. In *HCI and Design in the Context of Dementia*, Rens Brankaert and Gail Kenning (eds.). Springer International Publishing, Cham, 189–205. DOI:https://doi.org/10.1007/978-3-030-32835-1_12
- [13] Sandra Garrido, Laura Dunne, Catherine Stevens, and Esther Chang. 2021. Music playlists for people with dementia: Qualitative evaluation of a guide for caregivers. *Sci Prog* 104, 2 (April 2021), 00368504211014353. DOI:<https://doi.org/10.1177/00368504211014353>
- [14] William W. Gaver. 1993. How Do We Hear in the World? Explorations in Ecological Acoustics. *Ecological Psychology* 5, 4 (1993), 285–313. DOI:https://doi.org/10.1207/s15326969ecoo504_2
- [15] Sylwia Górska, Kirsty Forsyth, and Donald Maciver. 2017. Living With Dementia: A Meta-synthesis of Qualitative Research on the Lived Experience. *Gerontologist* 58, 3 (2017), e180–e196. DOI:<https://doi.org/10.1093/geront/gnw195>
- [16] Marjolein C. den Haan, Rens Brankaert, and Yuan Lu. 2020. Design for One: Personalisation and experiences of design researchers and participants. *Proceedings of the 6th International Conference on Design Creativity, ICDC 2020 (2020)*, 279–286. DOI:<https://doi.org/10.35199/ICDC.2020.35>
- [17] Katherine Hackett, Steven R. Sabat, and Tania Giovannetti. 2021. A person-centered framework for designing music-based therapeutic studies in dementia: current barriers and a path forward. *Aging Ment Health* 0, 0 (2021), 1–10. DOI:<https://doi.org/10.1080/13607863.2021.1931029>
- [18] Niels Hendriks, Karin Slegers, and Pieter Duysburgh. 2015. Codesign with people living with cognitive or sensory impairments: a case for method stories and uniqueness. *CoDesign* 11, 1 (January 2015), 70–82. DOI:<https://doi.org/10.1080/15710882.2015.1020316>
- [19] Maarten Houben, Rens Brankaert, Saskia Bakker, Gail Kenning, Inge Bongers, and Berry Eggen. 2019. Foregrounding Everyday Sounds in Dementia. In *Proceedings of the 2019 on Designing Interactive Systems Conference - DIS '19*, ACM Press, New York, NY, USA, 71–83. DOI:<https://doi.org/10.1145/3322276.3322287>
- [20] Lars-Christer Hydén. 2013. Storytelling in dementia: Embodiment as a resource. *Dementia* 12, 3 (February 2013), 359–367. DOI:<https://doi.org/10.1177/1471301213476290>
- [21] Lisa Kelly and Bill Ahessy. 2021. Reminiscence-

- Focused Music Therapy to Promote Positive Mood and Engagement and Shared Interaction for People Living With Dementia. *Voices: A World Forum for Music Therapy* 21, 2 SE-Research (June 2021). DOI:<https://doi.org/10.15845/voices.v21i2.3139>
- [22] Scott R. Klemmer, Anoop K. Sinha, Jack Chen, James A. Landay, Nadeem Aboobaker, and Annie Wang. 2000. Suede: A Wizard of Oz Prototyping Tool for Speech User Interfaces. In *Proceedings of the 13th annual ACM symposium on User interface software and technology - UIST '00 (UIST '00)*, ACM Press, New York, New York, USA, 1–10. DOI:<https://doi.org/10.1145/354401.354406>
- [23] Susan L. Mitchell, Joan M. Teno, Dan K. Kiely, Michele L. Shaffer, Richard N. Jones, Holly G. Prigerson, Ladislav Volicer, Jane L. Givens, and Mary Beth Hamel. 2009. The clinical course of advanced dementia. *New England Journal of Medicine* 361, 16 (2009), 1529–1538. DOI:<https://doi.org/10.1056/NEJMoa0902234>
- [24] S. Neves, A. Macdonald, M. Poole, and K. Harrison Dening. 2021. Participatory Co-design: Approaches to Enable People Living with Challenging Health Conditions to Participate in Design Research. In *Perspectives on Design and Digital Communication II: Research, Innovations and Best Practices*, Nuno Martins, Daniel Brandão and Fernando Moreira da Silva (eds.). Springer International Publishing, Cham, 193–216. DOI:https://doi.org/10.1007/978-3-030-75867-7_13
- [25] Kristina Niedderer, Vjera Holthoff-Deotto, Thomas J. L. van Rompay, Armağan Karahanoğlu, Geke D. S. Ludden, Rosa Almeida, Raquel Losada Durán, Yolanda Bueno Aguado, Jennifer N. W. Lim, Tina Smith, Dew Harrison, Michael P. Craven, Julie Gosling, Laura Orton, and Isabelle Tournier. 2022. This is Me: Evaluation of a boardgame to promote social engagement, wellbeing and agency in people with dementia through mindful life-storytelling. *J Aging Stud* 60, (2022), 100995. DOI:<https://doi.org/10.1016/j.jaging.2021.100995>
- [26] Chirag B. Rao, John C. Peatfield, Keith P. W. J. McAdam, Andrew J. Nunn, and Dimana P. Georgieva. 2021. A Focus on the Reminiscence Bump to Personalize Music Playlists for Dementia. *J Multidiscip Healthc* 14, (August 2021), 2195–2204. DOI:<https://doi.org/10.2147/JMDH.S312725>
- [27] Adriana Maria Rios Rincon, Antonio Miguel Cruz, Christine Daum, Noelannah Neubauer, Aidan Comeau, and Lili Liu. 2021. Digital Storytelling in Older Adults With Typical Aging, and With Mild Cognitive Impairment or Dementia: A Systematic Literature Review. *Journal of Applied Gerontology* (May 2021), 07334648211015456. DOI:<https://doi.org/10.1177/07334648211015456>
- [28] Paul A. Rodgers. 2018. Co-designing with people living with dementia. *CoDesign* 14, 3 (2018), 188–202. DOI:<https://doi.org/10.1080/15710882.2017.1282527>
- [29] Paul A. Rodgers (Ed.). 2022. *Design for People Living with Dementia*. Routledge, New York. DOI:<https://doi.org/10.4324/9781003095460>
- [30] Wina Smeenk, Janienke Sturm, and Berry Eggen. 2018. Empathic handover: how would you feel? Handing over dementia experiences and feelings in empathic co-design. *CoDesign* 14, 4 (October 2018), 259–274. DOI:<https://doi.org/10.1080/15710882.2017.1301960>
- [31] Mahsa Soufneyestani, Arshia Khan, and Mina Sufneyestani. 2021. Impacts of Music Intervention on Dementia: A Review Using Meta-Narrative Method and Agenda for Future Research. *Neurol Int* 13, 1 (2021), 1–17. DOI:<https://doi.org/10.3390/neurolint13010001>
- [32] Emmanuel Tseklevs, Amanda F Bingley, Maria A Luján Escalante, and Adrian Gradinar. 2018. Engaging people with dementia in designing playful and creative practices: Co-design or co-creation? *Dementia* 19, 3 (August 2018), 915–931. DOI:<https://doi.org/10.1177/1471301218791692>



4

Designing for Everyday Sounds at Home with People with Dementia and their Partners

People with dementia and their caregivers aging in place have expressed the need for social, emotional, and recreational interventions at home. Listening to everyday sounds evokes memories and provides conversational cues to support social relations and elicit emotional responses for people with dementia. However, research has yet to explore how these meaningful experiences can be transferred into home settings. This chapter presents the insights from our co-design study that involved three people with dementia and their partners in developing an interactive sound player for listening to everyday sounds at home. We report on the motivations of people with dementia and their caregivers to engage in meaningful sound-based activities at home and present the Tumbler as a prototype to foster initiative and agency in exploring familiar everyday sounds. We present design implications of how sound can enrich the everyday experiences of dementia by facilitating social and pleasurable moments at home.

This chapter is a reproduction of the paper published as:
Maarten Houben, Rens Brankaert, Gail Kenning, Inge Bongers, and Berry Eggen. 2022. Designing for Everyday Sounds at Home with People with Dementia and their Partners. In CHI Conference on Human Factors in Computing Systems (CHI '22). Association for Computing Machinery, New York, NY, USA, Article 514, 1–15. <https://doi.org/10.1145/3491102.3501993>

4.1 INTRODUCTION

As populations are aging, the number of people with dementia increases substantially and is expected to keep rising in the coming years [2]. Healthcare systems are currently under pressure to cope with this increasing care demand [66]. Therefore, policymakers and governments advocate the need for support strategies and care services to enable people with dementia to stay longer at home [98]. These strategies benefit people with dementia and their informal caregivers who prefer to live independently at home as their place of choice instead of moving to an assisted living environment [87]. People with dementia living at home rely on their partner or spouse to provide informal care and support them in activities of daily living [24]. However, providing care is difficult for informal caregivers since they experience emotional stress due to heavy workloads [77] and expressed the need for support in providing care activities at home [22].

Research in HCI is exploring the role of technology in contributing to the wellbeing of people with dementia and their caregivers [58,70]. This research has demonstrated how multisensory technologies that offer auditive [47,71,91] and visual cues [3,45,84,88] can support meaningful activities such as reminiscence therapy [1,34,59] and music sessions [20,60,71] to support a sense of selfhood and social participation in dementia care homes [34,47,71,84]. Technology aimed at people with dementia living at home often focuses on assisting daily activities [11], such as calendar reminders [81,97] or safe walking [17,93]. However, people with early-stage dementia prioritized different needs, such as psychosocial interventions that support emotional expression, recreational activity, and social engagement at home [22]. While people in the early to mid-stages of dementia benefit from meaningful activities such as music therapy, these activities are often limited to formal care settings such as adult daycare centers [9]. Therefore, researchers are increasingly investigating how technology can offer meaningful activities at home that enrich the everyday lives of people with dementia and their partners [19,20,94].

Everyday sounds can enrich the mundane [52] as sounds can evoke mindful experiences of everyday life [19,75]. For example, sounds that represent park settings can evoke stories from family trips to a local playground [19]. Similarly, experiencing sounds from everyday life can evoke storytelling, elicit emotional responses, and cue social interactions for people with dementia in institutionalized care settings [46,47]. But while research has previously explored how to make music accessible at home for people with dementia [20,89,94], there is still a gap of knowledge on how non-musical sounds

can support meaningful activities in home settings and how they evoke social engagement between people with dementia and their informal caregivers.

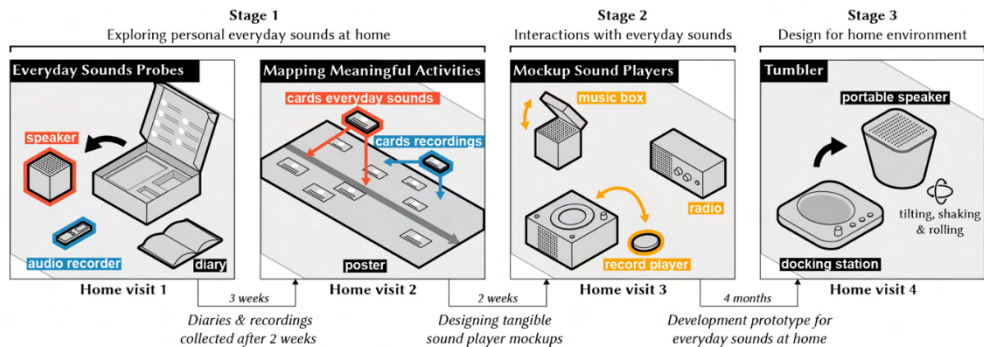


Figure 4.1: This co-design study involved three couples living with dementia in: stage 1) to map meaningful activities evoked by everyday sounds at home; stage 2) to explore interactions with mockups to play everyday sounds and; stage 3) to evaluate the Tumbler as an interface for meaningful sound-based experiences at home.

This chapter reports on our co-design study (see Figure 4.1) that closely involved three people with dementia and their partners to explore: 1) how listening to personal everyday sounds prompts meaningful experiences that enrich the home life of people with dementia and their informal caregivers, and; 2) how technology can enable these experiences at home. We adopted a three-stage inclusive research approach to explore, design, and evaluate technology with people with dementia and their partners [16]. In the *first stage* of the co-design study, we deployed a speaker with personal everyday sounds, an audio recorder, and a diary at the participants' homes to understand how everyday sounds could contribute to their daily activities and routines. In the *second stage*, the participants engaged with three sound player mockups to explore different interactions to select and experience their personal everyday sounds. In the *third stage*, we designed the Tumbler as a sound player prototype that the participants evaluated during an initial user test.

Our results reveal novel opportunities for technology that enables listening to everyday sounds to evoke conversations and social connections to support the care relationship between people with dementia and their partners. Furthermore, the outcome of the co-design study provides insight into the affordances and interaction design choices that can facilitate non-musical audio experiences in the home environment. We contribute to existing work by highlighting how technology that is accessible and inclusive can

focus on the experience of dementia at home by enriching everyday life and providing agency through exploration.

4.2 BACKGROUND

4.2.1 *Technology and Dementia*

Dementia is a chronic condition caused by various brain diseases such as Alzheimer's that result in a decline of physical and cognitive functioning, such as memory loss, aphasia, or affected motor skills [21,69]. Therefore, people with dementia have difficulties with everyday tasks such as cooking or bathing and require support from a caregiver [68]. Assisted living technologies aim to address these care needs [13] by compensating for the difficulties in performing everyday activities [11] and providing cognitive support in home environments [57]. For example, GPS-tracking devices can enable safe walking [17,93], conversational agents can prompt calendar reminders or grocery lists [97], or augmented reality applications can offer step-by-step guidance in everyday tasks such as cooking [96] or personal hygiene [67].

Over the years, researchers have also recognized how assistive technologies often reflect a medical perspective focused on disability [13] and have questioned the biomedical agenda of how people with dementia are often identified by their symptoms [4]. These viewpoints are reflected in the emergent body of work in HCI on how technology can support a broader range of experiences related to dementia [58]. These approaches have resulted in an emergent body of experienced-centered design [70] to facilitate meaningful social activities [33,45,71]. For example, digital media such as sound [47,71] or images [3,88] can provide conversational cues for people with dementia to actively support them in social participation and offer a sense of agency [33,47,84]. Similarly, virtual reality can offer meaningful experiences to people with dementia that can be shared with caregivers or relatives [44,85]. Recent works have indicated a similar value of sensory stimulation for people in early to moderate stages of dementia [45,46,91] to evoke reminiscence in daycare activities [46], physical activity with informal caregivers [91], and social engagement within families [45]. Therefore, there is an increasing interest in technologies that address the social and emotional experiences of people with mild to moderate stages of dementia at home [9,19,20].

4.2.2 *Everyday Sounds at Home*

Numerous studies have demonstrated the benefits of music for people with dementia [78], such as providing social connection [36,71], evoking positive emotions [7], and

stimulating physical exercise [51,60,91]. While there is a large body of research on music and dementia [8,78], there is a dearth of work on the impact of everyday sounds on people with dementia [19]. Ordinary or non-musical sounds are often disregarded, yet these everyday sounds shape our daily interactions and unconsciously guide our emotions and behavior [5]. HCI studies have indicated how familiar everyday sounds at home evoke memories associated with meaningful aspects of a household's family life [74] and result in positive emotional responses for the listener [75]. Audio recorders and sound players can therefore provide new opportunities for families to capture and relive sound-related memories [31]. Listening to everyday sounds can also connect community-dwelling older adults by sonically representing activities of each other's households [6].

In the context of dementia, everyday sounds generate cues for reminiscence and conversations that provide meaningful group activities in adult daycare settings [46]. Furthermore, sound-based interventions such as music pillows or sound players can provide verbal and non-verbal forms of communication in residential care settings between caregivers and people with dementia [47,61,86]. In addition, informal caregivers have expressed opportunities for using everyday sounds to facilitate shared activities with their loved one with dementia [19]. Therefore, we build further on existing research [20,89,94] by investigating how technology can support meaningful activities based on everyday sounds at home for people with dementia.

4.2.3 Co-Design in Dementia

Universal co-design methods pose several challenges for people with dementia, such as understanding abstractions or verbally expressing thoughts and opinions [41]. Therefore, co-design approaches need to be tailored to the remaining abilities of people with dementia to foster active participation [15,42,50,73,80]. Physical artifacts, materials, or prototypes provide tangible prompts for social engagement and create a pleasant activity that reduces the potential burden for the person with dementia [50,80]. Bespoke design probes can cue personal narratives and values in people with dementia and lead to a better understanding of the everyday experiences of dementia by the designer or researcher [35,92]. Concrete examples of technologies or designs can convey abstract concepts to people with aphasia [27]. For example, mockups can define expectations for people with dementia early in the design phase and elicit meaningful forms of interaction [72,73]. Similarly, physical prototypes enable people with dementia to evaluate user interfaces and raise design improvements to tailor the interactions to their abilities [33,81,89].

These studies have also argued against using dedicated methods or rigid protocols due to the highly diverse experiences of dementia in terms of cognitive abilities, social network, and cultural context [42]. Instead, a relational approach is required where the design researcher builds a mutual relation of trust with the person with dementia and their relatives [10,40,73]. Informal visits involving small talk and casual conversation can help researchers and designers to understand the participants' general life circumstances and create mutual familiarity before the research or design activities [10]. This personalized approach often requires the involvement of family members who have shared life experiences with the person with dementia and can contribute rich understandings about the participants' narratives and behaviors [15,27]. The presence of family also provides feelings of safety, but they might interfere and impede the person with dementia in voicing their opinions [76]. Therefore, adopting a reflective approach allows the researcher to address the asymmetric relations between the caregiver and receiver of care [26] by mediating attention to ensure family members amplify instead of suppress the person with dementia [27].

4.3 STUDY DESIGN

In this chapter, we report our co-design study involving three couples that consisted of a person with dementia and their partner in designing a tangible device to play personal and meaningful everyday sounds at home.

4.3.1 *Research Context: Part of Ongoing Longitudinal Study*

The co-design study reported in this chapter was the second part of a longitudinal study to explore how everyday sounds can support people living with dementia at home. In the first part, the couples identified personal everyday sounds that reflected their preferences, personal background, and shared memories. In this chapter, we report the second part of this study that builds on the results of the first part by exploring the context and interaction design of a prototype to play these personal everyday sounds at home. The personal everyday sounds that emerged from the first part of the longitudinal study (see Table 4.1) were used as audio content during all stages of the co-design study reported in this chapter.

Table 4.1: In total, three couples including a person with dementia and their spouse participated in this study.

Participant	Age	Stage of Dementia	Spouse	Age	Personal Everyday Sounds Collected in First Part of Longitudinal Study
Howard	88	Moderate	Lorraine	87	Radio Bulletin, Workshop, Harbor, Seaside, Birdsong, Motor
Roger	76	Moderate	Betty	75	Train Cabin, Spain, Paris, Mountains, German Shepard, Sparrows
Lloyd	80	Early-Moderate	Janet	79	Park, Drum Band, Concert, Train Ride, Fireplace, Cat, Seaside

4.3.2 Participants and Personal Everyday Sounds

In this study, we involved three care dyads consisting of a person with mild to moderate dementia and their spouse as an informal caregiver. The care organization of a daycare center recruited participants who: 1) were in an early to moderate stage of dementia caused by Alzheimer's disease; 2) lived at home and visited an adult daycare center at least once per week; 3) had no severe auditory processing disorders or had an electronic hearing aid; 4) had an interest in sound and music and were willing to participate; 5) had an informal caregiver who was also willing to participate. We also recruited the informal caregivers to share their own experiences of providing care. The husbands were diagnosed with Alzheimer's disease for all three couples, and their wife was the informal caregiver (see Table 4.1). Two participants [*Howard* and *Roger*] had moderate stage dementia, and one participant [*Lloyd*] had early to moderate dementia.

4.3.2.1 Howard & Lorraine

Howard (88) lives with his wife *Lorraine* (87) in a terrace house in a quiet suburban neighborhood. *Howard* worked in a large electronics company that was promoted in a *Radio Bulletin*. The *Workshop* sounds such as shaving, sawing, or hammering cued *Howard* to explain how he enjoyed woodworking in his spare time. *Harbor* sounds brought back memories from when *Howard* installed radar equipment at the coastline for his work. Sounds from the *Seaside* reminded the couple of their holidays, and they both enjoyed the *Birdsong* sounds. *Motor* sounds offered cues for *Howard* to talk about his brother, who drove a motorcycle back in his childhood.

4.3.2.2 Roger & Betty

Roger (76) and his wife Betty (75) live in a ground-floor assisted living apartment near the city center. Roger was a train driver for more than 40 years, and *Train Cabin* sounds refer to Roger's past work and passion which has always been trains. Sounds from *Spain* (e.g., waves and Spanish market), *Paris* (e.g., accordion music and traffic), or *Mountains* (e.g., howling wind and cowbells) evoked memories related to the many holidays of Roger and Betty. *German Shepard* sounds reminded Roger of the breed of dogs that his father used to own. The *Sparrows* reminded the couple of their old home, where these birds would nest in the hedge in front of the house.

4.3.2.3 Lloyd & Janet

Lloyd (80) and his wife Janet (79) live in a bungalow in a suburban neighborhood. The *Park* sounds resembled the sounds in the park near their house, where they often go for a walk. *Drum Band* recordings reminded Lloyd of his teenage years when he played the drums and was the foreman in a local percussion band that paraded in the streets. The *Concert* sounds represented the many concerts Lloyd and Janet attended due to their volunteering at the info desk in the local concert hall. Similarly, *Train Ride* sounds brought back memories of their city trips with the train and visiting art galleries and museums. *Fireplace* and *Cat* sounds provided feelings of comfort from home to the couple, and they both enjoyed the *Seaside* sounds.

4.3.3 Stages of the Co-Design Study

We adopted a three-stage co-design approach (see Figure 4.1) to involve people with dementia and their caregivers in exploring, designing, and evaluating technological interventions [16,83]. In *stage 1*, we explored the potential use of everyday sounds in the home of the participants. In a first home visit, we deployed a speaker with their personal sounds, an audio recorder, an information booklet, and a diary. The participants used the speaker with their personal everyday sounds and recorded additional meaningful everyday sounds in their surroundings while reporting their experiences in a diary. In the second home visit that followed three weeks later, the participants mapped their experiences of the speaker and recorder on a timeline poster which revealed novel opportunities for personal everyday sounds to cue meaningful activities in their household. In *stage 2*, the participants could engage with three mockups of potential sound players and explore the affordances and interactions that align with their abilities. In *stage 3*, the participants evaluated the Tumbler: a high-fidelity prototype that offered access to the participants' everyday sounds through an intuitive and accessible interface.

The co-design sessions were conducted as home visits moderated by the first author, further referred to as the researcher. The co-design study took place over four organized home visits for each couple that lasted for approximately one hour to one and a half-hour with all participants taking part in all three stages. The time between *stage 1* and *stage 2* was approximately two weeks, while *stage 3* followed four months later as this time was needed to develop the Tumbler prototype.

4.3.4 Data Collection and Analysis

During the home visits, we collected 1) audio recordings; 2) video recordings with a GoPro; and 3) photographic documentation. In total, 12,5 hours of audio recordings were transcribed verbatim. Similarly, 12,5 hours of video footage were analyzed for 1) non-verbal expressions, such as smiling, body posture, or opening eyes, 2) gestures between participants and their partners; and 3) physical interactions with the mockups or Tumbler. The audio transcriptions were expanded into field texts by annotating the transcriptions with the non-verbal responses observed from the video footage. The first author analyzed these rich field texts using thematic analysis as an inductive research analysis step [18]. The data analysis was performed for every stage separately to identify general themes and insights that informed the next stage. The first author classified statements from the field texts using codes considering reoccurring themes and trends and developed sub-codes based on the relevance to the research questions. The first initial set of codes was discussed and iterated with the second author, and the final set of themes was further refined, discussed, and iterated in consultation with all coauthors.

4.3.5 Ethics

This research was approved by the Ethics Review Board of Tilburg School of Social and Behavioral Sciences (RP-134) and by the scientific committee of the care organization involved in recruiting the participants. The research protocol and data management plan were reviewed and cleared by the University Data Steward following the General Data Protection Regulation (GDPR). Pseudonyms are used in this chapter to protect the participants' identities. Two contact persons at the involved care organization selected and recruited eligible participants with dementia when matching the inclusion criteria. We gained informed consent from the participants with dementia and their spouses, who also were the participant's legally authorized representatives. An information booklet was presented to the participants that explained all information of the formal information letters in a way that was understandable and accessible, such as research aim, activities, time investment, and benefits for the participant. The researcher also carefully explained the study setup and answered the participants' questions.

The participants were already acquainted with the researcher and had established a trust relationship as part of their participation in the first part of the longitudinal study. This study was set in the participants' homes, which provided a safe and familiar environment for the co-design activities [23]. The informal caregiver was present during all research activities, ensuring a safe inclusion in this study [76]. As dementia progresses, we adopted a process consent method [28] by responding to the in-context reactions in an ongoing dialogue with the caregivers and participants [25]. Therefore, the informal caregivers and the researcher continuously assessed whether participating in the study was still suitable for the person with dementia. Lastly, all activities and engagement with participants were in line with national COVID-19 measures and closely monitored by the care organization. After the study, the participants could keep the everyday sounds probes used in *stage 1* as compensation.

4.4 STAGE 1: EXPLORING PERSONAL EVERYDAY SOUNDS AT HOME

This section reports on the method and findings of *stage 1*, in which we gained insight into the context in which listening to personal everyday sounds is meaningful.

4.4.1 Method Stage 1: Everyday Sounds Probes

We provided the participants with everyday sounds probes (see Figure 4.2) that consisted of: 1) a speaker with personal everyday sounds; 2) an audio recorder; 3) an information booklet, and; 4) a diary. The speaker and recorder were commercially available products and were used in this study as technology probes [14] to sensitize the participants on the potential use of everyday sounds in their homes. While the speaker and recorder are not newly designed technologies, both probes are novel from the participants' perspectives, making them appropriate as technology probes [49]. We selected a speaker with a simple interface containing an on-off switch and two buttons for adjusting the volume and selecting sound files. The speaker contained an SD card with the personal everyday sounds identified in the first part of the longitudinal study (see Table 4.1) that would instantly play when switched on. Similarly, we used an audio recorder with a simple interface so the participants could easily record new additional everyday sounds. Both devices were annotated with stickers to make the interface clearer and match the instructions provided in the booklet. The diary contained questions for the participants to report daily on the use of the speaker and recorder.

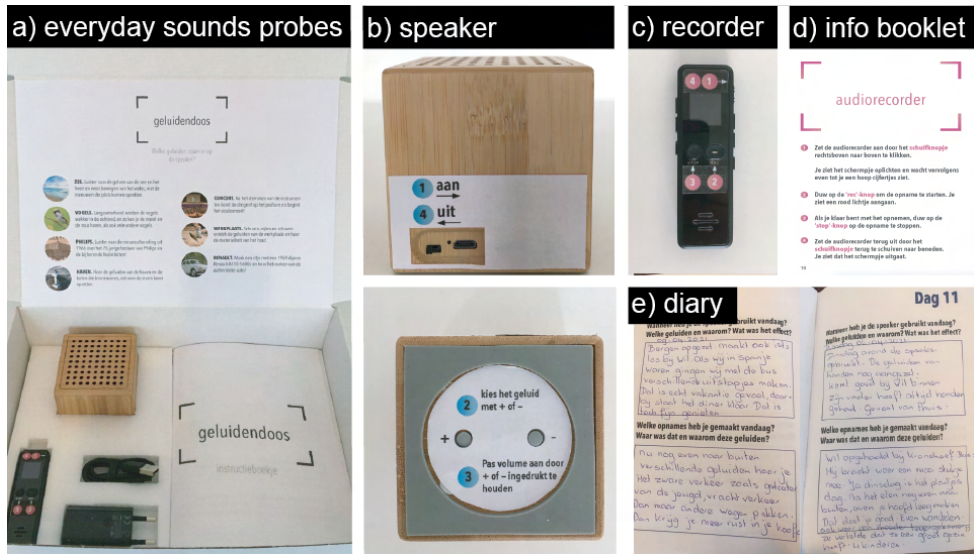


Figure 4.2: The everyday sounds probes (a) consisted of a speaker with personal everyday sounds (b), an audio recorder (c), an instructions booklet (d), a diary (e), presented in a box with a USB-charger and descriptions of the everyday sounds (a).

4.4.1.1 Home Visit 1: Handover Everyday Sounds Probes

In the first home visit, the researcher handed over the everyday sounds probes and explained the instructions in the booklet as the couples tested the speaker and recorder. The researcher invited the participants to use the speaker to listen to their everyday sounds at home, such as a joint activity between the partner and the person with dementia. The participants were also asked to record other sounds in their surroundings they found interesting or meaningful, such as sounds around the house, a walk to the park, or messages from family. The participants could keep track of their experiences in the diary included in the information booklet. After one week, the researcher checked on the participants by telephone. After two weeks, the researcher collected the diary entries and audio recordings to prepare for the second home visit a week later. The researcher listened to the audio recordings and searched for sounds that matched the diary entries or were interesting to address during the next visit. The researcher trimmed the original files into short 1-minute audio clips that could easily be played in the next session.

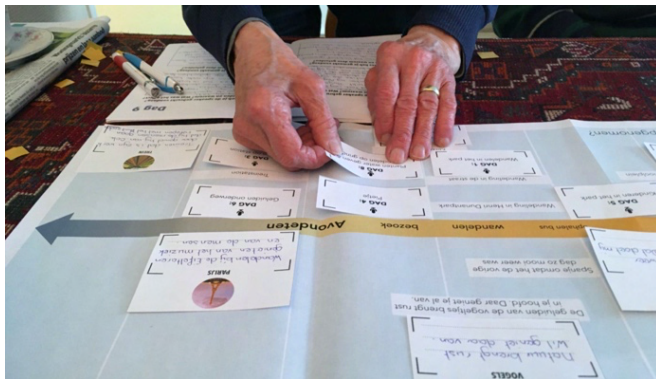


Figure 4.3: The participants created an overview of when they listened to personal everyday sounds and made recordings at home.

4.4.1.2 Home Visit 2: Mapping Personal Everyday Sounds and Recordings on a Timeline

During the second home visit, the participants discussed their use of the speaker and provided context to the sounds they recorded. Based on the diary entries, the participants mapped cards representing their personal everyday sounds on the speaker and the collected audio recordings on a poster with a timeline (see Figure 4.3). Mapping their experiences of the probes on the timeline with daily activities and home-based routines provided a general overview that further fueled the discussion and reflection of the participants [48]. The researcher played the everyday sounds on the speaker during the sessions and asked follow-up questions on the motivations for listening to these sounds at a specific moment. Similarly, snippets of the collected audio recordings were played, and the researcher asked the participants if they recognized the recording and why they had recorded it.

4.4.2 Findings Stage 1: Meaningful Activities at Home

The use of the probes by the participants revealed opportunities for personal everyday sounds to offer meaningful activity at home by cueing conversations, eliciting emotional experiences, and capturing recent everyday experiences.

4.4.2.1 Cueing Conversations at Home

Listening to personal everyday sounds offered auditory cues for the couples to engage in conversations by sharing their associations or memories evoked by the sounds. *Lloyd's* wife *Janet* acknowledged that they used the speaker to play sounds in the background to start a conversation: “Some extra sounds, just for a moment, so you immediately have

something to talk about.” The everyday sounds evoked memories and stories for *Lloyd*, who indicated that listening to the *Seaside*: *“does give me memories of the sea, with that sound I see the sea too.”* *Janet* and *Lloyd* listened to the personal everyday sounds during eating activities such as breakfast, lunch, or while drinking a cup of coffee at home. *Janet* explained:

“Well, Lloyd never says that much, so something in the background is nice. [...] I did that while eating during lunch, and then I ask ‘do you remember that or do you know this?’”

All informal caregivers expressed their struggles in finding ways to connect with their husbands and indicated how it is becoming more challenging to have everyday conversations or small talk with them. *Lorraine* explained: *“If I ever experienced something and want to tell him, I keep it to myself because he does not remember it anyway.”* Offering cues can support the caregivers in conversating with their partners at home about past experiences that can still be recalled by the person with dementia. For example, *Howard* reacted to the *Seaside* sounds in the second home visit to reminisce about their past vacations: *“When we are there [at the seaside], we are on vacation. Because I still have family living there, a niece [...], and if we are there, then we will go to the beach.”*

The personal everyday sounds also evoked memories in the informal caregivers who shared the past experiences with their partner: *“Then I close my eyes, and I see everything! Everything comes back!”* (*Betty*). Similarly, *Betty* used the personal sounds as cues to reminisce with her husband, but she further elaborated that she also needed to offer additional cues to *Roger*: *“I have to assist him a little and say ‘remember this, remember that’, and then it will come up.”*

4.4.2.2 Eliciting Emotional Experiences

All informal caregivers indicated they used the speaker to reconnect with their husbands and activate them in evoking interest and emotional responses, such as laughing or calming down. For example, *Betty* used the personal everyday sounds to connect to her husband non-verbally and reported how she could still see responses of *Roger* through his bodily expressions:

“I used it [speaker] often! I do not know if something sticks, but you can see in his eyes that it makes him happy! [...] He opened up completely, as it does something to him.”

In that way, *Betty* and *Roger* stood out in their use of the speaker, as they used it outside of their home to sonically enrich their outdoor experiences. For example, they went to the park on a sunny day and listened to *Spain* sounds to relive their past holidays, as *Betty* described: *“If the weather is nice and we can sit outside, we will take that speaker with us to listen! Then you are in the middle of it. The temperature is good, except we do not wear our bathing suit.”* The personal everyday sounds also provided rest and calmness for the informal caregivers. For example, *Lorraine* enjoyed the *Seaside* and *Birdsong* sounds in the morning to unwind after the home care service had left: *“It is very hectic in the morning when they [home care] all come, the seaside sounds make you calm and give a nice memory for me!”*

4.4.2.3 Capturing Recent Everyday Experiences

The audio recordings illustrated a potential for recording sounds at home, such as conversations, stories, or atmospheres, to capture and re-experience meaningful aspects of everyday life. For example, *Janet* recorded a conversation with *Lloyd’s* brother, who often called via FaceTime and indicated it could be meaningful for *Lloyd* to listen to these conversations because: *“Lloyd’s brother talks and asks about things from the past”*

Roger and *Betty* made several recordings of their outdoor trips, such as the park, the train station, or the local street atmosphere. Making audio recordings brought a focus on the ‘here and now’ and attention to the environment and surroundings that would often go unnoticed. This focus was brought forth by *Betty*, who noted in the diary:

“We pass everything too fast, and we do not take enough time to see and hear all things out there. There is still so much to enjoy. We need to focus on what we still can do! Keep thinking positive.”

Lorraine and *Howard* mainly made recordings of sounds in and around their house, such as the birds in the garden or the clock in the living room. However, *Howard* did not always recognize these recordings. For instance, *Howard* did not recognize the clock sound in the living room that they had have listened to for many years: *Howard* hears the recording of the clock striking 11 hours and says: *“No, we do not have that sound at home, not in here.”*

4.4.2.4 Conclusion Stage 1

The outcome of *stage 1* revealed opportunities for designing a sound player to provide meaningful activity at home by: 1) **supporting conversations** by providing auditory cues in the home environment; 2) eliciting **emotional responses** in intimate settings; and 3) **capturing recent experiences** of everyday life.

4.5 STAGE 2: INTERACTIONS WITH EVERYDAY SOUNDS

This section reports on the method and findings of *stage 2* in which we explored the affordances and interactions that align with the participants' physical and perceptual abilities.

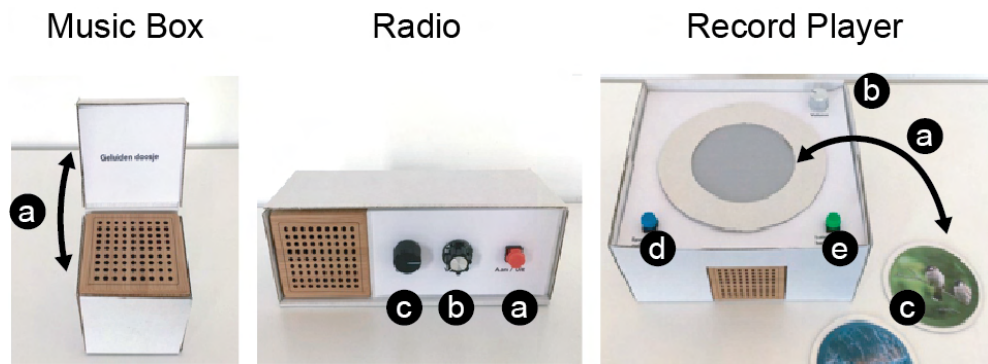


Figure 4.4: We made three mockups based on familiar sound players: a *music box*, a *radio*, and a *record player* that offered different interactions, such as: on/off (a), adjust volume (b), select a sound set (c), play sound event (d), or play a story cue (e).

4.5.1 Method Stage 2: Mockup Sound Players

As people with dementia have difficulties with abstract thinking and developing new concepts or ideas [41], concrete prototypes can provoke valuable feedback on the interface and functionality early in the design process [64,81]. Therefore, we designed three mockups [72,73] for listening to everyday sounds with different interfaces, such as buttons, knobs, or tokens (see Figure 4.4). The mockups were made out of a Bluetooth speaker enhanced by paper prototyping to present a shape and interaction with cardboard [82]. The speaker was connected to a laptop via Bluetooth during the session, and the researcher simulated the sound output based on the participants' interactions with the mockup using digital soundboard software as a Wizard of Oz technique [54]. The mockups were not intended to steer aesthetic or form-related design choices but to

enable people with dementia to express their opinions on the functionality and interactions with sounds.

The mockups were based on iconic or recognizable music devices, such as a *music box* [53], *radio* [95], and *record player* [89], as these can be more easily recognized and spark interaction in people with dementia [12,53,72,89,95]. Participants could play their everyday sounds with the *music box* by opening the lid and stop playing the audio by closing it. The next set of everyday sounds started to play in a predetermined order upon reopening the lid. After all personal everyday sounds were played, the first set of everyday sounds started to play again. The second mockup was designed to offer similar interactions as a traditional *radio*. The interface consisted of an on-off button, a knob for adjusting the volume, and a second knob for selecting the everyday sounds. The final mockup resembled a *record player* as participants could play a set of everyday sounds by placing a corresponding disk on the central circle on the prototype. Upon placing, the background sound was played (e.g., waves at the beach). The participants could play additional everyday sounds by pressing the ‘sound’ button that triggered a *sound event*, a short sound fragment related to the selected set (e.g., a seagull sound at the *Seaside*), to enrich and adapt the audio experience [46]. The ‘story’ button triggered a *story cue*, a half-minute narrated anecdote related to the personal everyday sounds, such as a holiday memory at the *Seaside*, as an additional cue to support a specific memory [32,39,79]. The researcher created the *story cues* by selecting snippets of stories that the participants shared during the first part of the longitudinal study. These snippets were converted into an audio file using an online voice generator.

4.5.1.1 Home Visit 3: Interactions with Mockups

During the third home visit, the researcher presented the three mockups to the participants, who could explore the mockups freely to their liking. The mockups were introduced in the same order for all participants starting with the *music box*, following the *radio*, and ending with the *record player*. By adhering to this order, we slowly increased the number of options and complexity of the interactions with the prototype. The participants could explore the different input forms of the device while the researcher simulated the audio output based on the input provided by the participants. The researcher asked questions on appearance and use, such as if the participant with dementia recognized the form or found it easy to use.

4.5.2 Findings Stage 2: Intuition, Initiative, and Exploration in Listening to Familiar Sounds

In this section, we report the main insights from the observed responses of the person with dementia and their partner when interacting with the mockups that inform the physical and interaction design of the sound player.

4.5.2.1 Intuitive and Simple Design

The participants considered opening and closing the *music box* intuitive as it offered a simple, safe, and non-intimidating interface to play the personal everyday sounds (see Figure 4.5), as described in the field texts:

Howard takes the music box and immediately opens the lid, sea sounds are heard, and he looks at the box. Howard hears a wave crashing, looks up with his eyes wide, and nods his head back. He puts it down but continues to hold it with both hands, looks to the side, and says: "I hear all clatter and water!"

The lid of the *music box* formed a physical interface between the everyday sounds and the participants who could decide if they were open to it or not, as we observed how: *Roger closes the lid with one hand, keeps his hand on it, and says: "Well if you do that, as it is now (closed), you will not hear anything!"*

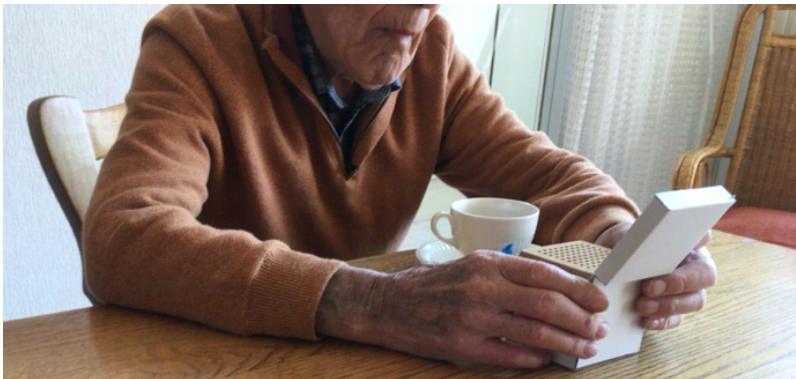


Figure 4.5: The participants preferred a simple and intuitive interface for exploring meaningful sound content.

We learned how the participants preferred a simple interface from the interactions with the mockups. For example, *Howard* found the *radio* easy to use as: *"There are no bells or*

whistles, just three buttons! [...] Only what is absolutely necessary!” Lloyd expressed that he preferred a simple interface without any buttons: *“I find it easy that there are no buttons, because if there are buttons, then it is again [difficult].”* Buttons were found difficult as it requires an understanding and abstraction of the functionality of each button, as explained by Roger: *“Then it is difficult because you need to know what [the buttons] all stand for.”*

4.5.2.2 Initiative in Listening to Sound

The mockups stimulated interaction and engagement from the participants during the sessions. They were offered a sense of agency and control in playing the everyday sounds by interacting with the mockups. For example, Lloyd ignored the instructions of his wife Janet when exploring the music box:

Lloyd now opens and closes the music box at a faster pace and switches between everyday sounds sets. Janet says: “Do not do it up and down! Then you get a different sound every time!” Lloyd opens the lid of the music box again and hears the cat sound: “Yes! (Hears Cat) That is [name cat]!”

Later, Lloyd explicitly expressed how he valued being independent of his wife in listening to the sounds: *“I think it is important that you can manage that yourself. Because if you have to let someone else do that, then you depend on that, of course.”* During the session with Roger, the researcher asked a brief question to Betty, while suddenly Roger was drawn to the token with the train image and interacted on his own initiative with the record player in front of him (see Figure 4.6):

Roger spontaneously places the token on the prototype and plays the Train Cabin sounds. The researcher stops his conversation with Betty and responds: “Well done, Roger!” Roger replies: “Yes, there it [the train] goes!” The sounds of an accelerating train are heard as Betty nods to Roger and says: “It is shifting gear!” and Roger points with his finger to the record player and laughs: “Let’s drive it! Haha.”



Figure 4.6: The participants played everyday sounds on their own initiative.

4.5.2.3 Exploration and Variation of Sound Content

The participants used the mockups to explore the different everyday sounds that could be played. Although they had listened to these everyday sounds many times, they were rediscovering the sounds during the session, as we observed how:

Lloyd opens and closes the lid again and hears Drum Band sounds. Janet explains to Lloyd: “Yes, you see! Those are the sounds we had [earlier]” and points to the speaker. Lloyd opens the lid again, and the Fireplace sounds play. Janet asks: “That’s the fireplace, you know?” as Lloyd replies: “Oh yes.”

Janet also commented on how people with dementia might find it challenging to select sound content, as these actions require a comprehension of what content is available: “Yes, but you have to know what you want to hear? That is also more difficult [...] And a person with bad memory does not want to hear ‘that’ sound, they just want to hear something.” This difficulty was observed as Roger was exploring the radio and stopped upon hearing a specific sound:

Roger keeps looking at the radio and turning the knobs. Upon hearing Spain sounds, Roger releases the knob and leans back. The researcher asks: “And do you find that easy to operate?” as Roger replies: “Yes, why... When you are in Spain, you have all those sounds!”

The participants also indicated the need to change the sound content or add new sounds over time, as was explained by Lloyd: “So you can do more than with this [music box]. You can only listen to this a couple of times, and then you want to put something else on

it.” Therefore, the participants expressed the value of recording and uploading new audio content to the everyday sound sets: “Then you can tell your own story during the Concert or the Seaside sounds!” (Janet)

Similarly, the participants expressed the need for more possibilities in exploring the different personal everyday sounds. For example, the *story cues* on the *record player* were able to link the personal everyday sounds to the related stories from the initial co-design sessions:

Howard presses the ‘story’ button and listens to the story of when he was stuck in a lighthouse during a storm. Lorraine replies: “Yes, they could not leave, and then such a lighthouse goes up and down!” Howard says: “Yes, that [lighthouse] could shake back and forth like that.”

The informal caregivers also appreciated the *story cues* as it offered additional support for reminiscing about their shared past experiences, as explained by Janet:

“Yes, it is nice of course, while this [music box] is more impersonal, also sounds nice, only you cannot [hear] a story with it. That [record player] is of course much more extensive than this.”

4.5.2.4 Conclusion Stage 2

The findings of *stage 2* revealed how the sound player should facilitate: 1) an **intuitive and straightforward interface** that feels safe and non-intimidating to use; 2) **initiative in listening** to everyday sounds; and 3) **variation and rich audio content** to stimulate rediscovery of past experiences and memories.

4.6 STAGE 3: DESIGN FOR HOME ENVIRONMENT

We synthesized the insights from *stage 1* and *stage 2* in a physical prototype to play personal everyday sounds in a home environment that was evaluated during the fourth and last home visit.



Figure 4.7: The Tumbler is an accessible audio player for people with dementia and their partners to play everyday sounds at home.

4.6.1 Method Stage 3: Designing the Tumbler

We designed the Tumbler as a tangible interface for people with dementia and their informal caregivers to play everyday sounds at home (see Figure 4.7). In this prototype, we implemented the insights gained from the participants' interactions with the mockups. The design of the Tumbler is based on the intuitive interactions with the *music box*, the rich content (e.g., *story cues* and *sound events*) offered by the *record player*, and the explorative nature of selecting personal everyday sounds in all mockups. A user can easily play everyday sounds by *rolling*, *tilting*, or *shaking* the device (see Figure 4.8). Objects with physical affordances that involve object manipulations provide more intuitive interactions for people with dementia [12]. Like 'rolling a dice', the Tumbler avoids complex cognitive tasks as the surprising nature of the interaction supports the discovery of sounds where users cannot make any mistakes.

Cubical shapes have been applied in intuitive interfaces in home settings for exploring digital photos [37], playing sounds [75], or selecting light presets [63]. To improve interactions such as *rolling* and *tilting*, we combined a cubical and spherical shape in an organic form with a circular bottom and a square top with rounded corners. The cylindrical form at the bottom makes the device easy to roll or tilt sideways, and the square top allows it to land on one side and prevents it from rolling further. The device is easy to handle for people with dementia as it weighs 0,6 kg and measures 13 cm in height and 14 cm in width. The Tumbler has a white 3D-printed ABS casing with a perforated oak veneered MDF board that protects the high-quality speaker.

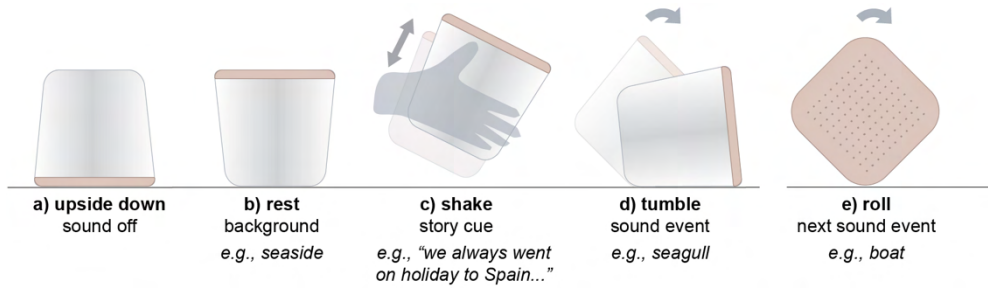


Figure 4.8: The Tumbler plays everyday sounds based on interactions, such as *shaking*, *tumbling*, or *rolling*.

The Tumbler renders multiple soundtracks in real-time to enable interactions with different sound layers and create a coherent composition of sounds. These different layers of everyday sounds can be activated or muted individually. The first layer contained the *background sounds* (e.g., the seaside) that were played continuously. The second layer consisted of *sound events* or short individual sound clips related to the background sounds, such as a seagull or boat sound. The third layer contained brief *story cues*, which were the same narrated stories created for *stage 2* as part of the *record player* mockup. The fourth layer contained auditory voice prompts, such as low battery notifications, the name of the sound set, and additional feedback sounds resembling a maracas instrument that mimics the rolling and shaking interactions with the device.

The Tumbler uses an accelerometer and gyroscope sensors to measure user input and allow for interaction with the everyday sounds (see Figure 4.8). The Tumbler is in sleep mode when turned upside down with the speaker facing downwards (a). *Tilting* the speaker in any other direction activates the next everyday sound set, and resting the speaker oriented upwards plays the *background sounds* (b). The *story cues* are activated when the user *shakes* the Tumbler (c). *Tumbling* or *tilting* the Tumbler sideways activates a *sound event*, and the speaker can be aimed at the user for an active listening experience (d). The user can select the next or previous *sound event* available for the sound set by *rolling* to right or left respectively (e). When the Tumbler is turned off and on again, it plays the next sound set.

The battery has 12 hours of use and is charged wirelessly by placing it on the docking station. This docking station also contains a knob for adjusting the volume, a button for an easy selection of a specific everyday sound set, and two buttons for recording audio

with the Tumbler and adding it to the everyday sound set as a *story cue*. We also developed an online platform to upload and customize everyday sounds.

4.6.1.1 *Home Visit 4: Participants Evaluating the Tumbler*

During the fourth and last home visit, the researcher introduced the Tumbler to the participants who could freely explore the interactions, affordances, and materiality of the Tumbler and the docking station. The goal of evaluating the Tumbler in this home visit was to gain first insights and critique from the participants on the usability and overall concept of the Tumbler. The researcher also invited participants to *tumble*, *shake*, or *roll* the device and asked them to elaborate on their understanding of interacting with the Tumbler. The participants were asked about the prototype's aesthetics, form, weight, material texture, and how they envisioned everyday use in their home. The online platform was not evaluated in this session as we focused on evaluating the first-time engagement of people with dementia and their partners with the Tumbler.

4.6.2 *Findings Stage 3: Usability and Envisioned Use of the Tumbler*

4.6.2.1 *Tangible Interactions with Sound*

The Tumbler offered a tangible interface for the participants that was non-intimidating and inviting, as we observed: *Howard spontaneously grabs the Tumbler that is upside down on the table with both hands and tilts the Tumbler a quarter turn facing towards him. Birdsongs sounds, and Howard gestures both hands to the Tumbler as in 'and there you go' and leans back.* Later, Howard explained how he found the interaction and form of the Tumbler easy to use: *"There is nothing there... no handle or anything like that, it weighs nothing, so it is easy to use."*

The Tumbler engaged the participants in making sense of the link between their interactions with the prototype and the output in the form of sound: *Roger grabs the Tumbler with both hands and first tilts it towards him, then turns the Tumbler upside down [on the table] and says: "Then we do not hear him! Haha!"* Similarly, *Lloyd* explained out loud how he could stop and play the next sound by turning the device:

"Yes, if I want to stop it now and continue later, then I can stop like this," and he tilts the Tumbler downwards with both hands and keeps his hands on it, then tilts it back towards himself and triggers Park sounds, and confirms: "Oh yes!"

Therefore, the participants could explore the device and gain understanding of how they can play the personal everyday sounds by simply interacting with it and listening to the

sounds, as observed by Janet: “Yes, I think it is easy that you can tilt it. You just need to know a little bit about how it works, but you will hear that!”

The shape of the Tumbler allowed the participants to point the speaker to themselves while listening, or to others when sharing the listening experience: *Roger spontaneously picks up the Tumbler with both hands and tilts it towards him, hears the Sparrows, and slides the Tumbler to the center of the table in front of him.* The form of the Tumbler was sturdy, robust, and easy to handle for the participants: “It is easy to handle, and you can adjust it well” (Howard).

But the participants also gave points for improving the design. We observed how the Tumbler would sometimes slip out of the participants’ hands on the table. Howard suggested making: “a few dents on this [side], that you can grab it like that [with more grip]!” Janet indicated that the size of the Tumbler was too large for her to handle since she had small hands: “Only I don’t find it very convenient to operate, it should be a bit narrower, that you can also turn it with one hand.”

4.6.2.2 Initiating Meaningful Activities

The Tumbler enabled the participants with dementia to explore the *story cues* and *sound events*, which led to the participants initiating conversations with their partner (see Figure 4.9). For instance, Howard interacted with the Tumbler, explored the *Seaside* sounds, and used the *story cue* to start a conversation with Lorraine based on their shared memory:

Howard raises the Tumbler again and shakes it until he hears the story of their vacations to the seaside, then puts the Tumbler back down in front of him and listens. At the end of the story, he raises his head to the Tumbler. The researcher asks: “Does that sound familiar?” Howard nods and says: “Yes, I remember!” to which Lorraine quickly adds: “Yes, he nodded yes, I saw that! Yes (laughs) Yes, that [story] all happened!”



Figure 4.9: The participants could evaluate and interact with the Tumbler during the fourth home visit.

For Roger, we observed that the *story cues* were more challenging to understand as he also had difficulties speaking during the sessions. However, rolling the Tumbler triggered various *sound events* that would elicit bodily responses from Roger, such as laughing, pointing, or mimicking the sound as form of non-verbal communication:

Roger lifts the Tumbler towards him, drops it softly on the table and hears the sound of the train announcement. Roger starts to laugh and points to the Tumbler when he hears the train announcement. Betty replies: “Hey! Yes, it sounded like that!”

Therefore, the Tumbler offered a sense of agency to the participants who could actively initiate and participate in meaningful activities with their partners.

4.6.2.3 *Envisioned Use at Home*

The participants and their partners appreciated the minimal and modern aesthetics of the Tumbler. The aesthetic qualities also motivated participants to keep the Tumbler in sight in their home rather than storing it in a cupboard. For example, Lorraine stated how she considered the Tumbler aesthetically pleasing and fitting with their home interior: “Yes, it is a sleek modern thing! [...] And it’s also nice to look at if you had it somewhere [at home].” The minimalistic aesthetics with neutral materials such as wood and the white casing enable the device to fit multiple interiors, as explained by Betty: “I like the combination [of materials], modern! It does not clash with our things here [at home].”

The informal caregivers also valued the functionality and design of the docking station as it was easy to use and charge the battery, as explained by Janet: *“It is just like a cup on a saucer! [...] I also do like that I can press a button for the next sound.”* Janet further explained that the docking station was convenient to charge the Tumbler and compared it to their cordless home phone: *“So if you always leave it [Tumbler] on top of it [docking station], the battery is always charged. That is the same as the phone!”* Similarly, Betty indicated the need to control the volume to avoid potential distress from loud sounds: *“Sounds are soothing, but when it gets loud, I get stressed.”*

The informal caregivers also indicated how the Tumbler could be easily used in the house: *“I can just put it down, then I can hear those sounds”* (Janet). The informal caregivers also expressed that the design lends itself to multiple use-cases in the house. Betty highlighted the portable qualities of the Tumbler and suggested using it: *“When Roger gets in bed so he can be with his thoughts in Spain!”* The value of the everyday sounds was the personal approach in providing reminiscence compared to listening to music. For example, Janet stated that the Tumbler was different from a radio as it was personalized to their shared past experiences: *“You do not use it as a radio, but as a nice memory, I like that too!”*

4.6.2.4 Conclusion Stage 3

The Tumbler: 1) offered **tangible interactions** with personal sound content; 2) enabled people with dementia to **initiate and participate in meaningful activities** with their partner; and 3) could **fit within everyday home settings**.

4.7 DISCUSSION

Our co-design study illustrated how everyday sounds delivered through thoughtfully designed technology offered meaningful activity for people with dementia and their partner at home.

4.7.1 Enriching Everyday Life at Home Through Meaningful Activities

The probes used in *stage 1* revealed opportunities for personal everyday sounds to support meaningful activities at home by evoking conversations with significant others or emotional experiences through sensory engagement with sound. Similar to how sound-based interventions provide conversational cues in care home settings [47], the personal everyday sounds enabled the couples living with dementia to engage in meaningful day-to-day conversations at home. The couples could also emotionally

connect by exploring personal sound content as non-verbal interactions, such as mimicking sounds, making eye contact, or personal touch, which are also meaningful forms of communication [38,56] to promote attachment and connection in care relationships [65].

The evoked memories also provided meaning for the partners who have to cope with the dementia of their loved one. Exploring these shared past experiences can further initiate partnership-based interventions at home to support *couplehood* as a form of reflection and sensemaking of their changing bond based on shared values, purpose, and life experiences [65]. Based on our findings, we recognize the home environment as a context for further exploring the shared identities of people with dementia and their relatives. We contribute to research on enabling music in home settings for people with dementia [20,39,72,89,94] by highlighting the potential of non-musical sounds to evoke meaningful activity at home. Therefore, our findings feed into the growing tendency of using technology to facilitate recreational and life-enriching interventions for people with dementia aging in place [19,20,22].

Literature in HCI has addressed the role of sound to enrich everyday life in the context of people's homes [6,62,75]. This chapter explored how this potential could benefit people with dementia at home. The act of listening to everyday sounds requires a preparedness to perceive sounds surpassing in time and space that in many cases remain unnoticed [5]. Therefore, listening to everyday sounds results in a focus on the 'here and now' that transforms everydayness into meaningful and mindful experiences [29]. As such, we highlight how **everyday sounds can cue small but unexpected, light-hearted, and playful gestures in everyday experiences of living with dementia.**

4.7.2 Agency Through Exploration

The design of intuitive interfaces for people with dementia often relies on familiar affordances that draw upon past experiences and familiarity [12]. The mockups represented stereotypical music players [53,89,95] and enabled the participants to voice their opinions on the functionality and interface needed to engage with everyday sounds, which informed the design of the Tumbler. We found that interactions associated with music devices do not directly translate to interactions with everyday sounds. Therefore, we challenge retrospective design approaches in which novel technologies often resemble stereotypical objects of the past. Instead, we argue that designers should offer appropriate aesthetic experiences that attract attention and cue exploration in line with the intended goal.

The Tumbler offered an intuitive and tangible interface that stimulated exploration as the participants rediscovered personal everyday sounds to relive past experiences and evoke meaningful memories. Loss of initiative hinders people with dementia from initiating and engaging in recreational, meaningful, and pleasurable activities that benefit quality of life [94]. The Tumbler offered a playful intuitive interface that does not require prior knowledge of the technical system as it relies on curiosity and haptic exploration to provoke interaction from people with dementia [72]. The Tumbler does not require a specific learning process as people with dementia can explore the device and make connections between their interactions and the sounds emerging from it. Therefore, people with dementia can explore the interactions with the Tumbler and rediscover their personal everyday sounds over time.

The Tumbler allowed for auditory experiences adapted to the participants' current abilities, moods, and mindset. For example, the *story cues* were easily recognized by *Howard*, while the *sound events* triggered more emotional responses from *Roger*. Technologies require this form of flexibility in addressing the sensory changes of people with dementia to enable sustainable use over time [30] and support forms of embodied communication [20]. Therefore, the sound content needs to support different activities and adapt to the changing mindset, willingness, and ability of the person interacting with the device. In this context, agency is thus not merely the ability to complete a set of tasks but also accounts for emotional expressions and social participation in their surroundings [33]. We argue that **intuitive design that offers everyday sounds can culminate in accessible, rich, and open-ended experiences that evoke agentic behavior from people with dementia towards their social surroundings.**

4.7.3 *Accessibility and Inclusion at Home*

The small participant sample allowed for a relational approach where the researcher invested time in connecting to the participants and building a relationship of trust [42]. This social involvement of the researcher was crucial in gaining a broad understanding of the everyday situations of the participants with dementia and making sense of their implicit forms of expression [40]. In long-term research projects, maintaining the ongoing engagement of participants and their partners is often challenging as dropout rates tend to increase over time [43]. During all home visits, the participants could listen and explore their personal sounds and stories, which maintained their ongoing interest, as highly tailored content motivates active participation in dyadic interventions [23].

By involving the participants and their partners in the different stages of the co-design study, we were able to design a device that addresses the participants' needs, values, abilities, and everyday contexts, as we explored their routines at home and observed the interactions with the mockups. Therefore, the probes and mockups enabled people with dementia to feed choices in the design process. Our design research culminated in proposing the Tumbler as a device to leverage the beneficial effects of everyday sounds in the home. The Tumbler was designed to resonate with the existing physical environment as a homelike object [90]. The minimal aesthetics and form can easily fit with different interiors, and the docking station provides a fixed place in the home for storing the device. Technology that remains in sight stimulates its use by people with dementia who often have trouble locating devices when stored in a hidden place [55].

The Tumbler was a physical prototype that resulted in authentic reactions and experiences. This design proposal was an early exploration that **embedded fundamental values, such as social agency, exploration, and adaptation, that were put forth by the participants**. The social atmosphere during the home visits also offered a pleasant experience to the participants which contributed to the participants' experience of testing the mockups and prototype. However, the probe study in *stage 1* indicated how the speaker's use was facilitated in the absence of the researcher and was mainly driven by the informal caregiver. The preliminary evaluation of the Tumbler offered insights for future iterations to be evaluated in home settings to investigate use over time. Therefore, future work should address if the Tumbler can evoke meaningful activity as observed in the last home visit during everyday life at home.

4.8 CONCLUSION

This chapter presents a novel approach to support the wellbeing of couples living with dementia through offering personal sounds at home. Exploring sounds that reflect past life experiences or evoke positive associations can cue conversations, elicit emotional responses or stimulate reflection on recent experiences of everyday life. Intuitive and straightforward interfaces can stimulate initiative in listening to everyday sounds and discovering rich bodies of audio content. We materialized these findings into a prototype of an everyday sound player: the Tumbler that enabled people with dementia to initiate and participate in meaningful activities with their partner within everyday home settings. We further emphasize the need for life-enriching activities at home for people with dementia and their partners and aim to inspire future design research that

adopts relational approaches to capture the everyday experiences of dementia and translate these experiences into meaningful, empathic, and thoughtful design solutions.

4.9 ACKNOWLEDGMENTS

This research was funded by ZonMw in the Create Health Program as part of the Everyday Sounds of Dementia project (443001122). We thank all participants and care organization Archipel. We also thank Serge Offermans, Teun Vinken and Emma Dhazez for their involvement in the development of the Tumbler.

4.10 REFERENCES

- [1] Sérgio Alves, Filipa Brito, Andreia Cordeiro, Luis Carriço, and Tiago Guerreiro. 2018. Enabling Biographical Cognitive Stimulation for People with Dementia. In *Extended Abstracts of the 2018 CHI Conference on Human Factors in Computing Systems - CHI '18*, ACM Press, New York, New York, USA, 1–6. DOI:<https://doi.org/10.1145/3170427.3188693>
- [2] Alzheimer Association. 2019. 2019 Alzheimer's disease facts and figures. *Alzheimer's Dement.* 15, 3 (March 2019), 321–387. DOI:<https://doi.org/10.1016/j.jalz.2019.01.010>
- [3] Arlene J. Astell, Maggie P. Ellis, Norman Alm, Richard Dye, and Gary Gowans. 2010. Stimulating People with Dementia to Reminisce Using Personal and Generic Photographs. *Int. J. Comput. Heal.* 1, 2 (2010), 177–198. DOI:<https://doi.org/10.1504/IJCIH.2010.037461>
- [4] Arlene Jean Astell. 2006. Technology and personhood in dementia care. *Qual. Ageing* 7, 1 (2006), 15–25. DOI:<https://doi.org/10.1108/14717794200600004>
- [5] Jean-François Augoyard. 2006. *Sonic experience: a guide to everyday sounds*. McGill-Queen's Press.
- [6] Hanif Baharin, Stephen Viller, and Sean Rintel. 2015. SonicAIR: Supporting Independent Living with Reciprocal Ambient Audio Awareness. *ACM Trans. Comput. Interact.* 22, 4 (July 2015). DOI:<https://doi.org/10.1145/2754165>
- [7] Ameer Baird and Séverine Samson. 2009. Memory for Music in Alzheimer's Disease: Unforgettable? *Neuropsychol. Rev.* 19, 1 (May 2009), 85–101. DOI:<https://doi.org/10.1007/s11065-009-9085-2>
- [8] Ameer Baird and Séverine Samson. 2015. Music and dementia. In *Progress in Brain Research*, Eckart Altenmüller, Stanley Finger and François Boller (eds.). Elsevier, 207–235. DOI:<https://doi.org/10.1016/bs.pbr.2014.11.028>
- [9] Felicity Anne Baker, Jodie Bloska, Sabine Braat, Anna Bukowska, Imogen Clark, Ming H Hsu, Tone Kvamme, Nicola Lautenschlager, Young-Eun Claire Lee, Agnieszka Smrokowska-Reichmann, Tanara Vieira Sousa, Karette A Stensaeth, Jeanette Tamplin, Thomas Wosch, and Helen Odell-Miller. 2019. HOMESIDE: home-based family caregiver-delivered music and reading interventions for people living with dementia: protocol of a randomised controlled trial. *BMJ Open* 9, 11 (2019). DOI:<https://doi.org/10.1136/bmjopen-2019-031332>
- [10] Jeanette Bell and Tuck Wah Leong. 2019. Collaborative Futures: Co-Designing Research Methods for Younger People Living with Dementia. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems - CHI '19*, ACM Press, New York, New York, USA, 1–13. DOI:<https://doi.org/10.1145/3290605.3300582>
- [11] Ashok J. Bharucha, Vivek Anand, Jodi Forlizzi, Mary Amanda Dew, Charles F. Reynolds, Scott Stevens, and Howard Wactlar. 2009. Intelligent Assistive Technology Applications to Dementia Care: Current Capabilities, Limitations, and Future Challenges. *Am. J. Geriatr. Psychiatry* 17, 2 (February 2009), 88–104. DOI:<https://doi.org/10.1097/JGP.0b013e318187dd e5>
- [12] Alethea Blackler, Li-Hao Chen, Shital Desai, and Arlene Astell. 2020. Intuitive Interaction Framework in User-Product Interaction for People Living with Dementia. In *HCI and Design in the Context of Dementia*, Rens Brankaert and Gail Kenning (eds.). Springer International Publishing, Cham, 147–169. DOI:https://doi.org/10.1007/978-3-030-32835-1_10
- [13] Stephanie Blackman, Claudine Matlo, Charisse Bobrovitskiy, Ashley Waldoch, Mei Lan Fang, Piper Jackson, Alex Mihailidis, Louise Nygård,

- Arlene Astell, and Andrew Sixsmith. 2016. Ambient Assisted Living Technologies for Aging Well: A Scoping Review. *J. Intell. Syst.* 25, 1 (January 2016), 55. DOI:<https://doi.org/10.1515/jisys-2014-0136>
- [14] Kirsten Boehner, Janet Vertesi, Phoebe Sengers, and Paul Dourish. 2007. How HCI Interprets the Probes. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. Association for Computing Machinery, New York, NY, USA, 1077–1086. DOI:<https://doi.org/10.1145/1240624.1240789>
- [15] Rita Maldonado Branco, Joana Quental, and Óscar Ribeiro. 2017. Personalised participation: an approach to involve people with dementia and their families in a participatory design project. *CoDesign* 13, 2 (2017), 127–143. DOI:<https://doi.org/10.1080/15710882.2017.1310903>
- [16] Rens Brankaert. 2016. Design for dementia : a design-driven living lab approach to involve people with dementia and their context. Eindhoven University of Technology, Eindhoven.
- [17] Rens Brankaert and Sandra Suijkerbuijk. 2019. Outdoor life and technology with dementia. In *Using technology in dementia care*, Arlene Astell, Sarah Smith and Phil Jodrell (eds.). Jessica Kingsley Publishers, 53–64.
- [18] Virginia Braun and Victoria Clarke. 2006. Using thematic analysis in psychology. *Qual. Res. Psychol.* 3, 2 (January 2006), 77–101. DOI:<https://doi.org/10.1191/1478088706qrp0630a>
- [19] Sarah Campbell, David Frohlich, Norman Alm, and Adam Vaughan. 2019. Sentimental Audio Memories: Exploring the Emotion and Meaning of Everyday Sounds. In *Dementia Lab 2019. Making Design Work: Engaging with Dementia in Context*. D-Lab 2019., Rens Brankaert and Wijnand IJsselstein (eds.). Springer, Cham, 73–81. DOI:https://doi.org/10.1007/978-3-03033540-3_7
- [20] Romina Carrasco, Felicity A. Baker, Anna A. Bukowska, Imogen N. Clark, Libby M. Flynn, Kate McMahon, Helen Odell-Miller, Karette Stensaeth, Jeanette Tamplin, Tanara Vieira Sousa, Jenny Waycott, and Thomas Wosch. 2020. Empowering Caregivers of People Living with Dementia to Use Music Therapeutically at Home: Design Opportunities. In *32nd Australian Conference on Human-Computer Interaction (OzCHI '20)*, Association for Computing Machinery, New York, NY, USA, 198–209. DOI:<https://doi.org/10.1145/3441000.3441082>
- [21] Joaquim Cerejeira, Luísa Lagarto, and Elizabeta Mukaetova-Ladinska. 2012. Behavioral and Psychological Symptoms of Dementia. *Front. Neurol.* 3, (2012), 73. DOI:<https://doi.org/10.3389/fneur.2012.00073>
- [22] Helen Chester, Paul Clarkson, Linda Davies, Caroline Sutcliffe, Sue Davies, Alexandra Feast, Jane Hughes, and David Challis. 2018. People with dementia and carer preferences for home support services in early-stage dementia. *Aging Ment. Health* 22, 2 (2018), 270–279. DOI:<https://doi.org/10.1080/13607863.2016.1247424>
- [23] Daphne Sze Ki Cheung, Shuk Kwan Tang, Ken Hok Man Ho, Cindy Jones, Mimi Mun Yee Tse, Rick Yiu Cho Kwan, Kit Ying Chan, and Vico Chung Lim Chiang. 2021. Strategies to engage people with dementia and their informal caregivers in dyadic intervention: A scoping review. *Geriatr. Nurs. (Minneap.)* 42, 2 (2021), 412–420. DOI:<https://doi.org/https://doi.org/10.1016/j.gerinurse.2021.02.002>
- [24] C.-Y. Chiao, H.-S. Wu, and C.-Y. Hsiao. 2015. Caregiver burden for informal caregivers of patients with dementia: A systematic review. *Int. Nurs. Rev.* 62, 3 (2015), 340–350. DOI:<https://doi.org/https://doi.org/10.1111/inr.12194>
- [25] Tim Coughlan, Kerstin Leder Mackley, Michael Brown, Sarah Martindale, Stephan Schlögl, Becky Mallaband, John Arnott, Jettie Hoonhout, Dalila Szostak, Robin Brewer, Erika Poole, Antti Pirhonen, Val Mitchell, Sarah Pink, and Nicolas Hine. 2013. Current issues and future directions in methods for studying technology in the home. *PsychNology J.* 11, 2 (2013), 159–184.
- [26] Yngve Dahl and Dag Svanæs. 2020. Facilitating Democracy: Concerns from Participatory Design with Asymmetric Stakeholder Relations in Health Care. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems (CHI '20)*, Association for Computing Machinery, New York, NY, USA, 1–13. DOI:<https://doi.org/10.1145/3313831.3376805>
- [27] Jiamin Dai and Karyn Moffatt. 2021. Surfacing the Voices of People with Dementia: Strategies for Effective Inclusion of Proxy Stakeholders in Qualitative Research. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems (CHI '21)*, Association for Computing Machinery, New York, NY, USA. DOI:<https://doi.org/10.1145/3411764.3445756>
- [28] Jan Dewing. 2007. Participatory research: A method for process consent with persons who have dementia. *Dementia* 6, 1 (February 2007), 11–25. DOI:<https://doi.org/10.1177/1471301207075625>
- [29] Helen Dilkes, Nigel Frayne, and Virginia Lewis. 2006. Sound in Health project: characterising the sound environment in a palliative care unit and implementing a soundscape intervention. In *Proceedings of the West Meets the East in Acoustic Ecology Conference*, World Forum for

- Acoustic Ecology, Hiroasaki, Japan, 1–22.
- [30] Emma Dixon and Amanda Lazar. 2020. The Role of Sensory Changes in Everyday Technology Use by People with Mild to Moderate Dementia. In *The 22nd International ACM SIGACCESS Conference on Computers and Accessibility (ASSETS '20)*, Association for Computing Machinery, New York, NY, USA. DOI:<https://doi.org/10.1145/3373625.3417000>
- [31] Tijs Duel, David M. Frohlich, Christian Kroos, Yong Xu, Philip J. B. Jackson, and Mark D. Plumbley. 2018. Supporting Audiography: Design of a System for Sentimental Sound Recording, Classification and Playback. In *Communications in Computer and Information Science*. Springer, Cham, 24–31. DOI:https://doi.org/10.1007/978-3-319-92270-6_4
- [32] James Edmeads and Oussama Metatla. 2019. Designing for Reminiscence with People with Dementia. In *Extended Abstracts of the 2019 CHI Conference on Human Factors in Computing Systems - CHI '19*, ACM Press, New York, New York, USA, 1–6. DOI:<https://doi.org/10.1145/3290607.3313059>
- [33] Sarah Foley, Daniel Welsh, Nadia Pantidi, Kellie Morrissey, Tom Nappey, and John McCarthy. 2019. Printer Pals: Experience-Centered Design to Support Agency for People with Dementia. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems - CHI '19*, ACM Press, New York, New York, USA, Paper 404, 1–13. DOI:<https://doi.org/10.1145/3290605.3300634>
- [34] David M Frohlich, Emily Corrigan-Kavanagh, Sarah Campbell, Theopisti Chrysanthaki, Paula Castro, Isabela Zaine, and Maria da Graça Campos Pimentel. 2020. Assistive Media for Well-being. In *HCI and Design in the Context of Dementia*, Rens Brankaert and Gail Kenning (eds.). Springer International Publishing, Cham, 189–205. DOI:https://doi.org/10.1007/978-3-030-32835-1_12
- [35] Julia Anne Garde, Mascha Cécile van der Voort, and Kristina Niedderer. 2018. Design Probes for People with Dementia. In *Design as a catalyst for change - DRS International Conference 2018*, Limerick, Ireland, 2607–2621. DOI:<https://doi.org/10.21606/drs.2018.492>
- [36] Karen Gold. 2014. But does it do any good? Measuring the impact of music therapy on people with advanced dementia: (Innovative practice). *Dementia* 13, 2 (2014), 258–264. DOI:<https://doi.org/10.1177/1471301213494512>
- [37] Connie Golsteijn and Elise van den Hoven. 2013. Facilitating parent-teenager communication through interactive photo cubes. *Pers. Ubiquitous Comput.* 17, 2 (2013), 273–286.
- [38] Connie Guan, Anya Bouzida, Ramzy M Oncy-avila, Sanika Moharana, and Laurel D Riek. 2021. Taking an (Embodied) Cue From Community Health: Designing Dementia Caregiver Support Technology to Advance Health Equity. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems (CHI '21)*, Association for Computing Machinery, New York, NY, USA. DOI:<https://doi.org/10.1145/3411764.3445559>
- [39] Marjolein den Haan, Nicole van Essen, Rens Brankaert, and Yuan Lu. 2021. Your Moments: Co-designing a Personalized Audio Player. In *Dementia Lab 2021: Supporting Ability Through Design*, Springer International Publishing, Cham, 63–71. DOI:https://doi.org/10.1007/978-3-030-70293-9_5
- [40] Niels Hendriks, Liesbeth Huybrechts, Karin Slegers, and Andrea Wilkinson. 2018. Valuing implicit decision-making in participatory design: A relational approach in design with people with dementia. *Design Studies* 59, 58–76. DOI:<https://doi.org/10.1016/j.destud.2018.06.001>
- [41] Niels Hendriks, Liesbeth Huybrechts, Andrea Wilkinson, and Karin Slegers. 2014. Challenges in doing participatory design with people with dementia. In *Proceedings of the 13th Participatory Design Conference on Short Papers, Industry Cases, Workshop Descriptions, Doctoral Consortium papers, and Keynote abstracts - PDC '14 - volume 2 (PDC '14)*, ACM Press, New York, New York, USA, 33–36. DOI:<https://doi.org/10.1145/2662155.2662196>
- [42] Niels Hendriks, Karin Slegers, and Andrea Wilkinson. 2020. Against Dedicated Methods: Relational Expertise in Participatory Design with People with Dementia. In *HCI and Design in the Context of Dementia*, Rens Brankaert and Gail Kenning (eds.). Springer International Publishing, Cham, 97–109. DOI:https://doi.org/10.1007/978-3-030-32835-1_7
- [43] Elisabeth T. P. van den Heuvel, Luc P. de Witte, Robbert Sanderman, Lidwien M. Schure, and Betty Meyboom-de Jong. 2002. Non-participation and drop-out in support programs for caregivers of cognitively impaired elderly. In *Supporting caregivers of stroke patients: An intervention study*, Elisabeth T. P. van den Heuvel (ed.). University of Groningen, Groningen, 99–114.
- [44] James Hodge, Madeline Balaam, Sandra Hastings, and Kellie Morrissey. 2018. Exploring the Design of Tailored Virtual Reality Experiences for People with Dementia. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems (CHI '18)*, ACM Press, New York, New York, USA, Paper 514, 1–13. DOI:<https://doi.org/10.1145/3173574.3174088>

- [45] James Hodge, Kyle Montague, Sandra Hastings, and Kellie Morrissey. 2019. Exploring Media Capture of Meaningful Experiences to Support Families Living with Dementia. In Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems - CHI '19, ACM Press, New York, New York, USA, 1–14. DOI:<https://doi.org/10.1145/3290605.3300653>
- [46] Maarten Houben, Rens Brankaert, Saskia Bakker, Gail Kenning, Inge Bongers, and Berry Eggen. 2019. Foregrounding Everyday Sounds in Dementia. In Proceedings of the 2019 on Designing Interactive Systems Conference - DIS '19, ACM Press, New York, NY, USA, 71–83. DOI:<https://doi.org/10.1145/3322276.3322287>
- [47] Maarten Houben, Rens Brankaert, Saskia Bakker, Gail Kenning, Inge Bongers, and Berry Eggen. 2020. The Role of Everyday Sounds in Advanced Dementia Care. In Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems, ACM Press, New York, NY, USA, Paper 450, pp. 1–14. DOI:<https://doi.org/10.1145/3313831.3376577>
- [48] Maarten Houben, Rens Brankaert, Gail Kenning, Berry Eggen, and Inge Bongers. 2020. The Perspectives of Professional Caregivers on Implementing Audio-Based Technology in Residential Dementia Care. *Int. J. Environ. Res. Public Health* 17, 17 (2020), 6333. DOI:<https://doi.org/10.3390/ijerph17176333>
- [49] Hilary Hutchinson, Wendy Mackay, Bo Westerlund, Benjamin B Bederson, Allison Druin, Catherine Plaisant, Michel Beaudouin-Lafon, Stéphane Conversy, Helen Evans, Heiko Hansen, Nicolas Roussel, and Björn Eiderbäck. 2003. Technology Probes: Inspiring Design for and with Families. In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '03), Association for Computing Machinery, New York, NY, USA, 17–24. DOI:<https://doi.org/10.1145/642611.642616>
- [50] Gail Kenning. 2018. Reciprocal design: inclusive design approaches for people with late stage dementia. *Des. Heal.* 2, 1 (January 2018), 142–162. DOI:<https://doi.org/10.1080/24735132.2018.1453638>
- [51] Gail Kenning, Alon Ilisar, Rens Brankaert, and Mark Evans. 2019. Improvisation and Reciprocal Design: Soundplay for Dementia. In Dementia Lab 2019. Making Design Work: Engaging with Dementia in Context. D-Lab 2019. Springer, Cham, 82–91. DOI:https://doi.org/10.1007/978-3-030-33540-3_8
- [52] Josephine Klefeker, Libi Striegl, and Laura Devendorf. 2020. What HCI Can Learn from ASMR: Becoming Enchanted with the Mundane. In Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems (CHI '20), Association for Computing Machinery, New York, NY, USA, 1–12. DOI:<https://doi.org/10.1145/3313831.3376741>
- [53] Rebecca Kleinberger, Alexandra Rieger, Janelle Sands, and Janet Baker. 2019. Supporting Elder Connectedness through Cognitively Sustainable Design Interactions with the Memory Music Box. In Proceedings of the 32nd Annual ACM Symposium on User Interface Software and Technology (UIST '19), Association for Computing Machinery, New York, NY, USA, 355–369. DOI:<https://doi.org/10.1145/3332165.3347877>
- [54] Scott R Klemmer, Anoop K Sinha, Jack Chen, James A Landay, Nadeem Aboobaker, and Annie Wang. 2000. Suede: A Wizard of Oz Prototyping Tool for Speech User Interfaces. In Proceedings of the 13th annual ACM symposium on User interface software and technology - UIST '00 (UIST '00), ACM Press, New York, New York, USA, 1–10. DOI:<https://doi.org/10.1145/354401.354406>
- [55] Agnieszka Barbara Kolasinska, Myrte Thoolen, Sebastiaan Peek, Yuan Lu, and Rens Brankaert. 2021. Co-creating Design Opportunities for Social Technology in the Context of Dementia. In Dementia Lab 2021: Supporting Ability Through Design, Springer International Publishing, Cham, 125–141. DOI:https://doi.org/10.1007/978-3-030-70293-9_11
- [56] Pia C. Kontos. 2004. Ethnographic reflections on selfhood, embodiment and Alzheimer's disease. *Ageing Soc.* 24, 6 (November 2004), 829–849. DOI:<https://doi.org/10.1017/S0144686X04002375>
- [57] L. Koumakis, C. Chatzaki, E. Kazantzaki, E. Maniadi, and M. Tsiknakis. 2019. Dementia Care Frameworks and Assistive Technologies for Their Implementation: A Review. *IEEE Rev. Biomed. Eng.* 12, (2019), 4–18. DOI:<https://doi.org/10.1109/RBME.2019.2892614>
- [58] Amanda Lazar, Caroline Edasis, and Anne Marie Piper. 2017. A Critical Lens on Dementia and Design in HCI. In Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems (CHI '17), ACM Press, New York, New York, USA, 2175–2188. DOI:<https://doi.org/10.1145/3025453.3025522>
- [59] Amanda Lazar, Hilaire Thompson, and George Demiris. 2014. A systematic review of the use of technology for reminiscence therapy. *Health Educ. Behav.* 41, 1 Suppl (October 2014), 51S–61S. DOI:<https://doi.org/10.1177/1090198114537067>
- [60] Micheline Lesaffre, Bart Moens, and Frank Desmet. 2017. Monitoring music and movement interaction in people with dementia. In The Routledge Companion to embodied music interaction. Routledge, 294–303.
- [61] Helle Nystrup Lund, Lars Rye Bertelsen, and Lars Ole Bonde. 2016. Sound and music interventions

- in psychiatry at Aalborg University Hospital. *SoundEffects - An Interdiscip. J. Sound Sound Exp.* 6, 1 (November 2016), 48–68. DOI:<https://doi.org/10.7146/se.v6i1.24912>
- [62] Stine S Lundgaard, Peter Axel Nielsen, and Jesper Kjeldskov. 2019. Interaction Design for Domestic Sound Zones. In Proceedings of the 14th International Audio Mostly Conference: A Journey in Sound (AM'19), Association for Computing Machinery, New York, NY, USA, 248–251. DOI:<https://doi.org/10.1145/3356590.3356630>
- [63] Remco Magielse and Serge Offermans. 2013. Future Lighting Systems. In CHI '13 Extended Abstracts on Human Factors in Computing Systems (CHI EA '13), Association for Computing Machinery, New York, NY, USA, 2853–2854. DOI:<https://doi.org/10.1145/2468356.2479545>
- [64] Julia M Mayer and Jelena Zach. 2013. Lessons Learned from Participatory Design with and for People with Dementia. In (MobileHCI '13), ACM, 540–545. DOI:<https://doi.org/10.1145/2493190.2494436>
- [65] Justine McGovern. 2011. Couple meaning-making and dementia: challenges to the deficit model. *J. Gerontol. Soc. Work* 54, 7 (October 2011), 678–690. DOI:<https://doi.org/10.1080/01634372.2011.593021>
- [66] May Helen Midtbust, Rigmor Einang Alnes, Eva Gjengedal, and Else Lykkeslet. 2018. Perceived barriers and facilitators in providing palliative care for people with severe dementia: the healthcare professionals' experiences. *BMC Health Serv. Res.* 18, 1 (2018), 709. DOI:<https://doi.org/10.1186/s12913-018-3515-x>
- [67] Alex Mihailidis, Jennifer N Boger, Tammy Craig, and Jesse Hoey. 2008. The COACH prompting system to assist older adults with dementia through handwashing: An efficacy study. *BMC Geriatr.* 8, 1 (December 2008), 28. DOI:<https://doi.org/10.1186/1471-2318-8-28>
- [68] Eneida Mioshi, Christopher M. Kipps, and John R. Hodges. 2009. Activities of Daily Living in Behavioral Variant Frontotemporal Dementia: Differences in Caregiver and Performance-based Assessments. *Alzheimer Dis. Assoc. Disord.* 23, 1 (January 2009), 70–76. DOI:<https://doi.org/10.1097/WAD.0b013e318182d293>
- [69] Susan L. Mitchell, Joan M. Teno, Dan K. Kiely, Michele L. Shaffer, Richard N. Jones, Holly G. Prigerson, Ladislav Volicer, Jane L. Givens, and Mary Beth Hamel. 2009. The clinical course of advanced dementia. *N. Engl. J. Med.* 361, 16 (2009), 1529–1538. DOI:<https://doi.org/10.1056/NEJMoa0902234>
- [70] Kellie Morrissey, John McCarthy, and Nadia Pantidi. 2017. The Value of Experience-Centred Design Approaches in Dementia Research Contexts. In Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems (CHI '17), ACM Press, New York, New York, USA, 1326–1338. DOI:<https://doi.org/10.1145/3025453.3025527>
- [71] Kellie Morrissey, Gavin Wood, David Green, Nadia Pantidi, and John McCarthy. 2016. 'I'm a rambler, I'm a gambler, I'm a long way from home': The Place of Props, Music, and Design in Dementia Care. In Proceedings of the 2016 ACM Conference on Designing Interactive Systems - DIS '16, ACM Press, New York, New York, USA, 1008–1020. DOI:<https://doi.org/10.1145/2901790.2901798>
- [72] Alexander Müller-Rakow and Rahel Flechtner. 2017. Designing Interactive Music Systems with and for People with Dementia. *Des. J.* 20, sup1 (July 2017), S2207. DOI:<https://doi.org/10.1080/14606925.2017.1352736>
- [73] S. Neves, A. Macdonald, M. Poole, and K. Harrison Dening. 2021. Participatory Co-design: Approaches to Enable People Living with Challenging Health Conditions to Participate in Design Research. In Perspectives on Design and Digital Communication II: Research, Innovations and Best Practices, Nuno Martins, Daniel Brandão and Fernando Moreira da Silva (eds.). Springer International Publishing, Cham, 193–216. DOI:https://doi.org/10.1007/978-3-030-75867-7_13
- [74] Gerard Oleksik and Lorna M. Brown. 2008. Sonic gems: Exploring the potential of audio recording as a form of sentimental memory capture. In Proceedings of the 22nd British HCI Group Annual Conference on People and Computers: Culture, Creativity, Interaction, BCS HCI 2008, British Computer Society, 163–172. DOI:<https://doi.org/10.14236/ewic/hci2008.16>
- [75] Gerard Oleksik, David Frohlich, Lorna M. Brown, and Abigail Sellen. 2008. Sonic interventions: Understanding and extending the domestic soundscape. In Conference on Human Factors in Computing Systems - Proceedings, ACM Press, New York, New York, USA, 1419–1428. DOI:<https://doi.org/10.1145/1357054.1357277>
- [76] Hanna-Mari Pesonen, Anne M Remes, and Arja Isola. 2011. Ethical aspects of researching subjective experiences in early-stage dementia. *Nurs. Ethics* 18, 5 (2011), 651–661. DOI:<https://doi.org/10.1177/0969733011408046>
- [77] Michelle Putnam, Joseph G Pickard, Carroll Rodriguez, and Erin Shear. 2010. Stakeholder Perspectives on Policies to Support Family Caregivers of Older Adults With Dementia. *J. Fam. Soc. Work* 13, 2 (March 2010), 173–190. DOI:<https://doi.org/10.1080/10522150903487479>

- [78] Alfredo Raglio, Stefania Filippi, Daniele Bellandi, and Marco Stramba-Badiale. 2014. Global music approach to persons with dementia: evidence and practice. *Clin. Interv. Aging* 9, (2014), 1669–1676. DOI:<https://doi.org/10.2147/CIA.S71388>
- [79] Karlijn van Rijen, Tom Cobbenhagen, Rens Janssen, Maria Væver Olsen, Rens Brankaert, Maarten Houben, and Yuan Lu. 2020. RelivRing: Reliving Social Activities for People with Dementia. In *Extended Abstracts of the 2020 CHI Conference on Human Factors in Computing Systems*, ACM Press, New York, NY, USA, LBW045, 1–8. DOI:<https://doi.org/10.1145/3334480.3383033>
- [80] Paul A. Rodgers. 2018. Co-designing with people living with dementia. *CoDesign* 14, 3 (2018), 188–202. DOI:<https://doi.org/10.1080/15710882.2017.1282527>
- [81] Kasper Rodil, Chatrine Elisabeth Larsen, Christoffer Caesar Faelled, Emil Færch Skov, Thomas Gustafsen, Antonia Krummheuer, and Matthias Rehm. 2020. Spending Time: Co-Designing a Personalized Calendar at the Care Center. In *Proceedings of the 14th Nordic Conference on Human-Computer Interaction: Shaping Experiences, Shaping Society (NordiCHI '20)*, Association for Computing Machinery, New York, NY, USA. DOI:<https://doi.org/10.1145/3419249.3420144>
- [82] Jim Rudd, Ken Stern, and Scott Isensee. 1996. Low vs. High-fidelity Prototyping Debate. *interactions* 3, 1 (June 1996), 76–85. DOI:<https://doi.org/10.1145/223500.223514>
- [83] Elizabeth B.-N. Sanders and Pieter Jan Stappers. 2014. Probes, toolkits and prototypes: three approaches to making in codesigning. *CoDesign* 10, 1 (2014), 5–14. DOI:<https://doi.org/10.1080/15710882.2014.888183>
- [84] Corina Sas, Nigel Davies, Sarah Clinch, Peter Shaw, Mateusz Mikusz, Madeleine Steeds, and Lukas Nohrer. 2020. Supporting Stimulation Needs in Dementia Care through Wall-Sized Displays. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems (CHI '20)*, Association for Computing Machinery, New York, NY, USA, 1–16. DOI:<https://doi.org/10.1145/3313831.3376361>
- [85] Luma Tabbaa, Chee Siang Ang, Vienna Rose, Panote Siriaraya, Inga Stewart, Keith G. Jenkins, and Maria Matsangidou. 2019. Bring the Outside In: Providing Accessible Experiences Through VR for People with Dementia in Locked Psychiatric Hospitals. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems - CHI '19*, ACM Press, New York, New York, USA, 1–15. DOI:<https://doi.org/10.1145/3290605.3300466>
- [86] Lisanne Teunissen, Tom Luyten, and Luc de Witte. 2017. Reconnecting People with Dementia by Using the Interactive Instrument CRDL. *Stud. Health Technol. Inform.* 242, (2017), 9–15.
- [87] Theresa Thoma-Lürken, Michel H C Bleijlevens, Monique A S Lexis, Luc P de Witte, and Jan P H Hamers. 2018. Facilitating aging in place: A qualitative study of practical problems preventing people with dementia from living at home. *Geriatr. Nurs. (Minneapolis)* 39, 1 (2018), 29–38. DOI:<https://doi.org/https://doi.org/10.1016/j.gerinurse.2017.05.003>
- [88] Myrte Thoolen, Rens Brankaert, and Yuan Lu. 2020. AmbientEcho: Exploring Interactive Media Experiences in the Context of Residential Dementia Care. In *Proceedings of the 2020 ACM Designing Interactive Systems Conference (DIS '20)*, Association for Computing Machinery, New York, NY, USA, 1495–1508. DOI:<https://doi.org/10.1145/3357236.3395432>
- [89] Myrte Thoolen, Rens Brankaert, and Yuan Lu. 2020. Designing Sentic: Participatory Design with People Living with Dementia. In *HCI and Design in the Context of Dementia*, Rens Brankaert and Gail Kenning (eds.). Springer International Publishing, Cham, 269–288. DOI:https://doi.org/10.1007/978-3-030-32835-1_17
- [90] Peter Tolmie and Andy Crabtree. 2008. Deploying Research Technology in the Home. In *Proceedings of the 2008 ACM Conference on Computer Supported Cooperative Work (CSCW '08)*, Association for Computing Machinery, New York, NY, USA, 639–648. DOI:<https://doi.org/10.1145/1460563.1460662>
- [91] David Unbehau, Sebastian Taugerbeck, Konstantin Aal, Daryoush Daniel Vaziri, Jasmin Lehmann, Peter Tolmie, Rainer Wieching, and Volker Wulf. 2020. Notes of memories: Fostering social interaction, activity and reminiscence through an interactive music exergame developed for people with dementia and their caregivers. *Human-Computer Interact.* (June 2020), 1–34. DOI:<https://doi.org/10.1080/07370024.2020.1746910>
- [92] Jayne Wallace, Peter C. Wright, John McCarthy, David Philip Green, James Thomas, and Patrick Olivier. 2013. A design-led inquiry into personhood in dementia. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems - CHI '13*, ACM Press, New York, New York, USA, 2617–2626. DOI:<https://doi.org/10.1145/2470654.2481363>
- [93] Lin Wan, Claudia Müller, Volker Wulf, and David Randall. 2014. Addressing the subtleties in dementia care: Pre-study & evaluation of a GPS monitoring system. In *Conference on Human*

- Factors in Computing Systems - Proceedings, ACM Press, New York, New York, USA, 3987–3996.
DOI:<https://doi.org/10.1145/2556288.2557307>
- [94] Rik Wesselink, Marike Hettinga, Geke Ludden, and Berry Eggen. 2020. Unforgetting Music: Exploring the role of music in the daily lives of people with dementia living at home. In Proceedings of the 6th International Conference on Design4Health, Lab4Living, Sheffield Hallam University, Amsterdam, 721–728.
- [95] Marjolein Wintermans, Rens Brankaert, and Yuan Lu. 2017. Together we do not forget: Co-designing with people living with dementia towards a design for social inclusion. *Des. Manag. Acad.* 2017 (2017).
- [96] Dennis Wolf, Daniel Besserer, Karolina Sejunaite, Matthias Riepe, and Enrico Rukzio. 2018. CARE: An Augmented Reality Support System for Dementia Patients. In The 31st Annual ACM Symposium on User Interface Software and Technology Adjunct Proceedings (UIST '18 Adjunct), Association for Computing Machinery, New York, NY, USA, 42–44. DOI:<https://doi.org/10.1145/3266037.3266095>
- [97] Tamara Zubatiy, Kayci L Vickers, Niharika Mathur, and Elizabeth D Mynatt. 2021. Empowering Dyads of Older Adults With Mild Cognitive Impairment And Their Care Partners Using Conversational Agents. In Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems. Association for Computing Machinery, New York, NY, USA. DOI:<https://doi.org/10.1145/3411764.3445124>
- [98] 2017. Global action plan on the public health response to dementia 2017- 2025. World Health Organization, Geneva.

III

EVALUATE

To explore the full potential of everyday sounds in enriching the wide range of lived experiences of dementia, Section 3 aims to further investigate how the beneficial effects of everyday sounds for people with dementia can be integrated into dementia care practice. This section will focus on the in-context deployment of the Vita sound cushion in two residential care facilities. Vita supports people with advanced dementia in playing everyday sounds in the care home.

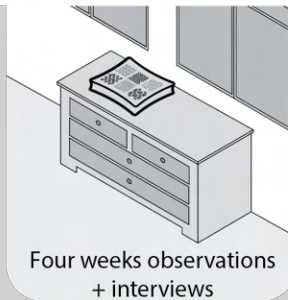
Chapter 5 reports the outcomes of the workshops held with the professional caregivers and activity supervisors who were going to use Vita in context prior to the field study. These workshops aimed to tap into the expertise of the professional caregivers to gain insight into existing care activities and how everyday sounds facilitated by Vita can add value to everyday care practice.

Chapter 5: The Perspectives of Professional Caregivers on Implementing Audio-Based Technology in Residential Dementia Care



Workshop 1

Care Facility A



Four weeks observations
+ interviews

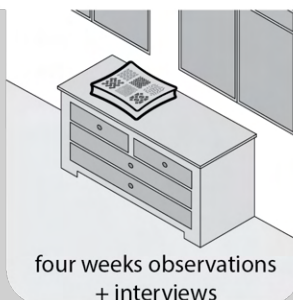


Workshop 2



Workshop 3

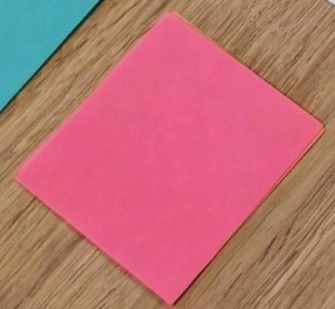
Care Facility B



four weeks observations
+ interviews

Chapter 6: The Role of Everyday Sounds in Advanced Dementia Care

Chapter 6 presents the findings from the in-context deployment of Vita. 16 professional caregivers, of which 12 participated in the workshops presented in Chapter 5, used Vita during activities in the care home for four weeks. The main researcher made observations of the responses of the care home residents and conducted exit interviews with the caregivers to understand their experiences and insights of using Vita and everyday sounds in context.



5

The Perspectives of Professional Caregivers on Implementing Audio-Based Technology in Residential Dementia Care

In this chapter, we present the outcome of three participatory workshops with 18 professional caregivers to explore how audio-based technology can add value to existing care processes and activities in residential dementia care. During the participatory workshops, professional caregivers (1) mapped existing care activities; (2) linked findings in research with practice, and (3) designed scenarios for the Vita sound cushion. Care professionals indicate how audio-based technology can support existing care practice by influencing the mood of residents and by supporting social interaction during moments of care, daytime activities, or situational sessions. This study bridges research findings with insights from practice, contributing to a shared understanding of opportunities for embedding audio-based technology in dementia care. These opportunities motivate future research to implement and evaluate audio-based technology in residential dementia care.

This chapter is a reproduction of the paper published as:

Maarten Houben, Rens Brankaert, Gail Kenning, Berry Eggen, and Inge Bongers. 2020. "The Perspectives of Professional Caregivers on Implementing Audio-Based Technology in Residential Dementia Care" *International Journal of Environmental Research and Public Health* 17, no. 17: 6333. <https://doi.org/10.3390/ijerph17176333>

5.1 INTRODUCTION

Dementia is a societal health challenge, as the global population is aging and the number of incidences rises [1]. Without a cure and with a lack of effective pharmacological interventions [2], there is an increasing need for nonpharmacological alternatives to increase the quality of the everyday lives of people with dementia [3]. Over the years, researchers from various disciplines have demonstrated the beneficial effects of music for people with dementia [4–7]. For instance, music can reduce stress and agitated behavior [8] and can positively influence residents' emotional states and mood in residential dementia care [5,9]. Furthermore, music from a person's past can evoke autobiographical memories [10–12] and can support recognizing and maintaining identity [13,14]. Alongside listening to music, people with dementia can also participate actively in music sessions by playing instruments, by singing, or by moving to music [6]. Therefore, music sessions can stimulate physical activity [15,16] and can provide opportunities for social interaction with professional caregivers and other residents in a care home [7,17,18].

Building on this extensive body of work on music in dementia [4–13,15–18], researchers have begun exploring the potential benefits of everyday sounds or nonmusical sounds perceived in everyday life for people with dementia [19–25]. Like music, everyday sounds that are perceived as pleasant can evoke positive emotions [24,26]. For instance, sounds of nature can relax and calm people with dementia [25]. Reexperiencing sounds from everyday life can provide feelings of comfort or safety [27], can prompt memories of life events and loved ones [20], and can support storytelling by people with dementia to relive meaningful past experiences in the present [18,19]. These responses to sound provide opportunities for social connection and interaction [21,22] and for improvement in the living environment of care facilities, where sounds can be perceived and enjoyed by residents regardless of their limitations or illness [23].

Motivated by the potential of music and everyday sounds in dementia, researchers from various disciplines investigated how to leverage these beneficial effects of sound into everyday care by using audio-based technology (ABT). Soundscapes or perceived collections of ambient sounds can augment the existing sonic environment with pleasant and familiar sounds to provide a sense of safety and structure for residents in residential dementia care [28–30]. For example, introducing soundscapes that contain nature sounds, such as bird songs or rustling tree leaves, to care home residents in the morning can cue time-related activities, such as waking up and getting dressed [31].

Moreover, researchers have been exploring the role of sound in daytime activities to stimulate social engagement and creativity [32], such as art therapy [33] and music sessions [6]. These research explorations have resulted in new accessible interfaces for people with dementia to enable them to play personal music content [34–36] and virtual instruments adapted to the skills and abilities of residents with dementia to support participation during music therapy sessions [7,17,37,38]. ABT, such as music pillows [22,29] and collaborative interfaces [17,21,39], support social activities and stimulate engagement between people with dementia, their relatives, and professional caregivers [21,22].

Initial research that explored the perspectives of professional caregivers on sound in care practice has indicated that ABT can alleviate part of their workload and can improve the quality of life of people with dementia by decreasing stress and agitation for people with cognitive impairments in general by providing a sense of safety, daily structure, and comfort [40]. However, there is a lack of understanding on how these interventions can be purposefully used in existing care processes. Professional caregivers suggest that the implementation of interventions involving sound in residential dementia care should not result in unintended behavior of residents, such as unrest [28]. For example, sound is not always desirable during moments in care that require silence, such as resting activities, or moments when ambient or incidental sounds are already noticeable, for example, when breakfast is served [28]. Overall, professional caregivers struggle to successfully incorporate novel technologies such as ABT into dementia care practices [41]. Research shows that technologies for health care settings in general often seem successful and show promise at first yet lack sustainability, and repeatedly fail to become implemented into health care programs [41,42]. Time constraints and heavy workloads are recurring barriers for the care staff in accommodating new technologies into their current care routines [42]. Therefore, while there is an urgent need for integrated care services that address the needs of both people with dementia and their caregivers, integrating technology into dementia care remains a complex process because of the various stakeholders and contextual factors [41]. More insights are needed into the lived experiences and everyday needs of working in residential dementia care to investigate how professional caregivers can successfully embrace ABT.

By adopting a participatory approach, we aim to contribute to existing research by mapping the perspectives of professional caregivers on opportunities for ABT to augment existing activities, routines, and habits in residential dementia care with meaningful audio content. A participatory design is established in the literature as an

effective method to gain insight into people's values, beliefs, preferences, and everyday living or working environments [43]. Participatory approaches have been applied in the context of health care interventions to assess the attitudes and perspectives of professional caregivers on the acceptance of new technologies or organizational innovations [44–46]. For instance, to gain a qualitative understanding of the everyday working experience within healthcare teams, such as care tasks, different or common goals, and interdependencies with other teams [45].

In this chapter, we discuss and present the outcomes of three participatory workshops where 18 professional caregivers divided over three sessions explored and mapped opportunities of ABT in residential dementia care. With our workshop approach, we aimed to bridge insights from relevant academic literature with personal lived experiences and expertise of care professionals. The participatory workshop approach focused on the professional caregivers' perspectives in using ABT to enrich and contextualize our previous research efforts on in-context responses of people with dementia on everyday sounds in dementia [19,22]. The results of our field study describing the in-context responses of the residents with dementia have been reported and published in other literature [22]. In this chapter, we contribute the outcomes of the participatory workshops that preceded the field study and discuss the opportunities for ABT in dementia care that emerged during these workshop sessions. The professional caregivers did not serve as a proxy for the residents in this study but as key stakeholders in their own right, with opinions on providing care for people with dementia [47].

By bridging existing research insights with professional caregivers' lived experiences, we established a shared understanding of opportunities for embedding ABT in residential dementia care to augment existing care activities, routines, and habits with everyday sounds. Furthermore, we discuss how these opportunities grounded in both practice and literature motivate further research on the implementation and evaluation of audio-based and experience-centered technologies in healthcare settings.

5.2 MATERIALS AND METHODS

Professional caregivers working in residential care facilities for people with dementia generated opportunities for integrating ABT in practice in three workshops using a participatory approach [45,48]. We sensitized the professional caregivers on the potential benefits of ABT [49], explored the personal lived experiences of professional caregivers [50], and facilitated group discussions between these relevant stakeholders

[51]. With this approach, we aimed to bridge insights from academic research to everyday practice and vice versa.



Figure 5.1. Vita served as an example of audio-based technology: (left) Vita is a cushion with conductive touchpads to play audio content and (right) with buttons on the reverse side to adjust the settings or volume.

5.2.1 Vita: Audio-Based Design Intervention

The participatory workshops were conducted as part of a field study aimed at exploring the role of everyday sounds facilitated by ABT in a real-life care environment. This field study [22] was centered around the deployment of Vita, an audio-based design intervention (see Figure 5.1), in two residential care facilities for people with dementia. Vita is a cushion equipped with a speaker and six conductive sensors embedded in the cushions' surface underneath colorful patterns of vinyl that serve as a safe and easy-to-use interface [52]. People with dementia can play audio files by touching one of six touchpads on the cushion. Upon touching such a touch pad, the corresponding sound starts to play until the resident stops touching it. This easily accessible interface enables people in advanced stages of dementia to play audio. Vita can be used in various ways in a care facility, such as at the table in the communal space, on the lap of the resident, or in bed in their private room. Vita was designed as a cushion so that it blends in with the interior of the care facility and is readily available for use. Caregivers and relatives can record, upload, and select personal audio content via an online platform. Vita is the outcome of a multidisciplinary collaboration between researchers, designers, and care practitioners and was developed in a codesign process involving people with dementia and their caregivers [53]. The participatory workshops served as introductory sessions for the professional caregivers overseeing Vita's deployment in the care facility. The aim was to encourage and stimulate creativity in the use of Vita by professional caregivers

during this field study by generating and designing concrete scenarios for using ABT in residential dementia care.

5.2.2 Workshop procedure

At the start of the workshop, the participants were asked to introduce themselves to the researcher and each other, stating their name, profession (nurse or activity supervisor), care unit, and why they were interested in participating in the workshop. The workshop approach consisted of three consecutive steps to explore the different areas of expertise of the caregivers. First, the professional caregivers mapped everyday activities in residential dementia care onto a 24-h timeline. Next, we asked the professional caregivers to interpret statements taken from literature on sound and dementia and to link these to their practice and expertise. Lastly, the researcher introduced the professional caregivers to Vita: a cushion-like sound player as a concrete example of ABT within everyday care.

5.2.2.1 Step 1: Mapping Everyday Activities in Care

The goal was to build an overview of the everyday care schedule and activities in residential dementia care [50]. During this step, the professional caregivers were asked to outline the typical day of a resident in a care facility (see Figure 5.2). A poster with a circle representing a 24-h timeline was provided to support the professional caregivers in mapping the daily activities to a specific timeframe and in sharing their views with the group [51]. The poster was placed in reach of all participants who were given pens, paper, and post-it notes to make individual notes or sketches.



Figure 5.2. The caregivers mapped the typical day of a resident with dementia: (left) First, they were asked to reflect and make notes individually. (right) Next, participants were asked to share their thoughts with the group and to place their notes on the 24-h timeline.

First, the professional caregivers were asked to individually think about typical everyday activities in the care facility and to make personal notes. Giving professional caregivers an individual exercise stimulates participant engagement and generates more in-depth topics [45]. Next, each caregiver was asked in turn to read their notes aloud and to place it on the circular 24-h timeline. Participants were then given the opportunity to respond and discuss the notes in the group to stimulate discussion between the professional caregivers [50].

5.2.2.2 Step 2: Relating Research to Everyday Care Activities

Step two was to inform the professional caregivers about academic research and evidence on how sound can support people with dementia and to broaden their understanding of how sound could contribute to their everyday practice [49]. They were provided with 12 statements collected from relevant literature on sound in general and more specific literature on sound in care facilities for people with dementia (see Table 5.1). To offer a clear overview of the research claims, we provided three categories of cards: nuisance (red), application (blue), and emotions and behavior (green). These cards guided and inspired the participants to design new scenarios for ABT [54].

Table 5.1. The cards contained statements and conclusions of relevant academic research to inform the professional caregivers of the opportunities and challenges of audio-based technology (ABT) for dementia care.

Category	Statements from Literature	Ref.
Red cards: potential nuisance of sound in a care environment.	“If a person cannot give meaning to a sound, it is considered noise.”	[55]
	“Sound can make people with dementia distracted, nervous, or scared.”	[30]
	“You can close your eyes but not your ears.”	[29]
	“Unpleasant sounds can cause stress and irritation in a care home.”	[56]
Blue cards: application areas of ABT.	“Pleasant sounds can mask unwanted or annoying sounds.”	[30]
	“Sound can evoke social interactions between people with dementia and caregivers.”	[21]
	“Sounds can provide structure and routine in a care facility.”	[40]
Green cards: emotional and behavioral responses to sound.	“Everyday sounds can evoke memories related to those sounds.”	[19]
	“Pleasant noises can calm a person with dementia.”	[27]
	“Personal sounds can support identity and selfhood in dementia.”	[14]
	“Joyful sounds can stimulate and revive people.”	[24]
	“By listening to a pleasant sound, someone can feel at ease and safe.”	[28]

The cards were stacked according to category and placed face-down in the middle of the poster. Each caregiver was asked in turn to draw a card from one of the piles, to read the statement out loud in the group, and to formulate if they could relate this statement to their own experience (see Figure 5.3). The aim of these cards was to provide a playful way of presenting insights from academic research and to include all participants in the discussions [54]. Next, other participants were asked to react to the statement in order to stimulate a group discussion where professional caregivers could compare potential similarities and differences in the interpretation of the statement. After the discussion, the caregiver was asked to place the card on the 24-h timeline where the specific statement from literature was applicable. If the statement did not apply to a particular time or activity, professional caregivers could place the card in the center of the poster.



Figure 5.3. During the second step of the workshops, the professional caregivers were asked to map statements from literature to practice: (left) The cards with statements from literature were stacked in piles, face-down on the poster as in a board game. (right) Each caregiver was asked in-turn to draw a card and to relate the statement to their own experience, after which the group discussed the statement.

5.2.2.3 Step 3: Designing Scenarios for Audio-Based Technology

Step three bridged the insights from step 1 and step 2 to design potential scenarios for using ABT in dementia care (see Figure 5.4). Here, Vita was presented as a concrete example of an audio-based technology to cue the professional caregivers in generating ideas and concepts for adopting ABT in their practice. The primary researcher explained the design rationale of Vita and gave instructions on how the device works. Vita was passed between the professional caregivers to allow them to hold the device and to explore the interface. Next, the professional caregivers were asked to individually write down several concrete scenarios for using Vita on the large yellow post-it notes, as depicted in Figure 5.4. These scenarios were to include a specific resident, an activity, a timeframe, and potential audio content. Finally, the professional caregivers were asked to share their scenarios with the group and to place their post-it notes on the timeline

to stimulate a final group discussion on the implementation of Vita and ABT in general, which concluded the session.

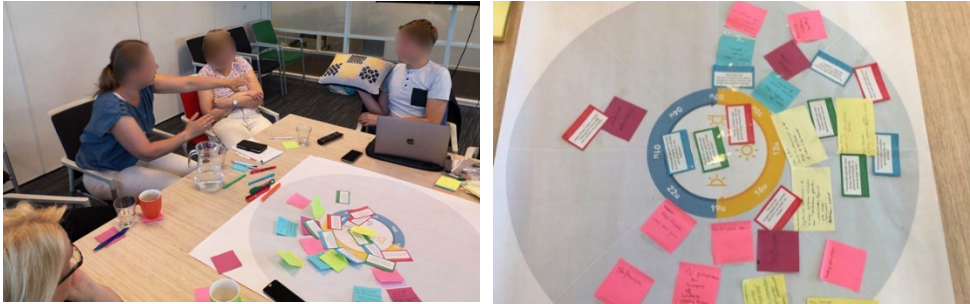


Figure 5.4. Lastly, the professional caregivers were asked to develop concrete use-cases for Vita: (left) The researcher explained the design rationale of Vita. (right) The professional caregivers were asked to think of specific cases to use Vita, which was then discussed during the final group discussion.

Table 5.2. In total, 18 professional caregivers participated in the participatory workshops, divided over three sessions organized at two different care facilities. The professional caregivers were either nursing staff (N) in charge of everyday care tasks or activity supervisors (A) who provide daytime activities. All caregivers were female (f), except C18 (m).

Care Facility A								Care Facility B									
Session 1								Session 2				Session 3					
C1	C2	C3	C4	C5	C6	C7	C8	C9	C10	C11	C12	C13	C14	C15	C16	C17	C18
A	N	A	N	A	A	A	A	N	N	N	N	A	A	N	N	N	A
f	f	f	f	f	f	f	f	f	f	f	f	f	f	f	f	f	m

5.2.3 Participants and Setting

In total, 18 professional caregivers who work in residential dementia care participated in the workshops, divided over three sessions (as depicted in Table 5.2). Nine caregivers were part of the nursing staff responsible for everyday care of the residents, such as washing, dressing, or eating. The other nine were activity supervisors who organize and accommodate social daytime activities, such as music sessions or art therapy. All participants were female, except C18. The workshops took place at two care facilities in the Netherlands that both accommodate long-term residential care for people in advanced stages of dementia. We conducted one session at care facility A in Eindhoven

with eight professional caregivers (C1–C8) and two sessions at facility B in Arnhem, with six (C9–C14) and four (C15–C18) professional caregivers, since not all professional caregivers at location B were able to attend the same session due to full agendas.

5.2.4 Data Analysis

The participatory workshops were audio-recorded and later transcribed verbatim. The primary researcher analyzed the transcriptions by conducting thematic analysis, following an inductive approach [57]. Statements relevant to the research question were clustered in codes and further refined into the themes discussed and iterated in consultation with the coauthors.

5.2.5 Ethics

The research activities in this chapter were part of a field study on the deployment of Vita, which was approved by the Ethics Review Board of the Tilburg School of Social and Behavioral Sciences, Tilburg University (reference number: EC-2019.22) in which the codesign sessions were reported as introductory sessions for the professional caregivers participating in the field study. The professional caregivers were briefed about the study's aim in general and the participatory workshops in specific. Next, informed consent was asked and collected according to the General Data Protection Regulation (GDPR), granting permission to record and analyze the audio of the participatory workshop sessions and to use photographic documentation in academic publications.

5.3 RESULTS

Our results provide insight into the perspectives of professional caregivers in residential dementia care on the following:

- the added value of ABT in the residential dementia care process as ABT can provide rest and relieve from stress during the transition between activities, can initiate social connection during everyday care tasks; and can relieve boredom by supporting daytime activities and situational social experiences in the care space, and;
- how the successful integration of ABT in residential care requires a person-centered approach adapted to activities and habits specific to a care unit or healthcare team and tailored to the residents' needs and preferences by exploring their individual responses.

5.3.1 *The Added Value of ABT in the Care Process*

The professional caregivers expressed their motivations for using ABT in the care facility by discussing areas for application and the potential added value for both the resident with dementia as well as the care staff.

5.3.1.1 *Relieve Moments of Stress and Boredom*

Nearly all professional caregivers (C1–C4, C6, C7, C9–C11, and C13–C18) mentioned how they would use sound to calm residents and to provide relief from stress. During moments when residents were not at rest due to boredom, “*recognizable relaxing sounds*” (C1) could be used as a nonmedical alternative to address agitated behavior. This potential application of ABT providing relaxing sounds can alleviate part of the workload of professional caregivers who often struggle with finding effective ways or tools to calm distressed residents, as illustrated by C15: “*At the end of the afternoon, in the evening, a resident often says: ‘I have to go home, my mother is very ill!’, and then, you have to try to calm her, for example, with piano music.*” In current practice, several professional caregivers (C4, C13, and C15–C18) often play music in the background (e.g., the radio) to prevent residents from becoming stressed “*because, in our group, they become very quiet when we put on music*” (C17). Two professional caregivers (C9 and C17) suggested that audio messages of family members might calm and reassure residents worrying that their partner or family members have forgotten about them:

“Her son always comes to visit on the weekends, but at some point, she becomes very restless when he is not there yet. Maybe a message [from her son] saying ‘see you mom, see you later’ can help here.” (C9)

However, the successful use of ABT should also address the need for moments of silence and rest as professional caregivers (C11, C13–C15, and C17) made it clear that not all moments require sound or music: “*why does music always have to be on?*” (C15). *At specific times during the day, silence is preferred to not distract the residents from essential activities, such as eating. For instance, C17 always switches off the TV in the evening when residents are having dinner “because, otherwise, residents will keep on singing and will not eat” (C17).* In several living areas, the TV or radio is often turned on to provide some background sounds, but caregivers indicated how loud music or the sound of the TV often have an opposite effect and leads to a restless and hectic atmosphere (C10, C12, C13, and C16), as illustrated by C13:

“Because, sometimes [I] walk into a living area, and then I think, ‘why is the TV on now?’—sometimes just on a children’s channel—and then there is a lot of sound! But, no one is watching, and the [terrible] things that are on TV...(sighs)”
(C13)

Most professional caregivers (C1, C4, C7, and C9–C18) saw opportunities to use audio-based interventions during transitions between scheduled activities. For instance, before scheduled daytime activities, when residents become *“agitated if the activity is not immediately happening”* (C9), or directly afterward, when *“all residents must return to the living area at the same time”* (C7), because *“then you have to keep them busy”* (C4). Similarly, ABT could be used directly before or after care tasks to calm residents (C1, C4, C7, and C10–C18). In the morning, sound could provide *“a little bit of excitement that might give them a peaceful moment to get out of bed”* (C18) or could be provided *“after breakfast to [help them] stay awake because, then, there is no activity”* (C11). Professional caregivers (C1, C10, C11, C15, C16, and C18) saw potential in using Vita to improve sleeping patterns: *“if someone is very restless before bed and you give [them] Vita with a recognizable relaxing sound, [then] it can also contribute [to relaxation].”* (C1). According to (C2, C15, C16, and C18), quiet and peaceful sounds could help with *“sleeping through [the night] and falling asleep [...] for people who wake up at night or [are] unable to fall asleep”* (C16).

In summary, there is potential for ABT to support the care process in relieving moments of stress and boredom in the care space and in easing moments of transition to other activities or care tasks, but ABT should also offer room for silence and rest.

5.3.1.2 *Facilitating Playful and Engaging Daytime Activities*

Professional caregivers suggested that ABT can support scheduled daytime activities that offer playful social experiences, such as music sessions or reminiscence therapy (C1, C3–C10, C13, C15, C16, and C18). Most professional caregivers (C1, C3–C9, C12, and C15–C18) had experience in providing sound-related activities during one-on-one sessions with the resident to specifically focus on multisensory stimulation of people in advanced stages of dementia. Professional caregivers (C1, C4, C5, C7, C9, C10, C12, C13, C15, and C18) also stated how sound could be a useful tool to support group activities involving multiple residents of the care facility, such as music activities (C1 and C7). Vita could facilitate an alternative group activity in the common living area for residents who do not attend daytime activities, for instance, during *“periods between breakfast and lunch*

and, then, afternoon between lunch and dinner, when there are no activities and visitors” (C10).

However, it was also remarked that these group activities in the living area might not work (C2, C5, C12–C13, and C17), as it *“is difficult in a group in the living room; if people do not want to listen, they can go read or something, but they will still hear it.” (C13).* Daytime activities can produce unwanted sounds and become a nuisance for other residents and professional caregivers who are not partaking in those activities but still want and have to reside in the communal living area (C15 and C16). For instance, *“when there is an activity in the hallway and the doors need to be open because people want to walk back and forth, [...] that causes a lot of noise and disturbance.” (C15).* Therefore, when using ABT in a real-life care space, the existing layer of ambient sounds and the acoustical impact of ABT need to be considered. Unwanted environmental sounds such as the dishwasher (C1, C2, C11, and C15), deliveries of meals or other supplies (C13, C14, and C16), and vacuum cleaners (C13 and C16) can cause restlessness among the residents or can disrupt daytime activities, as was the case for C13: *“Someone started to vacuum the common space while I was holding an activity. You can notice it in the residents. They get restless.”* During these moments, additional sounds or sound-related activities are often unwanted or not desirable as this might cause stress for the residents and the professional caregivers who already have to cope with heavy workloads and time constraints:

“Yes this is very personal, but I had quite a burnout myself, and when I had to come back to work for the first time, I was also very anxious because, over here, a resident was having a pedicure [and], over there, six people were wandering. The doors [to the hallway] were open. Someone had turned on the television because that is cozy, and there I was standing behind the counter as a frightened person thinking ‘what is going on here?’” (C16)

Often, residents sleep during the day, but these daytime naps can mix up day-to-day structure and can disrupt sleeping patterns and sleep quality. For instance, *“when there are no scheduled activities, she [a resident] is just staring ahead or taking a nap” (C10).* Professional caregivers (C10, C11, C13, C16, and C18) want to use sound to animate residents during the day to prevent them from falling asleep and to support a daily wake–sleep structure. Most professional caregivers (C1, C2, C4, C6, C7, and C9–C18) indicated how ABT could be used in the care space to initiate spontaneous, playful activities by using pleasant and exciting sounds *“to excite them a bit, so they do not*

disturb their rhythm of day and night, and they stay awake” (C13). From the experience of caregivers (C1, C2, C4, C7, and C15–C18), music effectively animates residents to make them more active or to wake them up in a spontaneous and meaningful way:

*“I have someone who, uhm, when I always turn on the radio with jazz and blues, [...] she immediately starts dancing then, and that reminds her of her past too.”
(C1)*

Professional caregivers expressed the value of ABT to support daytime activities and to instantly initiate spontaneous activities that provide social engagement in the care space to provide structure and daily rhythm. Nevertheless, the deployment of such interventions and activities requires careful consideration of the existing acoustic environment and the impact of augmenting this environment with additional sounds.

5.3.1.3 *Support Social Interaction in the Care Process*

The professional caregivers considered how ABT can offer cues for social interaction during their different care tasks within the daily care process. They (C1–C4, C6, C9, C10, and C12–C18) suggested a potential value of ABT to initiate and support social interactions during one-on-one activities with residents who are *“in advanced stages of dementia—to make contact—as it is often difficult to make contact with them”* (C14). Playing recognizable sounds and listening together can evoke broad topics of conversation (C2, C3, C10, C12, C13, C16, and C18). Caregivers suggest that sound could *“evoke memories, so you also get people talking about it”* (C2). In this context, professional caregivers (C1, C2, C6, C9, C12, C13, C15, C17, and C18) saw potential in using Vita to play familiar sounds to support reminiscence and to evoke emotions to facilitate meaningful and socially engaging experiences:

“That can be related to hobbies or something—or to work—or baby sounds if you happen to have worked in child care [...] when you have one-on-one conversations about their work, hobbies, or past, then you also come across those sounds.” (C15)

Professional caregivers (C2–C4, C6, and C13) made it clear that activity supervisors and the nursing staff have different perspectives and opinions on the use of ABT with residents. Residents can behave differently during organized daytime activities (e.g., music club) and when residing in the living area, as illustrated by (C2) (nurse): *“No, she [activity supervisor] wants to use it with a specific resident, but we [nursing staff] have a*

different opinion on that. But, that is the difference between people who do nursing and colleagues [who supervise activities], whether residents are below [in the activity space] or whether they are above [in the living area]" (C2). Therefore, to understand how ABT can support different facets of everyday dementia care, it is required to incorporate the different functions and care tasks of the professional caregivers, such as providing activities, household tasks, or personal care. For instance, C15 supports residents in performing everyday routines such as getting up in the morning or assisting with bathing and uses music to reduce awkwardness and to make these tasks more enjoyable for her and for the residents:

"With physical care, which is quite stressful or difficult for several people and annoying, music can certainly help. [...] I often sing songs with the people while providing morning care because, then, you can get a lot more done. I make a song from the activity or task that I am doing at that moment, especially with people in the advanced phases, so you can still try to make some contact. [...] The morning care of one of the residents is becoming increasingly difficult for her and us. [We could] accompany it with soft and friendly piano music, because she is very interested in that, to start the day off right." (C15)

Listening to music was mentioned by C1, C4, and C15 as a useful way to connect with residents who have difficulty in initiating and engaging in a conversation: *"especially when people are in advanced stages, you can still make contact that way"* (C15). These moments of contact can also be with family members who visit the care facility and often struggle to hold a conversation or to make contact with their relative with dementia (C15 and C18). The professional caregivers had previously experienced the value of sound in supporting nonverbal contact with people in advanced stages of dementia and those who are unable to communicate verbally:

"Hearing is the last [sense] to disappear. [...] You often see people whose dementia has progressed [being] involved in those activities [with sound] and they still respond by opening their eyes, but they can no longer speak. [...] The hearing remains!" (C2).

ABT can offer opportunities to stimulate social connection during care activities, household tasks, or personal care by cueing conversations and by evoking nonverbal responses that reduce awkwardness and support difficult tasks in the care process.

5.3.2 *Need for a Person-Centered and Reflexive Approach*

The professional caregivers strongly expressed how the successful integration of ABT in everyday practice demands a person-centered approach that addresses the needs and situation of the residents with dementia and how reflexivity is required to explore and evaluate the in-context responses of the participants.

5.3.2.1 *Person-Centered Approach*

Nearly all professional caregivers (C1–C7 and C9–C18) indicated that the use of ABT would strongly depend on the person with dementia as it *“can certainly make a contribution, especially if they are open to it, but it is not for everyone”* (C2). Sound content was seen as crucial in evoking meaning from residents by professional caregivers (C1, C5, and C9–C16). For instance, it is necessary to understand the preferences of the residents, and *“you must first filter out what is pleasant because what is pleasant for me is not pleasant for you (C11).”* Professional caregivers (C2, C4, C7, and C10–C18) imagined themselves in the situation of the residents and stated how responses to sound apply *“not only for people with dementia, [but] it also applies for yourself”* (C14). Similarly, professional caregivers (C7 and C10–C18) linked discussions on sound in the care home to their personal life or household. Therefore, professional caregivers (C12 and C14–C16) suggested looking at the social and cultural background of the residents for meaningful audio content. For instance, C12 has a migration background and grew up in a context different from a typical Dutch household:

“Oh, I always put the radio on: when I get up, when I take a shower, sing[ing] along in the shower. Yes, I also think it depends on the culture too. There were always many people in my house, it was always busy, and I am not used to silence at all.” (C12)

Similarly, professional caregivers are required to evaluate and monitor potential negative responses to sounds that evoke emotionally difficult memories and, as a result, to confront people with their dementia or to cause feelings of sadness. For instance, C11–C13 discussed how some residents became sad when listening to music or while reminiscing during daytime activities. However, feelings of sadness or nostalgia are not necessarily harmful as *“those are also feelings to talk about”* (C13). Furthermore, professional caregivers (C2, C3, C9, C11–C13, C16, and C17) expressed concern that listening to certain sounds can cause rest to one and unrest to the other: *“you put on, for example, chirping birds because that is so soothing, but then one resident thinks: ‘those rotten birds, can’t they shut up?’”* (C13). The professional caregivers discussed the

complexity of using ABT in a communal space in a care facility where multiple people with different backgrounds have to live together:

C14: “Yes, sometimes, I just do not want any sounds at all. I do not have to have sound around me all day—or music.”

C12: “Oh, but I do, I prefer music all day long!”

C13: “Yes, but then, suppose that you two are sitting in one communal area room? That is the same with that television and radio [that is always on]!”

The workshop outcomes also revealed how professional caregivers adopt different routines and habits in their current practice in terms of using music during everyday care. For example, a discussion between two professional caregivers (C15 and C17) illustrated how different care units within the same care facility could have different opinions on using music during eating activities based on the different responses of the residents within the same care unit:

C16: “A world of difference between your care unit and ours, you cannot imagine it!”

C17: “Yes, with us, it just helps at breakfast to turn on music, to make them eat. That makes a huge difference!”

C15: “Yes, I find that so contradictory. That is not possible with us because, during dinner, you do not have music on, you sit at the table, eat with the people, [and] possibly talk, but you have no music in the background.”

The personal reflections and discussions of the professional caregivers revealed how a person-centered approach is required to involve residents in sound-related activities and that a one-size-fits-all approach is not desirable for people with dementia.

5.3.2.2 *Reflexivity and Continuous Assessment*

The above examples illustrate the variety in the responses of the residents to sound. Even though professional caregivers have particular motivations for using ABT, as reported in the previous sections, there is no guarantee that these benefits and desired effects will apply for all residents. Professional caregivers (C2, C4, C5, and C14–C18) argued that the application of such interventions “*depends on the resident’s condition*” (C2) and can strongly vary over time:

“We try something with a resident, and today, it is going well and, tomorrow, it is not. The day after tomorrow, it works again, and after three weeks, it stops. There is nothing more variable than a person with dementia, and the group dynamics also change, depending on who of the caregivers is working. [There are] quite a lot of factors you cannot do much about.” (C15)

Therefore, ABT should not necessarily be used at fixed points in time but should be used to support certain situations in care that can arise during the day. For instance, professional caregivers (C2–C4, C6, C9, C11, C13, and C15–C18) indicated that they would use sound to calm residents *“in case of unrest, which also differs per person and can happen at any time, not just at a specific point in the day.”* In that sense, professional caregivers (C1–C3, C6, C12–C16, and C18) expressed that using ABT to evoke responses is a matter of *“trying it out”* (C6) by assessing their responses and *“feel[ing] for yourself if it is going well”* (C16). In using Vita, professional caregivers are required to continuously assess the individual responses of the residents to explore the specific potential value for each resident:

“I am curious how the residents [will] react to the pillow when they are restless or when they are just relaxed and at rest, if they then react differently.” (C3)

Reflexivity and continuous assessment are required in exploring individual responses to ABT, with room for experimentation for professional caregivers to question and investigate their interactions with the residents in context via introspection as they occur as well as to share their perspectives with colleagues.

5.4 DISCUSSION

Our participatory approach elicited a range of views and opinions from dementia care professionals about the potential benefits of introducing and incorporating ABT in their everyday working environment to support the care delivery process. We contribute to existing literature by synthesizing our analysis of the results into an overview of novel opportunities to integrate ABT in residential dementia care. Furthermore, we discuss how care professionals are vital stakeholders in facilitating the in-context use of technology and how the implementation of ABT should address their specific lived experiences and needs, such as care tasks, working culture, and multidisciplinary sharing of expertise.

5.4.1 Novel Opportunities for Integrating ABT in Residential Dementia Care

Firstly, ABT can provide new opportunities to support the transitions between scheduled activities in daily dementia care by offering peacefulness, distraction, or alternative activities. These moments of transition are identified as hectic and cause restlessness in both staff and residents. The literature reports that sound can provide a sense of safety and structure and can influence mood positively in dementia care environments [25,27,28,31,40]. Professional caregivers shared this view that sound can influence mood and support day-to-day structure and, most importantly, identified moments between activities as an opportunity for ABT to facilitate the anticipation, transition between, and the closing of daytime activities by countering impatience or by relieving nervousness.

Secondly, professional caregivers view ABT as a solution to improve the daily care process by providing meaningful audio content and by establishing verbal or nonverbal communication to enhance social interactions. In addition, ABT could also accommodate intimate moments in personal care, such as bathing or dressing, to contribute to the experience of both the residents and the caregivers. Therefore, the significance of sound in shaping social relationships among residents and between residents and professional caregivers should be recognized. This builds further on research that demonstrates how professional caregivers can establish an equal form of communication during moments of care by listening to or by playing sounds together with residents [9,22], as sound allows people to connect as it propagates through the care space [23].

Thirdly, the caregivers expressed how situational or opportunistic use of ABT during everyday care can evoke immediate and pleasurable in-the-moment experiences in the everyday living environment. However, to evoke these meaningful responses, the professional caregivers concluded that a person-centered approach is needed to consider the personal and sociocultural background of the residents. Research shows that people with dementia can associate sound with emotionally valued past experiences to evoke meaningful conversations with their relatives or caregivers [19]. The use of sound and music in scheduled daytime activities has been well established in relevant literature [7,11,19,37]. Sound and, in particular, music is referred to as a *universal* language [58] and can facilitate communication and social interactions with residents with aphasia or who have difficulty communicating verbally [16,22]. By adopting a person-centered approach and by engaging in pleasurable experiences with the residents, the care staff can create a positive atmosphere that reduces emotional

workloads and contributes to the wellbeing of both the residents and the staff in residential care [59]. Thus, ABT can offer meaningful audio content to support professional caregivers in including residents in enjoyable and accessible daytime activities by overcoming their challenges with engaging residents in a social setting.

Lastly, professional caregivers and people with dementia in residential dementia care require moments of silence and peacefulness during activities that are important for the health of the residents. The adoption of ABT in dementia care requires careful consideration of the existing sonic environment and the potential interference of additional sounds that might disturb residents or staff. For example, communal eating might be an activity where additional sounds negatively impact the shared experience [60]. Therefore, ABT should be designed in a way so they can also offer moments of silence in the care space to provide opportunities where residents and professional caregivers can unwind without experiencing unwanted auditory stimuli. This builds on research on acoustics in care facilities that stresses the need for regulated ambient noise levels in care environments to reduce stress and to prevent agitation among residents and staff [61]. With new forms of ABT, such as “sound zone technology”, individual listening experiences could be provided in communal areas to limit sound disturbances between individual listeners through a specific speaker setup [62]. We conclude that more research is required to gain a full understating of how ABT can cater universally and for the individual at the same time.

5.4.2 *The Needs and Lived Experiences of Care Professionals*

Our results illustrate how different care units within the same care facility could have different routines or processes in providing care or that residents in different living areas have contradictory attitudes towards ABT that provide music or sound. Professional caregivers from the nursing staff, e.g., providing care at night, had utterly different motivations and approaches towards using ABT compared to colleagues who only supervised daytime activities. The different care tasks that are performed by a team of care professionals might be often overlooked in the design of ABT and missed in academic research. We argue that the design and development of ABT needs to consider the lived experiences of the care professionals and the workplace culture as caregivers are an integral part of the system in mediating technology and in engaging people with dementia in social activities [22,63,64].

The professional caregivers stated that successful use of ABT in context requires a person-centered and reflexive approach. This approach corresponds with the reflexivity

required in the professional thinking of caregivers working in healthcare environments in general [65]. This reflexive process is mostly applied in complex clinical situations and can heavily vary between different caregivers as they have different experiences and perceptions of the perceived problems [66]. Recent research highlights how professional caregivers have not only other approaches in care but also different views on making sense of the actions and expressions of people with dementia [63]. Therefore, the professional caregivers appreciated the participatory workshops as they have a need to exchange their individual perspectives and to learn from each other's experiences in providing care.

The participatory workshops served as a co-learning process by creating a setting that encouraged the exchange of expertise and knowledge between the researcher and the professional caregivers and among the team of caregivers themselves. The care staff sharing their concerns and opinions with technology developers and care organizations is crucial to prevent resistance in implementing or adopting new technologies [67], as healthcare teams often have different levels of interest or are misinformed about the effort and potential benefits [68]. This collaborative aspect of working in dementia care shows potential for further consideration in ongoing research, as we stress the need for multidirectional and multidisciplinary sharing of insights and ways of working to develop a shared understanding in using technologies such as ABT in residential care. This continuous knowledge exchange with regard to utilization and advantages contributes to the broader acceptance and implementation of technologies such as ABT and encourages its use by the care staff in everyday care practice.

5.4.3 *Grounded Motivation for Future Field Studies*

Adoption and support in using technology by care professionals is an essential requirement for field studies that aim to evaluate or iterate newly designed technologies [42,69,70]. The opportunities presented in this chapter are the outcome of reflections and discussions with and from professional caregivers that were cued and triggered by matching academic insights to their personal experiences and practical expertise of providing care. As a result, these insights relate heavily to the existing care structures and activities of the involved care organizations and may differ between care institutions, countries, and cultures. Therefore, we do not present these opportunities for ABT as rigid guidelines but rather as a practice-informed foundation for future research on the implementation and evaluation of ABT in real-life care settings. We aim to broaden the scope of future work on ABT in care environments to explore the values and perspectives of critical stakeholders designated to facilitate and to use these

technologies in context. Hence, further in-context and longitudinal evaluation studies of ABT is essential to generate knowledge on the effectiveness and the successful implementation of meaningful sounds to augment care practice.

5.5 CONCLUSIONS

We have explored the integration of audio-based technologies in dementia care by consulting the expertise of 18 professional caregivers working in residential dementia care during three participatory workshops. The study outcome reveals opportunities for ABT to add value in the care process and insight into the needs and experiences of professional caregivers to enable the sustainable use and implementation of ABT in dementia care. We present these study outcomes as a well-motivated foundation grounded in practice to steer future research on the adoption and evaluation of technologies such as ABT in care settings. The workshops facilitated a multidirectional sharing of knowledge with literature as a starting point for professional caregivers to understand the possibilities of ABT and the theories behind it. The professional caregivers were able to build on their experiences of environments, care structures, responsibilities, and people to provide insights on operating ABT in practice. They were also able to extend the discussion and to consider the different perspectives and practices of colleagues. While there is a body of work that focusses on the impact and responses of people living with dementia to audio content, it is still unresearched how professional caregivers negotiate the daily activities to bring about change with audio-based technology. This study contributes to this gap in the literature by allowing caregivers to bridge theory to practice and provide a well-motivated foundation grounded in practice for future research on the adoption and evaluation of audio-based and experienced-centered technologies in care settings.

5.6 REFERENCES

- [1] Prince, M.; Ali, G.-C.; Guerchet, M.; Prina, A.M.; Albanese, E.; Wu, Y.-T. Recent global trends in the prevalence and incidence of dementia, and survival with dementia. *Alzheimer's Res. Ther.* 2016, 8, 23, doi:10.1186/s13195-016-0188-8.
- [2] Alzheimer's disease facts and figures. Available online: <https://www.alz.org/media/documents/alzheimers-facts-and-figures-2019-r.pdf> (accessed on 25 July 2020)
- [3] Olazaran, J.; Reisberg, B.; Clare, L.; Cruz, I.; Peña-Casanova, J.; Del Ser, T.; Woods, R.T.; Beck, C.; Auer, S.R.; Lai, C.K.Y.; et al. Nonpharmacological Therapies in Alzheimer's Disease: A Systematic Review of Efficacy. *Dement. Geriatr. Cogn. Disord.* 2010, 30, 161-178, doi:10.1159/000316119.
- [4] Baird, A.; Samson, S. Music and dementia. In *Progress in Brain Research*; Elsevier BV: Amsterdam, The Netherlands, 2015; Vol. 217, pp. 207-235.
- [5] Gold, K. But does it do any good? Measuring the impact of music therapy on people with

- advanced dementia: (Innovative practice). *Dement.* 2013, 13, 258–264, doi:10.1177/1471301213494512.
- [6] Raglio, A.; Filippi, S.; Bellandi, D.; Stramba-Badiale, M. Global music approach to persons with dementia: evidence and practice. *Clin. Interv. Aging* 2014, 9, 1669–1676, doi:10.2147/CIA.S71388.
- [7] Morrissey, K.; Wood, G.; Green, D.; Pantidi, N.; McCarthy, J. 'I'm a rambler, I'm a gambler, I'm a long way from home': The Place of Props, Music, and Design in Dementia Care. In Proceedings of the 2016 ACM Conference on Designing Interactive Systems - DIS '16, New York, USA, 2016; pp. 1008–1020.
- [8] Ihara, E.S.; Tompkins, C.J.; Inoue, M.; Sonneman, S. Results from a person-centered music intervention for individuals living with dementia. *Geriatr. Gerontol. Int.* 2018, 19, 30–34, doi:10.1111/ggi.13563.
- [9] Götell, E.; Brown, S.; Ekman, S.-L. The influence of caregiver singing and background music on vocally expressed emotions and moods in dementia care. *Int. J. Nurs. Stud.* 2009, 46, 422–430, doi:10.1016/j.ijnurstu.2007.11.001.
- [10] Baird, A.; Samson, S. Memory for Music in Alzheimer's Disease: Unforgettable? *Neuropsychol. Rev.* 2009, 19, 85–101, doi:10.1007/s10065-009-9085-2.
- [11] Lazar, A.; Thompson, H.; Demiris, G. A systematic review of the use of technology for reminiscence therapy. *Heal. Educ. Behav.* 2014, 41, 51S–61S, doi:10.1177/1090198114537067.
- [12] Simmons-Stern, N.R.; Deason, R.G.; Brandler, B.J.; Frustace, B.S.; O'Connor, M.K.; Ally, B.A.; Budson, A.E. Music-based memory enhancement in Alzheimer's disease: promise and limitations. *Neuropsychol.* 2012, 50, 3295–303, doi:10.1016/j.neuropsychologia.2012.09.019.
- [13] Baird, A.; Thompson, W.F. The Impact of Music on the Self in Dementia. *J. Alzheimer's Dis.* 2018, 61, 827–841, doi:10.3233/jad-170737.
- [14] E Graham, M. Re-socialising sound: investigating sound, selfhood and intersubjectivity among people living with dementia in long-term care. *Sound Stud.* 2018, 5, 175–190, doi:10.1080/20551940.2018.151051.
- [15] Lesaffre, M.; Moens, B.; Desmet, F. Monitoring Music and Movement Interaction in People with Dementia. In *The Routledge Companion to Embodied Music Interaction*; Informa UK Limited: London, UK, 2017; pp. 294–303.
- [16] Unbehaun, D.; Taugerbeck, S.; Aal, K.; Vaziri, D.D.; Lehmann, J.; Tolmie, P.; Wieching, R.; Wulf, V. Notes of memories: Fostering social interaction, activity and reminiscence through an interactive music exergame developed for people with dementia and their caregivers. *Hum.-Comput. Interact.* 2020, 1–34, doi:10.1080/07370024.2020.1746910.
- [17] Favilla, S.; Pedell, S. Touch screen ensemble music. In Proceedings of the the 25th Australian Computer-Human Interaction Conference; Association for Computing Machinery (ACM), 2013; pp. 481–484.
- [18] Frohlich, D.M.; Corrigan-Kavanagh, E.; Campbell, S.; Chrysanthaki, T.; Castro, P.; Zaine, I.; Pimentel, M.D.G.C. Assistive Media for Well-being. In *Primitive Interaction Design*; Springer Science and Business Media LLC: Berlin, Germany, 2020; pp. 189–205.
- [19] Houben, M.; Brankaert, R.; Bakker, S.; Kenning, G.; Bongers, I.; Eggen, B. Foregrounding Everyday Sounds in Dementia. In Proceedings of the 2019 on Designing Interactive Systems Conference; Association for Computing Machinery (ACM), 2019; pp. 71–83.
- [20] Campbell, S.; Frohlich, D.; Alm, N.; Vaughan, A. Sentimental Audio Memories: Exploring the Emotion and Meaning of Everyday Sounds. In *Communications in Computer and Information Science*; Springer Science and Business Media LLC: Berlin, Germany, 2019; pp. 73–81.
- [21] Luyten, T.; Braun, S.; Van Hooren, S.; De Witte, L. How groups of nursing home residents respond to “the CRDL”: a pilot study. *J. Enabling Technol.* 2018, 12, 145–154, doi:10.1108/jet-05-2018-0025.
- [22] Houben, M.; Brankaert, R.; Bakker, S.; Kenning, G.; Bongers, I.; Eggen, B. The Role of Everyday Sounds in Advanced Dementia Care. In Proceedings of the Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems; Association for Computing Machinery (ACM), 2020; Vol. 450, pp. 1–14.
- [23] E Graham, M. Long-term care as contested acoustical space: Exploring resident relationships and identities in sound. *Build. Acoust.* 2019, 27, 61–73, doi:10.1177/1351010x19890478.
- [24] Andringa, T.C.; Lanser, J.J.L. How Pleasant Sounds Promote and Annoying Sounds Impede Health: A Cognitive Approach. *Int. J. Environ. Res. Public Heal.* 2013, 10, 1439–1461, doi:10.3390/ijerph10041439.
- [25] Bosch, K.A.V.D.; Andringa, T.C.; Peterson, W.; Ruijsenaars, W.A.J.J.M.; Vlaskamp, C. A comparison of natural and non-natural soundscapes on people with severe or profound intellectual and multiple disabilities. *J. Intellect. Dev. Disabil.* 2016, 42, 301–307, doi:10.3109/13668250.2016.1250251.
- [26] Andringa, T.C.; van den Bosch, K.A. Core affect and soundscape assessment : fore-and background soundscape design for quality of life. In Proceedings of 42nd International Congress and Exposition on Noise Control Engineering 2013: INTER-NOISE 2013; Noise Control for

- Quality of Life; Innsbruck, Australia, 15-18 September 2013; pp. 2273–2282.
- [27] Bulsara, C.; Seaman, K.; Steuxner, S. Using sound therapy to ease agitation amongst persons with dementia: a pilot study. *Aust. Nurs. Midwifery J.* 2016, 23, 38–39.
- [28] Devos, P.; Aletta, F.; Thomas, P.; Petrovic, M.; Mynsbrugge, T.V.; Van De Velde, D.; De Vriendt, P.; Botteldooren, D. Designing Supportive Soundscapes for Nursing Home Residents with Dementia. *Int. J. Environ. Res. Public Heal.* 2019, 16, 4904, doi:10.3390/ijerph16244904.
- [29] Lund, H.N.; Bertelsen, L.R.; Bonde, L.O. Sound and music interventions in psychiatry at Aalborg University Hospital. *SoundEffects - Interdiscip. J. Sound Sound Exp.* 2016, 6, 48–68, doi:10.7146/se.v6i1.24912.
- [30] Hayne, M.J.; Fleming, R. Acoustic design guidelines for dementia care facilities. In *Proceedings of 43rd International Congress on Noise Control Engineering: Internoise 2014*; Melbourne, Australia, 16-19 November 2014; pp. 1–10.
- [31] Devos, P.; Aletta, F.; Thomas, P.; Filipan, K.; Petrovic, M.; Botteldooren, D.; Vander Mynsbrugge, T.; Van de Velde, D.; De Vriendt, P. Soundscape design for management of behavioral disorders : a pilot study among nursing home residents with dementia. In *Proceedings of the Impact of noise control engineering: proceedings of Inter-Noise 2018*; Chicago, USA, 26-29 August 2018; p. 8.
- [32] Craig, C.; Killick, J. Creativity and communication in persons with dementia: A practical guide; Jessica Kingsley Publishers: London, UK, 2011.
- [33] Chancellor, B.; Duncan, A.; Chatterjee, A. Art Therapy for Alzheimer's Disease and Other Dementias. *J. Alzheimer's Dis.* 2014, 39, 1–11, doi:10.3233/jad-131295.
- [34] Thoolen, M.; Brankaert, R.; Lu, Y. Sentic: A Tailored Interface Design for People with Dementia to Access Music. In the Companion Publication of the 2019 on Designing Interactive Systems Conference, Proceedings of the 2019 Companion - DIS '19 Companion; ACM Press: New York, USA, 2019; pp. 57–60.
- [35] Müller-Rakow, A.; Flechtner, R. Designing Interactive Music Systems with and for People with Dementia. *Des. J.* 2017, 20, S2207–S2214, doi:10.1080/14606925.2017.1352736.
- [36] Morrissey, K.; McCarthy, J. Creative and Opportunistic Use of Everyday Music Technologies in a Dementia Care Unit. In *Proceedings of the Proceedings of the 2015 ACM SIGCHI Conference on Creativity and Cognition - C&C '15*; Association for Computing Machinery (ACM), 2015; pp. 295–298.
- [37] Crowe, B.J.; Rio, R. Implications of Technology in Music Therapy Practice and Research for Music Therapy Education: A Review of Literature. *J. Music. Ther.* 2004, 41, 282–320, doi:10.1093/jmt/41.4.282.
- [38] Kenning, G.; Ilisar, A.; Brankaert, R.; Evans, M. Improvisation and Reciprocal Design: Soundplay for Dementia. In *Communications in Computer and Information Science*; Springer Science and Business Media LLC: Berlin, Germany, 2019; pp. 82–91.
- [39] Houben, M.; Lehn, B.; van den Brink, N.; Diks, S.; Verhoef, J.; Brankaert, R. Turnaround: Exploring Care Relations in Dementia Through Design. In *Proceedings of the Extended Abstracts of the 2020 CHI Conference on Human Factors in Computing Systems*; Honolulu, Hawaii, United States, 25-30 April 2020; pp. 351, 1.
- [40] Bosch, K.A.V.D.; Andringa, T.C.; Baskent, D.; Vlaskamp, C. The Role of Sound in Residential Facilities for People With Profound Intellectual and Multiple Disabilities. *J. Policy Pr. Intellect. Disabil.* 2016, 13, 61–68, doi:10.1111/jppi.12147.
- [41] Koumakis, L.; Chatzaki, C.; Kazantzaki, E.; Maniadi, E.; Tsiknakis, M. Dementia Care Frameworks and Assistive Technologies for Their Implementation: A Review. *IEEE Rev. Biomed. Eng.* 2019, 12, 4–18, doi:10.1109/rbme.2019.2892614.
- [42] Lourida, I.; A Abbott, R.; Rogers, M.; Lang, I.A.; Stein, K.; Kent, B.; Coon, J.T. Dissemination and implementation research in dementia care: a systematic scoping review and evidence map. *BMC Geriatr.* 2017, 17, 147, doi:10.1186/s12877-017-0528-y.
- [43] Spinuzzi, C. The methodology of participatory design. *Tech. Commun.* 2005, 52, 163–174.
- [44] Yoo, D. Stakeholder Tokens: a constructive method for value sensitive design stakeholder analysis. *Ethic- Inf. Technol.* 2018, 1–5, doi:10.1007/s10676-018-9474-4.
- [45] Ward, M.E.; De Brún, A.; Beirne, D.; Conway, C.; Cunningham, U.; English, A.; Fitzsimons, J.; Furlong, E.P.; Kane, Y.; Kelly, A.; et al. Using Co-Design to Develop a Collective Leadership Intervention for Healthcare Teams to Improve Safety Culture. *Int. J. Environ. Res. Public Heal.* 2018, 15, 182, doi:10.3390/ijerph1506182.
- [46] Galway, K.; Forbes, T.; Mallon, S.; Santin, O.; Best, P.; Neff, J.; Leavey, G.; Pitman, A. Adapting Digital Social Prescribing for Suicide Bereavement Support: The Findings of a Consultation Exercise to Explore the Acceptability of Implementing Digital Social Prescribing within an Existing Postvention Service. *Int. J. Environ. Res. Public Heal.* 2019, 16, 4561, doi:10.3390/ijerph16224561.
- [47] Berry, A.B.; Lim, C.; Hartzler, A.L.; Hirsch, T.; Ludman, E.J.; Wagner, E.H.; Ralston, J.D. Creating Conditions for Patients' Values to

- Emergence in Clinical Conversations. In Proceedings of the 2017 Conference on Interaction Design and Children-IDC '17; Association for Computing Machinery (ACM), 2017; Vol. 2017, pp. 1165–1174.
- [48] Sanders, E.B.-N.; Stappers, P.J. Co-creation and the new landscapes of design. *CoDesign* 2008, 4, 5–18, doi:10.1080/15710880500135987.
- [49] Buskermolen, D.O.; Terken, J. Co-constructing stories. In Proceedings of the 12th Participatory Design Conference; Association for Computing Machinery (ACM), 2012; Vol. 2, p. 33.
- [50] Visser, F.S.; Stappers, P.J.; Van Der Lugt, R.; Sanders, E.B.-N. Contextmapping: experiences from practice. *CoDesign* 2005, 1, 119–149, doi:10.1080/15710880500135987.
- [51] Kankainen, A.; Vaajakallio, K.; Kantola, V.; Mattelmäki, T. Storytelling Group – a co-design method for service design. *Behav. Inf. Technol.* 2012, 31, 221–230.
- [52] Schelle, K.J.; Gomez Naranjo, C.; ten Bhömer, M.; Tomico, O.; Wensveen, S. Tactile Dialogues: Personalization of Vibrotactile Behavior to Trigger Interpersonal Communication. In Proceedings of the Ninth International Conference on Tangible, Embedded, and Embodied Interaction-TEI '14; New York, USA, 2015; pp. 637–642.
- [53] Ijsselsteijn, W.; Tummers-Heemels, A.; Brankaert, R. Warm Technology: A Novel Perspective on Design for and with People Living with Dementia. In *Primitive Interaction Design*; Springer Science and Business Media LLC: Berlin, Germany, 2020; pp. 33–47.
- [54] Halskov, K.; Dalsgård, P. Inspiration card workshops. In Proceedings of the 6th ACM conference on Electronic commerce - EC '05 Association for Computing Machinery (ACM), 2006; p. 2.
- [55] Gaver, W.W. How Do We Hear in the World? Explorations in Ecological Acoustics. *Ecol. Psychol.* 1993, 5, 285–313, doi:10.1207/s15326969ec00504_2.
- [56] Aletta, F.; Mynsbrugge, T.V.; Van De Velde, D.; De Vriendt, P.; Thomas, P.; Filipan, K.; Botteldooren, D.; Devos, P. Awareness of 'sound' in nursing homes: A large-scale soundscape survey in Flanders (Belgium). *Build. Acoust.* 2017, 25, 43–59, doi:10.1177/1351010x17748113.
- [57] Braun, V.; Clarke, V. Using thematic analysis in psychology. *Qual. Res. Psychol.* 2006, 3, 77–101.
- [58] Campbell, P.S. Music, the universal language: Fact or fallacy? *Int. J. Music. Educ.* 1997, 32–39, doi:10.1177/025576149702900105.
- [59] Miller, E.; Devlin, N.; Buys, L.; Donoghue, G. The happiness initiative: Changing organizational culture to make 'brilliance' mainstream in aged care. *J. Manag. Organ.* 2019, 26, 296–308, doi:10.1017/jmo.2019.59.
- [60] de Groot, W.; Houben, M.; Hengeveld, B. Exploring How an Interactive Placemat Can Influence Eating Activities for People with Dementia BT - Dementia Lab 2019. *Making Design Work: Engaging with Dementia in Context.*; Brankaert, R., Ijsselsteijn, W., Eds.; Springer International Publishing: Cham, Switzerland, 2019; pp. 92–100.
- [61] Devos, P.; Aletta, F.; Thomas, P.; Mynsbrugge, T.V.; Petrovic, M.; Van De Velde, D.; De Vriendt, P.; Botteldooren, D. Application of a Prediction Model for Ambient Noise Levels and Acoustical Capacity for Living Rooms in Nursing Homes Hosting Older People with Dementia. *Appl. Sci.* 2020, 10, 4205, doi:10.3390/app10124205.
- [62] Lundgaard, S.S.; Nielsen, P.A. Personalised Soundscapes in Homes. In Proceedings of the Proceedings of the 2019 on Designing Interactive Systems Conference; Association for Computing Machinery (ACM), 2019; pp. 813–822.
- [63] Emma Emma Dixon University of Maryland, College Park, MD, USA; Amanda Amanda Lazar University of Maryland, College Park, MD, USA Approach Matters: Linking Practitioner Approaches to Technology Design for People with Dementia. In Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems; Honolulu, Hawaii, United States, 25–30 April 2020; pp. 1–15.
- [64] Unbehau, D.; Aal, K.; Vaziri, D.D.; Tolmie, P.D.; Wieching, R.; Randall, D.; Wulf, V. Social Technology Appropriation in Dementia: Investigating the Role of Caregivers in Engaging People with Dementia with a Videogame-based Training System. In Proceedings of the Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems; Association for Computing Machinery (ACM), 2020.
- [65] Bannigan, K.; Moores, A. A Model of Professional Thinking: Integrating Reflective Practice and Evidence Based Practice. *Can. J. Occup. Ther.* 2009, 76, 342–350, doi:10.1177/000841740907600505.
- [66] Mann, K.; Gordon, J.; MacLeod, A. Reflection and reflective practice in health professions education: a systematic review. *Adv. Heal. Sci. Educ.* 2007, 14, 595.
- [67] Ossebaard, H.C.; Van Gemert-Pijnen, L. eHealth and quality in health care: implementation time. *Int. J. Qual. Heal. Care* 2016, 28, 415–419, doi:10.1093/intqhc/mzw032.
- [68] Karabi, C.B.; Darla, P.; Jason, S. Management attitudes and technology adoption in long-term care facilities. *J. Health Organ. Manag.* 2014, 28, 344–365.
- [69] Brankaert, R.; Ouden, E.D.; Brombacher, A. Innovate dementia: the development of a living lab protocol to evaluate interventions in context.

- info 2015, 17, 40-52, doi:10.1108/info-01-2015-0010.
- [70] Müller, C.; Neufeldt, C.; Randall, D.; Wulf, V. ICT-development in residential care settings. In Proceedings of the the 2012 ACM annual conference; Association for Computing

Machinery (ACM), 2012; p. 2639.



6

The Role of Everyday Sounds in Advanced Dementia Care

The representation of sounds derived from everyday life can be beneficial for people with dementia by evoking memories and emotional responses. Despite this potential, integrating sound and sound-based interventions in care facilities has not received much research attention. In this chapter, we present the findings from a field study that explored the responses of 19 people with advanced dementia to a selection of everyday sounds presented to them in a care home and the role of these responses in the care environment. To study this, we deployed Vita, a 'pillow-like' sound player, in two dementia care facilities for four weeks, during which observations were recorded. Afterwards, we conducted interviews with caregivers who used Vita in everyday care practice. Our findings reveal how everyday sounds provided by Vita stimulated meaningful conversation, playfulness, and connection between residents and caregivers. Furthermore, we propose design implications for integrating everyday sounds in dementia care.

This chapter is a reproduction of the paper published as:

Maarten Houben, Rens Brankaert, Saskia Bakker, Gail Kenning, Inge Bongers, and Berry Eggen. 2020. The Role of Everyday Sounds in Advanced Dementia Care. Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems. Association for Computing Machinery, New York, NY, USA, 1–14. <https://doi.org/10.1145/3313831.3376577>

(Best Paper Award)

6.1 INTRODUCTION

As the global population is aging, the number of people living with dementia is increasing rapidly [61]. Unfortunately, there is currently no cure for dementia, and none is anticipated in the near future [20]. Non-pharmacological approaches are therefore being explored as alternatives to address the needs and wellbeing of people living with dementia. For example, music has been found to be beneficial for people with dementia, as it stimulates reminiscence [3], physical movement [49], and social interactions [58]. In addition, researchers in the field of HCI have been exploring the role of technology and design in adding value to the lived experiences of people with dementia and improving their quality of life [46,57]. This is why we see research bringing together music, technology, and dementia in exploring the role of technology in music therapy sessions, during which people with dementia play instruments or listen to music from their past [41,48,58].

However, in everyday life, people are impacted by many sounds other than music [63]. These everyday sounds support us in our day-to-day functioning by providing information about our surroundings [5], cueing behavior, and signaling required responses [25]. Our previous research [40] has shown how sounds selected from everyday life and re-presented for people with dementia can provide meaningful engagement and pleasurable experiences by evoking memories and emotions linked to past experiences. Furthermore, everyday sounds can offer cues for enjoyable social interactions between people with dementia and their extended care network [58,67].



Figure 6.1. Vita is a soft interface for people with advanced dementia to access audio, including everyday sounds.

While existing research [23,51,67] acknowledges the beneficial effects of sound for people with dementia, researchers have yet to effectively explore the integration of sound-based interventions in dementia care homes. This raises questions and reveals a gap in knowledge about how the beneficial effects of everyday sounds can be leveraged in care practice. For example, can exposing people with dementia to everyday sounds in daily care routines be beneficial against the backdrop of existing environmental noise. More insight is needed into whether sound can add value to the everyday life of people in the advanced stages of dementia living in long-term dementia care homes, and, if so, how sound interventions can be implemented in such environments.

This chapter presents the findings of a field study in which we deployed a sound-based intervention named Vita, a ‘pillow-like’ sound player (see Figure 6.1) in a day-to-day care context. More specifically, we explored 1) the responses of people with advanced dementia to everyday sounds facilitated by Vita in a care home, and 2) the relevance of these responses in the care environment and care practice. Prior to the field study, we organized introductory sessions where professional caregivers were introduced to Vita and reflected together on potential use-cases in dementia care homes to understand where and when it could be used. We then deployed three Vita devices in two care homes, each for four weeks during which 16 professional caregivers and 19 people with advanced dementia were invited to use the device. To gather data, the main researcher was present and conducted active and passive observations [26] on the residents’ responses and interactions with Vita. Finally, the main researcher held exit interviews with the professional caregivers which offered additional insights into how Vita was used in everyday care practice when the researcher was not present. A thematic analysis of the field notes and the transcriptions of the exit interviews revealed how everyday sounds facilitated by Vita stimulated meaningful conversations, playfulness and curiosity, and connection with caregivers. Furthermore, based on how Vita was used in existing care routines, we propose design implications for the implementation of sound-based interventions in care homes, for example, how sound offers a new tool for caregivers to facilitate meaningful experiences and how it can be situated in various contexts.

6.2 RELATED WORK

6.2.1 *Advanced Dementia and HCI*

People in advanced stages of dementia experience symptoms such as severe memory loss, disorientation, stress, and agitation [54]. Furthermore, the progression of dementia

in many cases results in aphasia, as people with dementia have difficulties with speaking or verbally expressing themselves [19]. As a result, people with dementia are often stigmatized as ‘sufferers’ and identified by these symptoms [45]. Current views on dementia have adopted a more inclusive approach, by looking at the potential and abilities of people with dementia [27] who, like everyone else, have values, beliefs, emotions, and a need for social interaction [45]. These views are based on care philosophies such as ‘person-centered care’ [14] which foregrounds the individual experience of the person with dementia in care practice [43]. People with dementia need to be recognized and acknowledged for their verbal and tacit forms of expression and supported in their sense of belonging and social membership [46]. Technology can include this perspective and reinforce a sense of self [10]. Its use in dementia care can therefore offer a sense of agency and support social connections between residents and their caregivers [30].

Recent research and developments in HCI and design have acknowledged these inclusive and socially just perspectives in dementia [46,65]. This research aims to address the daily lived experiences of people with dementia and explore how design can enrich everyday life in care settings [57]. This strand of research has resulted in various multi-sensory technologies for people with dementia designed to enrich their everyday lives [28,39,40,58,68]. For instance, tailored virtual reality experiences offer new worlds that can be shared between caregivers and people with dementia [39] and interactive installations that combine multiple modalities, such as vision, sound, and touch [28]. In this chapter, we build further on pre-existing work [30,39,40,46,58] within the context of HCI and dementia by exploring the value of everyday sounds in adding quality to the daily lives of people with advanced dementia living in residential care homes.

6.2.2 *Everyday Sounds in Dementia Care*

The impact of music in dementia care has been extensively studied [4,33,56,58,62,68], while the full potential of everyday sounds has yet to be demonstrated. This gap exists despite research in HCI demonstrating how sounds from everyday life evoke memories [7,31] and how people value familiar sounds that have positive associations linked to loved ones or meaningful events in their lives [52,60]. Everyday sounds that are perceived as pleasant and enjoyable can induce positive emotions [66], resulting in beneficial effects for physical and cognitive wellbeing [1].

For these reasons, researchers have begun to explore the responses of people with dementia to everyday sounds. Initial research with people with cognitive disabilities in

general [8,9] has shown how sounds that were perceived as pleasant or enjoyable resulted in observed behavioral and emotional changes [9]. For example, therapy sessions involving listening to calming sounds can reduce stress and agitation for people with dementia [17]. Similarly, researchers have been exploring opportunities for administering playlists of everyday sounds in private rooms and public spaces of dementia care facilities to reduce anxiety and improve sleeping patterns [23,51]. However, people with dementia cannot be viewed as a homogenous group [46], as the experience of dementia differs for every individual [43]. Sounds that evoke meaningful responses, such as memories or emotions, are highly personal, as people with dementia make associations through their own lived experiences [40].

In previous research, we illustrated how sounds from everyday life offered cues for exploring personal values, beliefs, past experiences, and emotions [40]. Research and practice are increasingly exploring how sound can be used as a tool for social connection in the care space [35], as it can foster social interactions between people with dementia and their caregivers through shared listening experiences [67]. While literature suggests opportunities for using sound in dementia care, there is limited work on how the positive effects of sound play out in day-to-day care practice [23,51]. The outcomes of our field study contribute to existing theories and practices in relation to dementia and sound by reporting on the personal responses to everyday sounds of people with advanced dementia situated within a care home.

6.2.3 Design Interventions in Care Homes

People with advanced dementia living in care homes often rely on professional caregivers to support them in everyday activities and provide personal care [53]. In addition, professional caregivers develop social relationships with residents [27]. This person-centered approach allows caregivers to meet the everyday needs of care residents in a dignified and respectful way [16]. Establishing and maintaining relationships are fundamental to self-identity and essential for recognizing 'selfhood' [27,44]. However, caregivers often lack sufficient resources, time, or tools for providing meaningful activities to facilitate and nurture social relationships due to the heavy workload involved in physical care tasks [10].

Within the field of HCI and design, there is an increasing amount of research on how design interventions can initiate and support social interactions and identity in people with advanced dementia in residential care homes [29,30,57,58]. Personal design probes in care homes have proven to be a valuable asset in exploring personal values and beliefs

[71] and interpersonal relationships [70] while providing meaningful activity and social engagement for the residents [42]. Ethnographic approaches have highlighted the importance of recognizing people with advanced dementia by acknowledging tacit forms of communication and regarding nonverbal responses and expressions as legitimate forms of agency [29,56,58]. Inclusive, accessible design interventions in care homes can stimulate agency for people in advanced stages of dementia and encourage social connection with caregivers and other residents [30]. By using Vita, we aim to capture the perspective of the residents in the care home [65] and offer a sense of agency when exploring everyday sounds.

6.3 METHOD

This chapter reports on our field study in which we explored the in-context responses of people with advanced dementia to everyday sounds, facilitated by Vita, and the potential impact of these responses on existing care practice. We also involved the perspective of the professional caregivers to gain insight into how to integrate technology in dementia care [11] and how this technology fostered connections between residents and caregivers [69]. However, we do not consider caregivers as spokespersons or proxies for people with dementia [38], but as valuable stakeholders who offer their own perspectives and experience of dementia [50].

6.3.1 *Vita: Interactive Sound Cushion*

Vita (see Figure 6.1) is an interactive cushion that offers an interface specifically designed for people with dementia to provide them with direct access to sound [51,64]. By touching one of the six textile touchpads of Vita, users can play a sound fragment. An interface integrated into the reverse side of Vita (see Figure 6.2) allows professional caregivers to select personal sound sets for each resident, access general sound sets, and adjust the volume. By pressing the buttons, caregivers can ‘scroll’ through the various sound sets, while voice feedback indicates which set is selected. Vita is portable and can be used in various settings in a care home. Furthermore, the cushion blends in with the existing care space, which lowers the barrier for using it. For these reasons, we selected Vita as the vehicle for a sound-based intervention in our field study. Vita is still in development by the researchers and not on the market at the time of this study.



Figure 6.2. The personal and general sound sets can be selected by pressing the buttons on the reverse side of Vita to go through the sets, with voice feedback indicating which set is selected.

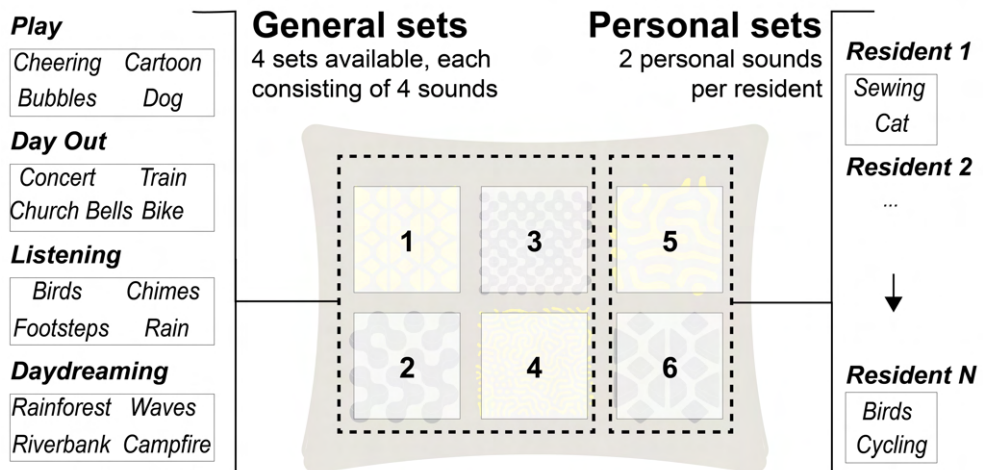


Figure 6.3. Vita provides access to general sets of four everyday sounds (e.g., Play) with touchpads 1 to 4 and to personal sets of sounds for each resident (e.g., Birds or Cycling) on touchpads 5 and 6.

6.3.1.1 General and Personal Sets of Everyday Sounds

To study the role of sounds in care practice, Vita offered access to both personal and general sounds (see Figure 6.3). The two right-side touchpads (5-6) provided access to two personalized sounds for each resident in line with their preferences. These sounds were selected in consultation with the caregivers and family members, for example, a racing car sound was selected for a resident who was a sports car enthusiast. The other four touchpads (1-4) provided a general set of four everyday sounds. Caregivers could choose between four general sets, resulting in a collection of 16 different sounds. The general sets were selected to represent a broad array of everyday sounds and potential ways that they could be used in the care setting. These sets were based on a soundscape

appraisal model [9] for rating sound in terms of pleasantness and arousal. We translated the four main components on the ‘pleasant’ spectrum: *active*, *interested*, *enjoying*, and *relaxed*, respectively into the following sets: *play*, *day out*, *listening* and *daydreaming* (as shown in Figure 6.3). Sound set *play* consisted of short, dynamic sounds to trigger playful responses, e.g., a dog barking. The set *day out* consisted of sounds representing leisure activities, e.g., a bike ride. With *listening*, we provided calming domestic sounds, such as raindrops on a window. Finally, *daydreaming* offered soundscapes of picturesque landscapes, such as a campfire with chirping crickets. For each set, we collected four high-quality sound files that matched the overall description of the set from an online open-source database [74]. All personalized and general sounds were provided by the researchers and tested for sound quality on the built-in speaker of Vita.

6.3.2 *Setting and Participants*

The field study took place in two residential care homes, one located in the south (A) and one in the middle (B) of the Netherlands. Both facilities provided long-term care for people in an advanced stage of dementia. In total, 19 residents with advanced dementia took part in this study; 10 residents at location A [R1-10] and 9 residents at location B [R11-19]. The age of the residents varied between 70 and 97. Most residents were female, except R3, R10, and R19. Healthcare professionals of the care organizations recruited participants based on whether the resident: 1) was willing to participate; 2) was diagnosed with dementia caused by Alzheimer’s or vascular diseases; 3) was in advanced stage of dementia (indicated by the care organization); 4) lived permanently at the dementia care home; 5) had no severe difficulty with processing audio; 6) was able to physically interact with Vita.

Proxy consent was sought from the legally authorized representative (i.e., legal guardian) of each resident, such as a spouse, family member, or caregiver. Furthermore, the ability of residents to be included in this research was assessed by professional caregivers who are familiar with the residents. In addition to the residents, 16 professional caregivers were recruited, eight of whom worked at location A [C1-8] and eight at location B [C9-16]. The professional caregivers were also invited to attend an introductory session.

6.3.3 *Ethics*

This research was approved by the Ethics Review Board of Tilburg School of Social and Behavioral Sciences (ref: EC-2019.22) and was evaluated and debriefed at the Client Representation Board of the care organization. This study is part of the ‘Everyday

Sounds of Dementia' project, a multi-disciplinary collaboration between partners from care practice, health, and design. The main researcher conducting the in-context observations had previous experience in doing research with people with dementia and was supported by a project representative from the care organizations. As interaction sessions with Vita were organized as part of the daily activities and routines at the care home, the residents and the care staff at the facility did not need to allocate additional time to engage with Vita, as it served as a meaningful substitute for or addition to regularly scheduled care activities. The residents who did not consent were not introduced to Vita and excluded from data collection. However, on occasions people who had not given consent wanted to interact with Vita, caregivers were instructed not to refuse this interaction and naturally include everyone when using Vita to avoid potential negative responses. No data was gathered from non-consenting residents who used Vita and their responses were not discussed during the exit interviews. The professional caregivers involved in this study were familiar with the residents and were designated the task of overseeing the deployment of Vita in the care unit they worked in. Therefore, the researcher was always in communication with the care staff and they were always present during observation. The duty of care at all times remained with the care staff. Gaining informed consent was not a singular act, but a continuous dialogue [18,24] between the care staff, researcher, and residents. The care staff continually assessed participants' involvement based on their in-context responses and by communicating with the researcher and participants directly. These measures provided a safe environment for the participant, researcher, and caregivers.



Figure 6.4. Vita was introduced in sessions during which the caregivers were encouraged to think about ways of using Vita in the care home.

6.3.4 Study Procedure

This study consisted of: 1) introductory sessions for caregivers; 2) deployment of Vita in care homes; and 3) exit interviews with caregivers.

6.3.4.1 Introductory Sessions for Caregivers

Three introductory sessions were organized for approximately one hour each, with one session at location A and two at location B to fit the schedules of the caregivers. In total, 12 caregivers participated in the introductory sessions, while four [C7-8, 15-16] were not able to attend the session and were therefore provided with information by the researcher at the beginning of the deployment phase. The goal of these sessions was to increase the engagement of the caregivers within the study. First, the caregivers were asked to map a 'typical day' of the residents on a 24-hour cycle. Secondly, the caregivers discussed cards with statements from sound-related literature, e.g., '*familiar sounds can evoke memories*' and placed this card on the 'typical day' map. Next, the researcher introduced Vita to the caregivers and explained the interface (see Figure 6.4). Then, the caregivers were invited to develop initial scenarios for using Vita in everyday care practice. These scenarios served to encourage and inspire the professional caregivers to explore how to use Vita during the deployment phase. The caregivers suggested that rigid individual use-cases were not practical and that the use of Vita would strongly depend on the situation and mood of residents.

6.3.4.2 Deployment of Vita in Care Homes

At each care home location, three Vita prototypes were deployed for four weeks. The devices were situated in the communal room of the care homes where residents who participated in the study often resided (see Figure 6.5). Vita was designed to blend into the existing interior and be easily accessible for participants during the deployment phase. The professional caregivers who were recruited for this study used Vita in-context with the residents during everyday care practices. At unspecified times, the primary researcher visited the care home to engage with participants and carry out participatory observations [26] of interactions with and responses to Vita. This participant-observer approach enabled the researcher to blend in with the care home context and build a trust relationship with the residents and care staff [29]. Engaging with the participants and establishing a social connection offers the researcher insight into the value of tacit and implicit forms of expression by residents with advanced dementia [37]. During the participatory observations, the researcher took field notes and made photographic

documentation, both annotated with date and time. The field notes were expanded to field texts, focusing on the phenomenological aspects of being within the care home.



Figure 6.5. On each location, three Vita devices were deployed in the communal space of the residents participating in the study.

6.3.4.3 *Exit Interviews with Caregivers*

After the deployment, 10 professional caregivers who used Vita without the researcher present took part in a brief semi-structured exit interview conducted by the main researcher, which lasted approximately twenty minutes. In this interview, they were asked to describe their experiences and their observations of the residents' reactions. Two caregivers were unavailable due to busy schedules, and four did not use Vita outside the observations.

6.3.5 *Data Analysis*

The following data was collected: 1) the field notes of the researcher during observations, 2) photographic documentation, and 3) audio of interviews with caregivers. In total, 23 sessions with Vita were observed over the course of 4 weeks on location A and 4 weeks on location B, with 9 days of observations on each location. The audio recordings of the 10 exit interviews with the caregivers were transcribed verbatim. Thematic analysis of the field notes and transcriptions was used inductively as research analysis steps [12]. Statements were classified using codes recording the responses of people with advanced dementia to Vita, and the social and physical contexts of these responses. New sub-codes were then developed, based on patterns and the reoccurrence of codes within each concept.

6.4 RESULTS

In this section, we discuss our analysis of the field notes combined with the transcriptions of the exit interviews.

6.4.1 Cueing Meaningful Conversations

Most residents [R1-4, 7-8, 10, 12, 14-16, 18-19] were able to recognize sounds triggered by Vita. Associations with these sounds formed the starting point of conversations between residents, caregivers, and the researcher who was present during the observations. More specifically, the sounds offered cues and potential conversation subjects for the caregiver to start a dialogue: “*And based on those sounds, we started to ask questions, to get a conversation going*” [C2]. For instance, after hearing *Play_Dog*, R19 began to talk about his pets, as described in the field notes:

R19 talks to me about his pets: “If the cat came in, it would go after [the dog] too.” C13 joins the conversation: “Are they not eating each other's food then?” R19 responds: “No, and [the dog] was colossal, he was too big for most people. I also had a cat, and two dachshunds, they would sometimes cuddle up and sleep together!”

Residents [R10, 15, 18-19] linked sounds to aspects of their personal life, which had emotional meaning to them, such as family and loved ones, house environment, and meaningful events. For instance, R18 made associations with going to the local football stadium to attend a soccer match of her favorite soccer team (this is facilitated by the care organization in partnership with the soccer team). This association was not linked to experiences from the past, but to an activity in her current life at the care home. She always took part in this activity and very much enjoyed it, so she wanted to share this experience:

After hearing Play_Cheering, R18 suddenly shouts ‘Yeah!’ and laughs to me [Researcher] and C15. “It’s just like when I go to support [her favorite soccer team].” R18 explains the activity: “Yes I have just been, yes, then we just sit together, women and men together, and then we see if we can get a good place” [...] C15 asks what they do when their favorite team scores. In response, R18 raises her arms in the air, starts waving and shouts “woohoo!”



Figure 6.6. A resident talks about his past experiences as a race car driver while listening to *Racecar* sounds.

Residents [R5, 7, 10, 15, 18-19] made associations with everyday sounds that were explicitly linked to experiences in the past. For R10, personal *Racecars* sounds evoked meaningful memories (see Figure 6.6). R10 is bedridden and individual care activities always take place in his private room on a daily basis. While talking is difficult for R10, the sounds served as cues for conversing with the caregiver, establishing a connection by exploring his past, and talking about his hobbies and interests. While listening to *Racecars* in conversation with C5, he talked about how he used to race on a well-known race circuit:

R10 touches and feels Vita, playing his Racecar and Porsche sounds. C5 asks: "Where can you hear those sounds?" "That is from the [city] racing circuit," R10 says. C5 looks surprised and replies: "Did you ever go there to watch the races?" R10 immediately responded: "I've raced there!"

6.4.1.1 Engaging in Different Realities

Although residents [R4, 8, 15, 19] misheard sounds, it did not seem to matter that sounds were misinterpreted or misidentified. Guessing and sharing interpretations worked as a conversation starter, despite the associations being 'incorrect'. The researcher and the caregiver did not correct the resident but further engaged in the interpretation during the conversation that followed:

Upon hearing the Listening_Footsteps sounds, R15 directs her left ear towards Vita and says: "I hear horses, I'm not doing anything wrong because I've told you before, I'm going to walk the horses with someone... Haha!"

Furthermore, R15 and R18 shared elaborate stories that seemed to mix elements of memories with situations and events in the present. They appeared to be in their own reality as they shared "inconsistent stories" [C8] or "stories you can't make head nor tail of, but still whole stories." [C14] For instance, upon hearing *Play_Bubbles*, R18 seemed to be telling a story from the past, when she suddenly mentions the researcher and Vita in the past tense, in a 'memory' in which she was telling her son about the current study:

C15 touches Vita and triggers Play_Bubbles. R18 imitates the sound: "Bloopbloopbloopbloop! Haha! It's like I'm at home... Then my youngest [child] came and would say: 'Grandma, are you home yet? [...] I said 'yes, I saw some beautiful things, a young man was here, and he had made a nice pillow, and then I looked at it!'"

These examples illustrate how conversations triggered by Vita offered opportunities for residents to share meaningful events and experiences, or a story that made sense to them, with caregivers in the care home setting.

6.4.2 Connecting Through Nonverbal Expressions

Residents in the late stages of dementia were not always capable of verbally responding to the sounds facilitated by Vita. However, nonverbal responses were also observed during the deployment. These nonverbal responses triggered by Vita were nonlinguistic forms of expression, which facilitated ways for the professional caregivers to (re)connect with people in an advanced stage of dementia.

6.4.2.1 Immersed in One's Own Reality

Caregivers indicated how some of the residents are often immersed in their own worlds: "a bomb could explode, so to speak, and she wouldn't have noticed. She's so immersed in her own mind." [C2] This disconnect with reality presents difficulties in connecting with residents with dementia, as verbal communication is no longer possible: "It is also difficult to communicate with her. You can't always understand what she means; maybe she understands it, but can't express it to me." [C8] It was observed how several residents [R1-3, 8, 14] would mumble or quietly say something indistinctly, which was not understandable for either the researcher or the caregiver. For instance, during an

individual care activity, R3 would start to mumble things after interacting with Vita. R3 was saying something incomprehensible, but appeared to make sense to him, as he was committed to telling his story:

Upon hearing DayOut_ChurchBells, R3 looks up and mumbles something unintelligible: “fai, fai, fai, fai...” [...] He starts to mutter a lot more than before, but it is not really understandable. C5 says: “He has a lot to say [...], but I don't really know what it is...”



Figure 6.7. The residents explored Vita together with caregivers.

6.4.2.2 Connecting Through Sound

During the deployment, Vita was used in one-on-one care sessions during which caregivers aimed to (re-)establish a social connection with the residents. In this regard, Vita was seen as: “a kind of tool, the cushion, the embroidery, the sounds, a means to communicate in any way.” [C5] Exploring Vita and engaging with the different sounds was therefore a nonverbal approach for caregivers to connect with people in an advanced stage of dementia who were limited in verbal communication or unable to participate in a fully developed conversation. Reacting to the sounds became a form of expression and communication between the person with dementia and the caregiver, even when the responses were not clear or understandable:

When R8 laughs in response to the Play_Cheering sound, the caregiver says “applause for you!” Several times, R8 gave the caregiver a kiss after looking at her. She also laughs with the Play_Dog sounds and seems to imitate it: “woof,

woof!” She says to the caregiver: “I hug them like that.” After hearing the dog, the caregiver asked her what she had heard. R8 doesn’t reply, but spontaneously grabs the stuffed dog cushion that lies behind her.

6.4.2.3 Touch and Proximity

In addition to sound, our findings also report on meaningful responses relating to touch and proximity with caregivers. In many cases [R4, 8-9, 12-15, 17-19], the caregiver or researcher would take the hand of a resident and start exploring Vita (as shown in Figure 6.7). When interacting with Vita, R13 and R17 were hesitant in the beginning. Touch and physical connection were a way for the researcher and the caregivers to connect with the residents to establish and recognize the presence of the person. R17 was very introverted at the beginning of the session with Vita and did not react to Vita when it was presented in front of her, holding her arms close to her body. After a handshake with the researcher, she started to feel more at ease in the setting, and connected with the caregiver who was also present:

C15 asks R17 to put her hand on Vita. R17 shakes her head indicating ‘no’ to the caregiver and pulls her hand back to her chest. The caregiver plays some sounds, but she doesn’t react. She suddenly looks at me [researcher] and laughs, she takes my hand and starts shaking it. I shake it back, and then C15 lays her hand on Vita and plays Play_Dog: “Oh a dog!?” R17 now smiles at the caregiver and nods ‘yes’. The caregiver asks her: “Did you also have dogs at home in the past?” R17 looks at the caregiver and nods ‘yes’. She still holds one hand to her chest but was looking at C15 who was pulling silly faces such as looking amazed and smiling at her. R17 smiles back, leans towards the caregiver, and gives her a kiss on the cheek. “Oh sweetheart” says C15.

These observations reveal how everyday sounds provide opportunities to establish a new connection between caregivers and residents, who cannot verbally connect anymore by expressing associations with sounds through gestures, facial expressions, movement, and imitation.

6.4.3 Curiosity and Playfulness in Care

Engaging with Vita and everyday sounds evoked emotional and lively responses from residents, such as laughing or displaying increased forms of interest and focus.

6.4.3.1 Agency and Discovery

When presented with Vita, residents were prompted to explore the artefact by fiddling slightly with the embroidered patterns with their fingertips [R2-3, 14-15], feeling the edges of the cushion [R1-4, 7, 9-10, 14-15, 17-18] or drumming [R8-9, 14]. Residents were actively exploring the six touchpads with their hand in order to ‘guess’ and explore all the sounds that were hidden in the cushion [R2-6, 8, 10-11, 14-15, 18]. When doing so, they displayed increased interest and attention in response to exploring the different sounds [R3-4, 10, 14-15]. It was observed how several residents became very curious about Vita, as they found it peculiar that sounds emerged from inside a cushion [R4, 6, 15-16, 19]. However, this feeling of curiosity encouraged participants to further explore the sounds from Vita. For example, R4 concentrated on exploring all the different touchpads and tried to recognize each hidden sound:

R4 explores the touchpads again with her hand flat on Vita. Upon hearing DayOut_ChurchBells, she says: “I hear music!” She continues to explore and says, “It’s strange!”[...] R4 explores further and after a while asks: “how does such a dog get in a cushion?”

This discovery evoked several joyful responses, such as laughing and mimicking the sound out loud. As described above, R4 was very interested in exploring Vita. Upon hearing the *Play_Cartoon* sounds, she produced a strange noise which seemed to mimic the sound she heard:

While playing the Play_Cartoon sounds, R4 turns to me and says: “That’s mama!” Again, she plays Play_Cartoon and turns back to me and looks surprised. While smiling, her eyes go back and forth, scanning the room. She looks at the pillow and makes the same sound again: “Mama... Papa!”

Some residents were also startled by the sounds and pulled their hands back upon hearing something, or were insecure and worried they would “break” Vita [R5-6, 15, 18]. For instance, R15 eventually felt comfortable in exploring Vita; however, she first needed to be reassured that nothing could go wrong with the artefact:

R15 moves her other hand away from Vita: “I won’t do this. Suppose it falls on the floor, then it’s my fault!” C15 and I [researcher] explain to her that she can’t do anything wrong and that she certainly cannot break the device. R15 further explains: “I don’t like things like that, I always lose.”

6.4.3.2 *Pretending and Acting Playfully*

Most residents experienced a sense of excitement and playfulness while interacting with Vita and listening to the everyday sounds [R1, 3-4, 6-8, 10, 14-16, 18]. After making associations with the sounds, residents imagined that the thing or object that was making the sound was present in the space, or hidden inside Vita [R5, 10, 14-15]. These imaginations provided scope for playfulness and pretending, as the caregiver went along with the imagination of the residents, e.g., “*There is a dog in the cushion!*”, with residents [R4, 13] putting their ear to Vita to better hear the sound that was hidden inside. In this context, these responses were not seen as confusion as the participants’ remarks were not off-topic. These responses could be interpreted as jokes or playful remarks based on their appropriateness and timing. For instance, this playfulness was also observed during a session with R15 and the researcher, when R15 wanted to get the sound out of Vita:

Upon hearing Play_Cartoon, R15 looks surprised and says: “oh haha, a chicken...” Among the cartoon sounds, a fart sound is heard, and her eyes open wide: “oh!” I ask jokingly if it was her. She looks at me and clearly says no, then starts to laugh loudly: “No, I was shocked! Haha” Then she hears her personal Cat sound, after which she imitates it: “woof, meow, I really want to get it out! So that they can walk here. How should I do that?” And she picks up Vita and looks at it: “Because that is possible, you know!”

Furthermore, the exploration of Vita offered cues for teasing and making jokes that were related to the sounds the residents were listening to. These playful interactions between caregivers, residents, and the researcher resulted in an enjoyable and informal atmosphere during everyday activities in the communal room:

C4 takes Vita from the couch and places it on the table where R4 and R5 are sitting, and first hands it to R4. They listen to the Play_Bubbles when the other caregiver starts joking: “Are you peeing in your pants?” “No, it’s the pillow!” says R4 while laughing. “That’s what they all say!” jokes the caregiver, and they laugh together.

Everyday sounds facilitated by Vita were able to stimulate curiosity, and the act of exploring and guessing sounds offered opportunities for playfulness, imagination, resulting in an informal and pleasant atmosphere in the residential care environment.

6.4.4 Role in Everyday Care

The thematic analysis gave insight into the various contexts Vita was used in, and how these influenced the interactions with Vita.

6.4.4.1 Scheduled Individual Sessions

Vita was used during scheduled individual care activities during which professional caregivers would socially engage with the residents: *“I try to give someone a bit of daytime activity at their bed. Something the resident wants to hear and talk about.”* [C5] These sessions took place in either an empty room or in the private room of the residents [R10, 14, 16]. Furthermore, these individual sessions were also used to activate the residents by letting them engage with various sensory stimuli: *“then I try to stimulate or relax the senses.”* [C5] Vita served as a means for facilitating these sessions: *“And I often look for things that you can do with them, like with lights and sounds or something extra.”* [C2]

6.4.4.2 In-between Moments in Everyday Care

Vita was also used during everyday care moments that were not scheduled care activities, but situations where one of the caregivers thought it might be useful. These spontaneous sessions mostly took place in the common living area. For instance, in between scheduled activities the residents were often bored, which would often lead to a general sense of unrest: *“a bit of boredom, after lunch or dinner... they have nothing to do, and then they get bored and start watching each other and often irritate each other.”* [C4] During these moments in between activities, residents would often remain seated in the common living space at the dining table. By using Vita, the caregivers aimed to provide a fun activity to stimulate positive interactions between the residents: *“because otherwise you will irritate each other, and now it was more like ‘look how nice it is’ and ‘do you also want to try it’ and laugh together.”* [C7] This resulted in a shared activity for relieving boredom, which also influenced the general atmosphere in the communal room. These interactions were also noticed by other residents, who became curious and wanted to see what was happening: *“because of course we had a lot of fun at that table and then others looked at what we were doing, and I asked them if they wanted to sit with us, but then they said ‘no’, they just looked from a distance. And that resulted in general interest, which was also positive!”* [C4]

6.4.4.3 Distractions in the Care Environment

The physical care space was a source of distraction for three residents [R14-15, 18]. For instance, R14 was at one point focusing on a picture of her family on the wall of her

private room. Other sounds present in the space could confuse residents in thinking these sounds from another source originated from Vita. For example, R15 mistook the sound of the creaking door of the communal space as if it had been triggered by Vita: “A door that is closed by the wind?” [R15]. Other residents present in the communal space also represented forms of distraction, making it difficult for some residents to engage with Vita. For instance, R15 was interacting with Vita when a group of other residents came in the communal space and disrupted the setting:

... in the meantime, the other residents are returning from an activity. Suddenly there is a lot of noise and buzz and R15 is distracted as a result and no longer has attention for Vita and me. Two residents who come in are singing aloud to each other, and R15 says: “It’s all a bit much right now!”

6.4.4.4 Moments of Unrest

The exit interviews revealed how caregivers also tried using Vita in moments of unrest [C2-4, 7 13-14]. However, the caregivers indicated that residents [R1, 5, 14-15, 19] did not want to interact with Vita when they were feeling stressed or angry: “If she is super restless, you just can’t calm her down. Eventually, she calms down by herself; you can’t do interventions on that.” [C2] A similar situation was observed by the researcher during a group session in the communal space. One of the residents was stressed because she was waiting for her husband, and she was worried her husband might have forgotten her (see Figure 6.8). While other residents were sitting at the table and interacting with Vita, she stood up to find the exit to go home. When offered Vita, she did not display any interest in interacting with it:

R6 is interacting with Vita at the table together with R5, C4, and C9, but R5, who is sitting next to R6, looks a bit angry. R5 is stressed because her husband is still not here, she also does not want to take her medication because she doesn’t know why. [...] When R5 is asked to interact with Vita, she shows little interest and only touches it for a few seconds.



Figure 6.8. A resident (middle) was distracted by another resident (right), who was nervously pacing around the communal room and did not want to interact with Vita herself.

This situation was in contrast to a few days later when the same resident [R5] was in a better mood, and suddenly did display interest in trying out Vita:

R5 enters the room with a big smile. In her hands, she holds some freshly picked strawberries from the garden and proudly shows them to the rest. “Are they already ripe?” R4 asks. The other caregiver is going to rinse the strawberries, and R5 is joining us at the table. I ask her if she also wants to play with the pillow. She agrees, and I put the pillow on the table for her. [...] She hears the Play_dog again. opens her eyes wide and quickly pulls her hand away from the pillow. “Is he going to bite?” she says jokingly and starts to laugh and shake her hand, pretending that the dog had bitten her as she laughs, almost teasingly at the others at the table.

Our findings indicate how Vita was used in everyday care, both individual as in a group, and was found most useful in facilitating meaningful and social activity when the residents were willing and seeking acknowledgment.

6.5 DISCUSSION

The results presented above provide insight into how the selection of everyday sounds represented through Vita cued meaningful conversations, facilitated nonverbal connection with the caregivers, and provided opportunities for curiosity and playfulness in the everyday context of dementia care. Furthermore, our findings identified how Vita was used both during scheduled activities in one-on-one sessions, and in spontaneous moments to relieve boredom and activate residents in between scheduled care activities. We further discuss these insights in relation to existing literature and outline

implications for design to integrate sound-based interventions in long-term residential dementia care.

The everyday sounds facilitated by Vita were able to evoke associations in the form of verbal responses that served as a conversation starter. This cueing of conversation is similar to the use of media in reminiscence therapy [2,13,72]. However, in reminiscence sessions, media such as images or videos are used to prompt memories and responses from people in early to mid-stages of dementia. While these types of sessions often rely on visual stimuli [2,22,48], the results of this study provide examples of how everyday sounds can evoke similar responses *in-situ* that are specifically related to sound. In addition, we observed how sounds could be misheard or misinterpreted while still evoking meaningful associations, memories, or emotional responses. This mishearing of sounds can be attributed to the inherent quality of sound and how different listeners interpret audio signals differently [59] based on their current mind-state or past experiences [15]. For people with advanced dementia, this interpretative step offers an associative perspective to enable them to assign personal meaning to sound, without being confronted with an inability to identify or remember specific events, places, or people [2,34]. This is why the ambiguous character [32] of sound makes it a suitable modality for technologies in dementia to provide associative and open-ended cues for conversations and responses that do not need to be authenticated in terms of ‘truth’.

Initiating and facilitating conversation is key to nurturing relationships between caregivers and residents in a care home setting [22] as people, including those with advanced dementia, are social beings, actively seeking out and engaging in social interactions [43]. Our findings suggest that by facilitating everyday sounds, technologies for people with dementia can accommodate an enjoyable and informal atmosphere with room for teasing, pretending, and acting playfully. While existing research tends to focus on reminiscence [3,48,73], our findings indicate how exploring unfamiliar sounds can result in curiosity, which affords opportunities for discovery in an environment where meaningful experiences are considered scarce [57]. These playful interactions facilitated by Vita were able to create a general sense of inclusiveness and social belonging among the residents. Furthermore, Vita was also used during individual sessions in care spaces with fewer sources of distraction and stimuli from other residents. Therefore, sound-based interventions such as Vita can offer opportunities for shared explorations of sound, resulting in intimate interactions between the caregiver and the resident, both in verbal and nonverbal responses [45].

Our results illustrate how residents with less verbal communication capacity express their reactions to sound through bodily responses [47], such as smiling, laughing, closing or opening eyes, mumbling, or imitating sounds. By engaging and responding to these nonverbal responses, caregivers were able to establish a mutual nonverbal communication and connect with the residents. This use of Vita in the care homes reveals new opportunities for sound-based interventions to initiate embodied connections between caregivers and people in advanced stages of dementia. Furthermore, touch and proximity play a role in these interactions, as caregivers and residents often explored Vita together. This is similar to music sessions where a sense of intimacy and shared movements are key in providing social participation [58]. Sound-based interventions are therefore not necessarily replacements for current care activities, but they support, supplement, and provide new opportunities for social connectedness between residents and caregivers.

6.5.1 Implications for Design

We further outline implications for designing sound-based interventions in long-term residential dementia care.

6.5.1.1 Meaningful Experiences in Everyday Care

Researchers studying soundscapes in care environments [8,17,36] have explored the potential of sound to remediate perceived behavioral disorders [23], change mood [9], and reduce stress and agitation [36]. However, our findings indicate that caregivers hardly used Vita in cases where such behavior was actively observed, as initial attempts to reduce agitation with Vita were unsuccessful. These findings offer a different perspective to literature [4,17] that positions sound or music as a therapeutic solution for agitated behavior. With Vita, caregivers mainly offered the residents a meaningful activity, for instance, in between organized activities to avoid boredom. The use of Vita in context is in line with the notion of ‘Experience-Centered Design’ (ECD) [57]. Whereas initial research in HCI on dementia mainly focused on assistive technologies to address the symptoms of dementia [6,21,55], ECD offers an alternative perspective by addressing the individual experiences of people with dementia, and the role of design to enrich these experiences [30,71]. Similarly, selecting and representing sounds from everyday life provides opportunities for meaningful activities and social engagement in everyday care settings [40]. In the care home context, we also emphasize the role of the professional caregivers in providing these experiences as a person-centered approach in daily care practice [69]. While highlighting meaningful responses of the residents, we

do not position everyday sounds as a solution for every individual, but as an additional tool for caregivers to enrich the everyday experience in care homes.

6.5.1.2 *Situated Nature of Sound*

Based on our results, the optimal selection of audio content for sound-based interventions in dementia care greatly depends on the personal and social context in which it will be used. As people living in residential care homes either prefer engaging with sound individually or in a group, designers should address these social dynamics in care homes by designing adaptable audio content [40] for both personal, intimate settings, as well as informal and playful group settings. We therefore argue that sound-based interventions should be able to provide access to both personal and general sound content. While personal sounds provide a sense of familiarity, general sounds can stimulate curiosity and discovery by offering new experiences in the present that do not necessarily rely on recapturing past experiences [42]. Our results show how residents were engaged in discovering sounds by exploring the general sound sets of Vita. These findings are in line with research suggesting that general content is more likely to stimulate more extended responses than personal content by allowing a broader scope for conversational topics [22]. Therefore, sound-based interventions should be able to facilitate these explorations by offering a wide variety of audio content to counter fatigue in interaction and provide space for discovery and opportunities for new experiences ‘in the now’ [56].

6.5.1.3 *Embracing of Ambiguity*

Research on reminiscence therapy indicates the value of social interactions during therapy sessions [73], as the sharing of evoked responses is more meaningful than the response itself [13]. However, as people move on into the advanced stages of dementia, recapturing memories and sharing these experiences becomes increasingly difficult [45]. We have reported how Vita offered an alternative way to stimulate social connectedness as residents and caregivers engaged in each other’s company and acknowledged bodily responses to the everyday sounds that were played. In addition to reminiscence, everyday sounds can be less prescriptive and create ambiguous cues that are open to interpretation and thus establish opportunities for mutual connection beyond verbal communication. Sound as a medium in this space can embrace both ambiguity and universal cues to elicit meaningful responses and embodied connectedness. We therefore challenge generalized preconceptions of using sound in care environments, such as stress relief and reminiscence and argue that design-based interventions should consider highly personal and situated responses to sounds.

6.6 CONCLUSION

In this chapter, we present insights from a field study that explored the relevance of everyday sounds in care homes for people with dementia through re-presenting selected sounds using Vita. The findings contribute to existing literature by reporting how everyday sounds in dementia care can stimulate social connections by eliciting meaningful conversations, as well as nonverbal responses. Furthermore, we have outlined design implications for sound-based technologies for use with people in advanced stages of dementia in real-life care settings. We aim to broaden the discussion on the use of sound to manage behaviors defined from a purely medical point of view, extending applications of sound to care settings by offering alternative perspectives that address social connection as well as individual and group experiences related to sound. However, more research is needed to build on these explorative findings and to further investigate the potential importance of everyday sounds in dementia care practice. With this work, we aim to inspire future design research in day-to-day care settings that involve both people with dementia and their caregivers.

6.7 ACKNOWLEDGMENTS

This study was part of the ‘Everyday Sounds of Dementia’ project, funded by ZonMw in the Create Health Program, under project number 443001122, and partly funded by STW VIDI grant number 016.128.303 of The Netherlands Organization for Scientific Research (NWO). We want to thank the participants, the care staff and care organizations Archipel and Pleyade for their involvement in this study.

6.8 REFERENCES

- [1] Tjeerd C. Andringa and J. Jolie L. Lanser. 2013. How pleasant sounds promote and annoying sounds impede health: A cognitive approach. *Int. J. Environ. Res. Public Health* 10, 4 (April 2013), 1439–1461. DOI:<https://doi.org/10.3390/ijerph10041439>
- [2] Arlene J. Astell, Maggie P. Ellis, Norman Alm, Richard Dye, and Gary Gowans. 2010. Stimulating People with Dementia to Reminisce Using Personal and Generic Photographs. *Int. J. Comput. Heal.* 1, 2 (2010), 177–198. DOI:<https://doi.org/10.1504/IJCIH.2010.037461>
- [3] Ameer Baird and Séverine Samson. 2009. Memory for Music in Alzheimer’s Disease: Unforgettable? *Neuropsychol. Rev.* 19, 1 (May 2009), 85–101. DOI:<https://doi.org/10.1007/s11065-009-9085-2>
- [4] Ameer Baird and Séverine Samson. 2015. Music and dementia. In *Progress in Brain Research*, Eckart Altenmüller, Stanley Finger and François Boller (eds.). Elsevier, 207–235. DOI:<https://doi.org/10.1016/bs.pbr.2014.11.028>
- [5] Saskia Bakker, Elise van den Hoven, and Berry Eggen. 2012. Knowing by ear: leveraging human attention abilities in interaction design. *J. Multimodal User Interfaces* 5, 3–4 (February 2012), 197–209. DOI:<https://doi.org/10.1007/s12193-011-0062-8>
- [6] Ashok J. Bharucha, Vivek Anand, Jodi Forlizzi, Mary Amanda Dew, Charles F. Reynolds, Scott Stevens, and Howard Wactlar. 2009. Intelligent Assistive Technology Applications to Dementia Care: Current Capabilities, Limitations, and Future Challenges. *Am. J. Geriatr. Psychiatry* 17, 2 (February 2009), 88–104. DOI:<https://doi.org/10.1097/JGP.0b013e318187dd>

- e5
- [7] Karin Bijsterveld and José van. Dijck. 2009. *Sound Souvenirs: Audio Technologies, Memory and Cultural Practices*. Amsterdam University Press, Amsterdam. DOI:<https://doi.org/10.5117/9789089641328>
- [8] Kirsten A. van den Bosch, Tjeerd C. Andringa, Deniz Başkent, and Carla Vlaskamp. 2016. The Role of Sound in Residential Facilities for People With Profound Intellectual and Multiple Disabilities. *J. Policy Pract. Intellect. Disabil.* 13, 1 (March 2016), 61–68. DOI:<https://doi.org/10.1111/jppi.12147>
- [9] Kirsten A. van den Bosch, Tjeerd C. Andringa, Wolter Peterson, Wied A. J. J. M. Ruijsenaars, and Carla Vlaskamp. 2017. A comparison of natural and non-natural soundscapes on people with severe or profound intellectual and multiple disabilities. *J. Intellect. Dev. Disabil.* 42, 3 (July 2017), 301–307. DOI:<https://doi.org/10.3109/13668250.2016.1250251>
- [10] Rens Brankaert and Elke den Ouden. 2017. The design-driven living lab: a new approach to exploring solutions to complex societal challenges. *Technol. Innov. Manag. Rev.* 7, 1 (May 2017), 44–51.
- [11] Rens Brankaert, Elke den Ouden, and Aarnout Brombacher. 2015. Innovate dementia: the development of a living lab protocol to evaluate interventions in context. *info* 17, 4 (June 2015), 40–52. DOI:<https://doi.org/10.1080/info-01-2015-0010>
- [12] Virginia Braun and Victoria Clarke. 2006. Using thematic analysis in psychology. *Qual. Res. Psychol.* 3, 2 (January 2006), 77–101. DOI:<https://doi.org/10.1191/1478088706qp0630a>
- [13] D. Brooker and L. Duce. 2000. Wellbeing and activity in dementia: A comparison of group reminiscence therapy, structured goal-directed group activity and unstructured time. *Aging Ment. Health* 4, 4 (November 2000), 354–358. DOI:<https://doi.org/10.1080/713649967>
- [14] Dawn Brooker. 2003. What is person-centred care in dementia? *Rev. Clin. Gerontol.* 13, 03 (August 2003), 215–222. DOI:<https://doi.org/10.1017/S095925980400108X>
- [15] Bennett M. Brooks, Brigitte Schulte-Fortkamp, Kay S. Voigt, and Alex U. Case. 2014. Exploring our sonic environment through soundscape research & theory. *Acoust. Today* 10, 1 (2014), 30–40.
- [16] Sonya Brownie and Susan Nancarrow. 2013. Effects of person-centered care on residents and staff in aged-care facilities: a systematic review. *Clin. Interv. Aging* 8, (January 2013), 1. DOI:<https://doi.org/10.2147/CIA.S38589>
- [17] Caroline Bulsara, Karla Seaman, and Silke Steuxner. 2016. Using sound therapy to ease agitation amongst persons with dementia: a pilot study. *Aust. Nurs. Midwifery J.* 23, 7 (2016), 38–39.
- [18] Tim Coughlan, Kerstin Leder Mackley, Michael Brown, Sarah Martindale, Stephan Schlögl, Becky Mallaband, John Arnott, Jettie Hoonhout, Dalila Szostak, Robin Brewer, Erika Poole, Antti Pirhonen, Val Mitchell, Sarah Pink, and Nicolas Hine. 2013. Current issues and future directions in methods for studying technology in the home. *PsychNology J.* 11, 2 (2013), 159–184.
- [19] Jeffrey L. Cummings, Frank D. Benson, Mary Ann Hill, and Stephen Read. 1985. Aphasia in dementia of the Alzheimer type. *Neurology* 35, 3 (March 1985), 394–397. DOI:<https://doi.org/10.1212/wnl.35.3.394>
- [20] Jeffrey Cummings, Garam Lee, Aaron Ritter, and Kate Zhong. 2018. Alzheimer’s disease drug development pipeline: 2018. *Alzheimer’s Dement.* (New York, N. Y.) 4, (2018), 195–214. DOI:<https://doi.org/10.1016/j.trci.2018.03.009>
- [21] Yngve Dahl and Kristine Holbø. 2012. Value Biases of Sensor-Based Assistive Technology: Case Study of a GPS Tracking System Used in Dementia Care. In *Proceedings of the Designing Interactive Systems Conference - DIS ’12*, ACM Press, New York, New York, USA, 572–581. DOI:<https://doi.org/10.1145/2317956.2318043>
- [22] Boyd H. Davis and Dena Shenk. 2015. Beyond Reminiscence: Using Generic Video to Elicit Conversational Language. *Am. J. Alzheimer’s Dis. Other Dementias* 30, 1 (February 2015), 61–68. DOI:<https://doi.org/10.1177/1533317514534759>
- [23] Paul Devos, Francesco Aletta, Pieter Thomas, Karlo Filipan, Mirko Petrovic, Dick Botteldooren, Tara Vander Mynsbrugge, Dominique Van de Velde, and Patricia De Vriendt. 2018. Soundscape design for management of behavioral disorders: a pilot study among nursing home residents with dementia. In *Impact of noise control engineering: proceedings of Inter-Noise 2018*, Institute of Noise Control Engineering of the United States of America, 8.
- [24] Jan Dewing. 2007. Participatory research: A method for process consent with persons who have dementia. *Dementia* 6, 1 (February 2007), 11–25. DOI:<https://doi.org/10.1177/1471301207075625>
- [25] Berry Eggen. 2016. Interactive Soundscapes of the Future Everyday Life. In *Peripheral interaction: challenges and opportunities for HCI in the periphery of attention*. 239–251. DOI:https://doi.org/10.1007/978-3-319-29523-7_11
- [26] Robert M. Emerson, Rachel I. Fretz, and Linda L. Shaw. 2001. Participant observation and fieldnotes. *Handb. Ethnogr.* (2001), 352–368.

- [27] Sam Fazio, Douglas Pace, Janice Flinner, and Beth Kallmyer. 2018. The Fundamentals of Person-Centered Care for Individuals With Dementia. *Gerontologist* 58, suppl_1 (January 2018), S10–S19. DOI:<https://doi.org/10.1093/geront/gnx122>
- [28] Yuan Feng, Suihuai Yu, Dirk van de Mortel, Emilia Barakova, Jun Hu, and Matthias Rauterberg. 2019. LiveNature: Ambient Display and Social Robot-Facilitated Multi-Sensory Engagement for People with Dementia. In *Proceedings of the 2019 on Designing Interactive Systems Conference - DIS '19*, ACM Press, New York, New York, USA, 1321–1333. DOI:<https://doi.org/10.1145/3322276.3322331>
- [29] Sarah Foley, Nadia Pantidi, and John McCarthy. 2019. Care and design: An ethnography of mutual recognition in the context of advanced dementia. In *Conference on Human Factors in Computing Systems - Proceedings*, ACM Press, New York, New York, USA, Paper 610, 13 pages. DOI:<https://doi.org/10.1145/3290605.3300840>
- [30] Sarah Foley, Daniel Welsh, Nadia Pantidi, Kellie Morrissey, Tom Nappey, and John McCarthy. 2019. Printer Pals: Experience-Centered Design to Support Agency for People with Dementia. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems - CHI '19*, ACM Press, New York, New York, USA, Paper 404, 1–13. DOI:<https://doi.org/10.1145/3290605.3300634>
- [31] David M. Frohlich. 2004. *Audiophotography*. Springer Netherlands, Dordrecht. DOI:<https://doi.org/10.1007/978-1-4020-2210-4>
- [32] William W. Gaver, Jacob Beaver, and Steve Benford. 2003. Ambiguity as a resource for design. In *Proceedings of the Conference on Human Factors in Computing Systems - CHI '03*, ACM Press, New York, New York, USA, 233–240. DOI:<https://doi.org/10.1145/642611.642653>
- [33] Karen Gold. 2014. But does it do any good? Measuring the impact of music therapy on people with advanced dementia: (Innovative practice). *Dementia* 13, 2 (2014), 258–264. DOI:<https://doi.org/10.1177/1471301213494512>
- [34] Gary Gowans, Jim Campbell, Norm Alm, Richard Dye, Arlene Astell, and Maggie Ellis. 2004. Designing a multimedia conversation aid for reminiscence therapy in dementia care environments. In *Extended abstracts of the 2004 conference on Human factors and computing systems - CHI '04*, ACM Press, New York, New York, USA, 825–836. DOI:<https://doi.org/10.1145/985921.985943>
- [35] Megan E. Graham. 2018. Re-socialising sound: investigating sound, selfhood and intersubjectivity among people living with dementia in long-term care. *Sound Stud.* 5, 2 (December 2018), 175–190. DOI:<https://doi.org/10.1080/20551940.2018.1551051>
- [36] Michael James Hayne and Richard Fleming. 2014. Acoustic design guidelines for dementia care facilities. In *Proceedings of 43rd International Congress on Noise Control Engineering: Internoise 2014*, Australia: Australian Acoustical Society, 1–10.
- [37] Niels Hendriks, Liesbeth Huybrechts, Karin Slegers, and Andrea Wilkinson. 2018. Valuing implicit decision-making in participatory design: A relational approach in design with people with dementia. *Design Studies* 59, 58–76. DOI:<https://doi.org/10.1016/j.destud.2018.06.001>
- [38] Niels Hendriks, Karin Slegers, and Pieter Duysburgh. 2015. Codesign with people living with cognitive or sensory impairments: a case for method stories and uniqueness. *CoDesign* 11, 1 (January 2015), 70–82. DOI:<https://doi.org/10.1080/15710882.2015.1020316>
- [39] James Hodge, Madeline Balaam, Sandra Hastings, and Kellie Morrissey. 2018. Exploring the Design of Tailored Virtual Reality Experiences for People with Dementia. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems (CHI '18)*, ACM Press, New York, New York, USA, Paper 514, 1–13. DOI:<https://doi.org/10.1145/3173574.3174088>
- [40] Maarten Houben, Rens Brankaert, Saskia Bakker, Gail Kenning, Inge Bongers, and Berry Eggen. 2019. Foregrounding Everyday Sounds in Dementia. In *Proceedings of the 2019 on Designing Interactive Systems Conference - DIS '19*, ACM Press, New York, New York, USA, 71–83. DOI:<https://doi.org/10.1145/3322276.3322287>
- [41] Emily S. Ihara, Catherine J. Tompkins, Megumi Inoue, and Sonya Sonneman. 2019. Results from a person-centered music intervention for individuals living with dementia. *Geriatr. Gerontol. Int.* 19, 1 (January 2019), 30–34. DOI:<https://doi.org/10.1111/ggi.13563>
- [42] Gail Kenning. 2018. Reciprocal design: inclusive design approaches for people with late stage dementia. *Des. Heal.* 2, 1 (January 2018), 142–162. DOI:<https://doi.org/10.1080/24735132.2018.1453638>
- [43] Tom Kitwood. 1997. The experience of dementia. *Aging Ment. Heal.* 1, 1 (1997), 13–22. DOI:<https://doi.org/10.1080/13607869757344>
- [44] Tom Kitwood. 1997. *Dementia reconsidered: The person comes first*. Open University Press, London.
- [45] Pia C. Kontos. 2004. Ethnographic reflections on selfhood, embodiment and Alzheimer's disease. *Ageing Soc.* 24, 6 (November 2004), 829–849. DOI:<https://doi.org/10.1017/S0144686X04002375>
- [46] Amanda Lazar, Caroline Edasis, and Anne Marie

- Piper. 2017. A Critical Lens on Dementia and Design in HCI. In Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems (CHI '17), ACM Press, New York, New York, USA, 2175–2188. DOI:<https://doi.org/10.1145/3025453.3025522>
- [47] Amanda Lazar, Jessica L. Feuston, Caroline Edasis, and Anne Marie Piper. 2018. Making as Expression: Informing Design with People with Complex Communication Needs through Art Therapy. In Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems - CHI '18, ACM Press, New York, New York, USA, Paper 351, 1-16. DOI:<https://doi.org/10.1145/3173574.3173925>
- [48] Amanda Lazar, Hilaire Thompson, and George Demiris. 2014. A systematic review of the use of technology for reminiscence therapy. *Health Educ. Behav.* 41, 1 Suppl (October 2014), 51S-61S. DOI:<https://doi.org/10.1177/1090198114537067>
- [49] Micheline Lesaffre, Bart Moens, and Frank Desmet. 2017. Monitoring music and movement interaction in people with dementia. In *The Routledge Companion to embodied music interaction*. Routledge, 294–303.
- [50] Kiel Long, Lyndsey Bakewell, Roisin McNaney, Konstantina Vasileiou, Mark Atkinson, Manuela Barreto, Julie Barnett, Michael Wilson, Shaun Lawson, and John Vines. 2017. Connecting Those That Care: Designing for Transitioning, Talking, Belonging and Escaping. In Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems - CHI '17 (CHI '17), ACM Press, New York, New York, USA, 1339–1351. DOI:<https://doi.org/10.1145/3025453.3025715>
- [51] Helle Nystrup Lund, Lars Rye Bertelsen, and Lars Ole Bonde. 2016. Sound and music interventions in psychiatry at Aalborg University Hospital. *SoundEffects - An Interdiscip. J. Sound Sound Exp.* 6, 1 (November 2016), 48–68. DOI:<https://doi.org/10.7146/se.v6i1.24912>
- [52] Stine S. Lundgaard and Peter Axel Nielsen. 2019. Personalised Soundscapes in Homes. In Proceedings of the 2019 on Designing Interactive Systems Conference - DIS '19, ACM Press, New York, New York, USA, 813–822. DOI:<https://doi.org/10.1145/3322276.3322364>
- [53] Eneida Mioshi, Christopher M. Kipps, and John R. Hodges. 2009. Activities of Daily Living in Behavioral Variant Frontotemporal Dementia: Differences in Caregiver and Performance-based Assessments. *Alzheimer Dis. Assoc. Disord.* 23, 1 (January 2009), 70–76. DOI:<https://doi.org/10.1097/WAD.0b013e318182d293>
- [54] Susan L. Mitchell, Joan M. Teno, Dan K. Kiely, Michele L. Shaffer, Richard N. Jones, Holly G. Prigerson, Ladislav Volicer, Jane L. Givens, and Mary Beth Hamel. 2009. The clinical course of advanced dementia. *N. Engl. J. Med.* 361, 16 (2009), 1529–1538. DOI:<https://doi.org/10.1056/NEJMoa0902234>
- [55] Karyn Moffatt, Joanna McGrenere, Barbara Purves, and Maria Klawe. 2004. The participatory design of a sound and image enhanced daily planner for people with aphasia. In Proceedings of the 2004 conference on Human factors in computing systems - CHI '04, ACM Press, New York, New York, USA, 407–414. DOI:<https://doi.org/10.1145/985692.985744>
- [56] Kellie Morrissey and John McCarthy. 2015. Creative and Opportunistic Use of Everyday Music Technologies in a Dementia Care Unit. In Proceedings of the 2015 ACM SIGCHI Conference on Creativity and Cognition - C&C '15, ACM Press, New York, New York, USA, 295–298. DOI:<https://doi.org/10.1145/2757226.2757228>
- [57] Kellie Morrissey, John McCarthy, and Nadia Pantidi. 2017. The Value of Experience-Centred Design Approaches in Dementia Research Contexts. In Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems (CHI '17), ACM Press, New York, New York, USA, 1326–1338. DOI:<https://doi.org/10.1145/3025453.3025527>
- [58] Kellie Morrissey, Gavin Wood, David Green, Nadia Pantidi, and John McCarthy. 2016. 'I'm a gambler, I'm a gambler, I'm a long way from home': The Place of Props, Music, and Design in Dementia Care. In Proceedings of the 2016 ACM Conference on Designing Interactive Systems - DIS '16, ACM Press, New York, New York, USA, 1008–1020. DOI:<https://doi.org/10.1145/2901790.2901798>
- [59] Raymond Murray Schafer. 1977. *The soundscape: Our sonic environment and the tuning of the world*. Vancouver Destin. Books (1977).
- [60] Gerard Oleksik, David Frohlich, Lorna M. Brown, and Abigail Sellen. 2008. Sonic interventions: Understanding and extending the domestic soundscape. In Conference on Human Factors in Computing Systems - Proceedings, ACM Press, New York, New York, USA, 1419–1428. DOI:<https://doi.org/10.1145/1357054.1357277>
- [61] Christina Patterson. 2018. *World Alzheimer's report 2018*.
- [62] Alfredo Raglio, Stefania Filippi, Daniele Bellandi, and Marco Stramba-Badiale. 2014. Global music approach to persons with dementia: evidence and practice. *Clin. Interv. Aging* 9, (2014), 1669–1676. DOI:<https://doi.org/10.2147/CIA.S71388>
- [63] Raymond Murray Schafer. 1993. *The Soundscape: Our Sonic Environment and the Tuning of the World*. Simon and Schuster.
- [64] Kimberly Johanna Schelle, Carolina Gomez Naranjo, Martijn ten Bhömer, Oscar Tomico,

- and Stephan Wensveen. 2015. Tactile Dialogues: Personalization of Vibrotactile Behavior to Trigger Interpersonal Communication. In Proceedings of the Ninth International Conference on Tangible, Embedded, and Embodied Interaction - TEI '14, ACM Press, New York, New York, USA, 637–642. DOI:<https://doi.org/10.1145/2677199.2687894>
- [65] Sandra Suijkerbuijk, Rens Brankaert, Yvonne A.W. De Kort, Liselore J.A.E. Snaphaan, and Elke Den Ouden. 2015. Seeing the first-person perspective in dementia: A qualitative personal evaluation game to evaluate assistive technology for people affected by dementia in the home context. *Interacting with Computers* 27, 47–59. DOI:<https://doi.org/10.1093/iwc/iwu038>
- [66] Ana Tajadura-Jiménez and Daniel Västfjäll. 2008. Auditory-Induced Emotion: A Neglected Channel for Communication in Human-Computer Interaction. In *Affect and Emotion in Human-Computer Interaction*. Springer, Berlin, Heidelberg, 63–74.
- [67] Lisanne Teunissen, Tom Luyten, and Luc de Witte. 2017. Reconnecting People with Dementia by Using the Interactive Instrument CRDL. *Stud. Health Technol. Inform.* 242, (2017), 9–15.
- [68] Myrte Thoolen, Rens Brankaert, and Yuan Lu. 2019. Sentic: A Tailored Interface Design for People with Dementia to Access Music. In *Companion Publication of the 2019 on Designing Interactive Systems Conference 2019 Companion - DIS '19 Companion*, ACM Press, New York, New York, USA, 57–60. DOI:<https://doi.org/10.1145/3301019.3325152>
- [69] David Unbehaun, Daryoush Daniel Vaziri, Konstantin Aal, Rainer Wieching, Peter Tolmie, and Volker Wulf. 2018. Exploring the Potential of Exergames to affect the Social and Daily Life of People with Dementia and their Caregivers. In Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems - CHI '18, ACM Press, New York, New York, USA, Paper 62, 1–15. DOI:<https://doi.org/10.1145/3173574.3173636>
- [70] Jayne Wallace, Anja Thieme, Gavin Wood, Guy Schofield, and Patrick Olivier. 2012. Enabling self, intimacy and a sense of home in dementia: An Enquiry into Design in a Hospital Setting. In Proceedings of the 2012 ACM annual conference on Human Factors in Computing Systems - CHI '12, ACM Press, New York, New York, USA, 2629. DOI:<https://doi.org/10.1145/2207676.2208654>
- [71] Jayne Wallace, Peter C. Wright, John McCarthy, David Philip Green, James Thomas, and Patrick Olivier. 2013. A design-led inquiry into personhood in dementia. In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems - CHI '13, ACM Press, New York, New York, USA, 2617–2626. DOI:<https://doi.org/10.1145/2470654.2481363>
- [72] Jenny Waycott, Hilary Davis, Frank Vetere, Aimee Morgans, Alan Gruner, Elizabeth Ozanne, and Lars Kulik. 2014. Captioned photographs in psychosocial aged care: Relationship Building and Boundary Work. In Proceedings of the 32nd annual ACM conference on Human factors in computing systems - CHI '14, ACM Press, New York, New York, USA, 4167–4176. DOI:<https://doi.org/10.1145/2556288.2557290>
- [73] Bob Woods, Laura O'Philbin, Emma M. Farrell, Aimee E. Spector, and Martin Orrell. 2018. Reminiscence therapy for dementia. *Cochrane Database Syst. Rev.* 3 (March 2018). DOI:<https://doi.org/10.1002/14651858.CD001120.pub3>
- [74] BBC Sound Effects - Research & Education Space. Retrieved from <http://bbcscfx.acropolis.org.uk/>

IV

REFLECT

Section 4 reflects on the value of everyday sounds and technology for people with dementia and their caregivers. Chapter 7 discusses how everyday sounds as open-ended cues facilitated through tangible interactions can enrich the everyday experiences of dementia. This chapter concludes with a reflection on the design approach to capture and enrich the lived experiences of dementia. Chapter 8 revisits the research questions stated in Chapter 1 and formulates the main research conclusions of this thesis. Based on the insights presented in this thesis, this last chapter provides directions for future work.



7

Discussion

This thesis has provided novel insights into how everyday sounds can support the wide range of lived experiences of people in different stages of dementia and their extended care networks, such as informal and professional caregivers. This chapter aims to bridge and discuss all the main insights and outline the benefits of everyday sounds facilitated by technology for people with dementia. First, we present a summary of the main findings. Next, we discuss the role of everyday sounds in enriching the lived experiences of people with dementia and their caregivers through open-ended engagement and tangible interactions in day-to-day settings. This chapter concludes by reflecting on the research through design approach used in this thesis by elaborating on the role and influence of the design researcher.

Partially (Sections 7.3.3 and 7.4.2) based on:

Maarten Houben, Rens Brankaert, Emma Dhaeze, Gail Kenning, Inge Bongers, and Berry Eggen. 2022. "Enriching Everyday Lived Experiences in Dementia Care." In Sixteenth International Conference on Tangible, Embedded, and Embodied Interaction. TEI '22. New York, NY, USA: Association for Computing Machinery.

<https://doi.org/10.1145/3490149.3501326>

7.1 SUMMARY OF FINDINGS

This thesis investigated the previously unexplored potential of everyday sounds in technology and design to address the emotional and social needs of people with dementia. The research presented in the previous chapters focused on the main research question of how everyday sounds can enrich the lived experiences of people with dementia.

Section 1 addressed the experiences of people with dementia evoked by everyday sounds and the social interactions that emerged from these experiences. The workshops in *Chapter 2* demonstrated how the personal responses to everyday sounds resulted in meaningful activity as generic soundscapes composed of everyday sounds evoked memories, emotional reactions, and shared experiences in a group setting. Everyday sounds played during the workshops triggered associations for the participants based on their past life experiences. The recollection of memories associated with the everyday sounds resulted in meaningful moments in the present by reliving and sharing past experiences in a group setting. Therefore, we concluded how the emotional benefits of listening to everyday sounds were situated in social interactions. These outcomes highlighted the potential of everyday sounds in technology to facilitate person-centered and meaningful activities for people with dementia.

Section 2 built further on the insights from the workshop study by investigating how we can design for meaningful experiences with everyday sounds to support people with dementia. This section reported the longitudinal study involving people with dementia and their caregivers in a one-year co-design project to explore how meaningful everyday sounds can be identified and how to design technology to facilitate meaningful experiences with everyday sounds in the home environment. *Chapter 3* offered insights into how people with dementia link everyday sounds to their past life experiences based on the emotional value behind a specific memory and how the relative provides support and collective memory during meaningful activities. *Chapter 4* provided insights into how technology with personal everyday sounds can offer meaningful activities in the home environment by supporting everyday conversations, stimulating emotional responses, and capturing everyday experiences. The sessions also revealed how tangible interactions with everyday sounds that focus on discovery and exploration can stimulate initiative in the person with dementia to engage with

rich collections of audio content. The co-design study resulted in the design of the Tumbler as an intuitive and non-intimidating interface that offered tangible interactions with sounds to empower people with dementia and their partners to engage in social activities within everyday home settings.

Lastly, *Section 3* addressed how interventions that enable listening to everyday sounds can be integrated into dementia care practice. To address the experiences of people in the advanced stages of dementia, *Section 3* focused on the in-context deployment of Vita in two residential care facilities. *Chapter 5* reported opportunities for sound and technology to add value to daily care practice by providing rest or stimulation, social contact, or meaningful personal responses during daytime activities, between planned activities, at moments of personal care, or during informal moments. *Chapter 6* reported the lived experiences of people with advanced dementia and their caregivers using Vita to engage with everyday sounds in a care home context. The field study provided insights into the role of everyday sounds in dementia care in stimulating meaningful conversations, giving playfulness or feelings of discovery, and establishing a social connection between residents and caregivers. Furthermore, we gained insights into how Vita was used during scheduled activities and everyday moments in the care environment.

Based on these findings, the following sections address how these novel insights contribute to existing literature.

7.2 EVERYDAY SOUNDS AS OPEN-ENDED CUES

Chapter 2 presented multilayered soundscapes of everyday sounds and revealed that four layers of everyday sounds were perceived as overwhelming. The research in the following Chapters 3 to 6 used sets of everyday sounds. The sets in Chapter 4 contained both short sound fragments of 30 seconds or less, e.g., *sound event* or *story cue*, and longer sounds that lasted several minutes e.g., *background layer*, that could be played simultaneously by the Tumbler. Vita also contained short sound fragments (e.g., *set play*) and longer sound files (e.g., *set daydreaming*) but played these sounds as separate sound sets to not overwhelm participants who were in the later stages of dementia. The study findings consistently revealed how the fragments of everyday sounds evoked more numerous and rich responses from people with dementia.

As described in this thesis, everyday sounds were used as external memory cues to prompt personal memories, similar to digital items collected and kept by people in interactive systems [45]. This thesis highlights the potential of everyday sounds as cues to facilitate meaningful activities that focus on social engagement, active participation, and personal identity. Digital media is broadly used as a cue to evoke reminiscence and provide meaningful social activity to support the well-being of people with dementia [33]. These cues work as stimuli to foster engagement from people with dementia towards their physical and social environment [20]. This section further discusses how the intrinsic properties of sound allow for open-ended engagement through the perception of everyday sounds that result in reliving memories in the present and collective experiences that can be shared with others (see Figure 7.1). We differentiate everyday sounds from commonly used media such as videos, images, or music by discussing the value of the idiosyncratic and temporal characteristics of everyday sounds in providing open-ended engagement during meaningful activities.

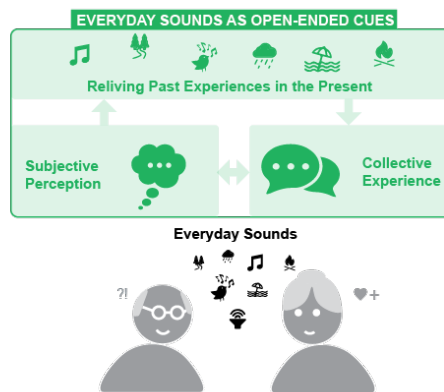


Figure 7.1: Everyday sounds can provide open-ended engagement during meaningful activities for people with dementia as the subjective perception of sound results in reliving memories and collective experiences that can be shared with others.

7.2.1 Subjective Perception of Sound

The studies presented in this thesis have provided numerous examples of how everyday sounds allow people with dementia to give their interpretations and recollections of memories or stories that were meaningful to them (see Chapter 2). This meaning assigned to everyday sounds is grounded in making open-ended

associations based on the subjective experiences of listening to sound (see Chapter 3). These findings follow the ‘interpretive paradigm’ in soundscape research that states the perception of sound depends not only on the nature of the sound source as a physical phenomenon but also on how the listener perceives the sound signals [10,78]. This thesis has highlighted how this subjective nature of perceiving everyday sounds is a valuable means for fostering open-ended engagement with people with dementia during meaningful activities suited to the abilities, personality, and uniqueness of every person with dementia. For example, the workshops in Chapter 2 and the first session reported in Chapter 3 illustrated how generic or non-personalized everyday sounds evoke associations based on the personal experience and background of people with dementia.

This open-ended engagement through everyday sounds during meaningful activities can reduce barriers or feelings of insecurity. For example, the field study with Vita in Chapter 6 revealed how residents made different interpretations of everyday sounds while the caregiver went along with the resident’s interpretation, resulting in meaningful or emotional conversations for the resident. In this context, the caregivers’ subjective perception of everyday sounds is also a matter of opinion and not a fact that needs to be verified by the person with dementia. Existing literature has indicated how providing room for interpretation allows people with dementia to bring personal meaning to the activity and avoids confrontation with the potential inability to recall details, such as time, place, or people [3,37]. As illustrated in this thesis, the subjective characteristics of everyday sounds enable people with dementia to recall essences or extracts of memories that allow for open-ended engagement by catering to the lived experiences of people with dementia that make sense in their reality. This open-ended engagement relieves the pressure that can arise for people with dementia when asked to recall specific details or facts from a particular memory [75]. Therefore, making open-ended associations with everyday sounds empower people with dementia to connect with past experiences as their present selves.

7.2.2 *Reliving Past Experiences in the Present*

The rich qualitative findings presented in this thesis have demonstrated how everyday sounds provide cues for reliving emotionally valuable memories. Recalling and sharing identity-defining life stories support people with dementia to explore and maintain a sense of selfhood [90]. For example, research on music

and dementia has indicated how people with dementia can best recall and recognize music from their teenage years while experiencing associated emotions linked to this period [71]. Therefore, it is not the stimulus in itself but the underlying and personal meaning that impacts the level of engagement and interest of the person with dementia. [21]. The findings in this thesis illustrated how non-musical or everyday sounds that match the recollection of past experiences of the person with dementia evoke recognition and feelings related to the meaning and emotions behind the associated memory. Furthermore, Chapter 3 offered examples of how everyday sounds can evoke mixed feelings by recalling emotionally challenging experiences. Nevertheless, these experiences are also valuable by supporting a sense of self and identity [13]. Therefore, this thesis contributes to the large body of literature on reminiscence therapy [94] by demonstrating how people with dementia recall valuable personal memories and engage in a wide range of identity-defining experiences based on their association with meaningful everyday sounds.

Chapter 2 provided a clear account of the different types of memories that people with dementia recalled during the workshops, such as childhood memories, anecdotes about loved ones, and meaningful past experiences that left a significant impact. Therefore, evoking memories related to sounds perceived in daily life can spark recollections of past everyday life as people with dementia link everyday sounds to their life histories, such as family, hobbies, work, home, or vacation. For example, one person with dementia described how to drive a train when hearing recordings from a train driver's cabin (see Chapter 3). While photos often represent significant life events, everyday sounds connect to aspects of daily life that are often forgotten [13,14]. Therefore, this thesis expands the scope of reminiscence for people with dementia as everyday sounds can uncover a wide range of the participants' past life experiences, values, and history.

“Back in the days, when we were heading to church, we always walked by under a tree, and that were trees like those we just heard, and they always created these beautiful sounds. Nice [I am] still able... I can still remember that! Yes, I still remember it very clearly. As a child, I already found it impressive that so many birds were sitting together...” (Participant with dementia– Chapter 2)

Whereas visual objects, such as photographs, are inherently static and exist over time, sound emerges and dissipates in time and conveys changing events, for example, a closing door [35]. This thesis has demonstrated how the transient nature of sound enables people with dementia to relive their memories and express associated emotions in the present. Being in the moment by engaging with the senses and allowing playful and pleasurable experiences brings positive emotions to people with dementia [85]. We highlight how everyday sounds provide dynamic cues in time that require a sense of focus and get people with dementia in contact with their surroundings as responding to sounds that emerge and dissolve over time becomes a way of being and acting in the now.

Most digital storytelling methods use personal edited videos to deliver predefined linear narratives [72]. In contrast, our findings illustrate how the temporal delivery of everyday sounds thrusts the evolution of a story or narrative by either building up to a soundscape, letting the story simmer, or offering new avenues for the story to further unfold. Chapter 3 provided examples of how the researcher dynamically played everyday sounds in real-time during the sessions with the Life Story Soundboard in response to the reactions expressed by the participants or based on where the conversation was heading. Therefore, this thesis illustrates how everyday sounds offer dynamic cues to tap into a broad range of aspects of past everyday life and let people with dementia build their story or memory in the 'now'. We emphasize how the immersive aspect of omnipresent sounds takes people with dementia on a mental journey to imagined spaces of past, present, and future life to create a sense of familiarity in which their story can take place.

7.2.3 *Collective Experiences*

The findings presented in Chapters 2-6 illustrate how everyday sounds work as a conversation starter as making and sharing interpretations is a social process by comparing opinions or expressing thoughts. In general, sound exists over space as the sound source can be heard from all around and is inherently different from visual information that can only be perceived when looking in the right direction [35]. Sound waves traveling through space engage and socially connect people through shared listening, as people make emotional and social connections while present in the same acoustic environment [74]. Similarly, this thesis illustrated how shared listening to everyday sounds offers opportunities for searching and

receiving social connections as everyday sounds started conversations, and participants responded or engaged in each other's stories.

Shared activities that involve reminiscing and telling stories during which the person with dementia is acknowledged result in a sense of encouragement and achievement [68]. Therefore, everyday sounds provide an accessible and open medium for social activity by sharing essential and identity-defining experiences from the past with others. These findings are similar to research on immersing people with dementia in digital environments to evoke memories and meaningful experiences during reminiscence activities [4,42,81]. However, everyday sounds cause a mental transposition into another space within a real-life physical environment as the person with dementia always remains in physical or visible contact with the relatives or caregivers, who are all immersed in the soundscape. Therefore, the verbal, bodily, social, and emotional responses evoked by everyday sounds reported in this thesis are situated in social activities and considered collective experiences.

Our findings also revealed how people with dementia express nonverbal responses to sounds through gestural communication, touch, or bodily expressions such as smiling to express appreciation, frowning to indicate confusion, or making gestures to mimic a sound (Chapters 2 & 6). Communicating or engaging with people in the late stages of dementia is challenging if they have language difficulties or aphasia [40]. Nevertheless, people with advanced dementia were actively involved in the evaluation of Vita, as the observations in Chapter 6 revealed the value of everyday sounds to support nonverbal communication, such as smiling, laughing, closing or opening eyes, mumbling, or imitating sounds. Offering sensory stimulation at the desired level of the person with dementia is necessary to accommodate their fluctuating sensory abilities [27]. Everyday sounds allow for open-ended embodied expressions that are comprehensible and open to people with mild to advanced dementia by tapping into the remaining sensory abilities.

For people with significant language impairments, these embodied responses are valid expressions of personhood and active forms of social initiative [58]. Respecting and acknowledging these nonverbal responses as social agency allows for mutual nonverbal communication and social connection between caregivers, relatives, and people with dementia [30]. Similarly, technologies that embrace

embodied cues such as mimicry or imitating gestures as communication modalities can support communication between caregivers and people with dementia in caregiving practices [38]. Therefore, this thesis demonstrates how interventions that provide engagement with everyday sounds empower care home residents to express embodied forms of communication to socially connect with others.

7.3 TANGIBLE INTERACTIONS WITH EVERYDAY SOUNDS

This thesis adopted a research through design approach through the development and evaluation of design artifacts as a method of inquiry [96]. This approach resulted in the development of three new design artifacts and the use of an existing artifact during the research activities to evoke and explore the responses to everyday sounds and evaluate the potential use and feasibility in real-life settings:

- The **Dementia Soundboard** is a design artifact developed for the workshops reported in Chapter 2 to interactively explore soundscapes as configurable compositions of everyday sounds during an activity at the daytime center, which provided unique insights into the participants' personal experiences with everyday sounds.
- The **Life Story Soundboard** is the next iteration of the Dementia Soundboard and was developed as a tangible interface to identify and categorize personal audio content during the co-design sessions reported in Chapter 3. The Life Story Soundboard was explicitly designed to offer flexibility and personalization during the subsequent steps in retrieving meaningful sounds and discovering personal narratives.
- The **Tumbler** was developed as an easy and accessible audio device to play everyday sounds at home for people with dementia and their relatives. The Tumbler is a finished prototype that can be used in field studies to capture the impact of personal sounds on people with dementia. Chapter 4 reported how the Tumbler was designed as a versatile product to be used in multiple contexts as the soundscapes can dynamically adapt to the abilities and the individual preferences of the person with dementia.

- **Vita** is an existing interactive sound player in the form of a soft cushion used as a design artifact during the field study reported in Chapter 6. Vita is a high-fidelity prototype developed by the Pleyade Innovation Team¹. Vita was used in two care facilities to play personal and generic everyday sounds during everyday care practice or activities.

These design artifacts offered physical representations and control of digital sound content for people with dementia and their extended care network. We frame the engagement of people with dementia with these artifacts as tangible interactions with everyday sounds as tangible interfaces rely on embodied interactions and tangible manipulations of digital content in a physical space [49]. In this section, we further discuss the role of tangible design artifacts in facilitating experiences with everyday sounds by supporting agency through exploration, providing shared activities, and enabling integration in everyday environments. (see Figure 7.2).

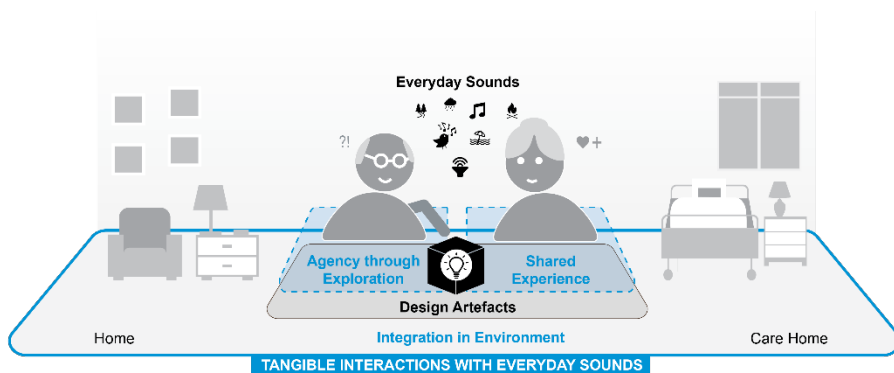


Figure 7.2: Tangible design artifacts provide agency through exploration and allow for shared experiences and integration in everyday surroundings.

7.3.1 Supporting Agency through Exploration

The design artifacts described in this thesis provided accessible and understandable interfaces for exploring and discovering everyday sounds. People

¹ <https://pleyadepit.nl/innovaties/vita-kussen>

with dementia could interact with these devices and perceive sound as output resulting from their actions. Tangible design artifacts that tap into the remaining cognitive and sensorimotor skills of the person with dementia result in feelings of achievement and self-efficacy [47]. Similarly, the Dementia Soundboard allowed the participants to select soundscapes using tactile everyday objects, such as a seashell. In addition, the soundboard also offered an interface to discover all the sounds embedded within the soundscapes as the different layers could be directly adapted by interacting with the touchpads (see Chapter 2).

In contrast to music which is linear audio content with a clear beginning and end, listening to everyday sounds is explorative as everyday sounds continuously change and require focus and attention to interpret the sound (see Chapter 3). The Tumbler fully embraces this explorative nature of engaging with everyday sounds by providing a tangible interface that the users can explore through gestures such as rolling, tilting, or shaking (see Chapter 4). Artifacts that facilitate tangible and embodied interactions in the here-and-now avoid linear cognitive thinking by allowing parallel coupling of action and perception [26]. Similarly, sound prompts in response to bodily actions and gestures support people with dementia in understanding their interactions and environments [25]. In addition, our findings demonstrate how tangible interfaces that offer direct manipulation of media content such as everyday sounds offer intuitive interactions by avoiding complex cognitive tasks and by stimulating active exploration.

The design artifacts enabled people with dementia to become active contributors during meaningful social activities. For example, residents using Vita in the care home would explore the six textile touchpads on the cushion to listen to the sounds with a caregiver (see Chapter 6). The vinyl patterns on the cushions were inviting for the residents to feel with their fingertips. These physical and embodied interactions allow people with dementia to connect the inner self with the physical environment [60] and reflect a sense of social agency [58]. In general, agency is often used in the narrow sense as the capability of intentional actions [80]. In the context of dementia, agency refers to how people with dementia manifest forms of self-expression and identity [68] and initiate and engage in social interactions [31]. This thesis demonstrates how tangible design artifacts that stimulate open-ended exploration and provide inviting forms of interaction allow for a wide range of individual expressions of agency.

Through engaging with these tangible design artifacts, people with dementia could express their opinions, thoughts, values, and preferences. For example, the Life Story Soundboard provided a tangible interface for co-creating personal audio content through reflection and recollections of meaningful and identity-defining past experiences (see Chapter 3). These findings feed into the increasing emphasis on agency for people with dementia to exercise choice in healthcare settings [48,89]. Experience-centered technology can support social agency by engaging people with dementia as active participants in social encounters to express a sense of self and identity [32]. Echoing this work in HCI, this thesis demonstrates how technology that facilitates meaningful experiences with everyday sounds that focus on discovery and exploration enables active participation, social agency, empowerment, and expressions of self and identity.

7.3.2 *Facilitating Shared Activity*

The design artifacts enabled people with dementia to share their experiences with others in a social setting. For example, the Dementia Soundboard accommodated social engagement in groups and stimulated discussion as participants watched or responded to the actions of the person using the soundboard (see Chapter 2). People with dementia actively seek validation and recognition as valuable members of society or a community [30]. Social belonging is a basic human need as people desire interpersonal attachment and strive to conserve existing social relationships [5]. Facilitating shared social activities allows people with dementia to seek out social encounters and supports a sense of belonging.

However, people with dementia often lack the confidence or initiative to start and engage in social and recreational activities that provide enjoyment and overall health benefits [92]. The Tumbler allowed for tangible interactions with personal sounds to empower people with dementia in the daily home situation to initiate and participate in meaningful activities with their partner (see Chapter 4). Similarly, the Life Story Soundboard afforded a shared activity for the person with dementia and their relative with clearly defined roles for the person with dementia who interacted directly with the sound disks. In contrast, the relative offered support and attention as the couples reminisced together about shared life experiences (see Chapter 3). This engagement of people with dementia and their relatives with both devices revealed how providing access to personal audio content can support couples living with dementia at home to participate in

shared social activities. These insights further contribute to research on technology that aims to address both the needs of people with dementia and their informal caregivers by providing social activity and supporting existing relationships with relatives and family [16,38,88].

Whereas everyday sounds in a shared space result in collective experiences, the design artifacts in this thesis demonstrate the role of technology in supporting shared activities through interfaces that invite collaboration, proximity, and touch. It remains challenging for people with dementia to socially engage in residential care homes as they are limited in social encounters [83]. Nevertheless, people with dementia desire feelings of intimacy by exchanging empathic and supportive responses [89]. Tangible design artifacts that stimulate human contact, physical connection, and joint engagement allow people with dementia who have difficulties with verbal communication to connect with others by collectively interacting with the artifact as a form of nonverbal and interpersonal communication [79,82]. Similarly, Vita enabled caregivers in the care homes to provide a shared intimate activity with the residents. The tangible qualities offered by Vita resulted in touch, presence, and warm-felt interactions between caregivers and residents while listening to meaningful audio content. For example, during the field study, we observed how the caregiver would often take the hand of the resident and explore the touchpads of the cushion together (see Chapter 6). Therefore, this thesis further contributes to research on technology for dementia by demonstrating the value of tangible interactions with design artifacts to allow for collaboration, social connection, and human presence.

7.3.3 *Integration in Everyday Environments*

In this thesis, we designed and evaluated design artifacts as carriers of meaningful sound content to integrate the beneficial effects of everyday sounds in the everyday surroundings of people with dementia. Tangible interactions are, by nature, embedded in our physical environment where people interact with their day-to-day surroundings [49]. This embedding of design artifacts in everyday life allows insight into the added value and potential application of these devices in real-life situations [46]. For example, the Tumbler (Figure 7.3) has minimal and modern aesthetics to fit multiple interiors and blend in the home environment for people with dementia (see Chapter 4). The Tumbler also has a docking station to charge the portable speaker, allowing the Tumbler to be stored in sight and

available for use in the home environment rather than keeping it in a cupboard. Technology designed as a household product that naturally blends in the home as *stuff* provides control over placement, creates a sense of ownership, and stimulates routine use [84]. Technology placed visibly in the home interior of people with dementia allows for overcoming the difficulties such as locating the device when stored in a confined place, such as a cupboard [57]. Therefore, technology that facilitates meaningful engagement with everyday sounds at home should be present in the physical home environment and be inviting to stimulate initiative and routine in listening to everyday sounds.



Figure 7.3: The Tumbler has minimal and modern aesthetics to fit multiple interiors and blend in the home environment for people with dementia.

Similarly, the developers of Vita² (see Figure 7.4) designed it as an everyday household object that could ‘linger’ around the communal space in the care home to be available for use during routine care practice (see Chapter 6). Vita is portable and could be used in various locations, such as the communal space, separate activity rooms, and the residents’ private rooms on multiple surfaces, such as on a table, on a resident’s lap, or in bed. In dementia care settings, the professional caregivers are mediators of technology that facilitate social or meaningful experiences for the residents [77,87]. Yet, time constraints and heavy workloads [61], unclear instructions and communication towards care professionals [52], and a lack of awareness of the availability of technology [59]

² <https://pleyadepit.nl/innovaties/vita-kussen>

are barriers to the adoption of such interventions in daily care practice. Technology experienced as straightforward and ready-to-use is more likely to be adopted by the care staff and used daily in dementia care practice [52]. Furthermore, the domestication of technology in care home settings requires the care staff to have ownership and take the lead in adopting technology into everyday care practice based on their expertise [77]. Therefore, we conclude how the tangible and portable qualities of the design artifacts enable technology to be visible and available in care environments which is crucial in stimulating use and engagement in everyday routines.



Figure 7.4: Vita was designed as an everyday object that could 'linger' around the communal space in the care home.

The insights gained from using the Tumbler and Vita revealed how technology should be integrated within everyday settings for people with dementia to enhance their user experience and provide a sense of home, comfort, and social connection within their environment. These insights further motivate current trends in healthcare technology to bridge the medical expertise of health practitioners with the lived experiences of people by designing devices that are fitted to domesticity and private life [51]. Therefore, this thesis contributes to research on developing technology for dementia by highlighting the need for non-stigmatizing and aesthetically pleasing tangible products that fit the immediate surroundings and stimulate use and engagement in everyday settings.

7.4 ENRICHING EVERYDAY EXPERIENCES IN DEMENTIA

To explore the potential of sound-based interventions in the everyday lives of people with dementia, the research in this thesis was conducted in real-life settings and the personal environments of people with dementia, namely at home, the daycare center, or the care home. In this section, we relate the findings of this thesis to the societal challenges of dementia in supporting people with dementia aging in place and in residential care facilities [95]. With life-enrichment, we refer specifically to enriching experiences that offer sensory stimulation [50] and a means to provide a momentary adventure or escape from the everyday reality [91] by engaging in a diverse set of activities that elevates the quality of care and general well-being [9]. The following section discusses how open-ended engagement with everyday sounds delivered through tangible design artifacts enriches the everyday lived experiences of dementia by supporting meaningful activity at home or reinforcing person-centered care (see Figure 7.5).

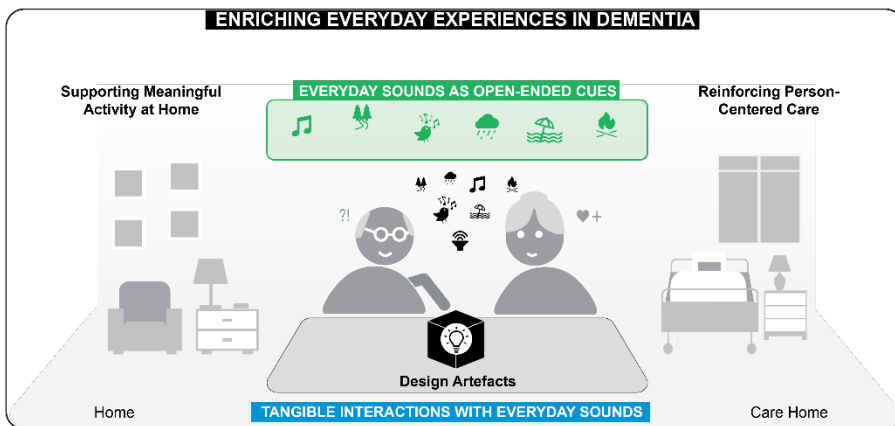


Figure 7.5: Everyday sounds can enrich the everyday lived experiences of dementia by providing meaningful activity at home and reinforcing person-centered care in residential dementia care.

7.4.1 *Meaningful Activity at Home*

People with dementia have prioritized the need for social and recreational activity at home [17]. Everyday sounds can support these social needs by cueing enjoyable, light-hearted, and intimate moments in the everyday home environment. Chapter 4 highlighted the potential for social and experience-centered activities in home situations for people with dementia to counteract forms of unrest or boredom and stimulate the social connection between people with dementia and their families. The co-design process of the Tumbler revealed possibilities for everyday sounds to provide meaningful activity at home by supporting conversations through auditory cues, eliciting emotional responses in personal settings, and recording recent experiences from everyday life (see Chapter 4). Our findings of how the Tumbler engaged both the person with dementia and the informal caregiver tie in with research proposing how technology can be viewed as an integral part of the conversational triad [70]. Therefore, this thesis responds to the increasing body of work that addresses the social and recreational needs of people with dementia to age in place [14,16].

While people with dementia strive to maintain continuity and well-being in life, they struggle to remain socially engaged due to the changes in their ability to participate in everyday social life [36]. Therefore, people with dementia require support to engage in activities and reach out to others which are essential aspects that constitute a meaningful everyday life [44]. The longitudinal co-design study in Chapters 3 & 4 addressed the social relationship between the person with dementia and their relative by exploring memories and reflecting on a shared life. The relationships between people with dementia and their life partners gradually transform from an equal life partnership into a caring relationship [34] and are often associated with feelings of grief [55]. Meaningful social activities that focus on shared values, purposes, and life experiences can support partnership-based activities to reinforce a sense of *couplehood* and support care relationships to flourish and evolve in a renewed commitment [62]. However, meaningful activities rarely involve informal caregivers as active participants [14].

In contrast, the Life Story Soundboard and the Tumbler were designed to facilitate meaningful activity between people with dementia and their informal caregivers living at home. Chapters 3 & 4 revealed how exploring shared memories evoked by everyday sounds served as a social activity for people with

dementia and their partners at home to reflect on their relationship based on shared values and life experiences. These findings support and complement a recent study indicating the potential of everyday sounds to support domestic reminiscence through rich conversations and learning new things about each other [13]. By recalling shared experiences and reflecting on their lasting bond, people with dementia and their partners can re-establish social connections within their households [62]. Therefore, this thesis promotes technologies that provide enrichment at home and facilitate meaningful activity with people with dementia and their informal caregivers to strengthen their enduring bond.

7.4.2 Reinforcing Person-Centered Care

Engaging in conversations and interpersonal interactions results in meaningful relationships between care providers, which is fundamental to providing qualitative person-centered care [29]. These interpersonal exchanges improve the quality of care by supporting the selfhood and well-being of the person with dementia while supporting the emotional and physical workload of the care staff [11]. This thesis has addressed these interpersonal relations between people with dementia and their caregivers and offered insights into how shared experiences facilitated by everyday sounds support building and maintaining of care relations. For example, Chapter 6 provided insights into how professional caregivers can retrieve meaningful stories and memories from care home residents by exploring everyday sounds. Exploring aspects of past everyday life helps caregivers understand the person, their life experiences, and values to build interpersonal relationships [56]. These relationships are not to be mistaken as being emotionally and personally over-attached to the client but as an exchange of personal information and establishing mutual trust, acceptance, and confidence in the care relationship [89].

Chapter 5 provided insights into the experiences and perspectives of the staff on the added value of sound and technology for daily practice. The professional caregivers stated that the implementation of audio-based technology in care practice requires a reflective and personalized approach by addressing the residents' personality, background, preferences, and mood. Consequently, the professional caregivers' knowledge of the interests and preferences of the residents is crucial in providing personalized activities for people with dementia and monitoring its impact [77]. Therefore, the successful use of technology for

enriching experiences in residential care depends on how caregivers assess the individual needs and interests of the person with dementia by engaging in a mutual and relational dialogue, facilitating a safe experience, and evaluating how the technology is perceived over time [91]. The workshops in Chapter 5 and interviews in Chapter 6 tapped into the lived experiences and expertise of the professional caregivers to extend the potential impact of everyday sounds for people with dementia into residential care. Therefore, this thesis contributes to the ethical perspectives on technology in residential care that recognize the long-term challenges, existing practices, and complexity of the care environment as factors for technology to be used effectively [43,66,91].

Meaningful activities for people with dementia are often scheduled as part of recreational programs [22,76], as residents experience most boredom and agitation between daytime activities [12]. Accordingly, the workshop outcomes in Chapter 5 revealed the need to address boredom and agitation between scheduled daytime activities. Chapter 6 illustrated how Vita was used spontaneously during routine care or between scheduled daytime activities and resulted in meaningful social engagement through interpersonal gestures such as teasing, laughing, and playful behavior. These insights confirm the potential of experienced-centered technology as a tool for providing opportunistic and spontaneous activities that result in social experiences and enjoyment during routine care [32,63,64]. These social encounters resulting from interacting with Vita culminated in an informal atmosphere and a sense of belonging in a setting often viewed as clinical, yet, is also a home (see Chapter 6). Such small moments of contact might seem insignificant to an outsider but are intentional acts of care to directly support the social and emotional needs of the person with dementia [15]. This thesis demonstrates how technology that facilitates open-ended engagement with everyday sounds supports person-centered care practices by allowing simple pleasures in everyday moments that provide a sense of belonging and contributes to the personhood of the resident with dementia.

7.5 THE ROLE OF THE DESIGN RESEARCHER

This section reflects on the design approach used in this thesis to understand the perspectives, experiences, and context of people with dementia and their extended care network. We elaborate on the value of this approach in gaining a rich understanding of the lived experiences of people with dementia necessary to

design effective and meaningful technologies for dementia. This section offers a reflection on the role of the design researcher during the research activities by acting in the moment, balancing all perspectives, and immersing in the context.

7.5.1 *Acting in the Moment*

The research through design approach [96] used in this thesis aimed to include people with dementia as active partakers during the exploration, design, and evaluation of technologies that facilitate experiences with everyday sounds. For example, the workshops in Chapter 2 were set in an informal, pleasant, and safe atmosphere to allow people with dementia to share opinions and thoughts in a non-threatening and social environment. Literature on involving people with dementia in design has emphasized how establishing an informal and enjoyable atmosphere allows the participant-researcher relationship to exist and develop over time [6,39,67]. By doing so, the designer can focus on the person's experience of dementia through building a relationship of trust and familiarity to value and make meaning of more implicit expressions of people with dementia during research activities [39]. Similarly, the research in this thesis adopted a relational approach in which the design researcher engaged in direct and personal contact with the participants with dementia.

Adopting a reciprocal approach enables design researchers to gain an understanding of the lived experiences of dementia, while the participants can experience direct benefits by engaging in social interactions and pleasurable activities [53]. Activities that focus on the experience of being in the moment by facilitating and savoring sensory engagement offer playfulness, pleasure and fun for people with dementia [85]. This approach was of value in engaging the couples in the longitudinal co-design study reported in Chapters 3 & 4. The findings revealed how participants benefited from engaging with personal sounds and exploring shared memories in a social and familiar setting.

A key feature of reciprocal engagement is flexibility to accommodate the changing needs of people with dementia and address suddenly changing situations [53]. Therefore, the design researcher needs to be sensitive to the expressions of participants with dementia and flexible in responding accordingly [7]. This thesis has offered numerous examples of how soundscapes of everyday sounds were dynamically adapted to shape and support the responses of the

person with dementia on the spot, as dynamic soundscapes can build up to the climax of a story or fade out at the end (Chapters 2-4). These findings further confirm the value of acting in the moment to the responses of the participant with dementia to establish a dialogue between researcher and participants, which is necessary to facilitate a co-creation process [86]. Therefore, the design approach in this thesis further argues against the rigorous application of methods in designing for people with dementia [41] by demonstrating how the design researcher needs to act in the moment through means of improvisation, flexibility, and playful provocation to elicit active contributions from people with dementia and establish a reciprocal dialogue.

7.5.2 *Balancing All Perspectives in Dementia*

This thesis addressed the lived experiences of dementia by incorporating the complex and dynamic relations within the care triad consisting of the person with dementia, the family, and the professional caregivers in the design process. The facilitator of design activities plays a subtle yet central role to what extent participants are given a voice in the design process, for example, by managing asymmetric power relations or tensions between caregivers and care receivers [23]. In that sense, 'giving voice' implies that 'voice' is something that has to be given to people with communication difficulties [1]. However, the work in this thesis illustrated how people with dementia already have clear opinions, wants, and likes. For example, the participants offered concrete feedback and suggestions on the functionalities of the mockups during the design process of the Tumbler, as reported in Chapter 4. Therefore, the design researcher acted as an interpreter to support people with dementia to voice their values and perspectives through tailored and adapted design methods [93]. As a result, the participants with dementia were not only given a voice but could actively influence decisions in the design process that led to the final functionalities proposed in the Tumbler. This thesis further highlights the societal relevance of design to empower people with dementia in decision-making of aspects of their personal life [73] and to integrate their fundamental human rights into the design process [19].

It is well established in literature that the family member is an essential point of contact in retrieving information or meaningful memories for the person with dementia because of their collective memory [2,18,24,67]. However, a potential

pitfall is that the family member takes the lead in the session, serves as a proxy, or even impedes the input of the person with dementia [18]. Similar actions from the informal caregivers were observed in the co-design process of the Tumbler, such as interrupting the participants with dementia which distracts them as they can quickly lose their train of thought. Furthermore, it is challenging for the design researcher to mediate these sensitive and emotional situations as these actions of the informal caregivers often originate from the struggle to come to terms with the dementia of their loved one as they compensate for their lost skills [55]. Therefore, the design researcher needs to moderate these different forms of input to allow the family member to vent potential frustrations or struggles while not hindering the person with dementia. The sessions with the Life Story Soundboard in Chapter 3 revealed how assigning clear roles and tasks in research activities guides the participants to refocus on their contributions. As such, the relatives can amplify the responses of their partner with dementia and allow novel insights or interesting contributions to surface [24]. Furthermore, Chapter 4 revealed how the involvement of informal caregivers is crucial to understanding the everyday routines at home and how technology can support these routines.

Similarly, the design researcher needs to allow the healthcare staff in residential care to share their concerns and opinions regarding the technology or intervention to avoid disinterest, resistance in use, or misinformation [69]. Developing technology in close collaboration with care organizations allows for reciprocal value exchange between stakeholders and interventions that provide clear benefits for the care staff and residents [8]. The direct collaboration between research and care practice reported in this thesis was crucial in understanding how professional and informal caregivers can embrace new technologies by encouraging and allowing them to contribute to how they can use novel interventions in their daily care practice. This thesis offered design research approaches that combined the perspectives of the care staff and informal caregivers with the lived experiences of people with dementia to gain a broad understanding of how sound-based technologies can enrich everyday experiences of dementia.

7.5.3 *Immersing in Context*

All research activities reported in this thesis were carried out in context, namely in the real-life everyday settings of the participants with dementia, such as their

home (Chapter 3 & 4), daycare center (Chapter 2), or the care home (Chapter 5 & 6). By integrating research into a familiar context, participants are followed up by a trusted caregiver in a safe environment where they feel comfortable as it creates a space for sharing experiences and receiving recognition [18]. In Chapter 6, the researcher conducted participatory observations [28] to capture the lived experiences of people with dementia and challenge the perspectives and views expressed by the care practitioners during the workshops, as reported in Chapter 5. This participant-observer approach allows the design researcher to blend into the daily activities in the care home environment, build a trusting relationship with the residents and care staff and gain unique insights into the lived experiences of advanced dementia [31,65]. While this presence in context might appear counterintuitive in supporting validity and avoiding bias, design researchers require an understanding and first-hand experiences of the context to incorporate the messiness and complexity of everyday life into the design process of effective interventions [54]. Therefore, the findings from Chapter 6 further add to this body of knowledge by demonstrating how this participant-observer approach allows to gain a rich understanding of how people with advanced dementia engage with design artifacts in a care home.

7.6 CONCLUSION OF DISCUSSION

This chapter analyzed and compared the insights from the studies presented in the previous chapters to provide a general understanding of how everyday sounds can enrich the everyday lived experiences of people with dementia. Experiencing everyday sounds, such as reliving memories and participating in social activities, allow for life enrichment in everyday surroundings, such as providing meaningful activity at home or reinforcing person-centered care practices. During these activities, technology is a means that offers tangible interactions for people with dementia to engage in open-ended experiences with everyday sounds. The insights are relevant for music therapists, activity counselors, and caregivers in care homes to use sound and soundscapes to attend to the psychosocial needs of people with dementia and increase social interactions and meaningful activity during everyday life. Furthermore, the insights regarding tangible interactions with everyday sounds contribute to the emerging work on technology and dementia in facilitating accessible and inviting interfaces with meaningful and thoughtful technologies. The reflections on the relational and reciprocal design approach demonstrate the relevance of involving people with dementia, relatives,

and caregivers in design research by challenging societal views on dementia and positioning people with dementia as co-creators and experts of their own experiences.

7.7 REFERENCES

- [1] Meryl Alper. 2017. Giving voice: Mobile communication, disability, and inequality. MIT Press.
- [2] Sérgio Alves, Filipa Brito, Andreia Cordeiro, Luís Carriço, and Tiago Guerreiro. 2019. Designing Personalized Therapy Tools for People with Dementia. In Proceedings of the 16th International Web for All Conference (W4A '19), Association for Computing Machinery, New York, NY, USA. DOI:<https://doi.org/10.1145/3315002.3317571>
- [3] Arlene J. Astell, Maggie P. Ellis, Norman Alm, Richard Dye, and Gary Gowans. 2010. Stimulating People with Dementia to Reminisce Using Personal and Generic Photographs. *Int. J. Comput. Healthc.* 1, 2 (2010), 177–198. DOI:<https://doi.org/10.1504/IJCIH.2010.037461>
- [4] Steven Baker, Jenny Waycott, Romina Carrasco, Thuong Hoang, and Frank Vetere. 2019. Exploring the Design of Social VR Experiences with Older Adults. In Proceedings of the 2019 on Designing Interactive Systems Conference - DIS '19, ACM Press, New York, New York, USA, 303–315. DOI:<https://doi.org/10.1145/3322276.3322361>
- [5] R F Baumeister and M R Leary. 1995. The need to belong: desire for interpersonal attachments as a fundamental human motivation. *Psychol Bull* 117, 3 (May 1995), 497–529.
- [6] Jeanette Bell and Tuck Wah Leong. 2019. Collaborative Futures: Co-Designing Research Methods for Younger People Living with Dementia. In Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems - CHI '19, ACM Press, New York, New York, USA, 1–13. DOI:<https://doi.org/10.1145/3290605.3300582>
- [7] Rita Maldonado Branco, Joana Quental, and Óscar Ribeiro. 2017. Personalised participation: an approach to involve people with dementia and their families in a participatory design project. *CoDesign* 13, 2 (2017), 127–143. DOI:<https://doi.org/10.1080/15710882.2017.1310903>
- [8] Rens Brankaert and Elke den Ouden. 2017. The design-driven living lab: a new approach to exploring solutions to complex societal challenges. *Technology Innovation Management Review* 7, 1 (May 2017), 44–51.
- [9] Dawn J Brooker, Rosemary J Woolley, and David Lee. 2007. Enriching opportunities for people living with dementia in nursing homes: An evaluation of a multi-level activity-based model of care. *Aging Ment Health* 11, 4 (July 2007), 361–370. DOI:<https://doi.org/10.1080/13607860600963679>
- [10] Bennett M. Brooks, Brigitte Schulte-Fortkamp, Kay S. Voigt, and Alex U. Case. 2014. Exploring our sonic environment through soundscape research & theory. *Acoust. Today* 10, 1 (2014), 30–40.
- [11] Sonya Brownie and Susan Nancarrow. 2013. Effects of person-centered care on residents and staff in aged-care facilities: a systematic review. *Clin Interv Aging* 8, (January 2013), 1. DOI:<https://doi.org/10.2147/CIA.S38589>
- [12] Linda L Buettner. 1999. Simple Pleasures: A multilevel sensorimotor intervention for nursing home residents with dementia. *American Journal of Alzheimer's Disease* 14, 1 (January 1999), 41–52. DOI:<https://doi.org/10.1177/153331759901400103>
- [13] Sarah Campbell, David Fröhlich, and Norman Alm. 2022. Exploring the Role of Everyday Sounds to Support People Living with Dementia. In *Design for People Living with Dementia*, Paul Rodgers (ed.). Routledge, 237–248.
- [14] Sarah Campbell, David Fröhlich, Norman Alm, and Adam Vaughan. 2019. Sentimental Audio Memories: Exploring the Emotion and Meaning of Everyday Sounds. In *Dementia Lab 2019. Making Design Work: Engaging with Dementia in Context. D-Lab 2019.*, Rens Brankaert and Wijnand IJsselstein (eds.). Springer, Cham, 73–81. DOI:https://doi.org/10.1007/978-3-030-33540-3_7
- [15] Tracy J Carr, Sandee Hicks-Moore, and Phyllis Montgomery. 2011. What's so big

- about the 'little things': A phenomenological inquiry into the meaning of spiritual care in dementia. *Dementia* 10, 3 (May 2011), 399–414. DOI:<https://doi.org/10.1177/1471301211408122>
- [16] Romina Carrasco, Felicity A. Baker, Anna A. Bukowska, Imogen N. Clark, Libby M. Flynn, Kate McMahon, Helen Odell-Miller, Karette Stensaeth, Jeanette Tamplin, Tanara Vieira Sousa, Jenny Waycott, and Thomas Wosch. 2020. Empowering Caregivers of People Living with Dementia to Use Music Therapeutically at Home. In 32nd Australian Conference on Human-Computer Interaction (OzCHI '20), ACM, New York, NY, USA, 198–209. DOI:<https://doi.org/10.1145/3441000.3441082>
- [17] Helen Chester, Paul Clarkson, Linda Davies, Caroline Sutcliffe, Sue Davies, Alexandra Feast, Jane Hughes, and David Challis. 2018. People with dementia and carer preferences for home support services in early-stage dementia. *Aging Ment Health* 22, 2 (2018), 270–279. DOI:<https://doi.org/10.1080/13607863.2016.1247424>
- [18] Daphne Sze Ki Cheung, Shuk Kwan Tang, Ken Hok Man Ho, Cindy Jones, Mimi Mun Yee Tse, Rick Yiu Cho Kwan, Kit Ying Chan, and Vico Chung Lim Chiang. 2021. Strategies to engage people with dementia and their informal caregivers in dyadic intervention: A scoping review. *Geriatr Nurs (Minneap)* 42, 2 (2021), 412–420. DOI:<https://doi.org/https://doi.org/10.1016/j.gerinurse.2021.02.002>
- [19] Shaan Chopra, Emma Dixon, Kausalya Ganesh, Alisha Pradhan, Mary L. Radnofsky, and Amanda Lazar. 2021. Designing for and with People with Dementia Using a Human Rights-Based Approach. In Extended Abstracts of the 2021 CHI Conference on Human Factors in Computing Systems (CHI EA '21), Association for Computing Machinery, New York, NY, USA. DOI:<https://doi.org/10.1145/3411763.3443434>
- [20] Jiska Cohen-Mansfield, Maha Dakheel-Ali, and Marcia S Marx. 2009. Engagement in persons with dementia: the concept and its measurement. *Am J Geriatr Psychiatry* 17, 4 (April 2009), 299–307. DOI:<https://doi.org/10.1097/JGP.0b013e31818f3a52>
- [21] Jiska Cohen-Mansfield, Khin Thein, Maha Dakheel-Ali, and Marcia S Marx. 2010. The underlying meaning of stimuli: Impact on engagement of persons with dementia. *Psychiatry Res* 177, 1–2 (May 2010), 216–222. DOI:<https://doi.org/10.1016/j.psychres.2009.02.010>
- [22] Lesley Collier and Anke Jakob. 2017. The Multisensory Environment (MSE) in Dementia Care: Examining Its Role and Quality From a User Perspective. *HERD: Health Environments Research & Design Journal* 10, 5 (October 2017), 39–51. DOI:<https://doi.org/10.1177/1937586716683508>
- [23] Yngve Dahl and Dag Svanæs. 2020. Facilitating Democracy: Concerns from Participatory Design with Asymmetric Stakeholder Relations in Health Care. In Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems (CHI '20), Association for Computing Machinery, New York, NY, USA, 1–13. DOI:<https://doi.org/10.1145/3313831.3376805>
- [24] Jiamin Dai and Karyn Moffatt. 2021. Surfacing the Voices of People with Dementia: Strategies for Effective Inclusion of Proxy Stakeholders in Qualitative Research. In Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems (CHI '21), Association for Computing Machinery, New York, NY, USA. DOI:<https://doi.org/10.1145/3411764.3445756>
- [25] Shital Desai, Joel Ong, Deborah Fels, and Arlene Astell. 2022. Sound Mixed Reality Prompts for People with Dementia. In Designing Interactions for Music and Sound. 151–176. DOI:<https://doi.org/10.4324/9781003140535-7>
- [26] Jelle van Dijk and Caroline Hummels. 2017. Designing for Embodied Being-in-the-World: Two Cases, Seven Principles and One Framework. In Proceedings of the Eleventh International Conference on Tangible, Embedded, and Embodied Interaction (TEI '17), Association for Computing Machinery, New York, NY, USA, 47–56. DOI:<https://doi.org/10.1145/3024969.3025007>
- [27] Emma Dixon and Amanda Lazar. 2020. The Role of Sensory Changes in Everyday Technology Use by People with Mild to Moderate Dementia. In The 22nd International ACM SIGACCESS Conference on Computers and Accessibility (ASSETS '20), Association for Computing Machinery, New York, NY, USA.

- DOI:<https://doi.org/10.1145/3373625.3417000>
- [28] Robert M. Emerson, Rachel I. Fretz, and Linda L. Shaw. 2001. Participant observation and fieldnotes. *Handbook of ethnography* (2001), 352–368.
- [29] Sam Fazio, Douglas Pace, Janice Flinner, and Beth Kallmyer. 2018. The Fundamentals of Person-Centered Care for Individuals With Dementia. *Gerontologist* 58, suppl_1 (January 2018), S10–S19. DOI:<https://doi.org/10.1093/geront/gnx122>
- [30] Sarah Foley, John McCarthy, and Nadia Pantidi. 2019. The Struggle for Recognition in Advanced Dementia: Implications for Experience-Centered Design. *ACM Transactions on Computer-Human Interaction* 26, 6 (November 2019), 1–29. DOI:<https://doi.org/10.1145/3359594>
- [31] Sarah Foley, Nadia Pantidi, and John McCarthy. 2019. Care and design: An ethnography of mutual recognition in the context of advanced dementia. In *Conference on Human Factors in Computing Systems - Proceedings*, ACM Press, New York, New York, USA, Paper 610, 13 pages. DOI:<https://doi.org/10.1145/3290605.3300840>
- [32] Sarah Foley, Daniel Welsh, Nadia Pantidi, Kellie Morrissey, Tom Nappey, and John McCarthy. 2019. Printer Pals: Experience-Centered Design to Support Agency for People with Dementia. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems - CHI '19*, ACM Press, New York, New York, USA, Paper 404, 1-13. DOI:<https://doi.org/10.1145/3290605.3300634>
- [33] David M. Frohlich, Emily Corrigan-Kavanagh, Sarah Campbell, Theopisti Chrysanthaki, Paula Castro, Isabela Zaine, and Maria da Graça Campos Pimentel. 2020. Assistive Media for Well-being. In *HCI and Design in the Context of Dementia*, Rens Brankaert and Gail Kenning (eds.). Springer International Publishing, Cham, 189–205. DOI:https://doi.org/10.1007/978-3-030-32835-1_12
- [34] Mary Galvin. 2016. Supporting positive interactions within dementia relationships of care. PhD Thesis, University College Cork.
- [35] William W Gaver. 1989. The SonicFinder: An Interface That Uses Auditory Icons. *Hum Comput Interact* 4, 1 (March 1989), 67–94. DOI:https://doi.org/10.1207/s15327051hcio401_3
- [36] Sylwia Górská, Kirsty Forsyth, and Donald Maciver. 2017. Living With Dementia: A Meta-synthesis of Qualitative Research on the Lived Experience. *Gerontologist* 58, 3 (2017), e180–e196. DOI:<https://doi.org/10.1093/geront/gnw195>
- [37] Gary Gowans, Jim Campbell, Norm Alm, Richard Dye, Arlene Astell, and Maggie Ellis. 2004. Designing a multimedia conversation aid for reminiscence therapy in dementia care environments. In *Extended abstracts of the 2004 conference on human factors and computing systems - CHI '04*, ACM Press, New York, New York, USA, 825–836. DOI:<https://doi.org/10.1145/985921.985943>
- [38] Connie Guan, Anya Bouzida, Ramzy M Oncy-avila, Sanika Moharana, and Laurel D Riek. 2021. Taking an (Embodied) Cue From Community Health: Designing Dementia Caregiver Support Technology to Advance Health Equity. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems (CHI '21)*, Association for Computing Machinery, New York, NY, USA. DOI:<https://doi.org/10.1145/3411764.3445559>
- [39] Niels Hendriks, Liesbeth Huybrechts, Karin Slegers, and Andrea Wilkinson. 2018. Valuing implicit decision-making in participatory design: A relational approach in design with people with dementia. *Design Studies* 59, 58–76. DOI:<https://doi.org/10.1016/j.destud.2018.06.001>
- [40] Niels Hendriks, Liesbeth Huybrechts, Andrea Wilkinson, and Karin Slegers. 2014. Challenges in doing participatory design with people with dementia. In *Proceedings of the 13th Participatory Design Conference on Short Papers, Industry Cases, Workshop Descriptions, Doctoral Consortium papers, and Keynote abstracts - PDC '14 - volume 2 (PDC '14)*, ACM Press, New York, New York, USA, 33–36. DOI:<https://doi.org/10.1145/2662155.2662196>
- [41] Niels Hendriks, Karin Slegers, and Andrea Wilkinson. 2020. Against Dedicated Methods: Relational Expertise in Participatory Design with People with Dementia. In *HCI and Design in the Context of Dementia*, Rens Brankaert and Gail Kenning (eds.). Springer International Publishing, Cham, 97–109. DOI:https://doi.org/10.1007/978-3-030-32835-1_12

- 32835-1_7
- [42] James Hodge, Madeline Balaam, Sandra Hastings, and Kellie Morrissey. 2018. Exploring the Design of Tailored Virtual Reality Experiences for People with Dementia. In Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems (CHI '18), ACM Press, New York, New York, USA, Paper 514, 1-13. DOI:<https://doi.org/10.1145/3173574.3174088>
- [43] James Hodge, Sarah Foley, Rens Brankaert, Gail Kenning, Amanda Lazar, Jennifer Boger, and Kellie Morrissey. 2020. Relational, Flexible, Everyday: Learning from Ethics in Dementia Research. In Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems (CHI '20), Association for Computing Machinery, New York, NY, USA, 1-16. DOI:<https://doi.org/10.1145/3313831.3376627>
- [44] Göran Holst and Ingalill R Hallberg. 2003. Exploring the meaning of everyday life, for those suffering from dementia. *Am J Alzheimers Dis Other Dement* 18, 6 (November 2003), 359-365. DOI:<https://doi.org/10.1177/153331750301800605>
- [45] Elise van den Hoven and Berry Eggen. 2014. The cue is key: Design for real-life remembering. *Zeitschrift für Psychologie* 222, 110-117. DOI:<https://doi.org/10.1027/2151-2604/a000172>
- [46] Elise van den Hoven, Joep Frens, Dima Aliakseyeu, Jean-Bernard Martens, Kees Overbeeke, and Peter Peters. 2007. Design Research & Tangible Interaction. In Proceedings of the 1st International Conference on Tangible and Embedded Interaction (TEI '07), Association for Computing Machinery, New York, NY, USA, 109-115. DOI:<https://doi.org/10.1145/1226969.1226993>
- [47] Stephan Huber, Renate Berner, Martina Uhlig, Peter Klein, and Jörn Hurtiene. 2019. Tangible Objects for Reminiscing in Dementia Care. In Proceedings of the Thirteenth International Conference on Tangible, Embedded, and Embodied Interaction - TEI '19, ACM Press, New York, New York, USA, 15-24. DOI:<https://doi.org/10.1145/3294109.3295632>
- [48] Wijnand IJsselstein, Ans Tummers-Heemels, and Rens Brankaert. 2020. Warm Technology: A Novel Perspective on Design for and with People Living with Dementia. In HCI and Design in the Context of Dementia, Rens Brankaert and Gail Kenning (eds.). Springer International Publishing, Cham, 33-47. DOI:https://doi.org/10.1007/978-3-030-32835-1_3
- [49] Hiroshi Ishii. 2008. Tangible Bits: Beyond Pixels. In Proceedings of the 2nd International Conference on Tangible and Embedded Interaction (TEI '08), Association for Computing Machinery, New York, NY, USA, xv-xxv. DOI:<https://doi.org/10.1145/1347390.1347392>
- [50] Anke Jakob and Lesley Collier. 2017. Sensory enrichment for people living with dementia: increasing the benefits of multisensory environments in dementia care through design. *Design for Health* 1, 1 (January 2017), 115-133. DOI:<https://doi.org/10.1080/24735132.2017.1296274>
- [51] Tom Jenkins, Anna Vallgård, Laurens Boer, Sarah Homewood, and Teresa Almeida. 2019. Careful Devices. In Proceedings of the Halfway to the Future Symposium 2019 (HTTF 2019), Association for Computing Machinery, New York, NY, USA. DOI:<https://doi.org/10.1145/3363384.3363474>
- [52] C Bezboruah Karabi, Paulson Darla, and Smith Jason. 2014. Management attitudes and technology adoption in long-term care facilities. *J Health Organ Manag* 28, 3 (January 2014), 344-365. DOI:<https://doi.org/10.1108/JHOM-11-2011-018>
- [53] Gail Kenning. 2020. Reciprocal Design. In HCI and Design in the Context of Dementia, Rens Brankaert and Gail Kenning (eds.). Springer International Publishing, Cham, 17-32. DOI:https://doi.org/10.1007/978-3-030-32835-1_2
- [54] Gail Kenning and Rens Brankaert. 2020. Framing in Context BT - HCI and Design in the Context of Dementia. In Rens Brankaert and Gail Kenning (eds.). Springer International Publishing, Cham, 1-14. DOI:https://doi.org/10.1007/978-3-030-32835-1_1
- [55] Gail Kenning and Cathy Treadaway. 2018. Designing for Dementia: Iterative Grief and Transitional Objects. *Design Issues* 34, 1 (January 2018), 42-53. DOI:https://doi.org/10.1162/DESI_a_00475
- [56] Tom Kitwood. 1997. Dementia reconsidered: The person comes first. Open University Press, London.

- [57] Agnieszka Barbara Kolasinska, Myrte Thoolen, Sebastiaan Peek, Yuan Lu, and Rens Brankaert. 2021. Co-creating Design Opportunities for Social Technology in the Context of Dementia. In *Dementia Lab 2021: Supporting Ability Through Design*, Springer International Publishing, Cham, 125–141. DOI:https://doi.org/10.1007/978-3-030-70293-9_11
- [58] Pia C. Kontos. 2004. Ethnographic reflections on selfhood, embodiment and Alzheimer’s disease. *Ageing Soc* 24, 6 (November 2004), 829–849. DOI:<https://doi.org/10.1017/S0144686X04002375>
- [59] Clemens Scott Kruse, Joanna Fohn, Gilson Umunnakwe, Krupa Patel, and Saloni Patel. 2020. Evaluating the Facilitators, Barriers, and Medical Outcomes Commensurate with the Use of Assistive Technology to Support People with Dementia: A Systematic Review Literature. *Healthcare* 8, 3 (2020). DOI:<https://doi.org/10.3390/healthcare8030278>
- [60] Amanda Lazar, Caroline Edasis, and Anne Marie Piper. 2017. A Critical Lens on Dementia and Design in HCI. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems (CHI ’17)*, ACM Press, New York, New York, USA, 2175–2188. DOI:<https://doi.org/10.1145/3025453.3025522>
- [61] Ilianna Lourida, Rebecca A Abbott, Morwenna Rogers, Iain A Lang, Ken Stein, Bridie Kent, and Jo Thompson Coon. 2017. Dissemination and implementation research in dementia care: a systematic scoping review and evidence map. *BMC Geriatr* 17, 1 (2017), 147. DOI:<https://doi.org/10.1186/s12877-017-0528-y>
- [62] Justine McGovern. 2011. Couple meaning-making and dementia: challenges to the deficit model. *J Gerontol Soc Work* 54, 7 (October 2011), 678–690. DOI:<https://doi.org/10.1080/01634372.2011.593021>
- [63] Kellie Morrissey and John McCarthy. 2015. Creative and Opportunistic Use of Everyday Music Technologies in a Dementia Care Unit. In *Proceedings of the 2015 ACM SIGCHI Conference on Creativity and Cognition - C&C ’15*, ACM Press, New York, New York, USA, 295–298. DOI:<https://doi.org/10.1145/2757226.2757228>
- [64] Kellie Morrissey, John McCarthy, and Nadia Pantidi. 2017. The Value of Experience-Centred Design Approaches in Dementia Research Contexts. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems (CHI ’17)*, ACM Press, New York, New York, USA, 1326–1338. DOI:<https://doi.org/10.1145/3025453.3025527>
- [65] Kellie Morrissey, Gavin Wood, David Green, Nadia Pantidi, and John McCarthy. 2016. ‘I’m a rambler, I’m a gambler, I’m a long way from home’: The Place of Props, Music, and Design in Dementia Care. In *Proceedings of the 2016 ACM Conference on Designing Interactive Systems - DIS ’16*, ACM Press, New York, New York, USA, 1008–1020. DOI:<https://doi.org/10.1145/2901790.2901798>
- [66] Cosmin Munteanu, Heather Molyneaux, Wendy Moncur, Mario Romero, Susan O’Donnell, and John Vines. 2015. Situational Ethics: Re-Thinking Approaches to Formal Ethics Requirements for Human-Computer Interaction. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems (CHI ’15)*, Association for Computing Machinery, New York, NY, USA, 105–114. DOI:<https://doi.org/10.1145/2702123.2702481>
- [67] S. Neves, A. Macdonald, M. Poole, and K. Harrison Dening. 2021. Participatory Co-design: Approaches to Enable People Living with Challenging Health Conditions to Participate in Design Research. In *Perspectives on Design and Digital Communication II: Research, Innovations and Best Practices*, Nuno Martins, Daniel Brandão and Fernando Moreira da Silva (eds.). Springer International Publishing, Cham, 193–216. DOI:https://doi.org/10.1007/978-3-030-75867-7_13
- [68] Kristina Niedderer, Vjera Holthoff-Detto, Thomas J. L. van Rompay, Armağan Karahanoğlu, Geke D. S. Ludden, Rosa Almeida, Raquel Losada Durán, Yolanda Bueno Aguado, Jennifer N. W. Lim, Tina Smith, Dew Harrison, Michael P. Craven, Julie Gosling, Laura Orton, and Isabelle Tournier. 2022. This is Me: Evaluation of a boardgame to promote social engagement, wellbeing and agency in people with dementia through mindful life-storytelling. *J Aging Stud* 60, (2022), 100995. DOI:<https://doi.org/10.1016/j.jaging.2021.100995>
- [69] Hans C Ossebaard and Lisette Van Gemert-

- Pijnen. 2016. eHealth and quality in health care: implementation time. *International Journal for Quality in Health Care* 28, 3 (2016), 415–419. DOI:<https://doi.org/10.1093/intqhc/mzw032>
- [70] Barbara A Purves, Alison Phinney, Wendy Hulko, Gloria Puurveen, and Arlene J Astell. 2014. Developing CIRCA-BC and Exploring the Role of the Computer as a Third Participant in Conversation. *Am J Alzheimers Dis Other Demen* 30, 1 (June 2014), 101–107. DOI:<https://doi.org/10.1177/1533317514539031>
- [71] Chirag B. Rao, John C. Peatfield, Keith P. W. J. McAdam, Andrew J. Nunn, and Dimana P. Georgieva. 2021. A Focus on the Reminiscence Bump to Personalize Music Playlists for Dementia. *J Multidiscip Healthc* 14, (August 2021), 2195–2204. DOI:<https://doi.org/10.2147/JMDH.S312725>
- [72] Adriana Maria Rios Rincon, Antonio Miguel Cruz, Christine Daum, Noelannah Neubauer, Aidan Comeau, and Lili Liu. 2021. Digital Storytelling in Older Adults With Typical Aging, and With Mild Cognitive Impairment or Dementia: A Systematic Literature Review. *Journal of Applied Gerontology* (May 2021), 07334648211015456. DOI:<https://doi.org/10.1177/07334648211015456>
- [73] Paul A. Rodgers. 2018. Co-designing with people living with dementia. *CoDesign* 14, 3 (2018), 188–202. DOI:<https://doi.org/10.1080/15710882.2017.1282527>
- [74] Jøran Rudi. 2013. Soundscape as social construct. *EMS-network conference 2013 January* (2013), 1–5.
- [75] Steven R Sabat. 2006. Implicit memory and people with Alzheimer’s disease: Implication for caregiving. *Am J Alzheimers Dis Other Demen* 21, 1 (2006), 11–14.
- [76] Alba Sánchez, José C Millán-Calenti, Laura Lorenzo-López, and Ana Maseda. 2012. Multisensory Stimulation for People With Dementia: A Review of the Literature. *Am J Alzheimers Dis Other Demen* 28, 1 (December 2012), 7–14. DOI:<https://doi.org/10.1177/1533317512466693>
- [77] Corina Sas, Nigel Davies, Sarah Clinch, Peter Shaw, Mateusz Mikusz, Madeleine Steeds, and Lukas Nohrer. 2020. Supporting Stimulation Needs in Dementia Care through Wall-Sized Displays. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems (CHI ’20)*, Association for Computing Machinery, New York, NY, USA, 1–16. DOI:<https://doi.org/10.1145/3313831.3376361>
- [78] Raymond Murray Schafer. 1993. *The Soundscape: Our Sonic Environment and the Tuning of the World*. Simon and Schuster.
- [79] Kimberly Johanna Schelle, Carolina Gomez Naranjo, Martijn ten Bhömer, Oscar Tomico, and Stephan Wensveen. 2015. Tactile Dialogues: Personalization of Vibrotactile Behavior to Trigger Interpersonal Communication. In *Proceedings of the Ninth International Conference on Tangible, Embedded, and Embodied Interaction - TEI ’14*, ACM Press, New York, New York, USA, 637–642. DOI:<https://doi.org/10.1145/2677199.2687894>
- [80] Markus Schlosser. 2015. Agency. *Stanford Encyclopedia of Philosophy Archive* (Winter 2019 Edition). Retrieved May 30, 2022 from <https://plato.stanford.edu/archives/win2019/entries/agency/>
- [81] Luma Tabbaa, Chee Siang Ang, Vienna Rose, Panote Siritayaya, Inga Stewart, Keith G. Jenkins, and Maria Matsangidou. 2019. Bring the Outside In: Providing Accessible Experiences Through VR for People with Dementia in Locked Psychiatric Hospitals. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems - CHI ’19*, ACM Press, New York, New York, USA, 1–15. DOI:<https://doi.org/10.1145/3290605.3300466>
- [82] Lisanne Teunissen, Tom Luyten, and Luc de Witte. 2017. Reconnecting People with Dementia by Using the Interactive Instrument CRDL. *Stud Health Technol Inform* 242, (2017), 9–15.
- [83] Kristine Theurer, W. Ben Mortenson, Robyn Stone, Melinda Suto, Virpi Timonen, and Julia Rozanova. 2015. The need for a social revolution in residential care. *J Aging Stud* 35, (December 2015), 201–210. DOI:<https://doi.org/10.1016/J.JAGING.2015.08.011>
- [84] Peter Tolmie and Andy Crabtree. 2008. Deploying Research Technology in the Home. In *Proceedings of the 2008 ACM Conference on Computer Supported Cooperative Work (CSCW ’08)*, Association for Computing Machinery, New York, NY, USA, 639–648.

- DOI:<https://doi.org/10.1145/1460563.1460662>
- [85] Cathy Treadaway, David Prytherch, Gail Kenning, and Jac Fennell. 2016. In the moment: designing for late stage dementia. In *Future Focused Thinking - DRS International Conference 2016*, Brighton, United Kingdom, 1442–1457. DOI:<https://doi.org/10.21606/drs.2016.107>
- [86] Emmanuel Tseklevs, Amanda F Bingley, Maria A Luján Escalante, and Adrian Gradinar. 2018. Engaging people with dementia in designing playful and creative practices: Co-design or co-creation? *Dementia* 19, 3 (August 2018), 915–931. DOI:<https://doi.org/10.1177/1471301218791692>
- [87] David Unbehau, Konstantin Aal, Daryoush Daniel Vaziri, Peter David Tolmie, Rainer Wieching, David Randall, and Volker Wulf. 2020. Social Technology Appropriation in Dementia: Investigating the Role of Caregivers in Engaging People with Dementia with a Videogame-Based Training System. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems (CHI '20)*, Association for Computing Machinery, New York, NY, USA, 1–15. DOI:<https://doi.org/10.1145/3313831.3376648>
- [88] David Unbehau, Daryoush Daniel Vaziri, Konstantin Aal, Rainer Wieching, Peter Tolmie, and Volker Wulf. 2018. Exploring the Potential of Exergames to affect the Social and Daily Life of People with Dementia and their Caregivers. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems (CHI '18)*, ACM Press, New York, New York, USA, Paper 62, 1–15. DOI:<https://doi.org/10.1145/3173574.3173636>
- [89] Jayne Wallace, Anja Thieme, Gavin Wood, Guy Schofield, and Patrick Olivier. 2012. Enabling self, intimacy and a sense of home in dementia: An Enquiry into Design in a Hospital Setting. In *Proceedings of the 2012 ACM annual conference on Human Factors in Computing Systems - CHI '12*, ACM Press, New York, New York, USA, 2629. DOI:<https://doi.org/10.1145/2207676.2208654>
- [90] Jayne Wallace, Peter C. Wright, John McCarthy, David Philip Green, James Thomas, and Patrick Olivier. 2013. A designed inquiry into personhood in dementia. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems - CHI '13*, ACM Press, New York, New York, USA, 2617–2626. DOI:<https://doi.org/10.1145/2470654.2481363>
- [91] Jenny Waycott, Ryan M Kelly, Steven Baker, Barbara Barbosa Neves, Kong Saoane Thach, and Reeva Lederman. 2022. The Role of Staff in Facilitating Immersive Virtual Reality for Enrichment in Aged Care: An Ethic of Care Perspective. In *CHI Conference on Human Factors in Computing Systems (CHI '22)*, Association for Computing Machinery, New York, NY, USA. DOI:<https://doi.org/10.1145/3491102.3501956>
- [92] Rik Wesselink, Marike Hettinga, Geke Ludden, and Berry Eggen. 2020. Unforgetting Music: Exploring the role of music in the daily lives of people with dementia living at home. In *Proceedings of the 6th International Conference on Design4Health, Lab4Living*, Sheffield Hallam University, Amsterdam, 721–728.
- [93] Cara Wilson, Roisin McNaney, Abi Roper, Tara Capel, Laura Scheepmaker, Margot Brereton, Stephanie Wilson, David Philip Green, and Jayne Wallace. 2020. Rethinking Notions of “Giving Voice” in Design. In *Extended Abstracts of the 2020 CHI Conference on Human Factors in Computing Systems (CHI EA '20)*, Association for Computing Machinery, New York, NY, USA, 1–8. DOI:<https://doi.org/10.1145/3334480.3375171>
- [94] Bob Woods, Laura O’Philbin, Emma M. Farrell, Aimee E. Spector, and Martin Orrell. 2018. Reminiscence therapy for dementia. *Cochrane Database of Systematic Reviews* 3 (March 2018). DOI:<https://doi.org/10.1002/14651858.CD01120.pub3>
- [95] World Health Organization. 2021. Global status report on the public health response to dementia. Geneva: World Health Organization (2021), 251. Retrieved May 23, 2022 from <https://digitalcommons.fiu.edu/cgi/viewcontent.cgi?article=1962&context=srhreports>
- [96] John Zimmerman, Jodi Forlizzi, and Shelley Evenson. 2007. Research through design as a method for interaction design research in HCI. In *Proceedings of the SIGCHI conference on Human factors in computing systems - CHI '07*, ACM Press, New York, New York, USA, 493. DOI:<https://doi.org/10.1145/1240624.1240704>

Design for Everyday Sounds in Dementia

8

Conclusion

8.1 INTRODUCTION

While most research on sound and dementia has focused on music, the effects and benefits of everyday sounds or ambient soundscapes have received little research attention. This thesis addressed this knowledge gap by exploring the role of everyday sounds or soundscapes in designing technologies for people with dementia. We focused on the experiences of people with dementia during meaningful engagement with everyday sounds. Therefore, we adopted a research through design method by developing and evaluating tangible design artifacts to enable people with dementia and their caregivers to play and explore everyday sounds during meaningful social activities. In this approach, we involved people with dementia as active contributors who have a say in exploring, designing, and evaluating technologies that facilitate experiences with everyday sounds.

The contributions in this thesis present a novel account of how everyday or non-musical sounds can contribute to the emotional and social well-being of people with dementia. Chapter 2 provided initial insights into the potential of everyday sounds to support reminiscence and social activity. Chapters 3 & 4 further explored participatory approaches to co-create rich collections of personal everyday sounds and design technologies to support meaningful social activity facilitated by personal sound content. Chapters 5 and 6 further explored how these beneficial effects can be embedded into care practice and support people living and working in residential care.

The previous chapter discussed how everyday sounds foster open-ended engagement for people with dementia through subjective interpretations of sound, reliving past experiences in the moment, and collective experiences of sounds. Next, we described the role of technology in providing tangible interactions with everyday sounds that stimulate agency and exploration, provide shared activities, and allow for integration within everyday settings. In addition, we discussed how everyday sounds could enrich the everyday life of people with dementia in their everyday surroundings, such as providing meaningful activity at home or reinforcing person-centered care practices. Lastly, Chapter 7 concluded with a reflection on the research through design approach, namely the role of the design researcher in engaging with the participants.

This final chapter revisits the three sub-questions stated in the introductory chapter of this thesis to summarize the main research conclusions concerning how everyday sounds facilitated by technology can contribute to the well-being of people living with dementia. Next, this chapter concludes by outlining three directions for future work on sound-driven design for healthcare, enriching everyday life in dementia, and designing for soft transitions in dementia.

8.2 RESEARCH CONCLUSIONS

This thesis focused on the potential of everyday sounds in contributing to the quality of life of people with dementia. The studies presented in this thesis addressed this open-ended research question in various settings, such as at home, the daycare center, or in residential care. We used multiple research methods such as co-creation sessions, workshops, and a field study that involved a wide range of users, from people in the early to late stages of dementia, their relatives, and professional caregivers. This approach resulted in unique and rich findings that demonstrated how everyday sounds have provided a lens through which the everyday lived experiences of people with dementia can be explored, understood, and enriched.

8.2.1 *What Are the Experiences of People with Dementia Evoked by Everyday Sounds?*

This thesis presents a novel and multi-stakeholder approach to sound-driven design for people with dementia by focusing on the experience of the listener [4]. Everyday sounds serve as open-ended cues to evoke meaningful responses, reflections, or insights that evolve in interpersonal and emotional engagement within social settings via nonverbal and verbal communication (Chapters 2 & 6). Actively and mindfully listening to sounds from everyday life offers opportunities to reflect on a lived life in terms of what has been and can still be done to transition and cope with the diagnosis of dementia (Chapters 3 & 4). Therefore, everyday sounds are a trigger to obtain these insights and support a journey to uncover people's identity and uniqueness (Chapter 3). The extensive qualitative findings in this thesis strengthen perspectives on sound as a social construct that shapes human interactions and relations [16]. The sociality of sound allows people with dementia to initiate connections and relationships that transcend social boundaries imposed by dementia, such as illness or disabilities [6].

Therefore, the experiences of people with dementia evoked by everyday sounds are situated and grounded in social interactions and collective meaning-making.

8.2.2 *How Can We Design for Meaningful Experiences with Everyday Sounds to Support People with Dementia and Their Caregivers?*

The research through design approach in this thesis offered insights into the daily aspects of living with dementia through the exploration of identity, personality, values, emotions, and life history. These findings contribute to current research efforts in HCI in exploring how technology and design can provide meaningful experiences for people with dementia through reminiscing, storytelling, and social engagement [5,7,17]. Personal sounds are evocative cues for recalling memories of the past, while the exploration of novel audio content offers new possibilities for discovery and stimulation (Chapters 3 & 6). This person-centered approach towards sound-based interventions in dementia requires technology that supports warmth and human contact through technological innovation [8].

Design artifacts that provide tangible interactions with everyday sounds work as facilitators to offer room for responses to sound to emerge and evolve by catering to different forms of self-expression (Chapters 4 & 6). For example, design artifacts can guide or navigate sound-based experiences into meaningful conversations and balance the active participation of the person with dementia, the caregiver, and the family in this setting (Chapters 2 & 3). In addition, interaction with prototypes can encourage participation, which gives a sense of agency and choice by encouraging people with dementia to explore and compare their experiences with others (Chapter 2). For example, physical objects and mockups enable people with dementia to provide input and feedback on abstract ideas and concepts in the early stages of the design process so that technology can be tailored to their values, routines, and social needs (Chapter 4). Technology needs to offer intuitive and easy-to-use interfaces that exploit tangible interactions to facilitate everyday engagement with audio content while allowing for flexibility and personalization to address the uniqueness of each person with dementia within their personal context (Chapters 4 & 6).

8.2.3 *How Can Interventions That Facilitate Meaningful Experiences with Everyday Sounds Be Integrated into Dementia Care Practice?*

This thesis offers a design perspective on soundscapes in dementia care by demonstrating how everyday sounds present a valuable alternative to generalized approaches in resolving behavior associated with the unmet psychosocial needs of people with dementia. Everyday sounds provide meaningful and person-centered experiences by facilitating human contact and 'warm' moments that contribute to the emotional and social needs of people with dementia (see Chapter 6). Interventions that offer enriching experiences with everyday sounds in residential care need to be adapted to the personal circumstances and preferences of the residents (Chapter 5). Therefore, the effective facilitation of sound-based activities requires a reflective approach from the healthcare staff to explore which reactions everyday sounds can elicit that are meaningful to people with dementia and match their reality (Chapters 5 & 6).

Technology for everyday sounds in dementia care should benefit the experiences of people with dementia and their caregivers by providing social engagement in everyday settings (Chapter 2). These positive experiences of engaging with everyday sounds can evolve in social habits and routines within communities or households by using sound as a social trigger during day-to-day care (see Chapters 5 & 6). Technology that facilitates personal experiences with everyday sounds should blend into everyday environments and care routines (Chapters 4 & 6). Therefore, the development of technology for dementia care as aesthetically pleasing and finished homely objects allows for everyday use by caregivers and people with dementia to enrich their lived experiences. This thesis challenges general presumptions on the application of technology in dementia care settings by reframing the potential of technology and design to reinforce a sense of community and belonging through everyday social and sensory enriched experiences.

8.3 FUTURE DIRECTIONS

Based on the contributions outlined in this thesis, this section outlines three avenues of future work on sound-driven design for healthcare, enriching everyday life in dementia, and designing for soft transitions.

8.3.1 Sound-Driven Design for Healthcare

This thesis has foregrounded how everyday sounds elicit personal associations and recollections of past life events or loved ones. The open-ended responses to everyday sounds provide novel opportunities to facilitate meaningful activities and support social interactions between residents and their caretakers in dementia care homes. Based on the initial findings in this thesis, future research can investigate how these beneficial effects of sound can be incorporated into everyday care practice through the long-term in-context deployment of sound-based design interventions. Technology is often incompatible with everyday care practice and fails to be successfully integrated into existing care routines [12]. A future avenue for research is to explore how sound-based technology can be seamlessly embedded in dementia care homes as everyday objects and offer audio experiences that can be personalized in situ. Future research can explore how residents with dementia and professional caregivers embrace, adopt and cultivate sound-based interventions as part of their everyday interactions and routines over time.

There exists a similar potential in other health-related settings to open the design space of sound-based interventions that go beyond the object-based approach in this thesis to enrich and familiarize clinical or healthcare environments. Research on soundscapes in HCI increasingly focuses on health and well-being [4]. Similarly, this thesis has indicated how everyday sounds facilitated through technology can provide a scalable and configurable solution to enrich healthcare environments with spatial auditory elements. For example, everyday sounds applied in a children's hospital can allow for imagined spaces or playful sound environments in care to provide a soothing and non-intimidating experience for children visiting the hospital [9]. Future research can further explore the role of immersive and spatial soundscapes in enriching and familiarizing care settings.

This thesis has also illustrated the value of everyday sounds to support nonverbal forms of communication and social interactions for people who experience aphasia or language difficulties. For example, minimally-verbal children on the autism spectrum engage in self-expression through sound to convey social intent or emotions [19]. Future research could further explore the scope of sound-based interventions for health to exploit the open-ended nature of engaging with

everyday sounds to support embodied and accessible forms of self-expression for people with verbal impairments or communication difficulties.

8.3.2 *Enriching Everyday Life in Dementia*

The open-ended research questions in this thesis addressed the untapped potential of everyday sounds in providing benefits for people with dementia. This explorative approach contrasts with solutionist thinking which aims to identify and solve specific problems yet risks dismissing the complexity and multifaceted nature of real-life situations [1]. Therefore, the work in this thesis ties in with explorative and open-ended approaches that aim to foster engagement from people with dementia by being open to a wide range of experiences and communication modalities [13,14]. Rather than proposing a specific solution, this thesis presents the value of technology to support meaningful activity during seemingly everyday yet significant moments that enrich people's experiences. However, future research is necessary to investigate how technology can be embedded within the care environment to support the formation of new habits and relations during everyday life in the care home.

Part of this research (Chapters 3 & 4) was conducted during the COVID-19 pandemic, which has shed light on pre-existing challenges in dementia care and highlighted the impact of social isolation and lack of human contact on the well-being of people with dementia. During the pandemic, online and remote communication was a useful short-term tool to address loneliness in care homes [11]. However, the tangible design artifacts offered insights into how technology for people with dementia should never replace physical contact yet facilitate physical connection and *warm* human presence [15]. Therefore, we advocate the need for person-centered and inclusive technologies that enable tangible and embodied forms of interaction, resulting in emotional, meaningful, and warm social experiences [8]. Future research can explore the tangible, material, and experiential design qualities that enable technologies to support warm-felt experiences by evoking agency and embodied expressions of selfhood by people with dementia.

8.3.3 *Designing for Soft Transitions in Dementia*

This thesis has involved people in various stages of dementia, such as people with early-stage dementia aging in place to people with advanced dementia living in care facilities. Furthermore, we elaborated in Chapter 7 on how everyday sounds can enrich everyday experiences in dementia by supporting meaningful activity at home and reinforcing person-centered care approaches in residential dementia care. However, transitioning from a home environment to a residential care facility remains challenging as it can be stressful for people with dementia and their informal caregivers [10]. As formal care settings are often perceived as unfamiliar, causing stress and restlessness [3,18], strategies are needed that offer a sense of familiarity and provide feelings of safety, comfort, and calmness to residents in care homes during this period of transition.

Based on the insights in this thesis, familiar everyday sounds can be vital in easing the transition from home into care environments by providing positive 'in-the-moment' experiences that evoke recollections of past everyday life. For example, the unique everyday sounds that emerged from the iterative co-creation process in Chapter 3 were intended for meaningful activity at home. We conducted these co-creation sessions with people in the early stages of dementia who were still able to recall meaningful memories and share these in a conversation. As dementia progresses, recollecting these valuable memories will become more challenging. When moving to the care home, these highly personalized sets of everyday sounds related to significant life events or experiences could also be meaningful for the person with dementia. Therefore, future research can explore how personal sounds can serve as digital mementos [2] of past life that can be experienced in the present to support times of transition.

8.4 CONCLUDING REMARKS

Based on the large body of evidence about how music provides emotional and behavioral benefits for people with dementia, this thesis has investigated the beneficial effects of everyday sounds for people with dementia. The research outlined in this thesis draws upon expertise from healthcare and adopts a research through design approach to investigate how everyday sounds can support the emotional and social needs of people with dementia, their relatives, and caregivers. By designing and evaluating audio-based technology, this thesis offers key insights into how everyday sounds evoke memories, emotional

experiences, and social connections for people with dementia and how these responses result in meaningful conversations, playfulness, curiosity, and verbal and nonverbal contact in residential care or the home environment. In conclusion, this thesis contributes to existing literature by foregrounding how everyday sounds foster open-ended engagement through tangible interactions with technology to enrich the everyday lived experiences of dementia.

8.5 REFERENCES

- [1] Mark Blythe, Kristina Andersen, Rachel Clarke, and Peter Wright. 2016. Anti-Solutionist Strategies: Seriously Silly Design Fiction. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems (CHI '16)*, Association for Computing Machinery, New York, NY, USA, 4968–4978. DOI:<https://doi.org/10.1145/2858036.2858482>
- [2] Simon Bowen and Daniela Petrelli. 2011. Remembering today tomorrow: Exploring the human-centred design of digital mementos. *Int J Hum Comput Stud* 69, 5 (2011), 324–337. DOI:<https://doi.org/https://doi.org/10.1016/j.ijhcs.2010.12.005>
- [3] Elke Daemen, Evert van Loenen, and Roel Cuppen. 2014. The Impact of the Environment on the Experience of Hospitalized Stroke Patients – An Exploratory Study. In *Ambient Intelligence, Emile Aarts, Boris de Ruyter, Panos Markopoulos, Evert van Loenen, Reiner Wichert, Ben Schouten, Jacques Terken, Rob van Kranenburg, Elke den Ouden and Gregory O'Hare (eds.)*. Springer International Publishing, Cham, 114–124. Retrieved from http://link.springer.com/10.1007/978-3-319-14112-1_10
- [4] Stefano Delle Monache, Nicolas Misdariis, and Elif Ozcan. 2021. Conceptualising Sound-Driven Design: An Exploratory Discourse Analysis. In *Creativity and Cognition (C&C '21)*, Association for Computing Machinery, New York, NY, USA. DOI:<https://doi.org/10.1145/3450741.3465258>
- [5] David M. Frohlich, Emily Corrigan-Kavanagh, Sarah Campbell, Theopisti Chrysanthaki, Paula Castro, Isabela Zaine, and Maria da Graça Campos Pimentel. 2020. Assistive Media for Well-being. In *HCI and Design in the Context of Dementia*, Rens Brankaert and Gail Kenning (eds.). Springer International Publishing, Cham, 189–205. DOI:https://doi.org/10.1007/978-3-030-32835-1_12
- [6] Megan E Graham. 2020. Long-term care as contested acoustical space: Exploring resident relationships and identities in sound. *Building Acoustics* 27, 1 (2020), 61–73. DOI:<https://doi.org/10.1177/1351010X19890478>
- [7] James Hodge, Kyle Montague, Sandra Hastings, and Kellie Morrissey. 2019. Exploring Media Capture of Meaningful Experiences to Support Families Living with Dementia. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems - CHI '19*, ACM Press, New York, New York, USA, 1–14. DOI:<https://doi.org/10.1145/3290605.3300653>
- [8] Wijnand IJsselsteijn, Ans Tummers-Heemels, and Rens Brankaert. 2020. Warm Technology: A Novel Perspective on Design for and with People Living with Dementia. In *HCI and Design in the Context of Dementia*, Rens Brankaert and Gail Kenning (eds.). Springer International Publishing, Cham, 33–47. DOI:https://doi.org/10.1007/978-3-030-32835-1_3
- [9] Antti Ikonen. 2019. Designing Soundscape for New Children's Hospital in Helsinki. In *Music, Sound and Wellbeing: A transdisciplinary symposium*.
- [10] Ursula M. Kellett. 1999. Transition in care: Family carers' experience of nursing home placement. *J Adv Nurs* 29, 6 (June 1999), 1474–1481. DOI:<https://doi.org/10.1046/j.1365-2648.1999.01035.x>
- [11] A Konstantinou. 2021. Telecommunication and neuropsychiatric symptoms in long term care dementia patients during the COVID-19 lockdown ERA. *European*

- Psychiatry 64, S1 (2021), S277–S278.
DOI:<https://doi.org/10.1192/j.eurpsy.2021.745>
- [12] L Koumakis, C Chatzaki, E Kazantzaki, E Maniadi, and M Tsiknakis. 2019. Dementia Care Frameworks and Assistive Technologies for Their Implementation: A Review. *IEEE Rev Biomed Eng* 12, (2019), 4–18.
DOI:<https://doi.org/10.1109/RBME.2019.2892614>
- [13] Amanda Lazar, Caroline Edasis, and Anne Marie Piper. 2017. A Critical Lens on Dementia and Design in HCI. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems (CHI '17)*, ACM Press, New York, New York, USA, 2175–2188.
DOI:<https://doi.org/10.1145/3025453.3025522>
- [14] Kellie Morrissey, John McCarthy, and Nadia Pantidi. 2017. The Value of Experience-Centred Design Approaches in Dementia Research Contexts. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems (CHI '17)*, ACM Press, New York, New York, USA, 1326–1338.
DOI:<https://doi.org/10.1145/3025453.3025527>
- [15] Jeannette Pols and Ingunn Moser. 2009. Cold technologies versus warm care? On affective and social relations with and through care technologies. *Alter* 3, 2 (2009), 159–178.
DOI:<https://doi.org/https://doi.org/10.1016/j.alter.2009.01.003>
- [16] Jøran Rudi. 2013. Soundscape as social construct. *EMS-network conference 2013 January* (2013), 1–5.
- [17] Corina Sas, Nigel Davies, Sarah Clinch, Peter Shaw, Mateusz Mikusz, Madeleine Steeds, and Lukas Nohrer. 2020. Supporting Stimulation Needs in Dementia Care through Wall-Sized Displays. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems (CHI '20)*, Association for Computing Machinery, New York, NY, USA, 1–16.
DOI:<https://doi.org/10.1145/3313831.3376361>
- [18] L K Sawyer, S Kemp, P A B James, and M Harper. 2020. Noisy and restless: 24 h in an NHS community hospital ward, a qualitative and quantitative analysis of the patient environment. *Build Environ* 175, (2020), 106795.
DOI:<https://doi.org/https://doi.org/10.1016/j.buildenv.2020.106795>
- [19] Cara Wilson, Laurianne Sitbon, Bernd Ploderer, Jeremy Opie, and Margot Brereton. 2020. Self-Expression by Design: Co-Designing the ExpressiBall with Minimally-Verbal Children on the Autism Spectrum. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems (CHI '20)*, Association for Computing Machinery, New York, NY, USA, 1–13.
DOI:<https://doi.org/10.1145/3313831.3376171>

Summary

The number of people with dementia is rising, and to this date, there is still no cure. Consequently, there is an urgent need for non-pharmacological approaches to support the quality of life of people with dementia. Over the years, there has been a large body of research demonstrating the positive effects of music on people with dementia. For example, listening to familiar songs can evoke memories, or moving to music can stimulate physical exercise. Non-musical sounds perceived in everyday life also strongly influence people's feelings, emotions, and behavior. Despite this potential, there has been limited research on the benefits of everyday sounds or soundscapes for people with dementia.

This thesis explores how everyday sounds can enrich the lived experiences of dementia. To address the multifaceted experiences of dementia and involve professional and informal caregivers, the research question is divided into three sub-questions:

RQ1: What are the experiences of people with dementia evoked by everyday sounds?

RQ2: How can we design for meaningful experiences with everyday sounds to support people with dementia and their caregivers?

RQ3: How can interventions that facilitate meaningful experiences with everyday sounds be integrated into dementia care practice?

This thesis adopts a research through design approach by developing and evaluating tangible design artifacts for and with people with dementia and their caregivers during meaningful social activities.

Section 1 focuses on exploring the lived experiences of people with dementia evoked by everyday sounds. The study presented in Chapter 2 reports the outcomes of three explorative workshops and offers initial insights into how generic soundscapes of everyday sounds evoke memories, emotional reactions, and shared experiences in a group setting.

Section 2 builds further on the insights from the workshop study by exploring how personal everyday sounds can be identified and how to design technology that can facilitate meaningful activities through everyday sounds. Chapter 3 reports a series of co-creation sessions that offer insights into how people with dementia link sounds to their past life experiences based on the emotional value of a specific memory and how the relative provides support and a collective memory. Chapter 4 presents the co-design study of the Tumbler: a sound player that offered tangible interactions with everyday sounds to empower people with dementia and their partners to engage in social activities within everyday home settings.

Section 3 addresses how technologies that enable listening to everyday sounds can be integrated into dementia care practice. Chapter 5 presents the outcome of participatory workshops that reveal opportunities for sound and technology to add value to care practice. These opportunities involve providing rest or stimulation, social contact, or personal responses during daytime activities, between planned activities, at moments of personal care, or during informal moments. Chapter 6 reports the results of a field study, providing insights into the role of everyday sounds in dementia care, such as stimulating meaningful conversations, playfulness, discovery, and social connection between residents and caregivers.

The final section of this thesis reflects on the value of everyday sounds and technology for people with dementia and their caregivers. Chapter 7 discusses the role of everyday sounds in enriching the lived experiences of people with dementia and their caregivers through open-ended engagement and tangible interactions with everyday sounds in day-to-day settings. This chapter concludes by reflecting on the research through design approach used in this thesis by elaborating on the role of the design researcher. Chapter 8 summarizes the main research conclusions on how everyday sounds can contribute to the well-being of people living with dementia and formulates directions for future research.

This thesis highlights the previously unexplored potential of everyday sounds in the context of dementia and results in unique findings demonstrating how everyday sounds enrich the lived experiences of people with dementia.

Samenvatting

Het aantal mensen met dementie neemt toe en tot op heden is er nog steeds geen remedie. Daarom is er een dringende behoefte aan niet-farmacologische interventies om de kwaliteit van leven van mensen met dementie te ondersteunen. Door de jaren heen is er veel onderzoek gedaan naar de positieve effecten van muziek op mensen met dementie. Zo kan het luisteren naar bekende liedjes herinneringen oproepen, of bewegen op muziek kan lichamelijke inspanning stimuleren. Niet-muzikale geluiden die in het dagelijks leven worden waargenomen, hebben ook een sterke invloed op de gevoelens, emoties en het gedrag van mensen. Ondanks dit potentieel is er beperkt onderzoek gedaan naar de voordelen van alledaagse geluiden of soundscapes voor mensen met dementie.

Dit proefschrift onderzoekt hoe alledaagse geluiden de beleving van dementie kunnen verrijken. Om de veelzijdige ervaringen van dementie aan te pakken en professionele en mantelzorgers erbij te betrekken, is de onderzoeksvraag opgedeeld in drie deelvragen:

OV1: Wat zijn de ervaringen van mensen met dementie die worden opgeroepen door alledaagse geluiden?

OV2: Hoe kunnen we ontwerpen voor betekenisvolle ervaringen met alledaagse geluiden om mensen met dementie en hun verzorgers te ondersteunen?

OV3: Hoe kunnen interventies die betekenisvolle ervaringen met alledaagse geluiden mogelijk maken, worden geïntegreerd in de zorgpraktijk?

Dit proefschrift hanteert een ontwerpgerichte onderzoeksaanpak doormiddel van het ontwerpen en evalueren van tastbare ontwerpobjecten voor en samen met mensen met dementie en hun verzorgers tijdens zinvolle sociale activiteiten.

Deel 1 van het proefschrift richt zich op het verkennen van de beleving van mensen met dementie opgeroepen door alledaagse geluiden. De studie gepresenteerd in hoofdstuk 2 rapporteert de resultaten van drie verkennende workshops en biedt eerste inzichten in hoe generieke soundscapes van alledaagse

geluiden herinneringen, emotionele reacties en gedeelde ervaringen oproepen in een groepsomgeving.

Deel 2 bouwt voort op de inzichten uit de workshopstudie door te onderzoeken hoe persoonlijke alledaagse geluiden kunnen worden geïdentificeerd en hoe technologie kan worden ontworpen om betekenisvolle activiteiten te bieden, ondersteund door alledaagse geluiden. Hoofdstuk 3 rapporteert een reeks co-creatiesessies die inzicht bieden in hoe mensen met dementie geluiden koppelen aan ervaringen uit het verleden op basis van de emotionele waarde van een specifieke herinnering, en hoe het familielid ondersteuning en gedeelde herinneringen biedt. Hoofdstuk 4 presenteert de co-design studie van de Tumbler: een geluidsspeler die tastbare interacties met alledaagse geluiden faciliteert voor mensen met dementie en hun partners ter ondersteuning van sociale activiteiten in de dagelijkse thuisomgeving.

Deel 3 behandelt hoe technologieën die het luisteren naar alledaagse geluiden mogelijk maken, kunnen worden geïntegreerd in de dementiezorg. Hoofdstuk 5 presenteert de resultaten van participatieve workshops die kansen laten zien voor geluid en technologie om waarde toe te voegen aan de zorgpraktijk. Deze mogelijkheden betreffen het bieden van rust of stimulatie, sociaal contact of persoonlijke reacties tijdens dagactiviteiten, tussen geplande activiteiten, op momenten van persoonlijke verzorging of tijdens informele momenten. Hoofdstuk 6 rapporteert de resultaten van een veldstudie die inzicht geeft in de rol van alledaagse geluiden in de dementiezorg, zoals het stimuleren van betekenisvolle gesprekken, speelsheid, ontdekking en sociale verbinding tussen bewoners en verzorgers.

Het laatste deel van dit proefschrift reflecteert op de waarde van alledaagse geluiden en technologie voor mensen met dementie en hun verzorgers. Hoofdstuk 7 bespreekt de rol van alledaagse geluiden bij het verrijken van de belevingswereld van mensen met dementie en hun verzorgers doormiddel van open betrokkenheid en tastbare interacties met alledaagse geluiden in de dagelijkse omgeving. Dit hoofdstuk sluit af met een reflectie op de ontwerpgerichte onderzoeks aanpak die in dit proefschrift is gebruikt, door in te gaan op de rol van de ontwerp end onderzoeker. Hoofdstuk 8 vat de belangrijkste onderzoeksconclusies samen over hoe alledaagse geluiden kunnen bijdragen aan

het welzijn van mensen met dementie en formuleert richtingen voor toekomstig onderzoek.

Dit proefschrift belicht het onontgonnen potentieel van alledaagse geluiden in de context van dementie en resulteert in unieke bevindingen die aantonen hoe alledaagse geluiden de levenservaringen van mensen met dementie verrijken.

Publications

FULL PAPERS

- 1. Foregrounding Everyday Sounds in Dementia**
Maarten Houben, Rens Brankaert, Saskia Bakker, Gail Kenning, Inge Bongers, and Berry Eggen. *In Proceedings of the 2019 Conference on Designing Interactive Systems (DIS '19)* 🏆 **Best Paper Award**
- 2. The Role of Everyday Sounds in Advanced Dementia Care**
Maarten Houben, Rens Brankaert, Saskia Bakker, Gail Kenning, Inge Bongers, and Berry Eggen. *In Proceedings of the 2020 ACM Conference on Human Factors in Computing Systems (CHI '20)* 🏆 **Best Paper Award**
- 3. The Perspectives of Professional Caregivers on Implementing Audio-Based Technology in Residential Dementia Care**
Maarten Houben, Rens Brankaert, Gail Kenning, Berry Eggen, and Inge Bongers. *In International Journal of Environmental Research and Public Health 2020, 17, 6333. (IJERPH)*
- 4. Smile: Capturing and Sharing Personal Photos to Stimulate Social Relations and Support Self-Identity in Dementia**
Maarten Houben, Veerle van Engen, Gail Kenning, and Rens Brankaert. *In Dementia Lab Conference 2021: Supporting Ability Through Design (D-Lab '21)*
- 5. Designing for Everyday Sounds at Home with People with Dementia and their Partners**
Maarten Houben, Rens Brankaert, Gail Kenning, Inge Bongers and Berry Eggen. *In Proceedings of the 2022 CHI Conference on Human Factors in Computing Systems (CHI' 22)*
- 6. Enriching Everyday Lived Experiences in Dementia Care**
Maarten Houben, Rens Brankaert, Emma Dhaeze, Gail Kenning, Inge Bongers and Berry Eggen. *In Proceedings of the 2022 Conference on Tangible, Embedded, and Embodied Interaction (TEI '22)*

7. **Soundscapes for Storytelling and Meaningful Activity in Dementia Care**
Maarten Houben, Melvin van Berlo, Gail Kenning, and Rens Brankaert.
In Proceedings of the 2022 Design Research Society Conference (DRS '22)

LATE-BREAKING RESEARCH PAPERS

8. **The Meaningful Integration of Interactive Media in Architecture**
Maarten Houben, Benjamin Deneff, Matthias Mattelaer, Sandy Claes, and Andrew Vande Moere. *In Companion Publication on Designing Interactive Systems Conference 2017 (DIS '17)*
9. **Citizen Dialogue Kit: Public Polling and Data Visualization Displays for Bottom-Up Citizen Participation**
 Jorgos Coenen, **Maarten Houben**, and Andrew Vande Moere. *In Companion Publication on Designing Interactive Systems Conference 2019 (DIS '19)*
10. **Exploring How an Interactive Placemat Can Influence Eating Activities for People with Dementia**
 Ward de Groot, **Maarten Houben**, and Bart Hengeveld. *In Dementia Lab 2019: Making Design Work: Engaging with Dementia in Context (D-Lab '19)*
11. **SoundscapePillow; a Design for Creating Personalised Auditory Experiences for People with Dementia**
 Daniel van Pel, **Maarten Houben**, and Berry Eggen. *In Dementia Lab 2019: Making Design Work: Engaging with Dementia in Context (D-Lab '19)*
12. **Turnaround: Exploring Care Relations in Dementia Through Design**
Maarten Houben, Benjamin Lehn, Noa van den Brink, Sabeth Diks, Jasmijn Verhoef, & Rens Brankaert. *In Conference on Human Factors in Computing Systems Extended Abstracts Proceedings (CHI' 20)*
13. **RelivRing: Reliving Social Activities for People with Dementia**
 Karlijn van Rijen, Tom Cobbenhagen, Rens Janssen, Maria Væver Olsen, Rens Brankaert, **Maarten Houben**, and Yuan Lu. *In Conference on Human Factors in Computing Systems Extended Abstracts Proceedings (CHI' 20)*

14. **Stakeholder Perspectives on Design Interventions in Dementia Care**
Maarten Houben, Rens Brankaert, and Eveline Wouters. *In Companion Publication on Designing Interactive Systems Conference 2020 (DIS '20)*

ACADEMIC PUBLICATIONS

15. **Exploring Everyday Sounds in Dementia: Practical Guidelines for Interactive Workshops**
Maarten Houben, Rens Brankaert, Saskia Bakker, Inge Bongers, and Berry Eggen. *Chapter in HCI and Design in the Context of Dementia. 2020. Human-Computer Interaction Series. Springer*
16. **Dementia Lab 2021: Supporting Ability Through Design: Proceedings of the 5th Dementia Lab Conference**
(Editors) Rens Brankaert, Caylee Raber, **Maarten Houben**, Paulina Malcolm, Jonathan Hannan. *In Design For Inclusion, vol 2. Springer, Cham, 2021, ISBN: 978-3-030-70293-9*
17. **Dementia Lab 2022: The Residue of Design: Proceedings of the 6th Dementia Lab Conference**
(Editors) **Maarten Houben**, Rens Brankaert, Niels Hendriks, Andrea Wilkinson, Kellie Morrissey. *In Design For Inclusion, vol 3. Springer, Cham, 2022, ISBN: 978-3-031-14465-3*

WORKSHOP AND CONFERENCE CONTRIBUTIONS

18. **Exploring your soundscape: Engaging with stakeholders in dementia care to explore the potential of sound**
Gail Kenning, Rens Brankaert, and **Maarten Houben**. *In 2018 Dementia Lab Event: stories from design and research publication (D-Lab '18)*
19. **VITA: Exploring the Role of Everyday Sounds in Dementia Care**
Maarten Houben, Rens Brankaert, Saskia Bakker, Inge Bongers, and Berry Eggen. *Position paper for the workshop 'Intersections in HCI, Design and Dementia: Inclusivity in Participatory Approaches' organised at the 2019 ACM SIGCHI Conference on Designing Interactive Systems (DIS '19)*

20. **Research and Design for People with Dementia in Contexts of End of Life**
Maarten Houben and Rens Brankaert. *Position paper for the workshop 'HCI at End of Life & Beyond' at the 2020 Conference on Human Factors in Computing Systems (CHI' 20)*

21. **Exploring the Integration of Sound-Based Design Interventions in Dementia Care**
Maarten Houben and Rens Brankaert. *Abstract published In Christer, K., C. Craig and P. Chamberlain, eds. 2020. Vol. 1 of Proceedings of the 6th International Conference on Design4Health, Amsterdam, 2020. P. 290. (D4H '20)*

22. **Designing for Tangible Interaction with Everyday Sounds in Dementia**
Maarten Houben, Rens Brankaert, Inge Bongers, and Berry Eggen. *Position paper for the workshop 'Tangible Interaction for Well-Being' at the 2022 Conference on Human Factors in Computing Systems (CHI' 22)*

Curriculum Vitae



Maarten Houben (22-Feb-1994, Genk, Belgium) obtained his master's degree in engineering sciences: architecture cum laude at the KU Leuven in 2017. In his thesis, Maarten explored how interactive media can be meaningfully integrated within architecture and developed the MUURmelaar: an interactive sound-emitting façade. He received the BESIX Master's Thesis Award and joined the Research[x]Design group at KU Leuven as a research assistant.

In 2018, Maarten started his PhD research at the Eindhoven University of Technology at the Department of Industrial Design and at TRANZO Scientific Center for Care and Wellbeing, Tilburg University. His PhD research focused on investigating the beneficial effects of everyday sounds and soundscapes in technologies for dementia. This research was part of the Everyday Sounds of Dementia project, financed by ZonMw Create Health in collaboration with the Eindhoven University of Technology, Tilburg University, Archipel, and Slimmer Leven. In 2021, Maarten received funding for the 'Sounds Like Home' project by CLICKNL Fieldlab Sense Of Home in collaboration with Eindhoven University of Technology, Fontys, Qwiek, and Vitalis. This project investigated how familiar and pleasant sounds can facilitate the transition from the home situation to a care institution for people with dementia. In 2022, Maarten joined the core team of the TU/e Expertise Center for Dementia & Technology.

Maarten has published and presented his work at international peer-reviewed conferences such as CHI, DIS, TEI, and DRS and has received two Best Paper Awards (CHI'20 & DIS'19). He served on the CHI Late-Breaking Work program committee (2021 & 2022), has peer-reviewed for CHI, DIS, TEI, and TBIT, and was editor of the Dementia Lab proceedings (2021 & 2022). In addition, Maarten's

design work received recognition as he was awarded a Media Architecture Award in 20218, and his design ‘Tumbler’ was shortlisted at the IxDA Awards in 2022.

Maarten is passionate about designing and researching ambient technologies and interactive spaces that have a meaningful impact on vulnerable user groups. Through an inclusive design research approach, he closely involves end-users and key stakeholders such as people with dementia, their relatives, care practitioners, and policymakers. With a background in architecture, engineering sciences, and design, Maarten adopts a multi-disciplinary approach to designing and researching novel technologies in everyday routines and real-life environments.

Acknowledgements

I want to express my thanks and gratitude to the committee members: *prof.dr. A.J. Astell*, *prof.dr. D.M. Frohlich*, and *prof.dr. W.A. IJsselsteijn*, for their time in reviewing this thesis and providing valuable constructive feedback.

I want to thank my first promotor *Berry Eggen*. I really enjoyed all our meetings, discussing study protocols, paper writing or just sharing stories. With your years of experience, you always provided the inspiration, connections and motivation that helped me further with my research. I want to thank you for your dedicated involvement and enthusiasm about the research topic, but especially for believing in me and showing your ongoing support and guidance during my PhD journey.

I want to thank my second promotor *Inge Bongers*. You guided me in finding my way in the challenging research context of health and dementia. As the expert from health, you always showed a lot of interest and openness to the design field as well. I want to thank you for your dedication and support during all our meetings, discussing ethical research protocols and working together on papers.

I want to thank *Rens Brankaert* for giving me the opportunity to do this PhD. You were always my first point of support in providing advice, feedback or guidance. I especially appreciate the dedication and enthusiasm in your supervision (such as reviewing papers during your vacations). You connected and introduced me to a wide network of renowned researchers and provided me with so many valuable opportunities to develop my academic career. I really enjoy(ed) working with you, as well as the many Karmeliet, Cornet, Omer, Brugge Trippel etc. we shared together. ;)

I want to thank *Saskia Bakker* for her supervision during the first year of my PhD. Your expertise in paper writing and design research helped me to find my way in academic research and I am very grateful for our short, but fruitful collaboration, and the resulting (awarded!) publications.

I want to thank *Gail Kenning* for all the many enjoyable meetings, of which I only wish we could have had more. When I was stuck or needed inspiration, you always offered so many new and interesting connections. I also appreciated your many efforts and support in all our papers, which certainly contributed to the publications reported in this thesis.

I want to thank all my PhD colleagues *Daphne, Carlijn, Ida, Marjolein, Roy, Loes, Kenji, Juan* and all the other ID PhDs for providing a friendly and welcoming environment for sharing both the pleasures and struggles of doing a PhD.

I want to thank *Myrte, Francesca, and Ans* for the enjoyable collaborations, research-related discussions, and conversations we had while working together on the topic of dementia. I also thank you for the nice drinks, coffee breaks, dinners, and conferences we shared over the years.

I want to thank all the people with dementia, care professionals and family members who participated in my research. I especially want to thank the couples of the co-design study for their ongoing involvement and interest for one entire year, as well as the many coffees, biscuits, and peperkoek we shared during all our nice conversations.

Ik wil mijn schoonfamilie bedanken, *Irena, Lucien, Melissa, Alessio, en Aurora*, voor de warme Italiaanse gezelligheid en al het lekkere eten!

Ik wil mijn broer *Steven* en zus *Marlies* bedanken om mij te inspireren om de academische wereld in te gaan, en voor jullie steun en delen van ervaringen die me enorm vooruitgeholpen hebben. Bedankt aan *Raf* en *Evi* voor jullie steun en interesse in mijn onderzoek, en bedankt aan *Lana, Arne, Finley, en Alexander* voor het steunen van hun nonkel.

Lieve *papa*, bedankt voor alle hulp en steun die je me altijd geeft. Jij staat altijd voor me klaar en zonder jouw advies en wijze raad was me dit waarschijnlijk nooit gelukt.

Lieve *mama*, ook al hebben we je veel te vroeg moeten verliezen, heb je me enorm geholpen. Je hebt me geleerd altijd door te zetten, niet op te geven, en te gaan voor wat je wil bereiken. Je zal voor mij altijd een bron van inspiratie blijven.

Mijn lieve vriendin *Rany*, bedankt voor al jouw liefde, steun en geduld. Je raapte me op na elke tegenslag, en hield mijn voetjes op de grond na elk succes. Je liet me altijd in mezelf geloven, en om in plaats van te stressen, er ook vooral van te genieten. Zonder jou had ik dit nooit kunnen doen, hou heel veel van je!

