

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

Emma Dixon

Information Studies, University of Maryland, College Park,
Maryland, US
eedixon@umd.edu

Amanda Lazar

Information Studies, University of Maryland, College Park,
Maryland, US
lazar@umd.edu

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.

CCS CONCEPTS

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

KEYWORDS

Dementia, Sensory Changes, Everyday Technology, Personalized Technology

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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.].

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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.].

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 experiences 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

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

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 off 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 off. 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 voracious 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 dictate 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 off 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 fit 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.

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