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The Role of Sensory Changes in Everyday Technology use by People with Mild to Moderate Dementia

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Abstract

Technology design for dementia primarily focuses on cognitive needs. This includes providing task support, accommodating memory changes, and simplifying interfaces by reducing complexity. However, research has demonstrated that dementia affects not only the cognitive abilities of people with dementia, but also their sensory and motor abilities. This work provides a first step towards understanding the interaction between sensory changes and technology use by people with dementia through interviews with people with mild to moderate dementia and practitioners. Our analysis yields an understanding of strategies to use technology to overcome sensory changes associated with dementia as well as barriers to using certain technologies. We present new directions for the design of technologies for people with mild to moderate dementia, including intentional sensory stimulation to facilitate comprehension, as well as opportunities to leverage advances in technology design from other disabilities for dementia.

Keywords

Dementia; Sensory Changes; Everyday Technology; Personalized Technology

1 INTRODUCTION

The World Health Organization describes dementia as “one of the major causes of disability and dependency among older adults” [110.]. Dementia is typically described as a condition which involves cognitive decline and affects domains such as memory, thinking, comprehension, learning capacity, language and judgment [111.]. Based on this understanding of dementia, it is not surprising that most technology focuses on cognitive support through task assistance [13., 16., 26.,41., 63., 64., 74., 107., 108.] or memory enhancement [8., 67., 97.].

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A body of work distinct from the literature on cognitive support focuses on technology for sensory stimulation for people with dementia [65., 66., 103.–106.]. The field of gerontology has developed multi-sensory stimulation as an approach to “provide appropriate and pleasurable experiences… without the need for complex intellectual reasoning” [22.]. Sensory stimulation has been a method used for many years to engage people with dementia, often in the later stages [21.], in meaningful sensory activities [14.]. This area has been picked up as a research direction in HCI, which often utilizes sensory stimulation technologies for those in the later stages of dementia living in care facilities [30.–32., 65., 66., 104.]. Work in this area targets the senses as a source of pleasure and to provide meaningful recreational activities. This is different from the cognitive support trajectory, which focuses on simplicity and breaking down tasks in order to support working memory [6., 51., 67., 84.].

Though research to date has treated the senses of people with dementia as avenues to promote recreation, Meiland et al. argue current technologies do not support the complex changes in people with dementia’s senses and perceptions [61.]. In other words, sensory changes in dementia – not just cognitive changes – may be affecting people’s ability to use technology. Agnes Houston, an advocate and person living with the condition, has raised awareness of how sensory changes affect the functioning of people with dementia [43.]. For example, in her book, *Talking Sense: Living with Sensory Changes and Dementia*, she describes how elaborate floor patterns can appear to be moving to individuals with dementia and affect their ability to walk [43.]. Technology and accessibility researchers are missing an understanding of the specific ways that sensory changes in dementia interact with technology use, limiting our ability to accommodate the full breadth of changes people with dementia experience.

Through semi-structured interviews with eleven people with mild to moderate dementia and nineteen practitioners who work primarily with people with dementia, we learned of the ways individuals accommodate sensory changes through technology use. We describe three strategies participants utilize to accommodate for changing sensory experiences in everyday life: stimulating at a desired level, adjusting technologies using built-in settings, and switching devices; as well as the cessation of use that occurs when these strategies are inadequate. Based on these findings, this paper makes the following contributions: an understanding of technological strategies that are useful for people with mild to moderate dementia to accommodate their fluctuating sensory needs, evidence for and discussion of the implications of the interrelationship between sensory stimulation and comprehension, and new directions for the design of technology for people with dementia.

2 RELATED WORK

The following section describes research on technology use in the everyday lives of people with dementia. Following this, we describe the main purposes of technologies that have been designed for use by people with dementia and how these have typically either been to provide cognitive assistance or to support sensory engagement.

2.1 Everyday Use of Commercially Available Technologies

With the nearly 50 million people worldwide living with a diagnosis of dementia – as well as a projected 10 million new cases each year [110.] – there is a growing body of work designing technologies to accommodate the changing needs of people with dementia. Researchers have conducted studies to report on the assistive technologies currently available to people with dementia [37., 56., 61., 82.], as well as projected mega trends for future assistive technology in dementia [112.]. Past research has looked at hinderances and difficulties with technologies [72., 73., 77.], as well as the reasons or purposes for technology adoption by people in the early stages of dementia [72.]. However, past research does not report on the sensory abilities that change in dementia, or how these affect the use of technology. Given the ways that sensory changes affect functioning [43.], this leaves a gap in our ability to design technologies to address the complex sensory changes people with dementia experience. Our work fills this gap by describing how sensory changes, such as fluctuating visual abilities, impact the kinds of technologies that are usable by people with dementia.

Recent work focuses primarily on the role of informal caregivers in facilitating technology use [7., 35., 36.]. For example, Gibson et al. conducted interviews with people with dementia and their informal caregivers to understand their use of assistive technologies in everyday life, finding that technology use was driven by and mainly benefitted caregivers [35.]. Similarly, Arntzen found that technology's integration with everyday life was typically dependent on the caregiver's willingness to engage with the technology [7.]. While the need for this kind of research is essential given how often informal caregivers play a role in facilitating activities for people with dementia (particularly at later stages), we do not have an understanding of how currently available technologies might be managed by people with dementia themselves. Our work contributes an understanding of how a group of technologically savvy individuals with young-onset dementia and experienced dementia practitioners successfully use everyday technologies to accommodate sensory changes, as well as the technologies that prove insurmountable for some individuals with mild to moderate dementia.

2.2 Technologies to Provide Cognitive Assistance

Cognitive assistance has been a major focus of technology design for people with dementia. Researchers are studying how to design technologies to increase cognitive ability by enhancing memory. For example, Alves et al. developed a web application, Scrapbook, to assist psychologists in performing reminiscence and cognitive therapy to increase memory [4.]. Similarly, the COGKNOW day navigator [67.], was developed to enhance memory function. Extensive research has been done to develop technologies to assist in the task of navigation using GPS tracking for wandering [107., 108.] or preventing individuals from becoming lost [41., 55., 80.]. Other technologies are designed to assist with cognitive challenges involving task completion by stimulating thinking using step-by-step instructions. Systems have been designed to assist in tasks such as hand washing [63.] and cooking [24., 74.]. Many approaches are similar to commercial systems such as MapHabit, providing multi-modal directions (i.e., visuals paired with audio or written directions) for different tasks [16., 59.].

Though past work providing cognitive assistance does include color and multi-sensory stimulation, our paper introduces nuances to the relationship between sensory stimulation and cognition: for example, that indiscriminate use of multi-modal stimulation can actually create anxiety and disrupt use, and that people with dementia vary in their ideal mode of sensory input for comprehension.

2.3 Technologies Designed for Sensory Engagement

People living with dementia experience complex sensory changes that differ from the normal process of aging [43., 69.]. These changes differ according to the stage of dementia [3.]. In HCI, most sensory stimulation technologies are designed for those in the later stages of dementia living in care facilities [30.–32., 65., 66., 104.], though recent work reflects a shift to designing multi-sensory technologies for those in early stages [39., 40., 42.]. Regardless of the intended stage of users, technologies that are designed to engage people with dementia in sensory experiences look different from the technologies described in 2.2, which focus on functioning (e.g., supporting safe walking [107.] and basic tasks such as handwashing [63.]). Currently, technologies that target the senses are primarily used for reminiscence or to enhance emotional wellbeing.

Both music and reminiscence are popular areas for technology design, and are typically facilitated via multimedia engagement [54.]. Researchers in HCI have designed technologies to facilitate the enjoyment of music, including supporting musical creativity [29., 78.] and the control of music choices [85.]. One of the first examples of a system for reminiscence is the CIRCA project, where touch screens were used to present music, videos, and pictures to stimulate long-term memories to prompt conversations [2., 38.]. Following the success of the CIRCA project, many prototypes have been developed to utilize multimedia engagement for reminiscence. For example, multimedia books which included audio, haptics, and visual elements [45.], gesture-based technology combined with virtual worlds [49., 87.], or tangible objects with multimedia engagement [44.]. Recent work continues to use multisensory prompts to provide enriching experienced but has moved away from reminiscence as the end goal [30., 39.].

Multi-sensory technologies have also been designed to provide enriching experiences by facilitating communication and reducing social isolation. Systems such as Printer Pal [32.] or Photostroller [34.] were developed to facilitate interactions among people with dementia living in care facilities, targeting their haptic, visual and auditory senses using custom built multi-media devices. Other multi-media systems have been developed for intergenerational communication between people with dementia and their families [40., 52., 109.]. For example, Hodge et al.’s work explored new ways to customize multi-media capture involving touch, smell, audio and 360 degree videos to support connection with family members with dementia [40.]. This work is inspired by multi-sensory environmental therapy, which uses multi-sensory stimulation rooms (e.g., [89.]) to provide relaxing, enriching engagement for people with dementia [79., 83., 92.].

Each of the technologies described above demonstrate the importance of sensory engagement for emotional wellbeing, but also raise questions about appropriate use of sensory stimulation. For example, design researchers analyzing the usability of multisensory stimulation rooms in care facilities found these rooms were unsuitable as they often caused sensory overstimulation [47.]. Our work reveals new possibilities for sensory technologies to facilitate functioning and engagement in everyday activities, as well as the importance of considering the sensory changes people with dementia experience when designing technology.

3 METHOD

Below, we present our approach to data collection, participant demographics, our analysis method, and the limitations of this study.

3.1 Data Collection

We recruited individuals with dementia and practitioners who work regularly with individuals with dementia. Both groups were recruited through organizations (e.g., large dementia advocacy groups, practitioner society Facebook pages) and snowball sampling. To qualify for the study, individuals with dementia had to self-report a formal diagnosis of mild to moderate dementia and regular use of technology. This focus on individuals already using technology yields two benefits. First, it is an approach to discover issues that may be exacerbated or even impossible for less technology savvy users [91.]. For example, if someone who is technology literate is having problems with a technology, these are likely far more difficult for those who have little technology experience – who may not even get to the point in technology use where they would run into an issue. Second, it provides unique insights into the potential benefits of technologies when adopted by a broader audience [113.]. Although we do not claim that these participants use technology in a way that is representative of the general population of people with dementia, as the generations of people living with dementia become more technologically literate, their approaches to managing technology use may become more widely applicable.

To extend the findings beyond people with dementia who were regular users of technology, practitioners who worked primarily with people with dementia were also interviewed. These interviews provided insight into the ways technology is used to accommodate sensory changes in the broader population of people with dementia. In order for practitioners to qualify to participate in the study they had to have at least three years of experience working primarily with people with dementia.

All procedures were approved by the University Institutional Review Board. Before each interview, participants with dementia were screened to assess their ability to consent using the UC Davis Alzheimer’s Disease Center procedures [95.]. All participants gave informed consent before participating in the study. All participants received a $20 Amazon gift card as compensation.

For both interview protocols, questions were structured to be very general concerning participants’ technology use. The general nature of the questions and the semi-structured nature of the interview allowed us to ask further probing questions depending on the answers given by participants. This helped us to obtain data on a variety of ways technology was used to address people with dementia’s unique sensory needs. In the first portion of the interviews, participants with dementia were asked questions concerning their current use of technology and practitioners were asked about their professional strategies to engage people with dementia, with us probing for more detail on the strategies which involved technology. Examples of questions here to participants with dementia included: “Have the changes you’ve experienced with dementia affected your technology use? If so, can you please explain in what ways your technology use has changed?” To practitioners we asked questions such as: “Can you tell me about strategies you use to make an activity accessible to people with dementia?”, and “How have you modified technologies so that people with dementia can still engage with them?” With both sets of participants, we asked in detail about motivations for using technology and the challenges that technologies were used to address. We probed deeply into the answers where sensory changes were discussed, asking about how these changes were experienced and how technologies were used to address them. Next, we asked both sets of participants questions concerning their ideas for future technologies. The interviews with participants with dementia concluded with a discussion of technologies that participants no longer used and why. Interviews with practitioners concluded by giving them the option to review a website database of assistive technologies in terms of usability and usefulness to people with dementia. Please see supplementary materials for further detail.

3.2 Participants

In total, 30 semi-structured interviews were conducted: 11 with people with mild to moderate dementia and 19 with practitioners. Each interview was audio recorded, resulting in 28.5 hours of recording. In the findings section participants are denoted as individuals with dementia ID[#] and practitioners Pr[#]. The average age of participants with dementia was 61.55 years (SD = 3.503 years). See Table 1 below for more detail on participants age, ethnicity, country, gender, and type of dementia.

We interviewed nineteen practitioners, with an average of 15 years of experience working with people with dementia (ranging from 3 to 46 years). All participants identified as female. All practitioners were interviewed separately with the exception of two who were interviewed together to accommodate their time constraints. Practitioners worked with a range of cognitive abilities from people with mild cognitive impairment through people with advanced dementia – for this paper we have only focused on interactions and strategies that were stated as used with clients with mild to moderate dementia. See Table 2 for a summary of each practitioner’s age, ethnicity, country of practice, occupation, and years of experience.

3.3 Analysis

We took a constructivist grounded theory approach to analyze the interview data [18.]. First, we familiarized ourselves with the data by conducting incident by incident open coding of all interviews. The first author then conducted focused coding of all interview transcripts to categorize the data into two major themes: 1) instances where participants used technology to overcome a change due to dementia, and 2) instances where participants experienced problems while using technology. Following this focused coding, based on an identified gap in the literature, the theme of technological strategies used to accommodate sensory changes stood out. The first author then open coded within each of the two major themes to develop a codebook specifically scoped to include only those findings related to the technologies used for sensory changes. An iterative process of engaging with the data, comparing codes, and memoing was then used to form connections between the code-book codes and create major themes. These themes were iteratively reviewed and critiqued by the second author to validate they were supported by the data. This process was repeated until data saturation was met, meaning no new codes were developed.

The constructivist grounded theory approach requires that we reflect on our own position as researchers and the perspectives that we bring to the research [18.]. We have been strongly influenced by the work done by dementia activists calling attention to the ways that people with dementia are not currently supported in caring for themselves and their own condition [94.]. We support the use of technology to facilitate interdependence [11.] and self-management [48.]; enabling people to take an active stance in their own health and well-being through supportive decision making and recovery-focused approaches [9., 19.]. Our stance on these issues is reflected throughout this paper by our intentional focus on the strategies and quotes of participants living with dementia, with strategies of practitioners included when they extended or contrasted findings from participants with dementia. Additionally, our focus on sensorial experiences resonates with the critical dementia perspective, which describes emerging understandings of dementia that take the lived experience of dementia as central [53.].

3.4 Limitations

The average participant with dementia’s age was 61.55. Any form of dementia diagnosed under the age of 65 is considered to be early onset [1.], representing 9% of diagnoses, or approximately 4,500,000 people world-wide [110.]. This relatively younger group of participants may be overrepresented in our research due to the hesitance of the general population of people with dementia to self-identify as a person living with dementia due to associated stigmas [10., 93.], making them unwilling to discuss their experiences with researchers [88.]. As all participants were active in various dementia advocacy organizations, our participants appear to be a part of the rise of the “young, active person with dementia”, who is involved in publicly sharing information about their condition with researchers [17.]. The recruitment requirement that participants had to use technology regularly may also have led to a relatively younger group of participants.

Another limitation of our study is the limited ethnic diversity of participants. Nearly all of our participants identified as Caucasian, with the exception of two practitioners. With research showing a higher prevalence of dementia in populations other than Caucasian, such as African Americans, this was not represented in our participant pool [5.]. Researchers have suggested several barriers in research recruitment of different ethnic groups including education level [60.], stigma consciousness [60.], and lack of trust in researchers [23., 28.]. There is a need for further work to ensure that research includes more diverse populations with dementia. Finally, our findings come from participants residing in the United States, the United Kingdom, or Canada. Therefore, our findings are certainly influenced by the geographic and cultural settings of our participants.

4 FINDINGS

Dementia affects engagement in everyday activities [46., 50., 81.]. Participants described a range of activities that were affected for them, including reading comprehension, decision making, keeping track of important documents, navigation, engaging in social gatherings, grocery store shopping, meal preparation, and grooming. Though current research primarily explains these challenges in terms of cognitive changes in dementia (e.g., [61., 67.]), all participants described changing sensory needs as posing barriers to everyday activities. As participants explained, with too much "sensory input" [ID4] "the brain is. . . maxed out" [ID5] and everyday tasks such as grocery shopping become extremely challenging. ID5 explains that "the physical world, just like you know the music that you hear playing and the conversations and the dishes clanking and the people moving and the trucks driving by, that's all stimuli." ID4 describes how "the world can feel very confusing and overwhelming when you have too much data to deal with... Too much, too many colors or flashing things in the eyes, or noise." Pr18 explains in these instances when people with dementia "get worked up" they "can't come down" without intervention. The overwhelming sensory input can cause "panic attacks" [ID6] or complete disengagement from reality, which ID11 describes as "just disappear[ing]."

Below, we describe three strategies participants utilize to accommodate for changing sensory experiences in everyday life, as well as the cessation of use that occurs when these strategies are inadequate. The first strategy, stimulating at a desired level, was used to overcome overwhelming sensory stimulation in both physical and technical environments. The second strategy involved adjusting technologies using built in features, and was used to assist with fluctuating sensory needs. When technologies did not include adjustable settings, participants utilized the third strategy, which was to shift devices. Finally, when stimulation could not be avoided, technologies did not include adjustable settings, and participants could not find adequate alternative devices, this led to cessation of use.

4.1 Stimulating at a Desired Level

The first strategy used to accommodate sensory changes in dementia was stimulating at a desired level. Participants utilized this strategy in two instances, when either technology or the physical environment was the source of overstimulation. Technology could be the source of overstimulation – such as in the case of cluttered webpages. But technology could also be a way of relieving overstimulation, such as through the use of music and noise cancelling headphones. To avoid becoming visually overwhelmed by large blocks of text, ID1 uses his "finger as a highlighter to cross out each line as you read it" on a touch screen device. This embodied approach to reading allowed ID1 to concentrate on small portions of text rather than becoming overwhelmed by the mass of information. ID3 explained similar issues with visual overstimulation when attempting to look up and follow a recipe for dinner. He describes this process as "a challenge to just get to where I need to go to find the information that I need and not go through all of the weeds you know in between" [ID3]. To overcome this challenge, ID3 scrolls straight to the bottom of the page to find the recipe, which is possible due to the generally standard structure of recipe websites.

Although technology could be a source of overstimulation, it could also be used to overcome stimulation in the physical environment. Several participants used noise canceling headphones to either play music or block out all auditory stimulation. When ID1 faces auditory sensory overload "because I don't do very well in crowds and traffic, when I go out my phone also has my music playing and I've got my Bluetooth noise canceling headphones." Similarly, when traveling in crowded airports ID11 "always had my headphones and I would plug in my music" to provide "soothing" or "joyful" auditory stimulation. ID1 also uses this strategy in conversations to obtain his optimal level of auditory stimulation: "Basically, when I'm having a conversation with somebody, I might just slip the headphone back or the earphones... Just take them of depending on, on, on the conversation." In settings where wearing the headphones may appear inappropriate, such as during a meeting, ID1 would take the headphones of. In other circumstances ID1 "can't handle anything" so he uses his headphones to block out all noise. This example shows an individual optimizing auditory stimulation to their desired level, and how they take into consideration the different circumstances in which they find themselves.

4.2 Adjusting Technologies Using Built-in Settings

A second strategy participants used to accommodate sensory changes occurring with dementia was adjusting the built-in settings of technologies. This strategy is distinct from the previous strategy, stimulating at a desired level, where participants decided to use or not use particular technologies in order to achieve desired levels of stimulation. In the strategy discussed in this section, participants made adjustments to devices in response to their unique sensory needs. Often these adjustments are made by utilizing the tools already "set into the operating system," and in response to fluctuating needs [ID1]. For example, ID1's vascular dementia has a varying effect on his dexterity. When he's "not having a very good day" he often experiences problems with fine motor ability. In these instances, ID1 will use voice-to-text to dictate a message to his phone or leave himself voice messages because the keyboard on the phone is "much too small" for him at that moment in time.

In regards to fluctuating visual abilities, color and lighting were described as important adjustable features to improve the accessibility of technologies. Pr3, an occupational therapist, explains that interface color choices are very important for people with dementia: "white can be overwhelming, not to mention if somebody has visual difficulties." Many interfaces already have the built-in ability to adjust the color and lighting, which Pr4, another occupational therapist, takes advantage of by "adjust[ing] the lighting on the iPad and things like that." Although participants with dementia described using similar strategies to practitioners, they often described a more nuanced use of the operating system settings, adjusting them according to their unique fluctuating visual needs. For example, if ID1 is "having a day where I'm getting headaches or eye strain, I can adjust the color or the intensity of the brightness so that I can still carry on being productive." And ID1 adjusted settings for font size even more regularly as his "vascular dementia causing sometimes hourly changes in my visual capabilities." This means that at "8 o'clock in the morning, I might be able to read font size 14, by 4 o'clock in the afternoon I'm up to font size 24. Now if that was on paper, I would have had to stop reading hours ago" [ID1]. In contrast to this sophisticated use of settings, Pr13, an occupational therapist, uses physical magnifying devices when font sizes are not adjustable. She even "will modify a TV screen by putting a magnifying screen on it" [Pr13].

Audio was also adjusted within existing systems to best match participants' needs. For example, ID7 prefers audio because "I can't read and remember a lot of stuff. And it leaves me really quickly." So, when reading his Bible, ID7 uses the read-aloud feature in The Bible App and he "read[s] along with it." ID1 even took advantage of Zedge, a phone personalization application, which assisted him in adjusting "every kind of notification" he receives on his phone to "have an audible word that tells me what it is. An audible sound, not just a musical sound because that wouldn't register." For example, when he gets a WhatsApp notification his phone will audibly say "WhatsApp" [ID1]. In these instances, participants took advantage of audio settings to increase comprehension.

Pr3, an occupational therapist, explained when playing music it is very important to "pay attention to the beat of the music", because "If the beat of music is too fast I find that, that's overwhelming for them, but if it's a nice steady and not elevator music so to speak. . . that will help keep them, some people focus." This statement ties auditory adjustments with people with dementia's ability to focus but also to emotion regulation. Participants with dementia further this point by describing their intentional choice to configure their voice-based smart home devices to provide peaceful auditory interactions so as not to cause emotional unease. For example, ID9, a veracious user of the voice assistant Alexa, discussed his preference for Alexa to use a feminine voice because "it's quite calming." ID9 explained he has a friend that uses a "Darth Vader voice" on their Alexa, which is not ideal for him – using the feminine voice is a "part of creating an environment that keeps me peaceful." Additionally, ID9 has "put some text into Alexa that works for me" to support his self-created peaceful environment. For example, his Alexa will say, "[ID9], you need to have a shower or you will smell" instead of "Today is Thursday. This is one of your shower days" as that comes across cold and commanding to ID9. In this example, ID9 adjusted his device to meet his unique auditory preferences in a way that helped him create a peaceful environment. In a similar vein, practitioners described used particular kinds of voices (e.g., pre-recordings of loved ones' voices) to "comfort" [Pr1] their clients and help them focus on positive stimuli to overcome overwhelming situations [Pr17]. These findings indicate that audio stimulation can be a way to help people focus on a task or cause distress depending on the context of the situation, fluctuations in auditory needs, the beat of the music, and the voice used by the device.

4.3 Switching Devices

The third strategy participants described was switching applications or devices entirely to devices that provide the form of input and output they found to be most accessible. The preferred mode varied with individuals, though those describing a particular mode that worked best (e.g., audio) had strategies in common. For example, ID6 explains her switch to audiobooks instead of hard copy books or e-books because: "I've found that I'm not a good reader anymore. I don't retain what I read but for some reason if I listen and imagine it, it works better for me."

Dyspraxia, a symptom of many forms of dementia which partially limits motor function, was often described by participants as limiting their ability to use technologies that require touch input. ID9 is no longer able to use a traditional keyboard to type. Instead he uses voice dictation to dictated his daily journal entries to Alexa. In contrast, practitioners described using various traditional assistive devices as work-arounds to help their clients overcome dexterity problems. For example, Pr13, an occupational therapist, introduced the tool Dragon Speak and Pr9, an activities director, used a "wireless keyboard" when their clients were unable to use a traditional keyboard. Some individuals preferred audio for reasons relating to comprehension.

Participants also described switching to tablets to overcome the small size of their cellphones which affected both their dexterity and vision. ID10 explains he is no longer "able to hit the right button" to answer phone calls. ID1 also had this problem, stating, "at least 1 in every 2 phone calls, when I go to answer it, I cut the person of instead of answering it." To overcome these visual and dexterity problems concerning answering the phone, both ID9 and ID10 use tablets enabled with Alexa capabilities to function as their mobile devices, where ID1 continues to struggle using his cell-phone. ID10, expressed he would much rather just say, "answer the phone", but because that's not a current feature, he has to use his tablet instead to provide him with the "capability to communicate." He also appreciates that the tablet is larger and therefore makes it easier to see what is on the screen. Pr5, a speech language pathologist, explains "the size of the piece of technology has to be relatable for their vision capabilities. So, the difference in the size between an iPhone, an iPod Mini, and a full-size iPad can have a substantial impact on the person's ability to read and receive the information."

4.4 Ceasing Use

When overstimulation could not be avoided, technologies did not have adjustable settings, and alternative technologies could not be found, participants ceased to use certain technologies. For ID5, when a task became too confusing due to fluctuations in her cognitive abilities, she utilized a non-technical, haptic approach to complete a task. On days when ID5's "memory's really bad," the steps to unlock her phone, open Google Calendar, and get directions to her next scheduled appointment become too challenging. Instead, ID5 "will physically keep [a Post-it note] in my hand" as a "tactile reminder" of where she is headed and how to get there. ID5 takes advantage of the persistence of information written on a post-it note, utilizing her tactile sense to maintain awareness of where the key information she needs is located.

Other participants described ceasing use of applications and platforms that could not be as easily replaced. Certain social media platforms were described as spurring visual overstimulation or information overload. ID3 described his inability to read large blocks of text at a time: "if somebody put something on Facebook and it says, click and I'll read more. And If I click and I read more and that story's this long [gestures with his hands to convey a long passage]. I'm moving on because my brain cannot process that." ID8 describes a similar experience of having to stop using "a website from a social media group" because "it's just too much for me... It's just getting buried under the clutter." ID3 even avoids using online forums designed specifically for use by people with dementia, because "They are not dementia friendly, not one. Not the Alzheimer's Associations or anybody else's for that matter. And, I stay away from them, unless I absolutely have to." Pr5, a speech-language pathologist, explained that people with dementia need word simplification in order to provide "pieces of information" that "are able to be understood by that person" without becoming visually overwhelming. For this reason the only social media platform ID3 has not stopped using is Twitter because "the thing I loved about Twitter was that, you know, is that it forced you to limit the amount of words you're going to say to get your point across... it makes it a lot easier for me to read."

5 DISCUSSION

Our analysis of interviews with eleven people with mild to moderate dementia and nineteen practitioners, uncovered three technological strategies used to address people with dementia's unique sensory accessibility needs: stimulating at a desired level, adjusting technologies using built-in settings, and switching devices. When these strategies were inadequate, this led to cessation of use. These tactics indicate areas where avid technology users in early stages of dementia and experienced practitioners are already customizing devices to ft their various and changing sensory needs and where these technologies need to be improved. Below, we position these findings within previous research and discuss future directions for technologies to better meet the sensory needs of people with mild to moderate dementia.

5.1 Intentional Sensory Stimulation

To date, most technologies for dementia target comprehension through simplification [6., 51., 67., 84.]. This design approach represents a focus on cognition in terms of working memory. Prior to our work, there has not been empirical research providing an overview of how, when using technology, different modes of sensory stimulation can assist with (or obstruct) comprehension in mild to moderate dementia. Our work yields an understanding of the ways that the sensory changes of people with dementia are interrelated with comprehension and focus.

Current sensory technologies designed for people with dementia often focus on multimodal interaction or multisensory stimulation. These multiple modes of interaction can include auditory, visual, and tactile prompting, with the aim that at least one of these modes will connect with an individuals' optimal mode of interaction. Our findings support previous work [57.], indicating that a vast amount of sensory stimulation may do more harm than good for people with dementia by causing overstimulation. We further this work by demonstrating the need to tailor and limit sensory input in order to enhance engagement and comprehension. The relationship between sensory changes and comprehension in dementia, where stimulation can cause (or relieve) anxiety and impair (or support) functioning, leads to our introduction of the concept of *intentional sensory stimulation*. Ways forward with this concept include leveraging the optimal mode of sensory interaction as well as limiting sensory input to enhance engagement.

5.1.1 Leveraging the Optimal Mode of Sensory Interaction.—Participants explained the need for technologies to be adaptable to their changing visual, auditory, and haptic sensory needs. These adaptations directly linked to their ability to comprehend the information being shared by an application or engage in a particular task. Our findings yield an initial understanding of ways to leverage optimal modes of sensory interaction for people with mild to moderate dementia.

In terms of visual changes, participants benefited from changing font size – as well as from existing accessibility features that have been designed for people with visual impairments. However, their visual abilities could become overwhelmed even when font size is appropriate when facing cluttered websites with "walls of text". We can learn from both the barriers they experienced – the need to minimize visual overstimulation and information overload and also draw inspiration for our technology design from workarounds, such as participants' tactics of learning page layouts in order to navigate to desired content.

Additionally, many participants valued the ability to utilize audio input and/or output. This sometimes occurred using existing features, such as using a read aloud setting on an applications. And sometimes, individuals temporarily or permanently switched to audio modes, such as using voice-to-text when the phone keyboard was too small or switching to audiobooks. These findings point to the promise of voice based interactions with technology for people with mild to moderate dementia – a topic beginning to be investigated [15.].

A third mode individuals benefited from was haptic, or tangible input and output. This finding links efforts to designing accessible interfaces for dementia with the extensive research designing for embodied interactions with people with dementia [12., 27., 53., 65., 103., 105.]. Our findings reveal the potential for a sense of touch in assisting with focus and comprehension, such as described by ID5's use of Post-it notes as "tactile reminder[s]" for assistance with navigation. Embodied interactions could therefore be used as assistive technology for people in the early stages of dementia by providing an avenue to assist with focus and comprehension to complete everyday activities. In particular, the permanence and continuous presence of physical objects appear to be beneficial. At the same time, the motor impairments individuals described should be taken into account when designing to support haptic senses. Uhlig et al.'s concept of designing digitally augmented everyday reminder objects to "break down and communicate complex information via sensory input and output" [96.] serves as inspiration for future work that aims to provide embodied reminders for people with dementia.

5.1.2 Limiting Sensory Input to Enhance Engagement.—Past work has indicated that technology can be a source of overstimulation [57.]. Our work shows technology also has the potential to assist with reducing stimulation and thereby facilitating comprehension. When environments are not properly configured to the sensory needs of people with dementia, individuals utilize the tactic of shutting out extra, unnecessary sensory input to help them focus. Participants blocked out external stimuli using noise canceling headphones or strategies to only view the needed information at one time (e.g. highlighting text as they read; scrolling straight to the recipe). With each of these strategies participants are intentionally restricting their physical and technological environment to address their changing sensory needs. These findings indicate blocking sound and introducing music as promising approaches to shut out harmful stimuli and assist with focus.

Much research has been done to understand the benefits of musical interactions for the decrease of behaviors [101.], as well as increase in reminiscence [86.] and quality of life for people with dementia [85., 100.]. Our findings indicate music has potential utility beyond promoting positive emotions, as it may also be able to support tasks and engagement in everyday activities for people in the early stages of dementia. This finding aligns with Frohlich et al.'s recent framework introducing the concept of assistive media for people with dementia in residential care settings [33.]. Our findings extend the utility of this concept to mild to moderate dementia as well. Researchers designing technologies to assist people with dementia in any activities that require focus or comprehension can consider integrating personalized music selection systems as well as the ability to mute all background sound. Additionally, it's essential to consider how the beat of the music can lead to anxiety or stress for people with dementia if not properly configured [68.], as reported in past work in HCI where a mix of soundscapes played together was overwhelming for people with dementia [42.].

5.2 New Directions for Assistive Technology for Dementia

The need for personalized assistive technologies to cater to changing needs in dementia has been extensively identified in the literature [13., 38., 46., 61., 71., 90.]. Personalized assistive technologies for people with dementia has even been identified by the United States National Institute of Aging as a significant need area for future research [70.]. However, what is less clear is how to design personalized technology in a way that is scalable, rather than custom built devices (as in [32., 39., 51., 66., 105.]). Our findings indicate the potential for mainstream technology use. In addition to workarounds such as using existing applications to personalize notification sounds (e.g. to read the application name out loud), individuals are benefiting from standard built-in accessibility features such as zoom, color contrast, and adjustable lighting.

Past research has noted that people with dementia can have difficulty adjusting settings [48.]. Caregivers are typically expected to play the primary role in customizing the "the look and feel" of a device for people with dementia [62., 71., 75.]. Our research exposes an opportunity to reevaluate the potential for supporting people with dementia in controlling the adjustments to their technology settings. For less technologically savvy individuals, researchers might benefit from investigating the automatic personalization of settings (e.g., [98., 99.]) in response to fluctuating accessibility needs of individuals with mild to moderate dementia. Here, there is a potential for artificial intelligence (AI) to play a role in determining when individuals may need setting changes (e.g. by detecting someone squinting eyes because of small text) as well as in automatically adjusting or suggesting adjustments according to the perceived sensory need. Additionally, AI might be used to track the history of setting changes by more technologically savvy people with dementia to learn unique patterns of sensory needs and user preferences. This would be particularly helpful as people with dementia could train their system to adjust to their sensory needs in preparation for a time when their condition has progressed to a point where they are no longer able to make these adjustments independently.

These efforts may require a shift to a more serious conception of dementia as a disability, as the techniques and advances of assistive technology and accessible design have the potential to revolutionize technology use for people with dementia. While the WCAG is leading efforts in this area, dementia is still primarily described in terms of cognitive decline [102.]. Continuing to investigate sensory changes will lead to more usable technologies. We have identified two useful distinctions as starting points for further work to understand the sensory accessibility needs of people with dementia. First, experiences with dementia are highly unique, and what one person needs sensory assistance with may be completely different from what another person may need (e.g., audio versus visual word descriptions). Second, people experience both permanent sensory changes and moment to moment fluctuations in sensory ability. Technology needs to both preserve settings for the long term and allow for daily and sometimes hourly changes. Together, these distinctions open up a new topic for discovery, how to design accessibility features for the changing sensory needs of people with dementia. As previously described, AI is one potential solution to address the unique and changing sensory accessibility needs of people with dementia. However, there is a need to study how this kind of AI system would be perceived by people with dementia. Could this type of system be perceived as the technology taking control or taking away autonomy, as confusing or disturbing, as a cause for the loss of ability? Future research is needed to understand the role people with dementia desire for AI and its use to address their unique and changing needs. Further, researchers need to reflect on the potentially adverse effects of designing technologies which incorporate AI into the daily routines of those living with dementia [25.].

Further research is therefore needed to understand both the unique technological challenges people with dementia face, such as the work being done by the WCAG cognitive task force [102.], as well as the areas where the technological needs of people with dementia overlap with those of people with other disabilities. For example, our findings show an intersection with other disability communities such as people with autism who are also sensitive to sensory stimulation [76.], or Deaf people who often find it difficult to read long passages of text-based online content [20.]. These similarities open up new opportunities for technologies designed for other disability communities to benefit people with dementia. For example, Rapp et al.'s interactive urban maps to support people with autism in finding places in cities that match their individual sensorial preferences [76.] and Chung et al.'s text augmentation system for Deaf people that converts complex sentences in long online articles into simple sentences [20.]. Both appear to be approaches that may benefit people with dementia.

A final area for future investigation is the intertwined relationships between emotion and the ability to utilize technology. Emotion, including how feelings of being overwhelmed limit the ability to use technologies and how inaccessible technologies can spur anxiety, permeated our findings. Previous researchers in HCI have found tracking technologies reduce feelings of anxiety for people with dementia [41., 55., 107., 108.]. Our findings point to the need to understand the breadth of emotions that may be caused by the technologies we design and how these emotions may affect technology uptake and continued use. For example, these findings suggest voice enabled devices should be configured with consideration for the emotions a voice evokes for people with dementia. Our findings also showed that an improperly configured physical or technological environment could lead to panic attacks or complete emotional withdrawal. This understanding of the importance of sensory regulation represents one step towards answering Malhotra et al.'s call to understand how to develop assistive technology to address the emotional state of persons with dementia during everyday activities [58.]. Further work is needed to understand the depth of the intertwined nature of emotions and utilization of technology.

6 CONCLUSION

This work details the interaction between sensory changes and technology use in dementia through an analysis of interviews with eleven technology savvy people with mild to moderate dementia and nineteen experienced practitioners. Findings from this study showed three unique tactics participants used to accommodate sensory changes: stimulating at a desired level, adjusting technologies using built-in settings, and switching devices. When these three strategies were inadequate, this led to cessation of use. Together, these findings show it is vital for technology designers to implement flexible systems that allow for adjustments of the interface for each person's preferred mode of interaction to facilitate comprehension. This paper contributes to the literature by providing a better understanding of the technological strategies used to deal with the fluctuating sensory needs of people with mild to moderate dementia, describing new areas for researchers to focus the design of technologies to better meet their unique sensory needs.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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REFERENCES

[1]. 2020 Alzheimer's Association. Younger/Early-Onset Alzheimer's. Alzheimer's Disease and Dementia. Retrieved March 16, 2020 from https://alz.org/alzheimers-dementia/what-is-alzheimers/younger-early-onset

[2]. Alm Norman, Dye Richard F., Astell Arlene, Ellis Maggie, Gowans Gary, and Campbell Jim. 2005. Making software accessible to people with severe memory deficits. 10.14236/ewic/AD2005.16

[3]. Alves Jorge, Petrosyan Agavni, and Magalhães Rosana. 2014. Olfactory dysfunction in dementia. World Journal of Clinical Cases: WJCC 2, 11: 661–667. 10.12998/wjcc.v2.i11.661 [PubMed: 25405189]

[4]. Alves Sérgio, Brito Filipa, Cordeiro Andreia, Carriço Luis, and Guerreiro Tiago. 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, 1–6. 10.1145/3170427.3188693

[5]. Alzheimer's Association. 2019.2019 Alzheimer's Disease Facts and Figures.

[6]. Ancient Claire, Good Alice, Wilson Clare, and Fitch Tineke. 2013. Can Ubiquitous Devices Utilising Reminiscence Therapy Be Used to Promote Well-Being in Dementia Patients? An Exploratory Study. In Universal Access in Human-Computer Interaction. Applications and Services for Quality of Life, Stephanidis Constantine and Antona Margherita (eds.). Springer Berlin Heidelberg, Berlin, Heidelberg, 426–435. 10.1007/978-3-642-39194-1_50

[7]. Arntzen Cathrine, Holthe Torhild, and Jentoft Rita. 2016. Tracing the successful incorporation of assistive technology into everyday life for younger people with dementia and family carers. Dementia (London, England)15, 4: 646–662. 10.1177/1471301214532263

[8]. Aruanno Beatrice and Garzotto Franca. 2019. MemHolo: mixed reality experiences for subjects with Alzheimer's disease. Multimedia Tools and Applications 78, 10: 13517–13537. 10.1007/s11042-018-7089-8

[9]. Baker Elina, Fee Jason, Bovingdon Louise, Campbell Tina, Hewis Elaine, Lewis Danny, Mahoney Lesley, and Roberts Glenn. 2013. From taking to using medication: recovery-focused prescribing and medicines management. Advances in Psychiatric Treatment 19, 1: 2–10. 10.1192/apt.bp.110.008342

[10]. Behuniak Susan. 2011. The living dead? The construction of people with Alzheimer's disease as zombies. Ageing and Society 31: 70–92. 10.1017/S0144686X10000693

[11]. Bennett Cynthia L., Brady Erin, and Branham Stacy M. 2018. Interdependence as a Frame for Assistive Technology Research and Design. In Proceedings of the 20th International ACM SIGACCESS Conference on Computers and Accessibility - ASSETS '18, 161–173. 10.1145/3234695.3236348

[12]. Bennett Peter, Hinder Heidi, Kozar Seana, Bowdler Christopher, Massung Elaine, Cole Tim, Manchester Helen, and Cater Kirsten. 2015. TopoTiles: Storytelling in Care Homes with Topographic Tangibles. In Proceedings of the 33rd Annual ACM Conference Extended Abstracts on Human Factors in Computing Systems (CHI EA '15), 911–916. 10.1145/2702613.2732918

[13]. Megan Witte Bewernitz William C. Mann, Dasler Patricia, and Belchior Patrícia. 2009. Feasibility of machine-based prompting to assist persons with dementia. Assistive technology: the official journal of RESNA 21, 4: 196–207. 10.1080/10400430903246050 [PubMed: 20066886]

[14]. Buettner Linda L. 2016. Simple Pleasures: A multilevel sensorimotor intervention for nursing home residents with dementia: American Journal of Alzheimer's Disease. 10.1177/153331759901400103

[15]. Carroll Clare, Chiodo Catherine, Lin Adena Xin, Nidever Meg, and Prathipati Jayanth. 2017. Robin: Enabling Independence For Individuals With Cognitive Disabilities Using Voice Assistive Technology. In Proceedings of the 2017 CHI Conference Extended Abstracts on Human Factors in Computing Systems - CHI EA '17, 46–53. 10.1145/3027063.3049266

[16]. Chang Wan Chih. 2008. CATPro: context-aware task prompting system with multiple modalities for individuals with cognitive impairments. In Proceedings of the 10th international ACM SIGACCESS conference on Computers and accessibility - Assets '08, 301. 10.1145/1414471.1414549

[17]. Charlesworth Georgina. 2018. Public and patient involvement in dementia research: Time to reflect? Dementia 17, 8: 1064–1067. 10.1177/2397172X18802501 [PubMed: 30373462]

[18]. Charmaz Kathy. 2014. Constructing Grounded Theory: A practical guide through qualitative analysis.SAGE, London.

[19]. Chefey Jo, Hill Laura, Roberts Glenn, and Marlow Ruth. 2013. Supporting self-management in early dementia: a contribution towards 'living well'? Advances in Psychiatric Treatment 19, 5: 344–350. 10.1192/apt.bp.112.011023

[20]. Chung Jin-Woo, Min Hye-Jin, Kim Joonyeob, and Park Jong C. 2013. Enhancing readability of web documents by text augmentation for deaf people. In Proceedings of the 3rd International Conference on Web Intelligence, Mining and Semantics (WIMS '13), 1–10. 10.1145/2479787.2479808

[21]. Cohen-Mansfield Jiska, Marx Marcia S, Dakheel-Ali Maha, Regier Natalie G., and Thein Khin. 2010. Can Persons With Dementia Be Engaged With Stimuli? The American journal of geriatric psychiatry: official journal of the American Association for Geriatric Psychiatry 18, 4: 351–362. [PubMed: 20306565]

[22]. Cruz Joana, Marques Alda, Barbosa Ana, Figueiredo Daniela, and Sousa Liliana X. 2013. Making Sense(s) in Dementia: A Multisensory and Motor-Based Group Activity Program. American Journal of Alzheimer’s Disease & Other Dementias®28, 2: 137–146. 10.1177/1533317512473194

[23]. Diaz Vanessa. 2012. Encouraging Participation of Minorities in Research Studies. The Annals of Family Medicine 10, 4: 372–373. 10.1370/afm.1426 [PubMed: 22778129]

[24]. Dishman Eric. 2004. Inventing wellness systems for aging in place. Computer 37, 5: 34–41. 10.1109/MC.2004.1297237

[25]. Dixon Emma and Lazar Amanda. 2020. 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 (CHI ‘20), 1–15. 10.1145/3313831.3376432

[26]. Donaldson Martin. 2018. An assistive interface for people with dementia. In Proceedings of the Australasian Computer Science Week Multiconference on - ACSW ‘18, 1–5. 10.1145/3167918.3167935

[27]. Dourish Paul. 2001. Where the Action is: The Foundation of Embodied Interaction. MIT Press.

[28]. Fayron Recha Epps Lisa Skemp, and Specht Janet. 2015. Using Culturally Informed Strategies to Enhance Recruitment of African Americans in Dementia Research: A Nurse Researcher’s Experience. Journal of Research Practice 11, 1: M2–M2.

[29]. Favilla Stu and Pedell Sonja. 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. 10.1145/2541016.2541088

[30]. Feng Yuan, Yu Suihuai, van de Mortel Dirk, Barakova Emilia, Hu Jun, and Rauterberg Matthias. 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, 1321–1333. 10.1145/3322276.3322331

[31]. Feng Yuan, Yu Suihuai, Dirk van de Mortel, Barakova Emilia, Rauterberg Matthias, and Hu Jun. 2018. Closer to Nature: Multi-sensory Engagement in Interactive Nature Experience for Seniors with Dementia. In Proceedings of the Sixth International Symposium of Chinese CHI on - ChineseCHI ‘18, 49–56. 10.1145/3202667.3202674

[32]. Foley Sarah, Welsh Daniel, Pantidi Nadia, Morrissey Kellie, Nappey Tom, and McCarthy John. 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, 1–13. 10.1145/3290605.3300634

[33]. Frohlich David M., Emily Corrigan-Kavanagh Sarah Campbell, Chrysanthaki Theti, Castro Paula, Zaine Isabela, and da Graça Campos Pimentel Maria. 2020. Assistive media for wellbeing. In HCI and design in the context of dementia. Springer, Chapter 12.

[34]. Gaver William, Boucher Andy, Bowers John, Blythe Mark, Jarvis Nadine, Cameron David, Kerridge Tobie, Wilkie Alex, Phillips Robert, and Wright Peter. 2011. The photostroller: supporting diverse care home residents in engaging with the world. In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI ‘11), 1757–1766. 10.1145/1978942.1979198

[35]. Gibson Grant, Dickinson Claire, Brittain Katie, and Robinson Louise. 2015. The everyday use of assistive technology by people with dementia and their family carers: a qualitative study. BMC Geriatrics 15, 1: 1–10. 10.1186/s12877-015-0091-3 [PubMed: 25559550]

[36]. Gibson Grant, Dickinson Claire, Brittain Katie, and Robinson Louise. 2019. Personalisation, customisation and bricolage: how people with dementia and their families make assistive technology work for them. Ageing & Society 39, 11: 2502–2519. 10.1017/S0144686X18000661

[37]. Gibson Grant, Newton Lisa, Pritchard Gary, Finch Tracy, Brittain Katie, and Robinson Louise. 2016. The provision of assistive technology products and services for people with dementia in the United Kingdom. Dementia 15, 4: 681–701. 10.1177/1471301214532643 [PubMed: 24803646]

[38]. Gowans Gary, Campbell Jim, Alm Norm, Dye Richard, Astell Arlene, and Ellis Maggie. 2004. Designing a multimedia conversation aid for reminiscence therapy in dementia care environments. In CHI ‘04 Extended Abstracts on Human Factors in Computing Systems (CHI EA ‘04), 825–836. 10.1145/985921.985943

[39]. Hodge James, Balaam Madeline, Hastings Sandra, and Morrissey Kellie. 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, 1–13. 10.1145/3173574.3174088

[40]. Hodge James, Montague Kyle, Hastings Sandra, and Morrissey Kellie. 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, 1–14. 10.1145/3290605.3300653

[41]. Holbo Kristine. 2013. Safe Walking Technology for People with Dementia: What. ASSETS ‘13: Proceedings of the 15th International ACM SIGACCESS Conference on Computers and Accessibility: 8.

[42]. Houben Maarten, Brankaert Rens, Bakker Saskia, Kenning Gail, Bongers Inge, and Eggen Berry. 2019. Foregrounding Everyday Sounds in Dementia. In Proceedings of the 2019 on Designing Interactive Systems Conference - DIS ‘19, 71–83. 10.1145/3322276.3322287

[43]. Houston Agnes and Christie Julie. 2019. Talking Sense: Living with Sensory Changes and Dementia. Hammond Care, Sydney, Australia.

[44]. Huber Stephan, Berner Renate, Uhlig Martina, Klein Peter, and Hurtienne Jörn. 2019. Tangible Objects for Reminiscing in Dementia Care. In Proceedings of the Thirteenth International Conference on Tangible, Embedded, and Embodied Interaction - TEI ‘19, 15–24. 10.1145/3294109.3295632

[45]. Huldtgren Alina, Mertl Fabian, Vormann Anja, and Geiger Christian. 2016. Reminiscence of people with dementia mediated by a tangible multimedia book. In ICT4AWE 2016: Proceedings of the International Conference on Information and Communication Technologies for Ageing Well and e-Health, Rome, Italy, April 21–22, 2016, 191–201. Retrieved March 21, 2020 from https://research.tue.nl/en/publications/reminiscence-of-people-with-dementia-mediated-by-a-tangible-multi

[46]. Hyry Jaakko, Yamamoto Goshiro, and Pulli Petri. 2011. Requirements guideline of assistive technology for people suffering from dementia. In Proceedings of the 4th International Symposium on Applied Sciences in Biomedical and Communication Technologies - ISABEL ‘11, 1–5. 10.1145/2093698.2093737

[47]. Jakob Anke and Collier Lesley. 2017. Sensory enrichment for people living with dementia: increasing the benefits of multisensory environments in dementia care through design. Design for Health 1, 1: 115–133. 10.1080/24735132.2017.1296274

[48]. Kerkhof Yvonne, Pelgrum-Keurhorst Myrna, Mangiaracina Floriana, Bergsma Ad, Vrauwdeunt Guus, Graf Maud, and Dröes Rose-Marie. 2019. Userparticipatory development of FindMyApps; a tool to help people with mild dementia find supportive apps for self-management and meaningful activities. DIG-ITAL HEALTH 5: 205520761882294. 10.1177/2055207618822942

[49]. Klein Peter, Uhlig Martina, and Will Hannes. 2018. The Touch and Feel of the Past—Using Haptic and VR Artefacts to Enrich Reminiscence Therapy for People with Dementia. Technologies 6: 104. 10.3390/technologies6040104

[50]. Lauriks Steve, Reinersmann Annika, Henriëtte Geralde van der Roest, Meiland Franka, Davies Richard, Moelaert Ferial, Mulvenna Maurice D., Nugent Chris D., and Dröes Rose-Marie. 2010. Review of ICT-Based Services for Identified Unmet Needs in People with Dementia. In Supporting People with Dementia Using Pervasive Health Technologies, Mulvenna Maurice D. and Nugent Chris D.(eds.). Springer London, London, 37–61. 10.1007/978-1-84882-551-2_4

[51]. Lazar Amanda, Cornejo Raymundo, Edasis Caroline, and Piper Anne Marie. 2016. Designing for the Third Hand: Empowering Older Adults with Cognitive Impairment through Creating and

Sharing. In Proceedings of the 2016 ACM Conference on Designing Interactive Systems - DIS '16, 1047–1058. 10.1145/2901790.2901854

[52]. Lazar Amanda, Edasis Caroline, and Piper Anne Marie. 2017. Supporting People with Dementia in Digital Social Sharing. In Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems - CHI '17, 2149–2162. 10.1145/3025453.3025586

[53]. Lazar Amanda, Edasis Caroline, and Piper Anne Marie. 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. 10.1145/3025453.3025522

[54]. Lin Hsiu-Ching, Yang Ya-Ping, Cheng Wen-Yun, and Wang Jing-Jy. 2018. Distinctive effects between cognitive stimulation and reminiscence therapy on cognitive function and quality of life for different types of behavioural problems in dementia. Scandinavian Journal of Caring Sciences 32, 2: 594–602. 10.1111/scs.12484 [PubMed: 28881430]

[55]. Lindsay Stephen, Brittain Katie, Jackson Daniel, Ladha Cassim, Ladha Karim, and Olivier Patrick. 2012. Empathy, participatory design and people with dementia. In Proceedings of the 2012 ACM annual conference on Human Factors in Computing Systems - CHI '12, 521. 10.1145/2207676.2207749

[56]. Lorenz Klara, Paul P Freddolino Adelina Comas-Herrera, Knapp Martin, and Damant Jacqueline. 2017. Technology-based tools and services for people with dementia and carers: Mapping technology onto the dementia care pathway. Dementia: 147130121769161. 10.1177/1471301217691617

[57]. Ly Nam Tung, Preßler Jan, Gall Dominik, Hurtienne Jörn, and Huber Stephan. 2016. Tangible interaction drawers for people with dementia: retrieving living experiences from past memories. In Proceedings of the 2016 ACM International Joint Conference on Pervasive and Ubiquitous Computing Adjunct - UbiComp '16, 157–160. 10.1145/2968219.2971434

[58]. Malhotra Aarti, Yu Lifei, Schroder Tobias, and Hoey Jesse. 2015. An exploratory study into the use of an emotionally aware cognitive assistant. Association for the Advancement of Artifcial Intelligence: 6.

[59]. MapHabitTM. 2019. MapHabit: Visualize Your Day. MapHabit. Retrieved April 3, 2020 from https://www.maphabit.com/product/

[60]. McDougall Graham J., Gaynell Simpson, and Friend Mary Louanne. 2015. Strategies for Research Recruitment and Retention of Older Adults of Racial and Ethnic Minorities. Journal of Gerontological Nursing 41, 5: 14–23. 10.3928/00989134-20150325-01

[61]. Meiland Franka, Innes Anthea, Mountain Gail, Robinson Louise, van der Roest Henriëtte, J Antonio García-Casal Dianne Gove, Jochen René Thyrian Shirley Evans, Rose-Marie Dröes Fiona Kelly, Kurz Alexander, Casey Dympna, Dorota Szcześniak Tom Dening, Michael P Craven Marijke Span, Felzmann Heike, Tsolaki Magda, and Franco-Martin Manuel. 2017. Technologies to Support Community-Dwelling Persons With Dementia: A Position Paper on Issues Regarding Development, Usability, Effectiveness and Cost-Effectiveness, Deployment, and Ethics. JMIR Rehabilitation and Assistive Technologies 4, 1. 10.2196/rehab.6376

[62]. Mentis Helena M., Madjarof Galina, and Massey Aaron K. 2019. Upside and Downside Risk in Online Security for Older Adults with Mild Cognitive Impairment. In Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems - CHI '19, 1–13. 10.1145/3290605.3300573

[63]. Mihailidis Alex, Boger Jennifer, Canido Marcelle, and Hoey Jesse. 2007. The use of an intelligent prompting system for people with dementia. interactions 14, 4: 34. 10.1145/1273961.1273982

[64]. Morrison Kenny, Szymkowiak Andrea, and Gregor Peter. 2004. Memojog – An Interactive Memory Aid Incorporating Mobile Based Technologies. In Mobile Human-Computer Interaction - MobileHCI 2004, Brewster Stephen and Dunlop Mark (eds.). Springer Berlin Heidelberg, Berlin, Heidelberg, 481–485. 10.1007/978-3-540-28637-0_61

[65]. Morrissey Kellie and McCarthy John. 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, 295–298. 10.1145/2757226.2757228

[66]. Morrissey Kellie, Wood Gavin, Green David, Pantidi Nadia, and McCarthy John. 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, 1008–1020. 10.1145/2901790.2901798

[67]. Mulvenna Maurice, Martin Suzanne, Sävenstedt Stefan, Bengtsson Johan, Meiland Franka, Rose Marie Dröes, Hettinga Marike, Moelaert Ferial, and Craig David. 2010. Designing & evaluating a cognitive prosthetic for people with mild dementia. In Proceedings of the 28th Annual European Conference on Cognitive Ergonomics - ECCE '10, 11. 10.1145/1962300.1962306

[68]. Nair Balakrishnan (Kichu), Heim Christian, Krishnan Chitra, D'Este Catherine, Marley John, and Attia John. 2011. The effect of Baroque music on behavioural disturbances in patients with dementia. Australasian Journal on Ageing 30, 1: 11–15. 10.1111/j.1741-6612.2010.00439.x [PubMed: 21395934]

[69]. National Institute of Health. 2002. Home Safety for People with Alzheimer's Disease. US. Retrieved January 28, 2020 from https://www.nia.nih.gov/health/home-safety-and-alzheimers-disease

[70]. National Institute of Health. 2017. Home Safety and Alzheimer's Disease. National Institute on Aging. Retrieved April 4, 2020 from https://www.nia.nih.gov/health/home-safety-and-alzheimers-disease

[71]. Nugent Chris D., Davies Richard J., Donnelly Mark P., Hallberg Josef, Hariz Mossaab, Craig David, Meiland Franka, Moelaert Ferial, Bengtsson Johan E., Savenstedt Stefan, Mulvenna Maurice, and Droes Rose-Marie. 2008. The development of personalised cognitive prosthetics. In 2008 30th Annual International Conference of the IEEE Engineering in Medicine and Biology Society, 787–790. 10.1109/IEMBS.2008.4649270

[72]. Nygård Louise. 2008. The meaning of everyday technology as experienced by people with dementia who live alone. Dementia 7, 4: 481–502. 10.1177/1471301208096631

[73]. Nygård Louise and Starkhammar S. 2007. The use of everyday technology by people with dementia living alone: Mapping out the difficulties. Aging & mental health 11: 144–55. 10.1080/13607860600844168 [PubMed: 17453547]

[74]. Olivier Patrick, Xu Guangyou, Monk Andrew, and Hoey Jesse. 2009. Ambient kitchen: designing situated services using a high fidelity prototyping environment. In Proceedings of the 2nd International Conference on PErvsive Technologies Related to Assistive Environments - PETRA '09, 1–7. 10.1145/1579114.1579161

[75]. Anne Marie Piper Raymundo Cornejo, Hurwitz Lisa, and Unumb Caitlin. 2016. Technological Caregiving: Supporting Online Activity for Adults with Cognitive Impairments. In Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems - CHI '16, 5311–5323. 10.1145/2858036.2858260

[76]. Rapp Amon, Cena Federica, Mattutino Claudio, Boella Guido, Schifanella Claudio, Keller Roberto, and Brighenti Stefania. 2019. Designing an Urban Support for Autism. In Proceedings of the 21st International Conference on Human-Computer Interaction with Mobile Devices and Services (MobileHCI '19), 1–6. 10.1145/3338286.3344390

[77]. Riikonen Merja, Paavilainen Eija, and Salo Hannu. 2013. Factors supporting the use of technology in daily life of home-living people with dementia. Technology & Disability 25, 4: 233–243. 10.3233/TAD-130393

[78]. Riley Philippa, Alm Norman, and Newell Alan. 2009. An interactive tool to promote musical creativity in people with dementia. Computers in Human Behavior 25, 3: 599–608. 10.1016/j.chb.2008.08.014

[79]. Riley-Doucet Cheryl K. 2009. Use of Multisensory Environments in the Home for People with Dementia. Journal of Gerontological Nursing; Thorofare 35, 5: 42–52.

[80]. Robinson Louise, Brittain Katie, Lindsay Stephen, Jackson Dan, and Olivier Patrick. 2009. Keeping In Touch Everyday (KITE) project: developing assistive technologies with people with dementia and their carers to promote independence. International Psychogeriatrics 21, 03: 494. 10.1017/S1041610209008448 [PubMed: 19193255]

[81]. van der Roest Henriëtte G., Meiland Franka J. M., Comijs Hannie C., Derksen Els, Jansen Aaltje P. D., van Hout Hein P. J., Jonker Cees, and Dröes Rose-Marie. 2009. What do community-dwelling people with dementia need? A survey of those who are known to care and welfare services. International Psychogeriatrics 21, 05: 949. 10.1017/S1041610209990147 [PubMed: 19602305]

[82]. Van der Roest Henriëtte G., Wenborn Jennifer, Pastink Channah, Dröes Rose-Marie, and Orrell Martin. 2017. Assistive technology for memory support in dementia. Cochrane Database of Systematic Reviews, 6. 10.1002/14651858.CD009627.pub2

[83]. Alba Sánchez, Millán-Calenti José C., Lorenzo-López Laura, and Maseda Ana. 2013. Multisensory Stimulation for People With Dementia: A Review of the Literature. American Journal of Alzheimer's Disease & Other Dementias®28, 1: 7–14. 10.1177/1533317512466693

[84]. Vardit Sarne-Fleischmann Noam Tractinsky, Dwolatzky Tzvi, and Rief Inbal. 2011. Personalized reminiscence therapy for patients with Alzheimer's disease using a computerized system. In Proceedings of the 4th International Conference on PErvasive Technologies Related to Assistive Environments (PETRA '11), 1–4. 10.1145/2141622.2141679

[85]. Seymour P. Frazer, Matejka Justin, Foulds Geof, Petelycky Ihor, and Anderson Fraser 2017. AMI: An Adaptable Music Interface to Support the Varying Needs of People with Dementia. In Proceedings of the 19th International ACM SIGACCESS Conference on Computers and Accessibility - ASSETS '17, 150–154. 10.1145/3132525.3132557

[86]. Sherratt Kristy, Thornton Amanda, and Hatton Chris. 2004. Music interventions for people with dementia: a review of the literature. Aging & Mental Health 8, 1: 3–12. 10.1080/13607860310001613275 [PubMed: 14690862]

[87]. Siriaraya Panote and Ang Chee Siang. 2014. Recreating living experiences from past memories through virtual worlds for people with dementia. In Proceedings of the 32nd annual ACM conference on Human factors in computing systems - CHI '14, 3977–3986. 10.1145/2556288.2557035

[88]. Slegers Karin, Wilkinson Andrea, and Hendriks Niels. 2013. Active collaboration in healthcare design: participatory design to develop a dementia care app. In CHI '13 Extended Abstracts on Human Factors in Computing Systems (CHI EA '13), 475–480. 10.1145/2468356.2468440

[89]. Snoezelen®Multi-Sensory Environments. 2020. Room & Space Design | Snoezelen Multi-Sensory Environments. Retrieved April 24, 2020 from https://www.snoezelen.info/room-designs/

[90]. Span Marijke, Hettinga Marike, Vernooij-Dassen Myrra, Eefsting Jan, and Smits Carolien. 2013. Involving people with dementia in the development of supportive IT applications: A systematic review. Ageing Research Reviews 12, 2: 535–551. 10.1016/j.arr.2013.01.002 [PubMed: 23318684]

[91]. Strengers Yolande, Kennedy Jenny, Arcari Paula, Nicholls Larissa, and Gregg Melissa. 2019. Protection, Productivity and Pleasure in the Smart Home: Emerging Expectations and Gendered Insights from Australian Early Adopters. In Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems (CHI '19), 1–13. 10.1145/3290605.3300875

[92]. Strøm Benedicte S, Ytrehus Siri, and Grov Ellen-Karine. 2016. Sensory stimulation for persons with dementia: a review of the literature. Journal of Clinical Nursing 25, 13–14: 1805–1834. 10.1111/jocn.13169

[93]. Swafer Kate. 2014. Dementia: Stigma, Language, and Dementia-friendly. Dementia 13, 6: 709–716. 10.1177/1471301214548143 [PubMed: 25326220]

[94]. Swafer Kate. 2015. Dementia and Prescribed DisengagementTM. Dementia 14, 1: 3–6. 10.1177/1471301214548136 [PubMed: 25503628]

[95]. UC Davis Alzheimer's Disease Center. 2002. Policy and Procedures for Assessing Capacity To Consent for Research. Retrieved from https://health.ucdavis.edu/clinicaltrials/StudyTools/Documents/ResearchCapacityPolicy7=02.pdf

[96]. Uhlig Martina, Rieß Henrik, and Klein Peter. 2017. Reminder objects in the connected home of the future and beyond. In Proceedings of the 10th International Conference on PErvasive Technologies Related to Assistive Environments - PETRA '17, 138–141. 10.1145/3056540.3064949

[97]. Unbehaun David. 2018. Designing an ICT-based Training System for People with Dementia and their Caregivers. In Proceedings of the 2018 ACM Conference on Supporting Groupwork - GROUP '18, 388–392. 10.1145/3148330.3152700

[98]. Vanderheiden Gregg, Lazar Jonathan, Jordan J. Bern, Ding Yao, and Wood Rachel E. 2020. Morphic: Auto-Personalization on a Global Scale.

[99]. Vanderheiden Gregg, Treviranus Jutta, Usero José Angel Martinez, Bekiaris Evangelos, Gemou Maria, and Chourasia Amrish. 2012. Auto-Personalization: Theory, Practice and Cross-Platform Implementation. Proceedings of the Human Factors and Ergonomics Society Annual Meeting 56: 926–930. 10.1177/1071181312561193

[100]. Vasionytė Ieva and Madison Guy. 2013. Musical intervention for patients with dementia: a meta-analysis. Journal of Clinical Nursing 22, 9–10: 1203–1216. 10.1111/jocn.12166

[101]. Vink Annemieke C Marij, Boersma Froukje, De Jonge Peter, Zuidema Sytse, and Slaets Joris. 2013. The effect of music therapy compared with general recreational activities in reducing agitation in people with dementia: a randomised controlled trial. International Journal of Geriatric Psychiatry 28, 10: 1031–1038. 10.1002/gps.3924 [PubMed: 23280604]

[102]. W3C- Cognitive Accessibility Task Force. 2014. Gap Analysis/Aging and Dementia. Retrieved April 28, 2020 from https://www.w3.org/WAI/GL/taskforces/coga/wiki/Gap_Analysis/Aging_and_Dementia

[103]. Wallace Jayne, John McCarthy Peter C. Wright, and Olivier Patrick. 2013. Making design probes work. In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems - CHI '13, 3441. 10.1145/2470654.2466473

[104]. Wallace Jayne, Thieme Anja, Wood Gavin, Schofield Guy, and Olivier Patrick. 2012. Enabling Self, Intimacy and a Sense of Home in Dementia: An Enquiry into Design in a Hospital Setting. In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '12), 2629–2638. 10.1145/2207676.2208654

[105]. Wallace Jayne, Wright Peter C, McCarthy John, Green David Philip, Thomas James, and Olivier Patrick. 2013. A design-led inquiry into personhood in dementia. In Proceedings of the 2013 CHI Conference on Human Factors in Computing Systems - CHI '13, 10.

[106]. Wallace Jonathan, Mulvenna Maurice D., Martin Suzanne, Stephens Sharon, and Burns William. 2010. ICT Interface Design for Ageing People and People with Dementia. In Supporting People with Dementia Using Pervasive Health Technologies, Mulvenna Maurice D. and Nugent Chris D.(eds.). Springer London, London, 165–188. 10.1007/978-1-84882-551-2_11

[107]. Wan Lin, Müller Claudia, Randall Dave, and Wulf Volker. 2016. Design of A GPS Monitoring System for Dementia Care and its Challenges in Academia-Industry Project. ACM Transactions on Computer-Human Interaction 23, 5: 1–36. 10.1145/2963095

[108]. Wan Lin, Müller Claudia Volker, and Randall David William. 2014. Addressing the subtleties in dementia care: pre-study & evaluation of a GPS monitoring system. In Proceedings of the 32nd annual ACM conference on Human factors in computing systems - CHI '14, 3987–3996. 10.1145/2556288.2557307

[109]. Welsh Daniel, Morrissey Kellie, Foley Sarah, McNaney Roisin, Salis Christos, McCarthy John, and Vines John. 2018. Ticket to Talk: Supporting Conversation between Young People and People with Dementia through Digital Media. In Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems - CHI '18, 1–14. 10.1145/3173574.3173949

[110]. World Health Organization. 2019. Dementia. World Health Organization. Retrieved April 2, 2020 from https://www.who.int/news-room/fact-sheets/detail/dementia

[111]. World Health Organization and Alzheimer's Disease International. 2012. WHO | Dementia: a public health priority. Retrieved January 28, 2020 from http://www.who.int/mental_health/publications/dementia_report_2012/en/

[112]. Zanwar Preeti, Heyn Patricia C., McGrew Greg, and Raji Mukaila. 2018. Assistive technology megatrends to support persons with alzheimer's disease and related dementias age in habitat: challenges for usability, engineering and public policy. In Proceedings of the Workshop on Human-Habitat for Health (H3) Human-Habitat Multimodal Interaction for Promoting Health and Well-Being in the Internet of Things Era - H3 '18, 1–9. 10.1145/3279963.3279971

[113]. Zolyomi Annuska and Snyder Jaime. 2020. Early adopters of a low vision head-mounted assistive technology. ACM SIGACCESS Accessibility and Computing, 122: 2:1. 10.1145/3386410.3386412

CCS CONCEPTS

• **Human computer interaction (HCI)** → HCI theory, concepts and models.

Table 1:

Participants with Dementia Demographic Information

PID	Age	Ethnicity	Country	Gender	Type of Dementia
ID1	63	Caucasian	UK	male	Mixed Vascular Dementia/Alzheimer's
ID2	65	Caucasian	UK	female	Alzheimer's
ID3	58	Caucasian	US	male	Lewy Body
ID4	60	Caucasian	US	female	Subcortical Dementia
ID5	57	Caucasian	US	female	Younger Onset Alzheimer's
ID6	59	Caucasian	US	female	Vascular Dementia
ID7	67	Caucasian	US	male	Vascular Dementia
ID8	67	Caucasian	US	female	Major Neuro-Cognitive Impairment
ID9	61	Caucasian	UK	male	Lewy Body
ID10	61	Caucasian	US	male	Alzheimer's/Semantic Dementia
ID11	59	Caucasian	US	male	Alzheimer's/Vascular Dementia

Table 2:

Practitioners Demographic Information

PID	Age	Ethnicity	Country of Practice	Type of Practitioner	Years of Experience
Pr1	70	Multi-ethnic	US	Occupational Therapist	4
Pr2	31	Caucasian	US	Occupational Therapist	5
Pr3	31	Caucasian	US	Occupational Therapist	8
Pr4	32	Caucasian	US	Occupational Therapist	8
Pr5	54	Caucasian	US	Speech Language Pathologist	30
Pr6	30	Caucasian	US	Activities Service Supervisor	7
Pr7	56	Caucasian	US	Activities Director	12
Pr8	61	Caucasian	US	Life Style Director	15
Pr9	56	Caucasian	US	Life Enrichment Associate	15
Pr10	58	Caucasian	US	Activities Service Provider	4
Pr11	26	Asian	US	Memory Care Activities Coordinator	4
Pr12	54	Caucasian	US	Gerontologist Consultant	30
Pr13	53	Caucasian	US	Occupational Therapist	20
Pr14	55	Caucasian	Canada	Executive Community Director	30
Pr15	40	Caucasian	Canada	Manager of Community Development and Engagement	12
Pr16	39	Caucasian	US	Director of Adult Day Care and Respite	20
Pr17	52	Caucasian	US	Dementia Consultant/Advocate	20
Pr18	62	Caucasian	US	Director of Quality Assurance and Education	46
Pr19	42	Caucasian	US	Dementia Care Educator	3