# ABSTRACT

Title of Dissertation: *INVESTIGATING THE USE OF EVERYDAY TECHNOLOGY AND WAYS TO IMPROVE ITS ACCESSIBILITY FOR PEOPLE WITH MILD TO MODERATE DEMENTIA*

Emma Elizabeth Dixon, Doctor of Philosophy, 2022

Dissertation directed by: Dr. Amanda Lazar, College of Information Studies

Individuals living with dementia experience changes in their cognitive, motor, and sensory abilities. These changes in ability invariably affect the way people with dementia use technology. Past work on technology use in the dementia context has found technology use is primarily driven by and benefits caregivers rather than the person living with dementia. Further, much of this past work asserts technology use by people with dementia is only feasible when caregivers are able to provide the necessary technical support to aid the person with dementia.

In my dissertation, I provide an alternative perspective. First, I uncover ways technology savvy individuals in the mild to moderate stages of dementia use everyday technologies to manage their daily lives. Findings from this study begin to describe some barriers to technology use participants experience as their abilities change. In the second study of this dissertation, I examine the barriers people with dementia experience due to changes in sensory ability and describe ways these changes can negatively affect technology use. With this understanding of the

sensory barriers that people with dementia experience with technology use, the third study of this dissertation uncovers ways people with dementia and healthcare professionals adapt technology to address changing sensory needs, as well as limits in adaptability of commercially available systems that can lead to cessation of technology use. Finally, in the fourth study of my dissertation I investigate opportunities for the design of future systems that are accessible to people with dementia as they experience progressive changes in ability. Taken together my dissertation takes first steps towards addressing the following research questions:

- How do technology savvy people living with mild to moderate dementia use technology to manage their daily life and condition?
- What barriers do people living with mild to moderate dementia experience with technology use?
- What adaptations are people making to commercially available systems to meet the changing accessibility needs of people with dementia?
- What opportunities are there for technology to support people with mild to moderate dementia as they encounter challenges with technology use?

INVESTIGATING THE USE OF EVERYDAY TECHNOLOGY AND WAYS TO IMPROVE ITS ACCESSIBILITY FOR PEOPLE WITH MILD TO MODERATE DEMENTIA

by

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# Dedication

To my husband, Connor Dixon, for his unwavering support that made this dream a reality

To my mother, Kimberly Zerbst, a true champion of education, who instilled in me the love of discovery and the ambition to use my skills to make the world a better place

To my father, David Scharett, for the consistent reminders to enjoy the journey

And to God: "for the Lord gives wisdom; from His mouth comes knowledge and understanding" Proverbs 2:6

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# List of Abbreviations

| | |
|---|---|
| HCI | Human Computer Interaction |
| NIH | National Institute of Health |
| CHI | Computer Human Interaction |
| WHO | World Health Organization |
| DEEP | Dementia Engagement and Empowerment Project |
| GPS | Global Positioning System |
| AI | Artificial Intelligence |
| WCAG | Web Content Accessibility Guidelines |
| W3C | World Wide Web Consortium |
| IRB | Institutional Review Board |
| IOT | Internet of Things |

# Chapter 1: Introduction

The central focus of this research is to understand the ways people with mild to moderate dementia use technology to manage their daily life and condition, the barriers they encounter with technology use, ways they work to overcome these barriers, and design opportunities to address these barriers in order to prolong their use of technology. This dissertation consists of four interconnected studies.

Through an initial semi-structured interview study (Chapter 2) with technology savvy people with mild to moderate dementia (N = 17), I identified a group of people who use socio-technical systems to help manage their condition. Not only do they use technology within these systems, but in this study, participants also demonstrated they are inventive creators, often making adaptations to devices and systems of devices to help them manage their condition. Additionally, participants in this study described a few barriers to technology use they experienced as their abilities changed, such as having to rely more on others to help with updating devices and setting up new devices, which they did not see as ideal.

Following this thread of understanding barriers to technology use, the second study in my dissertation (Chapter 3) investigates the sensory changes people with dementia experience and the effect of these changes on their technology use. In this study, I conducted a thematic analysis of previously collected interview data from the interviews conducted for Chapter 2 of this dissertation, previously collected data from 19 interviews with healthcare professionals who worked primarily with people with dementia, as well as conducted an additional 5 interviews with people with subjective cognitive decline (N = 41). Through this analysis, I outlined how changes in vision, hearing, speech, dexterity, proprioception, and smell can cause barriers to technology use for people with dementia.

With a better understanding of the sensory barriers people with dementia can experience with technology use, in Chapter 4 of this dissertation, I describe an analysis of semi-structured interviews with 11 people with mild to moderate dementia and 19 healthcare professionals (N = 30) where I identify technological strategies that are useful for people with mild to moderate dementia to accommodate their fluctuating sensory needs. These strategies included using technology to be stimulated at a desired level, adjusting technology using existing accessibility settings originally designed for people with other disabilities, and switching devices. I also learned that when overstimulation could not be avoided, technologies did not have adjustable settings, and alternative technologies could not be found, participants ceased to use certain devices. This work uncovers ways commercially available products are limited in their adaptability to meet the changing accessibility needs of people with dementia.

Therefore, in Chapter 5 of this dissertation I conducted 14 interviews with people with mild to moderate dementia (N = 14) to investigate their ideas for future systems to support the changing accessibility needs of people with dementia with the progression of the condition. This study uncovers design opportunities such as the potential of utilizing context-aware adaptive user interfaces, proactive technological support, and activity-centric computing to support people with mild to moderate dementia as they experience progressive changes in ability and encounter new challenges with technology use.

The findings from these studies demonstrate how people with dementia can be capable technology consumers, inventive creators of technology systems to manage their condition, and innovative in generating ideas for future technologies to meet their changing needs. Therefore, this research contributes to the literature by providing an alternative perspective to past work [13,105,106], which largely positions people with mild to moderate dementia as incapable of and apathetic towards technology use. Taken together, this work opens up new directions for the design of future systems for people with dementia that focus on augmenting and enhancing the abilities of individuals living with dementia as they progress with the condition.

## *Background: Why focus on technology use by people with mild to moderate dementia?*

Dementia is an umbrella term for conditions which cause changes in cognitive, motor and sensory functioning beyond what might be expected from normal ageing [344]. There are nearly 55 million people worldwide living with a diagnosis of dementia – as well as a projected 10 million new cases each year [343]. Dementia is often described as involving cognitive decline and affects domains such as memory, thinking, comprehension, learning capacity, language, judgment and ability to perform everyday tasks [344]. Not only does dementia affect one's cognitive abilities, but recent work has shown that people living with dementia also experience serious changes in sensory and motor abilities which affect every day functioning [133].

Although there are general changes in ability people living with dementia experience, dementia affects each person uniquely. This uniqueness is in part due to the many different forms of dementia. Some of the more well-known and researched forms of dementia include Vascular dementia, Lewy bodies, Frontotemporal dementia, and the most common form Alzheimer's disease [344]. Additionally, mixed forms of various types of dementia are common [344].

The uniqueness of the effects on someone living with dementia's functional abilities is also in part due to the stage of dementia they are in. The NIH's function-based stage classification include mild, moderate and severe dementia [220]. People in the mild stage of dementia may start to experience difficulty with some combination of the following: remembering names, coming up with the right word, difficulty performing tasks, increased trouble with planning, and misplacing belongings [220]. People in the moderate stage of dementia may experience some combination of the following: deepening confusion, forgetfulness of events or personal history, becoming lost, needing help with some daily activities, and personality or behavioral changes [220]. People in the severe stages of dementia may be unable to communicate verbally, have difficulty swallowing, and no longer be able to recognize close relatives or friends [220].[1]

Although these stages are often presented as distinct, in reality, abilities are fluid. For example, someone could experience more difficulty with a certain task one day - demonstrating a more moderate stage – and the next day they may be much

[1] These are not meant to be comprehensive lists of all symptoms and changes people with dementia experience. But, they do provide a picture of some of the changes in ability people with dementia experience

more able to complete the same task – demonstrating a more mild stage. In my research, I've found that this fluctuation in ability can happen hour to hour or moment to moment [79]. Although there may be fluctuations in daily ability, dementia is a degenerative condition, where there is currently no medical treatment or lifestyle change to indefinitely stop the progression and eventual complete loss of functional abilities.

For my dissertation, I focus on working with people who self-report a clinical diagnosis of dementia, including the specific type of dementia they were diagnosed with (e.g., Alzheimer's disease, Vascular dementia, etc.). Participants were also asked to self-report their clinically diagnosed stage of dementia. When participants with dementia did not know their clinically diagnosed stage, we asked them to self-assess their stage of dementia at the time of the study based on the categories we drew from the US Center of Disease Control and Prevention and National Institute of Aging's function-based stage classification [220,221,305]. These categories included subjective cognitive decline, mild cognitive impairment, mild, moderate, and advanced dementia as well as vignettes of functional changes associated with each of these categories (see [217,218,298]). Each category was read to participants where they indicated which best fit their functional abilities. Function-based stage classifications is a particularly relevant measure to technology use, as it indicates one's ability to carry out daily activities and tasks.

By understanding technology use, barriers to technology use, accommodation strategies, and design opportunities to provide the technical support to overcome these barriers, my work strives to facilitate sustained technology use by people with dementia. In doing so, I hope to take a small step towards making technology use more accessible [88] for people with mild to moderate dementia, meaning they can do what they need to do in a similar amount of time and effort as someone without dementia.

### *Problem Statement*

There has been very limited past work to understand technology use by people with mild to moderate dementia. Nygard's 2008 work in the aging and mental health literature, provides one exception [227]. In this work, Nygard provides a few reasons participants with dementia decided to utilize technology in their daily life including: self-initiated compensatory purposes, and as an enabler or hindrance of social interaction [227]. Nygard found that habit and familiarity with technology were not enough to sustain technology use, calling for studies to further understand the conditions necessary to facilitate technology use by people in early stages of dementia [227].

More recent work has sought to understand how people with dementia and their families personalize assistive technology to optimize care [13,105,106]. However, this work focuses primarily on the role of informal caregivers in facilitating technology use [13,105,106]. For example, Arntzen, Holthe, and Jentoft found that technology's integration with everyday life was dependent on the caregiver's willingness to engage with the technology [13] not the person living with dementia. Similarly, Gibson, Dickinson, Brittain, and Robinson found that technology use was driven by and mainly benefitted caregivers [106]. Much of this past work, with the exception of Nygard's work [227], positions the person living with dementia as uninterested in utilizing technology and completely dependent on their caregivers to facilitate technology use.

Research has also identified barriers that people living with mild to moderate dementia have to technology use such as the cost of devices [152], ethical issues [112,152], attitudinal aspects [112,152,251], condition related challenges [112,152,184,228,259], and technology related challenges [112,152,228]. This past work looking at barriers to technology use due to condition related challenges [112,152,184,228,259], largely focuses on cognitive challenges related to technology use. Though clinicians have researched the differences in sensory changes people experience due to dementia, which are different than normal age related sensory changes, for several decades [5,122,211,219,242,264]. We are missing an understanding of the specific ways that the sensory changes people with dementia experience affect their technology use, limiting our ability to accommodate the full breadth of changes this user group experiences.

We are also missing a nuanced understanding of the specific technical difficulties people living with mild to moderate dementia experience. Nygard and Starkhammar's 2007 work provides some insight into the specific barriers to technology use by people in the early stages of dementia, including problems with interpreting and understanding information from technology, and difficulty understanding technical assistance instructions [228]. With advancements in technology since the publication of Nygard's 2007 work (e.g., the 2007 release of the first Android and iPhone smartphone), there is a need to understand what technical barriers people living with dementia currently encounter and to what extent accommodations are available through commercially available systems to address these barriers.

Understanding these technical barriers and accommodation strategies are essential to designing future systems to provide the necessary technical support to combat these barriers. Research to date has largely placed the role of the provision of technical support on the informal caregivers of people living with dementia [70,106,147,148,193,213,223,251,267]. Although past research has suggested alternatives to the provision of technical support (e.g., adaptive or simplified systems for people with dementia [79,152]), to date, no research has investigated what people living with dementia want for the provision of technical support.

### *Objectives*

I conducted four studies for this research, and the overarching goals for this work are as follows: (1) To investigate ways more technologically savvy people with mild to moderate dementia are using technology to yield insights into the potential benefits of technologies that might exist when adopted by a broader audience of users with dementia; (2) To outline ways changes in sensory ability affect technology use for people with dementia in unique ways to the typical sensory changes people experience with aging; (3) To examine ways existing commercially available systems are being adapted to meet the changing accessibility needs of people with dementia, as well as the limitations to these adaptations; and (4) To uncover new directions for the design of future systems to better support the fluctuating accessibility needs of people with dementia.

*Research Questions*

The specific overarching research questions and sub-research questions driving each study in this dissertation are:

Study 1 (Chapter 2): "Taking care of myself as long as I can": How People with Dementia Configure Self-Management Systems [80]

RQ1: How do technology savvy people living with mild to moderate dementia use technology to manage their daily life and condition?

> 1a: What considerations do tech-savvy people with mild to moderate dementia take into account while configuring and customizing their self-management systems?

Study 2 (Chapter 3): Understanding How Sensory Changes Experienced by Individuals with a Range of Age-Related Cognitive Changes can Effect Technology Use [77]

RQ2: What barriers do people living with mild to moderate dementia experience with technology use?

> 2a. How do sensory changes people with age-related cognitive changes experience affect their technology use?
>
> 2b. What differences, if any, does different stages in the progression of age-related cognitive changes have on the effects of sensory changes on technology use?

Study 3 (Chapter 4): The Role of Sensory Changes in Everyday Technology use by People with Mild to Moderate Dementia [79]

RQ3: What adaptations are people with lived and professional experience with dementia making to commercially available systems to meet the changing accessibility needs of people with dementia?

3a. What are the limits, if any, of commercially available systems to accommodate the changing accessibility needs of people with dementia?

Study 4 (Chapter 5): Mobile Phone Use by People with Mild to Moderate Dementia: Uncovering Challenges and Identifying Opportunities

RQ4: What opportunities are there for technology to support people with mild to moderate dementia as they encounter challenges with technology use?

4a. How do people with dementia use their mobile phones?

4b. What, if any, pain points or barriers exist in completing tasks on mobile phones?

4c. What opportunities are there for technology to support people with dementia when they encounter challenges with their mobile phone use?

*Structure of the Dissertation*

The following four sections of the dissertation are comprised of my four published articles. Each chapter includes subsections that describe in detail the motivations for the study, related work, methods employed, limitations of the study, findings, and discuss implications of the work. In Chapter 2, I examine every day technological use by technology savvy individuals in the mild to moderate stages of dementia to understand ways they configure socio-technical systems to support the management of their daily lives. The results of this study have been published in the Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems (CHI'21)

[80]. In Chapter 3, I analyze interviews with people with age-related cognitive changes and healthcare professionals to investigate the effects of different sensory changes on technology use. The results of this analysis are accepted for publication in a Special Issue of the Journal ACM Transactions on Accessible Computing in 2022 [77]. In Chapter 4, I investigate ways people with dementia and healthcare professionals who work primarily with people with dementia adapt commercially available systems to meet changing accessibility needs, as well as the limits to these adaptations which ultimately led to cessation of use. This work is published in the 22nd International ACM SIGACCESS Conference on Computers and Accessibility (ASSESTS'20) [79]. In Chapter 5, through semi-structured interviews with 14 people with mild to moderate dementia I work to understand what people with dementia envisioned for future more accessible and supportive technologies. This manuscript is under review for publication. Finally, in Chapter 6, I conclude this dissertation by summarizing the contributions of this work and discussing future next steps.

# Chapter 2: "Taking care of myself as long as I can": How People with Dementia Configure Self-Management Systems

This chapter appears in the proceedings of the 2021 CHI Conference on Human Factors in Computing Systems: Dixon, Emma, Anne Marie Piper, and Amanda Lazar. "'Taking Care of Myself as Long as I Can': How People with Dementia Configure Self-Management Systems." In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems*, 1–14. Yokohama Japan: ACM, 2021. https://doi.org/10.1145/3411764.3445225.

Self-management research in HCI has addressed a variety of conditions. Yet, this literature has largely focused on neurotypical populations and chronic conditions that can be managed, leaving open questions of what self-management might look like for populations with progressive cognitive impairment. Grounded in interviews with seventeen technology savvy people with mild to moderate dementia, our analysis reveals their use of technological and social resources as part of the work of self-management. We detail how participants design self-management systems to enable desired futures, function well in their social world, and maintain control. Our discussion broadens the notion of self-management to include future-oriented, sociotechnical, self-determinate design. We advocate for expanding the way technologists, designers, and HCI scholars view people with mild to moderate dementia to recognize them as inventive creators and capable actors in self-management.

*Introduction*

Self-management is the ability to manage the symptoms, treatments, and lifestyle changes necessary to live with a chronic condition [21,22,31,71,87,157]. HCI researchers have studied self-management strategies [71,166,225,226,297] and designed technologies to support self-management through tracking symptoms and triggers [47,114,319]. The majority of HCI self-management research has focused on chronic illnesses with symptoms that can be regulated given the proper support and medications (e.g., diabetes [186,238,247]). The goal is often to facilitate behavior change so that individuals can cease using the self-management technology [182]. But, researchers are beginning to study self-management for progressive medical conditions requiring continued support, such as Multiple Sclerosis [15–17] and Parkinson's Disease [224,226]. This work has found that self-management technologies largely neglect the mundane tasks that constitute a great portion of daily self-management of a chronic condition [224–226]. Much work is needed to understand every day, technologically mediated self-management for the increasing number of people with chronic conditions.

One growing area of interest in everyday self-management involves neuro-divergent populations, particularly since self-management research has largely focused on neurotypical populations. Some researchers have begun to work with people on the autism spectrum [149,261,276], primarily to support adolescents in behavior change (e.g., to regulate emotions and form new communication habits with parents [149,261]. Yet, cautionary pushback has emerged, pointing out that these interventions require neuro-diverse people to adhere to dominant social practices without considering their wishes [337]. In this paper, we turn to how people with dementia themselves choose to engage in self-management, and discover how dominant social practices shape the way that people invent their own self-management workflows and systems.

Since dementia is a progressive condition that affects cognitive functioning [344], with no medical treatment or lifestyle change to indefinitely stop the progression, and involves non-typical cognition, it presents an important case in the study of self-management. Dementia advocates define the self-management of dementia as: “a person-centred approach in which the individual is empowered and has ownership over the management of their life and condition. The role of health and social care providers is to support the person’s journey towards living well in the presence or absence of symptoms” [299]. Until about a decade or so ago, the concept of self-management in dementia was not widely accepted: people with dementia have been traditionally viewed as “a body to be managed” [25] rather than as social actors in their own lives [40] who are able to establish priorities and make decisions about their daily activities [221,306]. Further, people often stop viewing individuals who have been diagnosed with dementia as able to make choices and exert agency, effectively limiting their ability to do so – when with support, continued engagement in everyday life and self-management may be entirely possible [292]. Dementia activists and researchers have begun pushing back on these views, arguing that people with dementia have many years in which they can meaningfully manage their condition [43–45,189,209,292,296]. This perspective calls attention to the ways that people often equate a dementia diagnosis with symptoms of someone in the end stages of dementia [25,210,291], where self-management can become difficult or impossible. Past research has begun to identify which areas of living with dementia can involve self-management (e.g., maintaining an active lifestyle) [190] as well as how to design social interventions to teach people with dementia self-management strategies [57,209,210,245,246]. Throughout this paper, we anchor on the definition of the self-management of dementia put forth by dementia advocates [299], which emphasizes empowerment and self-determination of the individuals living with the condition.

Through analysis of interviews with seventeen technologically savvy people with mild to moderate dementia, this paper makes three primary contributions. First, we fill an empirical gap by centering our study around how people with dementia use technology to engage in self-management. Second, we detail how participants configure their self-management systems with consideration for the future, the social world in which they live, and maintaining control over their self-management systems. Finally, based on these findings, we discuss a broader view of self-management that includes the design of future oriented, socio-technical, and self-determinate systems. With this work, our aim is to further expand the way the field of HCI sees people with dementia, shifting perspectives towards understanding and viewing people with dementia as capable consumers and inventive creators of their own self-management systems.

*Related Work*

Below we summarize research on self-management of chronic conditions in HCI, drawing out how researchers engage with the concept self-management; describe research in the broader health and dementia literature on the self-management of dementia; and describe past research on technology design for people with dementia.

### Self-management in HCI

People are becoming increasingly involved in managing their own care of chronic illnesses, a task referred to as self-management. Researchers in the HCI literature define self-management as "manag[ing] the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent to living with a chronic condition" ([21] cited in [22,31,71,87,157]). This past work examines technology for self-management for a range of conditions, including rosacea [47], chronic fatigue syndrome [71], arthritis [114], chronic respiratory conditions [297], heart failure [319], and diabetes [186,238,285]. Past work has focused on understanding self-management strategies [71,166,225,226,297], designing tools to identify symptom triggers [47], and tracking activity [319] to provide clinicians with data to personalize care plans [114].

Less research is focused on progressive conditions or neuro-divergent populations. One exception is Ayobi et al.'s work with people with Multiple Sclerosis [15–17]. This research points to the need for self-tracking technologies to be designed for agency and not "persuasion and compliance" [16]. A similar critique has emerged in response to self-management research for autism for attempting to train children to adhere to dominant social practices without considering their agency [337]. Another critique of existing approaches to self-management emerged in research studying the self-management practices by people with Parkinson's Disease [224,225], which characterizes past work as taking a medicalized view of self-management that leads to a primary focus on symptom tracking while ignoring everyday life management [87,224–226,313]. This research urges researchers to shift to an understanding of "the practical work of patients" by "observing practices that contribute to self-knowledge and decision making in everyday life" [225] – a call to which our work responds.

### Self-management of Dementia

Scholarship on self-management in dementia is fairly recent and comes from research outside of HCI. Martin et al. labeled the main target areas for the self-management of dementia (e.g., relationship with carer, psychological well-being) [190]. Barriers to self-management perceived by people with dementia, caregivers, and clinicians include societal stigma of dementia affecting people's ability to self-manage [188], a lack of general public's education about dementia [210], and the failure to understand that people with dementia actually have many years in which they can meaningfully manage their condition before needing full external support [189,292]. Additional obstacles in self-management include negative self-image and diminished self-esteem resulting from role shifts in relationships (e.g. when a person with dementia becomes a receiver of care, instead of caring for a child) [188,210]. Our research investigates the strategies people with dementia devise to overcome such obstacles and maintain more balanced relationships with care partners.

The self-management literature for dementia largely focuses on group programs or learning experiences [57,189,209,210,245,246]. These self-management group interventions have been found to increase people with dementia's self-efficacy [246], confidence [283] and cognitive functioning [154]. People with dementia themselves have published literature since the 1990s advocating for their human rights, agency, and ability to manage their condition [43–45,201,292,296]. Dementia advocacy groups have published informative booklets and programs outlining practical steps people with dementia can take to self-manage their condition [299]. In these past interventions and resources, references to technology are limited or not described at all. Our work offers a view of the role technology can play to assist people with dementia in self-managing their daily lives with this condition.

### Assistive Technology for Dementia

Past research has looked at open technological opportunities to support caregivers and people living with dementia at home [335,336]. These opportunities typically focus on assisting people with dementia in completing activities of daily living [336,346]. One area that has been extensively examined is technologies to assist in the task of navigation to prevent individuals from becoming lost [129,168,255]. The COGKNOW day navigator [213], which consisted of a tablet linked to sensors and computer-mediated controls throughout the home, aimed to provide reminders and support in activities of daily living [213]. Similarly, the ReACT application was developed to enhance memory and provide structure to daily life by providing a calendar that interacted with other planning features (e.g. diary, checklists, contacts, etc.) [232]. Other research focuses on assisting people with dementia to complete routine activities by providing step-by-step instructions to assist with specific tasks (e.g. hand washing [199], brushing teeth, dressing [30], and cooking [336,340]). Still others use AI-based reminder systems to provide proactive assistance, such as the Robin system, which verbally prompts users to do tasks programmed in their schedule (e.g. taking overdue medication) [51]. Rather than prompting users to complete tasks, Donaldson's conceptual design envisions hidden sensors throughout the home to recognize incomplete tasks (e.g. flushing the toilet) and complete the missed steps without user involvement [82].

Past research has also reviewed the assistive technologies currently available to people with dementia [107,113,194,257], finding assistive technology use is driven by [13,106,232] and mostly benefits caregivers [13,105]. Research to develop assistive technologies to support individuals living with dementia in managing their condition focuses on the design and testing of prototypes without directly addressing technology adoption and dissemination [231]. Further, Øksnebjerg et al. report the literature is "lacking a holistic approach to the dynamic interrelationship between technology, user, and context" [231]. In our work, we aim to fill this gap by providing a holistic view of tech-savvy people with mild to moderate dementia's priorities and preferences for the adoption of assistance (both technically and socially mediated) within the self-management systems they design.

### *Method*

Below, we present our approach to data collection, participant demographics, analytic approach, and limitations.

#### Procedures

We recruited people with dementia through our networks, which include large dementia advocacy organizations, and snow-ball sampling. Initial contacts were made at a large dementia organization conference in 2019. These participants then shared our study information with other tech-savvy people they knew in their online support groups as well as on Twitter. To qualify for the study, participants had to self-report a diagnosis of mild to moderate dementia and regular use of technology[2]. We chose to focus on individuals already using technology as a way to discover issues that may be exacerbated or even impossible for less technology savvy users [286] and to yield insights into the potential benefits of technologies that might exist when adopted by a broader audience [348]. Although we do not claim these participants use technology in a way that is representative of the general population of people with dementia, there appears to be a trend towards greater technology use by individuals with dementia: recent work found that 54.14% of people with mild cognitive impairment or dementia reported using their smart phones and tablets almost every day [117].

After initial contact with recruited participants, each potential participant was screened to ensure their ability to give informed consent using the UC Davis Alzheimer's Disease Center procedures [307]. When capacity to consent was verified and the interview was scheduled, we emailed participants interview protocols and verbal consent forms three days before their interview. This was to give participants time to go through materials and have any questions they had about the study answered. All interviews were conducted remotely using Zoom, with the exception of Helen, whose interview was conducted in person in the fall of 2019. Participants had the option to participate in the interview with their partners or carers, but all opted

[2] All participants self-reported a clinical diagnosis of dementia including the specific type of dementia they were diagnosed with (e.g., Alzheimer's disease, Vascular dementia, etc.). Participants were also asked to self-report their clinically diagnosed stage of dementia. When participants with dementia did not know their clinically diagnosed stage, we asked them to self-assess their stage of dementia at the time of the study based on the categories we drew from the US Center of Disease Control and Prevention and National Institute of Aging's function-based stage classification [220,221,305]. These categories included subjective cognitive decline, mild cognitive impairment, mild, moderate, and advanced dementia as well as vignettes of functional changes associated with each of these categories (see [217,218,298]). Each category was read to participants where they indicated which best fit their functional abilities. Function-based stage classifications is a particularly relevant measure to technology use, as it indicates one's ability to carry out daily activities and tasks.

out. Several participants with moderate dementia had their partner sitting nearby during the interview in case of technical difficulties with Zoom. This was useful when one participant lost connection and had trouble navigating back to Zoom and another had trouble with their Bluetooth headphone audio connection.

Directly before starting the interview, any questions participants had were answered before they gave verbal consent to participate in the study. Each semi-structured interview was approximately one hour and was audio/video recorded. Interviews were conducted between March 2019 and May 2020. The interview protocol was structured to broadly understand participants' technology use (see supplementary materials for interview questions). The semi-structured nature of the interview allowed us to ask further probing questions when necessary, and to pursue topics, guided by the informants themselves. During the study, we were careful to avoid situations where individuals might show us personal account information while describing technology use. Following each interview, participants received a $20 Amazon gift card. All procedures were approved by our University Institutional Review Board.

### Participants

Seventeen participants with mild to moderate dementia, with an average age of 62.5 years old (range 55-73) completed the interviews (see Table 1 for additional demographics). Participants included individuals who identified as dementia advocates and others who were a part of advocacy organizations' peer-support groups but were not participating in active roles within these organizations.

*Table 1: Chapter 2 Participant Demographic Information*

| Pseudonym | Age | Gender | Ethnicity | Country | Type of Dementia | Stage of Dementia |
|---|---|---|---|---|---|---|
| **Frank** | 63 | Male | Caucasian | UK | Mixed Vascular Dementia/ Alzheimer’s | Mild/Moderate |
| **Annette** | 65 | Female | Caucasian | UK | Alzheimer’s | Mild/Moderate |
| **Bill** | 58 | Male | Caucasian | US | Lewy Body | Mild |
| **Sharon** | 60 | Female | Caucasian | US | Subcortical Dementia | Unknown |
| **Helen** | 57 | Female | Caucasian | US | Younger Onset Alzheimer’s | Mild |
| **June** | 59 | Female | Caucasian | US | Vascular Dementia/ White Matter Disease | Mild/Moderate |
| **David** | 67 | Male | Caucasian | US | Vascular Dementia | Mild/Moderate |
| **Linda** | 67 | Female | Caucasian | US | Major Neuro-Cognitive Impairment | Mild/Moderate |
| **Arthur** | 61 | Male | Caucasian | UK | Lewy Body | Mild |
| **Phillip** | 61 | Male | Caucasian | US | Alzheimer's/Semantic Dementia | Mild |
| **Andrew** | 59 | Male | Caucasian | US | Alzheimer's/Vascular Dementia | Moderate |
| **Joseph** | 71 | Male | Caucasian | US | MCI[1] | Mild |
| **Griffin** | 67 | Male | Caucasian | Canada | Vascular Cognitive | Moderate |
| **Ben** | 59 | Male | Caucasian | US | Early Onset Alzheimer’s | Mild |
| **Luke** | 61 | Male | Caucasian | UK | Vascular Dementia | Mild |
| **Jade** | 73 | Female | Caucasian | US | Vascular Dementia | Mild |
| **Everly** | 55 | Female | African-American | US | MCI[2] | Mild |

1. Joseph was originally diagnosed with Mild Dementia and has since been re-diagnosed as having Mild Cognitive Impairment (MCI). 2. Everly throughout the interview referred to herself as being in the early stages of dementia though when completing the demographics form, she reported being diagnosed with MCI.

## Analysis

Our approach to data generation and analysis drew from constructivist grounded theory [56]. We conducted interviews and analysis with three samples, which allowed us to refine the questions in our semi-structured interview protocol; we were thus able to elaborate on emerging themes in the data. The interview protocol used in the third sample of recruitment is included as supplementary material. After the first two interviews with Frank and Annette, we familiarized ourselves with the data by open coding the transcripts. Initial codes included: “offloading cognition to the device” and “technology for survival.”

After iterating on the interview protocol to probe these themes, we recruited and interviewed seven additional participants (Bill-Arthur). These interviews were then open coded to expand on the initial codes. Some examples of these additional codes include: “AI/Automation,” “humanity/normality,” “information retrieval/search,” “limiting technology,” “reliance on tech,” “memory problems and tools” and “tech for social situations.” Through an iterative process of memoing and research team discussions, connections between these open codes were drawn. This resulted in two major themes emerging from the data: 1) “sustaining everyday life through technology,” which included participants automating tasks in their life in order to continue to do things for themselves, and 2) “negotiating the boundaries of technological support,” where participants limited automation and technological assistance out of fear of losing abilities. Through further memoing and research team discussions, we began to realize that all participants were willing to use technology in some ways and hesitant in others. This concept was then probed deeply in the third sample of eight interviews (Phillip-Everly).

Interview transcripts from the third sample of interviews, were first open coded building on the codebook developed in the second interview sample. By the fifteenth transcript (Luke) we reached data saturation, as no new codes were added. All transcripts were then focused coded using the established codebook. During focused coding, many of the codes were rephrased to reflect the data more closely. For example, “Tech for social situations” was rephrased to “attending to the perceptions and preferences of others” and “humanity/normalcy” was rephrased to “fitting in and projecting normalcy.” Through a collaborative and iterative process considering different groupings of our focused codes, this resulted in the three major themes corresponding with the three sections described in the findings. The opening section of the findings is to provide context for readers by describing an overview of our participants perceptions and use of technology.

After each of the three samples of interviews and analysis, we sent drafts and summarized versions (which many preferred) to participants for comment and to check their views were accurately captured. We made minor changes based on comments from two participants, who provided further context to clarify the meanings of their quotes.

Part of the constructivist approach requires that we reflect on our position as researchers and the perspectives that we bring to the research [56]. We have been strongly influenced by the work done by dementia activists which calls attention to the ways that people with dementia are not adequately supported in caring for themselves and their condition [292]. Similarly, our analysis is shaped by notions of interdependence, which centers people as agents in securing access to resources [27]. Additionally, our intention is to align with the critical dementia perspective, which calls for an epistemological shift in technology design to valuing the ways people with dementia experience the world [160]. And yet, the findings presented in this work could be perceived as deficit-driven in their focus and thus in tension with this perspective. We resolve this tension in situating our work within Frauenberger’s critical realist perspective of disability and technology, which recognizes the multifaceted approach to understanding the experiences of disability and “points very pragmatically to different ways in which the lives of people with disabilities can be improved” [97]. By representing our informant’s views as they were expressed, reacting to their social positioning as people living with dementia in a hypercognitive society that values self-sufficiency, we aim to compliment and even extend past work to inform the design of future technologies to better align with the way people with dementia experience the world [160].

### Limitations

The average participant age was 62.5 years. Dementia diagnosed under the age of 65 is considered early onset [1], representing 9% of diagnoses [342]. This relatively younger group of participants may be overrepresented in our research due to the hesitance of the general population to self-identify as a person living with dementia due to stigma [25,291] that can lead to unwillingness to discuss experiences with researchers [279]. As many of our participants were active in various dementia advocacy organizations, these participants appear to be a part of the rise of the “young, active person with dementia” involved in publicly sharing information about their condition with researchers [55]. The recruitment requirement that participants had to use technology regularly may also have led to a relatively younger group of participants [26,229].

The limited racial diversity of participants is another limitation of our study. Nearly all of our participants identified as Caucasian. Research shows a higher prevalence of dementia in the African American and Latinx communities [8], [8]which was not represented in our participant pool. Researchers have suggested several barriers in research recruitment of different ethnic groups such as lack of trust in research due to a history of ethical issues [74,89], institutional barriers to education [192], and stigma consciousness [192]. There is a need for further work to ensure that research includes more diverse demographics of people with dementia. Finally, our findings come primarily from participants residing in the United States, the United Kingdom, or Canada. Our findings are certainly influenced by the geographic and cultural settings of our primarily Western participants.

Given our study utilized a single interview, the scope of the data collected is limited to the perceptions and accounts of people with dementia. Further, interviews were conducted remotely, which made observing technology use difficult. As a result, we had to rely on participants' verbal explanation of their technology use, which can be arduous and suboptimal as an approach for some individuals with dementia.

*Findings*

Through our interviews, we learned of the complex and diverse ways that individuals design systems to support self-management in the face of changing abilities and perceptions of others. Participants describe technology as an integral part of their self-management systems: "from the dementia point of view it's a vital part of what I do" [Frank]. The language participants use to describe these technologies reveal their importance: Frank describes his smartphone as "my brain," Linda draws a parallel of her smart home devices to a "wheelchair ramp" and "cognitive prosthetic," while Everly says "My phone is my best friend." Others describe the smartphone as a "crutch" [Ben] or a "safety-net" [Andrew] to complete everyday activities, where without it, "I feel really lost in the desert" [Joseph]. Devices are constantly present.

Everly uses her phone “every day all day long” [Everly], and Joseph forgets “lots of things, but I never forget to have my phone.” Informants ensure devices are always nearby: Frank’s cellphone “never leaves my hand” [Frank], and Bill and Andrew bought an Apple Watch because it’s “always attached to me” [Bill], and so they can “ping” their phones if they lose track of them. Individuals’ self-management systems often rely on a number of interconnected devices, at times alongside or in place of human assistance, used in a particular sequence. Here, we provide a vignette describing how Arthur designed his self-management system so that he could engage in everyday self-management without burdening his wife, who works a full-time job:

> Arthur’s daily routine starts the night before, when his Amazon Alexa voice assistant reminds him to refill his teapot, which is connected to an Alexa-enabled smart plug. The teapot automatically heats up each morning, at which point his Alexa has been programmed to wake him up by saying “[Arthur], your tea is ready.” With his tea in hand, Arthur then receives his “flash briefing” from Alexa at the time in the morning which he’s previously specified. Following his news briefing, Arthur does a mindful exercise to “get rid of the cobwebs” followed by a longer set of games to promote neuroplasticity. When Arthur is ready to leave his home, he takes his tablet, selected because it is part of the Amazon ecosystem (“so I can take Alexa out with me”), creating a single, portable system. Arthur has a background in programming, which he draws on to “put routines into Alexa,” including reminders that use non-standard phrases – such as telling him "[Arthur], you

> need to have a shower or you will smell," which “works for me better than, ‘Today is Thursday. This is one of your shower days.’” He says he has designed a system, which “keep[s] me in that routine” that he has established to work within the context of his daily life and social relationships.

The above example does not involve Arthur’s wife, in part because the system was explicitly built to avoid burdening her. Other systems involve intertwined support from people and technology. The most striking example is Linda’s self-management “support system,” which consists of 20 hired caregivers along with a plethora of smart home devices. Although Linda uses these devices in many of the same ways as Arthur, she has also selected caregivers to assist her with better managing her health and activities of daily living, through support with physical training, home organization, geriatric health consultations, calendar management, and financial assistance. Through trial and error, Linda has “created this world over the last nine years,” where people and technology “all work together” to keep her “independent, upright, mobile, connected and safe.”

These examples emphasize the diversity of individuals’ self-management systems. Across all of the practices and strategies described by informants, we identified three central considerations in their design of self-management systems: (1) a future focused approach that recognizes and works with the progressive cognitive changes that they face; (2) socially-situated awareness of other people’s perceptions and needs; and (3) maintaining control over their self-management systems.

Future Proofing

Participants devise systems to support their self-management in the short term as well as the longer-term future, centered around an expectation that they could not rely on memory alone. Frank uses the term “future proofing” to describe the work of learning skills and putting systems in place to create a desirable future for himself. He describes this as “any advancements I can do now, I do, even though I don't necessarily need them now – because then it would be natural in the future when I do need it but couldn’t learn it.” Frank’s “advancements” include switching to a smart-phone and starting to use a Google Home. Individuals explain that the window of time in which future proofing is possible is finite, meaning that there is time pressure to put together effective self-management systems: “From what I understand... the earlier someone can start using something, the longer they'll retain it” [June]. Frank observes similar changes when he thought back to the self-management system he set up only a year before: “nearly all these things, all this stuff that I use and how I do it, I kind of put in place I suppose up to about a year ago. And, I don't think my capabilities to do the setting up are quite the same as they were a year ago.” Participants consider the short and long-term ramifications of their progressive condition and actively work to protect their desired future. They design to accommodate future cognitive changes by building redundancy in their systems; using devices to provide just-in-time information; and outsourcing tasks that are becoming increasingly difficult.

*Building Redundancy:* Not being able to depend on one’s memory means that it is essential to verify information through redundancy. Frank describes intentionally being hours early for an event because, “I've got it in my calendar for 1:30 but I couldn't find anything anywhere to back that up.” This caused distress for Frank who wasn’t sure if he actually had the meeting at that time, “as I was given that information (verbally) I was putting it into my phone into the calendar, right there and then. But I had nothing to back it up and that troubled me.”

Informants design for redundancy through prompts and information saved in devices and applications. Helen uses repeated alarms to be on time for social commitments: “by being reminded frequently of something it helps me to remember it and do it.” Others use reminder applications, such as Any.do, which will “kind of ping you” [June] until the task is done. Some use a combination of digital and physical resources: Annette has built a “this is me library,” which includes physical and digital spaces where she builds redundancy. As Annette explains, her study serves as a “memory room... [which has] paper cuttings, newspaper cuttings and all this. I ask people to send them (information) to me… then I put it on Facebook or Twitter.” Placing memories in a physical space and duplicating them online provides redundancy in her self-management system, which means that when Annette is uncertain she can “do a little investigation. There's the pictures and it says this date. I'll get my diary and have a look and I can build up a big picture of events that I was at. A bit like a Jigsaw you relate it all.” Building redundancy meant that individuals could triangulate to verify accuracy and recreate lost memories.

In the above example, Annette asks people to send her information for her “this is me library.” Other informants also involve social partners in building redundancy into their self-management systems. Ben puts reminders of important things to do throughout the day in his Outlook Calendar. But, “sometimes I'll, I'll forget to do something that's even on my calendar. I'll just overlook it. I've missed doctor's appointments” [Ben]. For this reason, his wife places sticky-notes throughout their house, including the bathroom mirror and the front door to provide redundant reminders. Several informants share calendars with others to build redundancy, including Jade: “the longer I have this in dementia, the more my short-term memory is erasing… I don't remember getting them [reminders from Google Calendar], but with [husband], he can know about it and, and, and just mentioned it to me maybe two or three times. So, right, it helps all the reminders you can get.”

*Providing Just-in-Time Information*: A second strategy used by participants to prepare for future events was building self-management systems that could provide just-in-time information. Here, participants are aware that they need to complete a particular task (versus redundancy, which was necessary to remind them of the task in the first place) – but they need a particular piece of information at a precise moment. Sharon explains, “the advantage of the technology is that it gives me the piece of information that I need contemporaneous with what I'm trying to accomplish.”

Several participants describe using their phone to provide “that bit of information” they need so that they can “move on” from their task [Joseph]. One of the most common needs for just-in-time information was in navigating outside of the home. Annette described times where she’s “gone somewhere and all of a sudden my mind is blank and I think, ‘Oh crikey, where am I?’” In these instances she, “look[s] at Google Maps and you can see where you are” [Annette]. By having previously saved her address as home in her Google Maps app, she can press the home button “and it gives you directions on how to get home!” [Annette]. Helen takes photographs of the exit signs for her metro stop on her phone. Then “while I'm still on the metro, I refreshed my memory by looking at the pictures,” which helps her be “more oriented to time and place when I got off the metro and better able to navigate to where I was going” [Helen]. Establishing these practices ahead of time, before leaving home, means that individuals are prepared to deal with moments of forgetfulness or disorientation.

Just-in-time information was particularly useful for tasks with multiple steps. Annette explains, “Doing a task takes lots and lots of different steps, you find with Alzheimer's what happens you can do one and two, four and five, the middle bit, you don't know… that's where technology is good because you think, ‘Alright, I've got this and that but what happens next?’” Though individuals describe using YouTube and Google to deliver those steps, they wanted future technologies to better facilitate just-in-time information for computer support, where “I could just hit a button and it would give me sort of those quick steps” or “simple instructions” [Ben] for basic computer tasks such as copy and paste. June even refers to the Window’s former “little wizard” that “popped up you know and he kind of walks around the screen waiting for me to click” so he could say, “how can I help?” David takes this one step further by imagining a future device that attaches to his head to give him just-in-time information.

*Outsourcing Tasks:* When designing self-management systems for future use, participants create workflows that enable them to outsource tasks that are becoming difficult given their changing abilities. This was particularly important for handling “bureaucratic administrative requirements,” or the “minutia of life, which is increasingly difficult” [Sharon]. Keeping track of time has become more challenging for Sharon, as she “can sit for five or six hours writing and working at my computer and not notice the time go by… it feels like 90 minutes or maybe a couple of hours, but six or seven hours could have gone by.” Sharon outsources the task of keeping track of time to her Apple Watch Breath App which “alert[s] me to time passage” as it tells her to move every two hours. Other participants outsource tasks using applications to help with finances and paying bills [Sharon, Helen, David], mathematical calculations [Annette, June], spelling [Annette, Helen, June, Luke], word-finding [Frank, David], navigating [Bill, Sharon, Helen, Griffin], and cooking [Annette].

Participants describe wanting to outsource to technology remembering birthdays and important events because as “events happen you don’t know how long ago you talked to that person or when they told you that, or really maybe who told you that" [June]. June shares “the worst part about of the dementia for me is missing or forgetting my friend fell and broke her ankle, and then I don't follow up or I'm not a part of when she has surgery.” As a solution to this June expresses the need for a “stay in the game app.” She gives an example of how this app might help her outsource some of the aspects of maintaining relationships, which had become increasingly difficult for her, such as “if it had on my calendar… ‘We’ve noticed that you haven’t spoken with [friend] in three weeks or so. May I suggest a call?’” [June]. This envisioned application would assist June in sustaining important relationships by outsourcing the task of remembering times and occurrences.

Participants also describe outsourcing tasks to social partners to prepare for the future. David explains that, “right now I’m trying to let her [wife] drive more when we’re together…it helps me cope with giving up that, that part of my life.” Many participants describe preparing for the future when they are no longer able to set up new technologies in their self-management systems by preemptively outsourcing this increasingly difficult task to other people. For example, Joseph explains how he now outsources upgrading the devices he uses in his self-management system to his nephew because “it's hard for me to retain” how to do updates and upgrades. While understood as necessary, these kinds of arrangements that shift participants to a more passive role in the development of their self-management systems were not seen as ideal.

### Self-management in a Social World

As the above excerpts begin to reveal, participants’ design of self-management systems is situated within a social context that involves partners, children, caregivers, and society more broadly. Below, we describe ways in which self-management systems are designed in response to and in the context of the social world.

*Fitting in and Projecting Normalcy*: Dementia is an enormously stigmatized condition [25]. Participants describe practices they employed to obscure the appearance of cognitive impairment in order to blend in socially and project normalcy. Luke has a Twitter account where he discusses politics and current affairs. To maintain credibility with his followers given the stigma of dementia, he manages another account “solely for talking about dementia” [Luke]. As we can see with this example, fitting into one's social world is often about appearing to have typical cognition. Frank uses Google Sheets to store "notes about people and previous meetings… You need their first name, their surname, their wife's name, where they live and these sorts of things." This approach lets him "compensate for the fact that I'm not going to remember things," as he "can look back through my research … and find out what I need to know about those people before going into the meeting, and it makes me appear better than I am" [Frank].

Using technology to "fit in" and conceal the presence of dementia extends to how people present themselves physically, whether through the way they dress or their behavior in public spaces. Annette, Sharon, and David express a desire for technology to help them manage their appearance to avoid the possibility of public scrutiny. Currently, Annette judges the appropriateness of her attire by looking outside "to see what people are wearing" so that she can blend in and dress appropriately for the weather, because she's no longer able to make these judgements on her own. However, this method is not always reliable. Similarly, Sharon expresses her desire for a device that could provide "social background information" including "how I need to be presented so that I can feel I can participate like everybody else." Social background information meaning, "How to dress… should I be dressed in a ball gown because it's going to be a formal affair" [Sharon]. This information would keep her from being labeled as different, even as her ability to pick up on cues are changing.

Helen uses technology to manage her appearance in a different way – when she is having a hard time navigating her public surroundings, she will "step to the side and just simply take my time and look" at her surroundings and the directions on her phone, while "still have[ing] a body posture of you know where you're going." She explains that though her phone helps with directions, simply looking at her phone with the right posture keeps her from giving off the impression of "act[ing] like you're lost, right? You become a victim at that point." Though technology was essential to self-management, including the management of other's perceptions, participants felt the need to hide from others the extent to which they depend on technology. June explains, "I don't run around and say, 'Oh my gosh I wouldn't be able to be here if I didn't have my cell phone and my calendar.'" She compares this to paying someone to provide a cleaning service, "if you have a cleaning lady and everyone that comes to your front door you don't say, 'Oh my house is immaculate because I have a cleaning lady.'"

*Managing Emotions to Avoid Negative Social Consequences:* Participants describe how dementia has changed their overall emotional well-being and how these emotional changes relate to their personal relationships. Ben describes how "most folks that know me, as a, as a parent, as a husband, as a leader in an organization. I think I was a… I'm a pretty good guy." However, he's "seeing less of that with me now, my frustration tolerance, I get frustrated very quickly. Angry, you know, I'll you know, throw a bunch of F bombs out and I'll bang my hand" [Ben]. By using technologies to manage emotional well-being or emotional appearance to others, participants maintain their social relationships and social status.

Luke, who had a separate account for political discussions on Twitter, took advantage of the asynchronous nature of the platform. He now "no longer join[s] in a conversation straight away" because "a lot of the time it (his tweet) doesn't come across the same way as I intended it. You know, it may come across as being flippant or aggressive or angry." By taking time before engaging, Luke can manage how he comes across to others. Other informants describe using technology to manage the increased frustration that accompanied living with dementia. Individuals use meditation apps [June, Arthur], the Apple Breathe App [Andrew], and listen to music [Andrew] for this purpose. Bill envisions an approach that would help him, a watch that could detect if he was agitated and automatically "send a signal to my smart home." That signal would trigger a prerecorded video of his wife speaking to him "that would help calm me down," or "send a text message to [wife] and she could call me." In this example, the combination of a technological setup and established practices with a social partner was envisioned to help restore a balanced emotional state.

Participants explain the frustration that difficulties with technology generates, but also how technologies can provide an outlet for negative emotion. Andrew links the centrality of technology in self-management systems with the level to which they could become frustrating: "Our devices, we become dependent upon them to help us through the day. But when they don't cooperate, it's, it's basically like, you know, why 'Why are you not helping me?'" [Andrew]. When participants reach this level of frustration Andrew describes, "You yell at 'em. I mean, you get you get upset because you know you (the device) are what I use in order to live my life, and to live my life as well as I possibly can." Andrew actually saw this frustration towards the technology as helping him maintain appropriate social relationships, as it provides an avenue to "take out" or "aim" his anger at a "non-human" rather than his partner. In this way, the technology is used as a sort of buffer for the relationship between a social partner or caregiver and the person with dementia.

*Attending to the Preferences of Others:* Participants actively consider the preferences of their loved-ones when designing their self-management systems. Everly wants to implement a smart home alarm device but remarks "my husband probably would not want me to have a smart home for opening the door because he'd be afraid that somebody probably would come in." Helen wants to implement an electronic geofence application to future proof for when/if she starts "wandering." With this application, the caregiver is alerted if the person with dementia leaves the perimeter of the electronic geo-fence and can then track them. However, her caregiver "wasn't ready for it" in terms of emotionally accepting that this kind of tool might be needed. Both Helen and Everly have held off on implementing these applications to care for the emotional needs of their loved ones.

This care for the needs of others extended into Arthur's thoughts about far-out technologies. Arthur envisions living on through AI using his "virtual memory system" where he could "transfer everything I knew, all my emotional content, into it. Because that would keep me, me." He elaborates that if "I had the option…I would go for it…But I don't think my wife would like it." He walks through the impact this might have on his wife, that this would be like "RoboCop coming home every night" and that's "not something that I think she'd want… I think she prefers me as I am." In this and the examples above, some technologies were off limits because of the preferences of loved ones, who would also be living with these technologies if they were to be implemented.

In other instances, technologies were used to appease the preferences of loved ones, even when individuals did not necessarily wish to include them in self-management systems. GPS tracking applications were often described in this way, with adult children concerned for their parent getting lost while walking. June and Griffin share their locations with their children using applications on their cell-phones. June at first found this “depressing.” But, by ensuring there was a mutuality of tracking, this helped her come to terms with this technology: “I track her too. I can see where she's at…you can see me and I can see you.”

Still in other situations, participants configured their self-management systems to avoid burdening loved ones. David and his wife moved in together with his daughter and son-in-law as a way to “relieve [his wife] with pressure” of being the sole form of support. Everly describes how she was considering implementing an approach to self-management suggested by another person with dementia, where, “alarms tells him everything he has to do for him.” She brought this up because she felt her husband “wants to go on vacation,” but “he's almost afraid to leave me because he feels like ‘If I'm not there, she can't do it.’” Similarly, Arthur explains: “My wife is too young to retire. She wants to work and go abroad and do stuff... I don't want to stop her doing that because of some stupid condition.” Arthur uses Alexa to provide the assistance his wife could provide but that he doesn’t want to burden her with, such as managing his daily schedule, medication, hygiene, and getting around town.

Maintaining Control

Even as informants incorporated others' preferences and created roles for social partners to play in their self-management systems, they took great care to maintain control over the technologies and social support they included. Helen explains she "continue[s] to remain in control" of her self-management system – her system is "just advising me... I'm in charge" of all decisions made concerning her self-management. Sharon acknowledges that it can be "tempting, especially for people with dementia, to let go of decision making, to let go of choices and problem solving and resolving confusion and chaos because it's so tiring." However, it is key to ensure that technology and others are not "leading them or guiding them in another direction than they would not naturally or willfully already want" [Sharon]. Participants expressed the need to be vigilant about both nefarious parties and well-intentioned others.

*Avoiding Nefarious Interference*: Participants avoided certain technologies that might otherwise fill a need in their self-management systems in order to prevent being exploited through scams or hacks. Luke has difficulty managing his finances, but is not comfortable with "using things like online banking, online shopping, things like that, because you know, it's open to exploitation," and attributes this risk as linked to changes in his ability to perceive the risk of certain online sites. Similarly, Helen no longer searches online for dementia related health information because her Google searches "just spits back a bunch of vendors sites that are advertising stuff and you get a preponderance of these bogus sites that are just selling miracle cures." To protect herself from falling for scams, she avoids searching for dementia related information online – meaning that she may be missing useful information to assist her in self-management. Other participants avoid technologies such as artificially intelligent (AI) devices, because of "the hack-ability, there could be some nefarious things that computers, laptops, if they are hacked and had this technology, it could get 'em [people with dementia] to do things that were not safe or against the law or something like that" [Griffin]. Phillip also expresses his concern for AI: "I think there's too many idiots out there in this world that just like to hack systems, create some serious havoc. And it's a little scary. I mean, I think AI is great, but I think AI can be dangerous." AI itself was not seen as dangerous, but rather that others might hack the devices to take advantage of individuals with dementia whose ability to make accurate judgments is often lowered was perceived as the real threat to their self-management. AI was also avoided because it was not explainable: "if you're using AI, you know, you don't know who you're trusting there… it's all down to algorithms" and you don't know who wrote those algorithms or their motivations [Luke]. Any sort of AI to assist with self-management was only acceptable if the participants could "make it clear that they are controlling the technology at all times" [Sharon], which may not be possible for people with dementia as they progress with the condition. Therefore, some participants chose to exclude AI devices altogether from their self-management systems although they may have been beneficial to their self-management goals.

*Protecting Against Well Intentioned Others*: Participants also avoided well-intended resources that threatened their control over their self-management systems. For example, Frank describes how he uses settings "set into the operating system" to adjust accessibility settings like brightness and contrast on his various devices. When asked if he would like these setting to be automatically adjusted for him using AI, he rejected this idea because “only I can determine what I need, at that moment.” This imagined automatically adjusting system would be “trying to anticipate someone’s moves” [Griffin] by “just looking at it (symptoms of dementia) from the outside” without looking at “a deeper level than just kind of surface” [Linda]. Although well-intentioned, this kind of assistance was perceived as “take[ing] away my autonomy and my agency and my choices. If you change my computer screen without my deciding it, forget it. That's a game changer, you have taken away my control” [Sharon]. For this reason, many participants were strongly opposed to the idea of automatically adjusting accessibility settings due to the threat it posed to their control of their self-management systems.

Others described support from other individuals, though often well-intended, as posing the bigger threat to their self-management than any technology could. Linda explains that “There's an awful lot of people that think they know what's going on with people with dementia and they don't, and that's a huge problem. Because they're really trying, they're doing their best... and they don't understand.” Annette describes the importance of living alone to her self-management: “if I did have somebody with me… they would, would feel they were helping, they were doing things for me.” Receiving this help from other people was seen as impairing “my capabilities, the skills I already have… They would easily go and I'd lose these skills forever” [Annette]. To avoid other people’s interference in their self-management systems, even those who intend to be helpful, participants describe turning to technology to receive needed assistance. Arthur relies on his smart home devices rather than people because “People always assume they know what’s best for you. Alexa doesn't make any assumption like that at the moment.” Helen and David share the sentiment that: “If I don't use those tools [technologies] then I have to hire somebody to come and care take for me… now somebody else is doing things for me – not with me – for me. The technology is helping me do for myself” [Helen]. David’s comment elaborates on this notion: while others sometimes come in and do the task for them, technology “spell[s] it out for you and you just go ahead” and complete the task yourself. In the most extreme cases participants explain that including formal caregivers in their self-management systems brings the risk of being “forced to go into assisted living or a group home” [David].

As demonstrated in this section, participants considered the longer-term impact of social and technical support on their ability to self-manage, restricting support from various resources in order to maintain control over their self-management systems.

## *Discussion*

Our analysis uniquely details the experiences of individuals with dementia using technology to engage in everyday self-management. The approaches our informants described cannot be broken down into discrete devices and applications, but involves systems created through connecting different forms of social and technical support, often in particular orderings that are defined and refined over time. Our findings offer a new perspective, where technology use for self-management is driven by people with dementia rather than caregivers [106,107,251]. Systems are designed with key priorities that link to the experience of dementia: preparing for a future, whether a moment or a year away, when one cannot rely on one's memory; concern for the social world with a condition where membership is (wrongfully and harmfully) contested [25,292] and a focus on retaining control in a condition where others come in to make decisions [25,221,306]. Below we discuss what these priorities, and a view of people with dementia as capable consumers and creators of self-management systems, offers HCI researchers.

### Turning to the Future

Self-management technologies for dementia often focus on needs in the moment, such as day planners [213,232] and reminder systems for task completion [51,195]. And, self-management systems may be designed to be used until no longer necessary [182]. In dementia, the situation is different: self-management systems become more important as time goes on, with time pressure to set them up while one is capable of doing so.

While a body of literature questions the concept of awareness about one's changing abilities in dementia [170,260], participants in our study attune us to their self-awareness and intentionality. They consider how their abilities will likely change with dementia, and design self-management systems with these projected changes in mind. Participants shared what is at stake should they fail to self-manage or not properly guard against unwanted external interference: a future without the ability to make choices on a day to day basis, most saliently captured in the fear of being put in a nursing home against their will. Individuals constructed self-management systems to guard against this future. For those not as technologically literate as the individuals in this study, we as designers have an imperative and an opportunity to equip and empower novice makers [196,258] with dementia who are desperately seeking opportunities to self-manage a condition with so little guidance for living well available [292]. Much future research can be conducted on this topic, from creating accessible, customizable technologies for people with dementia to considering unique security considerations that emerge in doing so.

Individuals spoke of technologies that they found acceptable or unacceptable as their condition progressed, including far-out approaches such as embedding themselves in AI. We might consider documenting preferences for technologies in a similar way to advanced directives, where in addition to planning for different health-related circumstances, participants plan for different potential technological advances. Speculative design or design fictions may be one useful approach to modify for this purpose (e.g., [270]). In pursuing this vein of research, however, it is key to keep in mind that preferences change over time and there are questions to whether the decision made by someone in the past should be kept if it goes against their wishes in the present.  Further, future work should consider using other methods such as observational and longitudinal studies to understand how people's self-management strategies and preferences change overtime, and at what point people experience significant barriers to using or adapting their self-management systems.

### Socio-Technical Self-management Systems

The ways in which participants configured self-management systems is best understood through a socio-technical lens. That is, our analysis attends less to the discrete use of socially and technologically mediated devices for assistance, and instead highlights the interconnected nature of how individuals' social worlds shape their technology usage and how technology shapes what it means to live in society. Devices for people with dementia are not typically understood as socio-technical systems, which could relate to the low adoption of customized assistive technologies [106]. Consider, for example, the way people with dementia use technology to fit in and project normalcy (e.g., Helen looking at her phone to blend in when she feels lost). This usage resonates with past work with survivors of traumatic brain injury who use technology to cue them into forgotten social protocols [93]. Another study found people with Fibromyalgia used multiple social media accounts to manage other's perceptions [141], mirroring Luke's use of Twitter. A socio-technical perspective understands the ways in which one's social experience, stigma included, is inextricable from technology design and use.

Not only does technology help shape the social; the social inherently shapes technology use. Informants assembled diverse ecosystems of assistance with an intention to preserve important close social relationships. Participants chose to use or not use devices based on the needs and preferences of loved ones: Everly does not use a smart home alarm device because her husband does not want to; Andrew takes his anger out on his devices instead of his partner. Others used technologies as a way to relieve their caregivers of burden, whether that be emotionally, through taking their time, or needing their assistance. This conscientiousness provides a new way of thinking about caregiver burden in dementia: the dementia health literature often focuses on the burden caregivers feel [345,347] in a way that does not consider that people with dementia register or work to reduce this burden. A socio-technical view of self-management systems requires a balance of designing for people with dementia's desires while recognizing technology use is not in a vacuum – others' preferences and needs must be taken into consideration not only for the sake of caregivers, but also because it is a priority for people with dementia.

When discussing the social experience of living with dementia, it is key to note the ways that self-management systems are shaped by the (internalized) pressures of a hyper-cognitive society, which esteems high-functioning cognition and places less value on those with cognitive impairment [135]. An emphasis on supporting people with dementia in conforming to normative expectations (such as dressing appropriately for events) without considering this context opens us to criticisms made for technology for behavior modification in Autism, to ensure these individuals adhere to dominant social norms without considering the wishes of the individuals themselves [337]. There is an opportunity for HCI dementia research to join in conversation with critical disability researchers to understand how to best move through this tension. One way forward will surely be working on attitudinal and structural changes that better value and accept the experience of dementia.

### Principles of Self-determination within Self-management

The dementia advocate definition of self-management as "a person-centered approach in which the individual is empowered and has ownership over the management of their life and condition" [299] resonated with the work individuals in our study did to maintain their role as in charge even with the support that they received. The notion of self-determination can take us further in understanding these ideas of ownership and empowerment that infused our study. Wehmeyer's definition of self-determination for people with severe disabilities [329,330] positions self-determined people as the "causal agent in their lives." This involves "intentionally subjective and contextual determination of what is an acceptable level of influence from others, as what may be perceived by one individual to be an acceptable level of influence may appear to another as an unacceptable level of interference" [330]. This individual evaluation was visible in our study – what one participant saw as an acceptable level of influence (e.g. Arthur's use of Alexa) was rejected by others (e.g. Jade). By centering the person with dementia, as an individual with their own histories, needs, values, and contexts as the primary decision maker in what outside assistance to include and exclude from their self-management systems, we may be able to confront thorny ethical issues such as the appropriateness of technology acting as a caregiver [19,304], or monitoring technology [327,328].

Self-determination refers to people acting volitionally – making conscious choices – based on their own will [330]. Our findings showed participants were greatly concerned this principle would be violated if they used AI within their self-management system. When this principle even has the potential of being violated, participants choose to exclude resources, both people and technology, from their self-management systems. The awareness and intentionality displayed by participants demonstrates the potential in and imperative to include people with dementia as partners in agendas that concern their risk, such as studying security and privacy (as in [198]). Future research is needed to understand people with dementia's appreciation for risk and potential negative consequences of using technology, as work to date primarily frames people with age related cognitive impairment as in need of protection through the restriction of access to certain technologies [180,191,198]. We echo Dourish's call for implications for design to include the why and how these implications were arrived at, including the moral and political commitments they support [85], especially when designing for populations considered more vulnerable to coercion.

We believe that this self-determination emphasis has much to offer for self-management research, shifting from a traditional approach [21] where the self-management technology is the driver for maintaining health to the person with the condition maintaining ownership and management over the entire self-management system and consequently their health. Though past work has included principles of self-determination in technology design for people with dementia [96,158,160], to our knowledge this is the first paper to draw explicitly on the theory of self-determination in regards to technology usage to manage a degenerative condition (past work has pointed to the need for self-determination in the design of cardiac rehabilitation systems to assist people in "getting back to 'normal life'" [182] that would then "allow for gradual disengagement" [182]). The definition of self-management put forth by dementia advocates and Wehmeyer's theorizing of self-determination also align with recent work on interdependence [27], in which people with disabilities are positioned as agents in securing access to resources rather than passive recipients of support. Overall, this shift aims to move away from paternalistic forms of healthcare to one that sees people as agents in their own lives and care. In this way, the work of participants in this study answers a call to shift self-management systems to incorporate the everyday tasks of self-management of chronic conditions [225,226].

*Conclusion*

This work details the active role of individuals with dementia in configuring their self-management systems through an analysis of interviews with seventeen technology savvy people with mild to moderate dementia. Findings from this study showed three unique priorities participants had when designing self-management systems: enabling desired futures, functioning in the social world, and maintaining control. Together these findings demonstrate what self-management looks like for people with progressive cognitive impairment, providing implications for research in both neuro-divergent and chronic condition self-management. Each of these findings broaden the notion of self-management to include future-oriented, sociotechnical, self-determinate design. This paper contributes to the literature by demonstrating that people with mild to moderate dementia are inventive creators and capable actors in self-management.

# Chapter 3: Understanding How Sensory Changes Experienced by Individuals with a Range of Age-Related Cognitive Changes can Affect Technology Use

This chapter appears in the journal ACM Transactions on Accessible Computing: Dixon, Emma, Jesse Anderson, and Amanda Lazar. "Understanding How Sensory Changes Experienced by Individuals with a Range of Age-Related Cognitive Changes Can Affect Technology Use." *ACM Transactions on Accessible Computing*, January 17, 2022. https://doi.org/10.1145/3511906.

Clinical researchers have identified sensory changes people with age-related cognitive changes, such as dementia and mild cognitive impairment, experience which are different from typical age-related sensory changes. Technology designers and researchers do not yet have an understanding of how these unique sensory changes affect technology use. This work begins to bridge the gap between the clinical knowledge of sensory changes and technology research and design through interviews with people with mild to moderate dementia, mild cognitive impairment, subjective cognitive decline, and healthcare professionals. This extended version of our ASSETS conference paper includes people with a range of age-related cognitive changes describing changes in vision, hearing, speech, dexterity, proprioception, and smell. We discuss each of these sensory changes and ways to leverage optimal modes of sensory interaction for accessible technology use with existing and emerging technologies. Finally, we discuss how accessible sensory stimulation may change across the spectrum of age-related cognitive changes.

*Introduction*

There are a variety of age-related cognitive changes, including subjective cognitive decline, mild cognitive impairment, and different types of dementia. Subjective cognitive decline is defined as "the self-reported experience of worsening or more frequent confusion or memory loss" which can be associated with a variety of conditions in individuals over the age of 45 [298]. Mild cognitive impairment includes a diagnosis of the presence of cognitive impairment in one or more domains of cognitive functioning without fulfilling the severity diagnostic criteria for dementia [341]. Mild cognitive impairment is often considered an intermediate stage of cognitive progression from subjective cognitive decline to dementia. However, subjective cognitive decline and mild cognitive impairment do not always lead to dementia [288,341]. Dementia is an umbrella term for conditions which cause changes in cognitive, motor and sensory functioning beyond what might be expected from "normal ageing" [344]. Dementia is typically described in terms of cognitive decline, affecting domains such as memory, thinking, comprehension, learning capacity, language, judgment and ability to perform everyday tasks [344]. Based on this cognitive-centered definition of dementia and other types of age-related cognitive changes, it is not surprising that most technology focuses on cognitive support through task assistance (e.g., [30,53,82,129,199,204,233,327,328]) or memory enhancement (e.g., [14,213,311]).

Researchers have shown people with dementia also experience changes in sensory and motor functions, which are different than typical age-related changes [133,219] and are correlated with the progression of dementia [5]. Clinical researchers have begun to identify the sensory changes that people with age-related cognitive changes can experience that are unique to the normal process of aging [5,122,211,237,264,268]. Our prior work, published at the 2020 ACM SIGACCESS Conference on Computers and Accessibility (ASSETS'20), described three strategies people with dementia and healthcare professionals who work with people with dementia used to overcome sensory changes associated with dementia, including: stimulating at a desired level, adjusting technologies using built-in settings, and switching devices [79]. When these strategies were inadequate, participants ceased to use devices that were inaccessible [79]. The primary contribution of our past work included an understanding of technological accommodation strategies that are useful for people with dementia, evidence for the interrelationship between sensory stimulation and comprehension for those living with dementia, and new directions for technology design in this space [79].

This present paper is an extended version of our past ASSETS'20 paper [79]. We expand on our initial paper by including an additional eleven interviews (four with people with dementia, two people with mild cognitive impairment and five with people with subjective cognitive decline). These additional interviews expand the scope of our work to include participants experiencing a range of age-related cognitive changes. In addition, we take a new analytical direction in this present paper to uncover a spectrum of accessible sensory interactions for people with a range of age-related cognitive changes. This paper makes three primary contributions. First, we provide an overview of the clinical literature concerning sensory changes people with age-related cognitive changes may experience that are distinct from typical age-related changes (see background). Second, we detail the sensory changes participants in our study experienced and the effects of these sensory changes on their technology use. Finally, we discuss ways to leverage optimal modes of sensory interaction for accessible technology use with existing and emerging technologies across the spectrum of age-related cognitive changes. With this work, our aim is to take a step towards bridging the clinical research on the different sensory changes people with age-related cognitive changes experience and the body of research aiming to design technologies for accessible interactions for those experiencing age-related cognitive changes.

## *Related Work*

The following section describes research reporting on currently available technologies for use by people with dementia and mild cognitive impairment as well as the work that has been done to understand how these technologies are used in everyday life. Following this, we describe the main purposes of technologies specifically designed for use by people with age-related cognitive changes – to provide cognitive assistance or sensory engagement.

### Technology Use for Those with Dementia and Mild Cognitive Impairment

There are nearly 1 billion adults over the age of 60 worldwide [343], with 6-12% of these adults diagnosed with mild cognitive impairment [262]. In addition, there are nearly 50 million people worldwide living with a diagnosis of dementia, and a projected 10 million new cases each year [344]. With consideration for the number of people living with age-related cognitive changes, researchers are conducting studies to report on the assistive technologies currently available for use by people with dementia and mild cognitive impairment. One study projected technology trends for people who will be living with dementia in the future [346]. In terms of technologies that are currently available, Gibson et al. surveyed the landscape of available assistive technologies, dividing the resulting types of technologies into three categories: devices used “by,” “on,” and “with” people with dementia [104]. Lorenz et al. note how technologies are designed for use by people with mild cognitive impairment or those in the earlier stages of dementia and shift to targeting family carers and health care professionals as the condition progresses [174]. Despite this use, little research has focused on the usability of assistive technology that supports everyday life – how people can understand, use, and learn to use these technologies [194].

Some research has gone in depth on barriers to everyday technology use. Many studies discuss the importance of recognizing individuality for successful technology introduction, such as abilities, habits, attitudes, and environments [251]. Some research includes accessibility and usability issues in their accounts of barriers. While sensory barriers are sometimes mentioned, they have not been examined thoroughly. For example, in an analysis of the difficulties people with early-stage dementia have using everyday technology, Nygård and Starkhammar refer to weak vision in a section on the design of artefacts as one contextual condition that can be a hindrance to technology use, or appropriate force (e.g., holding a remote volume button too long) as an example of communication difficulties in the use of technology [228]. In the present paper, we directly study the sensory changes people with age-related cognitive changes experience, with a focus on how these changes effect everyday technology use.

### Technologies to Provide Cognitive Assistance

Changing cognition has often been centered in technology design for people with dementia and mild cognitive impairment. One vein of work seeks to use technology to screen for age-related cognitive changes [118,271,302], prevent cognitive decline [202,321], or improve cognition [7,14,311] using varying kinds of technologies. For example, Alves et al. developed a web application, Scrapbook, to support psychologists in performing cognitive therapy as well as reminiscence with people with dementia [7]. MemHolo, a mixed reality system, was developed as a cognitive training tool to practice short term and spatial memory for people with Alzheimer's disease [14]. One project, MobiAssist, targets both physical and cognitive capabilities of people with dementia through exergames [309–312]. Virtual reality has been used as a cognitive training tool for people with mild cognitive impairments to simulate typical daily activities [320]. Other immersive technologies like PENCODER rely heavily on experiences and objects that are familiar to people with mild cognitive impairment, and have positively influenced upward trends in self-esteem among participants [274].

Other research seeks to accommodate cognitive changes people experience in dementia. Much research has been done developing technologies to assist in navigation in case the person with dementia walks to places that the caregiver is not comfortable with [327,328] or if the person with dementia forgets where they are and cannot get home [129]. Other technologies are designed to assist with cognitive barriers to task completion. These technologies often aim to stimulate thinking through step by step directions [53] and are targeted to support specific tasks such as hand washing [199], flushing the toilet [82], and cooking [76,233]. Researchers used an augmented reality system called GhostHands to build upon similar types of task prompting tools, with the platform offering multi-sensory prompts that involved primary visual and auditory cues [338]. CoasterChat's designers, Diks et al., also found that the instructions accompanying the app pilot were most well-received when they combined visual movements and auditory instruction [75]. This approach has also been taken in commercially available systems, such as MapHabit, which pairs visual with audio or written instructions to support everyday task completion [53,187]. Muñoz et al. found that their touchscreen app called "A Better Visit" enabled interactions between caregiver-person with dementia dyads by curating content that specifically supported "pre-existing interests" [214]. This application created multi-sensory experiences in apps like Tic-Tac-Tango - which played familiar ballroom music and replaced typical X's and O's with visually-stimulating dance moves - and sought to "support personhood" through personalization and familiar experiences [214]. Like MapHabit, both of these systems use multimodal prompts – the designers explain this design decision was made to ensure "interfaces that are highly adaptable to the cognitive support needs and any perception disabilities" [187].

The above examples that utilize multimodal prompts indicate that even when designing for cognitive support (rather than, for example, recreation), sensory abilities matter for the design of usable and accessible systems. Our past work introduces nuances to the relationship between sensory stimulation and cognition:

such as 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 [79]. The present paper takes a systematic approach to understanding sensory changes people with dementia experience as they affect technology use.

### Technologies Designed for Sensory Engagement

Human Computer Interaction (HCI) technologies for people with dementia, particularly in later stages, and people with mild cognitive impairment, often recognize sensory abilities as ways to engage people with dementia. Design decisions that leverage sensory experiences are supported by research: a critical dementia perspective recognizes the importance of multisensory experiences and that physical and embodied experiences are ways of knowing [160]. The experience-centered design perspective attends to aesthetics and touch as both providing insights into the lives of people with dementia as well as creating opportunities for absorbing experiences [206]. Froehlich et al. posit that media has such an important role for people with dementia that there should be a new category of assistive technologies that involve media creation and consumption for wellbeing [100].

Researchers have used a variety of technologies to engage sensory abilities, often including multimedia. For example, the CIRCA project used touchscreens to present music, videos, and pictures to stimulate long-term memories to prompt conversations [4,110]. More recent research may reflect an understanding of the importance of embodiment in dementia, adding haptics [136], gesture-based interaction [150,277], and tangible objects to support multimedia engagement to support reminiscence [134]. Guan et al. also found that technology could act as a "communication modality" when adapted from embodied cues, noting that embodied cuing can be more successful than abstract verbal language when encouraging people with dementia to mimic activities or behaviors [111]. Further, embodied cues that stimulated several senses - such as a caregiver visually depicting the activity while humming - were particularly effective [111]. Another example leveraging embodied interaction alongside sensory modalities is in the Closer To Nature Installation, which used a display of a farm scene, old fashioned water pump, and sensor-enabled, touch-responsive goat [92].

Audio has received particular focus. Researchers have investigated conversational assistances, such as through Google home and Amazon Alexa, to facilitate conversations between people with mild cognitive impairment and their care-partners [349]. Other researchers have focused auditory interactions due to the documented benefits of music therapy for people with dementia [318]. Researchers in HCI have designed technologies to facilitate musical creativity [207,252,253] and to give people with dementia more control over playing music [272]. When developing their application "A Better Visit," Muñoz et al. found that embedding musical elements throughout the cooperative games encouraged engagement and concentration among people with dementia, especially if that music was familiar to them [214]. Houben et al., point out that music only represents a subset of the sounds that people perceive, and in contrast to experiences with music, experiences of everyday sounds for people with dementia are significantly under studied [132]. The authors explored the reactions of people with early and moderate dementia to generic, everyday sounds, finding that this provided opportunities for meaningful interactions, but also that soundscapes could feel chaotic and overwhelming [132]. Muñoz et al. found similar success when using sounds to facilitate accurate guessing in the game Reveal, using animal sounds to help users recognize what animal was represented in a picture before they could see it fully [214].

*Background: Sensory Changes Unique to Age-related Cognitive Changes*

The aim of this present paper is to better understand accessible sensory interactions with technology for those experiencing age-related cognitive changes. To provide supporting evidence for the sensory changes described in our findings, this section reviews clinical research investigating how sensory changes associated with age-related cognitive changes are distinct from typical age-related changes. Within the last two decades, clinical research has begun to explore the unique sensory changes experienced by people with dementia when compared to the sensory changes experienced as a part of the typical aging process. Most of these studies have been done in regards to dementia, though some examine changes with mild cognitive impairment.

This past clinical work has shown the way a person with dementia interprets what they see, hear, taste, feel and smell changes due to the condition [219], and that these changes may correlate with the progression of dementia [5]. Some of these changes are more common with specific types of dementia, (e.g., dementia with Lewy bodies [99,109,131,240] or Frontotemporal dementia [243]), but many sensory changes are common across various types of dementia [122,211,242,264]. Below, we review some of these changes experienced by people with dementia and mild cognitive impairment based on clinical literature.

Vision loss is common for people as they age. However, there are specific aspects of vision which change differently than normal age-related vision changes. Individuals living with dementia often have significantly lower visual acuity, meaning less sharp vision (e.g., the ability to determine letters at a distance) compared to control groups [264]. People with dementia experience increased difficulty with contrast sensitivity - the ability to determine the foreground from the background - and color perception [264]. People often experience difficulty with visual integration, meaning the ability to look at an object and properly orient it in space [264]. Some experience surface dyslexia, meaning additional difficulty identifying words while reading and classifying stimuli as words or not as words [242]. Additionally, people may experience difficulty with "seeing" more than one thing at a time, which is referred to as "simultanagnosia," grasping the "big picture," and selecting something specific from among a cluster of items [34,290]. Changes in vision are significant to the extent that differences in the retina are being explored as an option for early detection of neurodegenerative changes associated with mild cognitive impairment and Alzheimer's disease [2,32,115,172,266]. Other visual changes may include visual hallucinations, which are more typical for dementia with Lewy bodies [240].

The loss of some hearing ability is also a typical aspect of the aging process. Researchers are finding that  people with dementia experience changes in ability to process auditory input with dementia which are unique to typical age-related hearing loss [122]. One example is auditory agnosia, or impairment in sound perception and identification of select types of sounds without any clinical hearing dysfunction [122]. Word deafness is one form of auditory agnosia, where individuals can comprehend written information drastically better than spoken information [139,153,235]. As another example, people living with Alzheimer's disease often have difficulty following conversations and other sounds when in a busy auditory environment [95]. Researchers have also documented people with dementia’s difficulty with nonverbal sound recognition, including difficulty recognizing familiar voices even while being able to distinguish between voices [39,109,119,120]. Other auditory changes unique to typical aging include auditory hallucinations, including muffled sounds, voices and musical tunes [59,109,131]. Like visual hallucinations, auditory hallucinations are most often reported by people with Lewy bodies [59,108,131]. Researchers have also found that people with Frontotemporal dementia and some people with Alzheimer’s disease may have sound aversion, which is when certain sounds trigger emotional or physiological responses that some people may perceive as unreasonable given the circumstance [95], as well as increased sensitivity to sound [181]. Researchers are investigating hearing loss as a possible indicator and risk factor for cognitive decline and dementia [176].

Speech and language patterns can also change in dementia. Individuals living with dementia have been found to have distinct differences in “syntactic complexity, speech fluency, vocal parameters, and pragmatic language” as compared to control groups [211]. One study even found that measures of speech (e.g., reduced number of words spoken per minute) could be used to identify frontotemporal dementia [243].

Additionally, people who are bilingual and are in the more advanced stages of dementia often have difficulty maintaining their second language [197]. Researchers have not found a significant difference in speech and language patterns between control groups and people with mild cognitive impairments [211].

Olfactory (smell) dysfunction, where people experience changes in their ability to smell things, is a part of the normal aging process [83]. However, odor identification has been found to be more difficult for people with Alzheimer's disease or vascular dementia [5,208,250] as well as for those with mild cognitive impairment [101] compared to people without any known neurodegenerative condition. Changes in olfactory ability may influence taste and appetite for people with dementia, which can lead to a lack of nutrition and lower overall health [3].

Balance, gait speed and stride length are also affected by dementia. Researchers have found people with dementia experience significantly less static balance, as well as lower gait speed and stride length than the average person [268,317]. The changes in balance and gait may be associated with different types of dementia. One study found participants with dementia with Lewy bodies and Parkinsonism dementias walked significantly slower, with shorter stride lengths and demonstrated less balance than people with Parkinson's without dementia or Alzheimer's disease [99].

Dexterity and fine motor skills are also affected differently for people with dementia. When comparing groups of individuals experiencing "normal aging," mild-cognitive impairment, and Alzheimer's disease, researchers found a progressive decrease in fine motor dexterity from those experiencing normal aging to mild cognitive impairment to Alzheimer's disease [237]. Past work notes differences in finger dexterity between individuals with different types of dementia, where people with dementia with Lewy bodies had less finger dexterity than people with Parkinson’s or Alzheimer’s disease [99].

Clinical research to understand the sensory changes people with dementia experience has started to gain public attention within the latter half of the last decade. With this being a relatively novel area of study, many general practitioners and the general public are still unaware of the sensory changes people can experience due to dementia. In this paper, we provide findings related to some of the sensory changes that people with dementia experience in relation to technology use

### *Methods*

Below, we present our approach to data collection, participant demographics, analytic approach, and limitations.

#### Data Collection

We recruited from four groups: people who self-reported subjective cognitive decline, people diagnosed with mild cognitive impairment, people diagnosed with mild to moderate dementia, and healthcare professionals with experience working with people across the spectrum of dementia. We include individuals with subjective cognitive decline and mild cognitive impairment in this study as a way to compare and contrast the effects of sensory changes on technology use to those diagnosed with dementia. Data from interviews with healthcare professionals were included to provide perspectives on technology use for a broader population of people with dementia, given the specifics of the sample of people with dementia (who were largely regular technology users) and also to expand our understanding to those in the later stages of dementia.

We recruited people with dementia and mild cognitive impairment through large dementia advocacy organizations and snow-ball sampling. Initial contacts were made at a large dementia organization conference in 2019. These participants then shared our study information with other people they knew in their online support groups as well as on Twitter. We recruited a smaller number of people who experience subjective cognitive decline through personal contacts and snow-ball sampling. We recruited healthcare professionals through various professional societies Facebook pages (e.g., Therapeutic Recreation Directory) and snowball sampling.

For participants with cognitive impairments to qualify for the study, they first had to complete a screener call with the researchers where they were asked questions to determine their eligibility for the study as well as their capacity to consent. Capacity to consent was determined using the UC Davis Alzheimer's Disease Center procedures [307]. All participants gave informed consent before participating in the study.

To determine eligibility, we chose to rely on self-reporting a diagnosis of dementia, mild cognitive impairment[3], or experience with subjective cognitive decline rather than formal staging of the severity of cognitive impairment by a

[3] All participants self-reported a clinical diagnosis of dementia including the specific type of dementia they were diagnosed with (e.g., Alzheimer's disease, Vascular dementia, etc.). Participants were also asked to self-report their clinically diagnosed stage of dementia..

clinician (e.g., instruments such as the Mini-Mental State Exam or Montreal Cognitive Assessment). Relying on self-reported diagnosis is in alignment with accepted approaches in HCI which recognize that “It may be hard to get detailed information about the medical status of someone with a disability... because of the sensitivity involved in sharing personal health data” [165]. When participants with dementia did not know their clinically diagnosed stage, we asked them to self-assess their stage of dementia at the time of the study based on the categories we drew from the US Center of Disease Control and Prevention and National Institute of Aging’s function-based stage classification [220,221,305]. These categories included subjective cognitive decline, mild cognitive impairment, mild, moderate, and advanced dementia as well as vignettes of functional changes associated with each of these categories (see [217,218,298]). Each category was read to participants where they indicated which best fit their functional abilities. Function-based stage classifications is a particularly relevant measure to technology use, as it indicates one’s ability to carry out daily activities and tasks. Though we include the self-assessed stage in the table, throughout our findings we focus more on the self-reported diagnosis and not on the self-assessment of stage as these self-assessments may not align with a clinical diagnosis of stage.

All participants also had to self-report regular use of technology. We chose to include regular technology use as a criteria so that we could gain insights into experiences with technology – while recognizing that these participants may not be representative of the broader population of people with dementia (although there is a trend towards greater technology use by people with dementia: research has found that 54.14% of people with mild cognitive impairment or dementia reported using their smartphones and tablets almost every day [119]). Inclusion criteria for healthcare professionals were that they had at least three years of experience working with people with dementia. All procedures were approved by the University Institutional Review Board.

Interviews were semi-structured, lasting approximately one hour. Nearly all of the interviews were conducted remotely via video-conferencing. Though several of the interviews were conducted in-person (prior to COVID-19 quarantine restrictions) when participants were located within a reasonable distance from our university. Each interview was audio/video recorded with the consent of participants, resulting in 40 hours and 40 minutes of recording used for analysis.

For the 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, mild cognitive impairment, and subjective cognitive decline were asked questions concerning their current use of technology and healthcare professionals 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 in this section 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 healthcare professionals 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 all participants, we asked in detail about their 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 all participants questions concerning their ideas for future technologies. The interviews with participants with dementia, mild cognitive impairment and subjective cognitive decline concluded with a discussion of technologies that participants no longer used and why. Interviews with healthcare professionals 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. All participants received a $20 Amazon gift card after completing the interview.

### Participants

This is an extended version of our accepted ASSETS paper [79]. As such, our analysis included the thirty participants from the previous version of this work (11 people with mild to moderate dementia and 19 healthcare professionals). In this extended version we include an additional eleven participants. Four of these additional participants are individuals living with dementia, 2 are individuals living with mild cognitive impairment, and 5 are people who self-report subjective cognitive decline. In the findings section these participants are denoted with pseudonyms, with additional context of either their type of dementia or subjective cognitive decline. We use pseudonyms as a way to avoid dehumanization [25].

The average age of participants with dementia was 62.5 years old (range 57-73). The average age of participants with mild cognitive impairment was 63 years old (range 55-71). The average age of participants with subjective cognitive decline was 75.8 years old (range 71-84). All participants with dementia, mild cognitive impairment, or subjective cognitive decline identified as Caucasian with the exception of Everly who identified as African-American and Margaret who declined to self-identify her ethnicity. See Table 2 for more detail on participants age, gender, country of residency, type of dementia or cognitive impairment and stage of dementia. Participants with dementia included individuals who identified as dementia advocates and others who were a part of advocacy organizations' peer-support groups but were not participating in active roles within these organizations.

*Table 2: Chapter 3 Participant with Dementia, Mild Cognitive Impairment, and Subjective Cognitive Decline Demographic Information*

| Pseudonym | Age | Gender | Country | Type of Dementia or Cognitive Impairment | Stage of Dementia |
|---|---|---|---|---|---|
| **Frank** | 63 | Male | UK | Mixed vascular dementia/ Alzheimer's disease | Mild/Moderate |
| **Annette** | 65 | Female | UK | Alzheimer's disease | Mild/Moderate |
| **Bill** | 58 | Male | US | Dementia with Lewy bodies | Mild |
| **Sharon** | 60 | Female | US | Vascular microangiopathy | Unknown |
| **Helen** | 57 | Female | US | younger onset Alzheimer's disease | Mild |
| **June** | 59 | Female | US | Vascular dementia/white matter disease | Mild/Moderate |
| **David** | 67 | Male | US | Vascular dementia | Mild/Moderate |
| **Linda** | 67 | Female | US | Dementia (major neuro-cognitive impairment) | Mild/Moderate |

| Pseudonym | Age | Gender | Country | Type of Dementia or Cognitive Impairment | Stage of Dementia |
|---|---|---|---|---|---|
| **Arthur** | 61 | Male | UK | Dementia with Lewy bodies | Mild |
| **Phillip** | 61 | Male | US | Alzheimer's disease/semantic dementia | Mild |
| **Andrew** | 59 | Male | US | Alzheimer's disease/vascular dementia | Moderate |
| **Joseph** | 71 | Male | US | mild cognitive impairment[1] | N/A |
| **Griffin** | 67 | Male | Canada | Vascular Cognitive | Moderate |
| **Ben** | 59 | Male | US | early onset Alzheimer's disease | Mild |
| **Luke** | 61 | Male | UK | Vascular dementia | Mild |
| **Jade** | 73 | Female | US | Vascular dementia | Mild |
| **Everly** | 55 | Female | US | mild cognitive impairment[2] | N/A |
| **Alina** | 80 | Female | US | Subjective Cognitive Decline | N/A |
| **Ted** | 71 | Male | US | Subjective Cognitive Decline | N/A |
| **Chris** | 84 | Male | US | Subjective Cognitive Decline | N/A |
| **Peter** | 72 | Male | US | Subjective Cognitive Decline | N/A |
| **Margaret** | 72 | Female | US | Subjective Cognitive Decline | N/A |

1. Joseph was originally diagnosed with Mild Dementia and has since been re-diagnosed as having mild cognitive impairment (MCI). 2. Everly throughout the interview referred to herself as being in the early stages of dementia though when completing the demographics form, she reported being diagnosed with MCI.

We interviewed nineteen healthcare professionals, with an average of 15 years of experience working with people with dementia (ranging from 3 to 46 years). All participants identified as female and Caucasian, with the exception of Esther who identified as multi-ethnic and Tiffany who identified as Asian. All healthcare professionals were interviewed separately with the exception of two who were interviewed together to accommodate their time constraints. Healthcare professionals worked with a range of cognitive abilities from people with mild cognitive impairment through people with advanced dementia. Their average age was 47.8 years old (range 26-70). Throughout the findings, healthcare professional quotes are denoted with Pr# rather than pseudonyms as a way to distinguish their quotes from quotes by participants with dementia, mild cognitive impairment, or subjective cognitive decline. To provide further context for healthcare professionals' quotes we distinguish the type of healthcare professional when introducing their quote in the findings. See Table 3 for a summary of each healthcare professional's age, country of practice, occupation, and years of experience.

*Table 3: Chapter 3 Healthcare Professional Demographic Information*

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

Analysis

For this extended version of our original paper [80] we took a thematic analysis approach [41]. This involved a secondary analysis of the data that was used for the ASSETS paper [79] and the additional data described above. We initially familiarize ourselves with the data by open coding six transcripts. These six transcripts included two transcripts from interviews with people with dementia, one transcript from an interview with a participant with mild cognitive impairment and three transcripts from interviews with healthcare professionals. Our initial open codes from these six transcripts included codes such as: “switching visual to audio,” “dexterity affected,” “when visual is hard.” This open coding process resulted in our interest in further understanding two aspects of the data: a) the sensory changes people with age-related cognitive changes experience affecting technology use, and b) accommodation strategies that are used when changes in sensory abilities occur. We designed a codebook that was organized by sense, with open codes that seemed relevant to those senses. We then went back through all interview transcripts, including the six transcripts used for open coding, and categorized the data using this code-book, adding to it when new codes emerged. Codes reflecting accommodation strategies were added, such as “speech slowing,” “mirroring,” “embodied cueing,” and “audio still too hard.” By the twentieth transcript we reached data saturation, as no new codes were added. All transcripts were then focus coded using the established codebook. Following focused coding, through a collaborative and iterative process of considering the fit of each code with different sensory categories, each code was finalized in terms of where it was grouped within specific sensory categories, and the higher level sensory categories were determined: visual, auditory, dexterity, proprioception and smell. For example, we determined that the accommodation strategy of “embodied cueing” should be included under the sense “proprioception.” We coded all instances, including where participants did not talk about technology directly. In our findings we include instances that do not refer to technology use only when they reveal future opportunities for technical interventions to engage the changing sensory abilities of people with age-related cognitive changes. When quoting participants in the findings we have removed false starts and filler words (e.g., “like”) only when they affected readability.

The larger aim of our analysis was to explore how sensory changes experienced by people with a range of age-related cognitive changes effect technology use. To reach this aim, when writing the paper we were intentional to include quotes in each section from all applicable participants in each participant group who described related sensory changes. We then structured our findings sections in a way that demonstrates the sensory changes experienced by participants from those experienced by all participant groups to those experienced by participants in the most advanced cognitive changes. Visual and auditory changes are included as the first and second findings section as these changes were described by all participants across the range of age-related cognitive changes. One participant with subjective cognitive decline described dexterity changes but these were largely described by people with dementia or healthcare professionals who worked with people with dementia, which is why it is the third findings section. Proprioception is described in the fourth findings section as these changes were only described by people with dementia and healthcare professionals who worked with people with dementia. Finally, olfactory (smell) changes were only described by healthcare professionals in relation to their clients in the most advanced stages of dementia. These examples and organization of our findings serve to go beyond description of the data to illustrate sensory changes experienced by participants across the spectrum of age-related cognitive changes – which we discuss in further detail in the discussion.

### Limitations

One limitation of this study is the reliance on self-reporting rather than requiring clinically confirmed diagnosis of dementia, diagnosis of mild cognitive impairment, or experience with subjective cognitive decline. We did not formally assess participants' cognitive abilities. And not all participants knew what stage of dementia they were in, so some self-assessed. Future work should consider partnering with clinicians to conduct these formal assessments of cognitive ability.

The average age of participants with dementia was 62.5 years. Dementia diagnosed under the age of 65 is considered early onset [9], representing 9% of diagnoses [1]. This relatively younger group of participants may be overrepresented in our research due to the hesitance of the general population to self-identify as a person living with dementia due to stigma [25,291] that can lead to unwillingness to discuss experiences with researchers [279]. As many of our participants were active in various dementia advocacy organizations, these participants appear to be a part of the rise of the "young, active person with dementia" involved in publicly sharing information about their condition with researchers [55]. In addition, the recruitment requirement that participants had to use technology regularly may also have led to a relatively younger group of participants [26,229]. Finally, recruiting participants with dementia using Twitter may have resulted in a sample of younger participants with dementia who are also dementia advocates, as has been found in previous work [293].

The limited racial diversity of participants is another limitation of our study. All but one participant with dementia, mild cognitive impairment or subjective cognitive decline identified as Caucasian and one participant chose not to identify. Research shows a higher prevalence of dementia in the African American and Latinx communities in the United States [9], which was not represented in our participant pool. Additionally, the healthcare professionals who participated in our study were also primarily Caucasian. Researchers have suggested several barriers in research recruitment of different ethnic groups such as lack of trust in research due to a history of ethical issues [74,89], institutional barriers to education [192], and stigma consciousness [192]. There is a need for further work to ensure that research includes more diverse demographics of people with dementia and healthcare professionals. Finally, our findings come primarily from participants residing in the United States, the United Kingdom, or Canada. Our findings are certainly influenced by these geographic and cultural settings.

Given our study utilized a single interview, the scope of the data collected is limited to the perceptions and accounts of participants which they shared within our one hour interview.  Future work should consider using an ethnographic or longitudinal method to understand how sensory changes fluctuate and affect technology use as people progress with dementia. Further, most interviews were conducted remotely, which limited data collection to participants' verbal explanation, which can be arduous and suboptimal as an approach for some individuals. Future work should consider including observations, and diary studies to further document sensory changes and their effect on technology use.

*Findings*

Our past ASSETS paper [79] described technological accommodation strategies people with dementia and healthcare professionals who work with people with dementia used to overcome sensory changes associated with dementia as well as instances when no accommodations were available, which led to participants ceasing to use inaccessible technologies [79]. In this extended version of our previous work, we detail each of the different sensory changes participants with a range of age-related cognitive changes in this study described as well as ways these sensory changes effected the accessibility of technology use.

Visual

Participants described visual changes they experienced due to age-related cognitive changes that interacted with their technology use, including changes in visual acuity, color perception, ability to select an object out of a busy environment, ability to see the big picture and surface dyslexia. Changes in vision have been associated with mild cognitive impairment and Alzheimer's disease in clinical research [2,32,115,172,266].

*Visual Acuity:* Many people experience vision changes as they age. Although everyone's vision changes with age, fluctuating changes in visual acuity, or sharpness of vision, are specifically linked to dementia [264]. Frank, living with mixed vascular dementia and Alzheimer's disease, said, "I struggle now, visually with reading and dealing with emails on the phone." He experiences a fluctuation in vision that is different than in typical aging, "because of vascular dementia causing sometimes hourly changes in my visual capabilities." In another instance, June, living with vascular dementia and white matter disease, described how she now uses the voice assistant on her phone to “voice text because for some reason my texting skills since my stroke[4] I don’t know what that is but I’m just visually off a cog,” meaning “if I type something really fast and send it, people will write back, ‘What? Where are you? This is like a foreign language’” because the letters June believes she is typing based on her visual abilities are not what she actually is typing.

Participants used several strategies to accommodate changes in visual acuity. One strategy was to use devices that supported larger text, as Pr13, an Occupational Therapist, described simply “modify[ing] a TV Screen by putting a magnifying screen on it” [Pr13]. Modifying the size of a device was particularly important, as Speech Language Pathologist Pr5, 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.” Phillip, living with Alzheimer's and semantic dementia, described a use that was consistent with Pr5’s observation, where he uses a tablet as his phone because it’s larger and therefore makes it easier to see what is on the screen. An alternative accommodation was used by Frank, who is living with mixed vascular dementia and Alzheimer’s disease, who “use[s] the phone to let me know I've had the emails... then when I get home I'll bring them up on the smart tv screen where it's big enough to see."

Another strategy participants used to accommodate visual acuity changes was utilizing other mediums for interacting with the phone rather than vision, such as

[4] The strokes June experienced were linked to the development of vascular dementia and white matter disease.

voice to text dictation. For instance, Frank describes the necessity of using voice to text when “I need to be making a note, if I can't see clearly enough or operate the phone well enough… I can still dictate into it.” Participants with dementia also described using voice recorded messages on their phones, which Frank refers to as: “leav[ing] myself voice messages.” Similarly, Arthur, who is living with dementia with Lewy bodies, regularly records “spoken” journal entries through his Alexa. In contrast, using voice to text was not described by participants with subjective cognitive decline with the same level of need as participants with dementia described. For instance, Alina stated “The only time I use voice to text is on my [phone]. When I'm texting sometimes” but not because she needed to use this feature to communicate via message due to visual acuity changes.

*Color Perception*: People with dementia can experience increased difficulty with color perception [264]. In our study, participants with dementia and healthcare professionals who work with people with dementia described the loss of the ability to distinguish visual features, where bringing in more color contrast was key to aid technology use. One participant living with vascular dementia explains intentionally choosing contrasting colors for his phone case “blue on black” because he often can’t visually distinguish his phone because “it’s black. And so I got this case so that now I can see it. I’ll recognize it” [Griffin]. Similarly, Pr13 and Pr1, both Occupational Therapists, described increasing color contrast to support everyday technology use. Pr1 describes, “For one person operating the CD player we used nail polish to highlight the buttons that he should push” where he “press[ed] the green button for go to start it.” Pr13 would take “a really bright yellow or bright green duct tape and I’ll cut like a little square to put over either the on button or a number button... So, this colored button on the microwave, it pops out. So, you're more apt to push that button. You may not remember what it's for but that bright color against that black microwave stands out and you just will automatically put your finger there to use the microwave." The need for color distinction to draw people with dementia's attention extends from physical devices to web-pages as Occupational Therapist, Pr3, describes web-pages that are "white can be overwhelming" because it's "too much negative space." This is especially relevant for people in the "moderate or maybe mild [stages of] dementia" because with "all that white space… they don't know where to look" [Pr3].

Some participants actually used the attention-drawing properties of color, along with conventions of meaning assigned to different colors, to accommodate cognitive changes. Pr13 described the usefulness of the stoplight system to signal go or stop – though they did not note this specifically in regards to technology, participants with dementia described employing these colors in their own accommodations, with red signaling an urgent action. Helen, living with early onset Alzheimer's disease, explains how she organizes her digital calendar system: "red is the absolutely, positively you have to do it. And if it has a time assigned to it, you have to do it at this time... darker green is just a recurring reminder for me to do something financial... if I'm expecting an action from someone else that's financially related... then that'll be a lighter green... just a regular navy blue is just an act. It's just an action that I need to take with no specific meaning… a lighter [blue] for things that are related to my health care… activities that are for people with dementia. Those are kind of a magenta, purplish, pinkish kind of color.” Her intricate color coding system, “makes it easy for, easier for me to find a specific item on the calendar. Out of all the clutter” [Helen].

*Selecting an Object from a Busy Environment:* People with dementia can experience difficulty with “seeing” more than one thing at a time, which is referred to as “simultanagnosia” [34,289]. Sharon, who is living with vascular microangiopathy, explains, “the world can feel very confusing and overwhelming when you have too much data to deal with. Sensory input. Too much, too many colors or flashing things in the eyes or noise.” For example, Bill becomes visually overwhelmed with online forums because of “The way they’re all laid out… first you have to try to search to see if somebody’s already had that question before. Then try to find the question… It’s just a mess, it’s just a total mess” [Bill].

In these overwhelming sensory environments, participants describe not being able to pick out certain objects they may be looking for. For example, Griffin, living with vascular dementia, explains how “I have visual problems… [an object] could be right in front of me. I wouldn’t recognize it because it might blend in with everything else” [Griffin]. Similarly, Helen, who was in the early stages of Alzheimer’s disease at the time of the study, explains her common experience with not seeing something that is directly in front of her. This visual change affects her engagement in both the physical and the digital world where “even though my eyes still work perfectly fine, the brain doesn’t process. [I] wouldn’t see” whatever it is she’s looking for [Helen]. Margaret, living with subjective cognitive decline, experiences similar moments when using her computer where “I don’t know where all my documents are.” For

Helen and Margaret, using visuospatial organization by positioning documents on their desktop computer in a particular way helps accommodate moments of not seeing by helping them know to look "specifically [at] that area of the screen or image" [Helen]. Margaret uses regions of the space and layering to support organization, where "if it's [a document] on the left, it means I've been working on that one longer. If it's on the right, it's an older a draft of an older piece. So if I move it with that left side it's closer to being finished" [Margaret]. Related documents are "even superimposed on top of each other… That way they don't take up too much room" [Margaret]. This strategy may not work for all people with age-related cognitive changes as June, who is living with vascular dementia and white matter disease, did not arrive at a visuospatial approach to accommodating simultanagnosia – she mentioned the challenges she experienced when she had "400 notes all over the place." Instead, June has switched to an online calendar and reminder system as "a way to stay organized" and not become overwhelmed with busy visual environments.

*Seeing the Big Picture:* People with dementia may have difficulty grasping the "big picture" [34,289] when everything needed for a task is not visible at one time. Pr16, a Director of Adult Day Care and Respite, explains when there are "a ton of options" such as in "drop downs" menus, this creates "areas for them to get lost" because people can't see everything at once [Pr16]. Phillip, living with Alzheimer's disease and semantic dementia, describes his "difficulty knowing which is which, when I got to go down the bottom and click the tab. So I might click the wrong tabs multiple times till I find my way where I want to be." To avoid becoming disoriented when working on multiple tabs, Phillip describes how he now uses split screen on a

24 inch monitor where he “tend[s] to open up multiple screens at a time” which is “much easier on a desktop versus utilizing a laptop to do that” because he needs the surface areas to see all that he is working on at once. Jade, living with vascular dementia, also utilizes a split screen to keep everything needed for a task visible. For example, when “read[ing] some kind of directions while I’m doing something else” like “filling out a form for example.”

*Surface Dyslexia:* People with dementia can experience surface dyslexia, meaning it can be difficult to read irregular words and classify stimuli as words or not words [242]. Bill, living with dementia with Lewy bodies, explains his difficulty with restaurant menus: “there’s just these big long words, it’s just descriptions of things” which causes him to “have a hard time making a decision… for me that was never a problem” before dementia. Difficulty reading irregular words likely contributed to Occupational Therapist, Pr3’s observation that a website with a paragraph describing an assistive technology was “too hard to follow” for many people with dementia because “the words for these products have been standard across the industry” but included a lot of technical jargon.

Participants also discussed limiting the text on interfaces as an accommodation. Information needs to include only “very brief descriptions of what something is” in order to not be “overwhelming” because of “too much text” [Pr2]. Pr5, a Speech Language Pathologist, provides an example of how she would change text descriptions over-time with the progression of dementia, “perhaps the person is able to read, sentence level material. I might label a photograph that that person has that says, “This is my son Allan and his wife, June, visiting London England.” Then over time that might be too much information for that person, so I might change the label you know, "My son, Allan, and his wife, June." Then so on until it gets to, "Son, Wife," because those pieces of information are able to be understood by that person."

Some participants preferred pictures and icons as helpful accommodations when they experienced difficulty reading irregular words. For example, Bill describes how restaurant menus are much more accessible to him when they have "pictures of things" on the menu rather than just word descriptions of menu items. Pr17, a Dementia Consultant and Advocate, notes how visuals become increasingly important with the progression of dementia. Where when working with people in the moderate to later stages of dementia, "if you're cueing them, that it's done both with words and with pictures of some sort... it's got to be more than words" [Pr17]. In Sharon's experience living with vascular microangiopathy "I think that words are going to go before the icons are going to go." Though Sharon sees the value in computer icons, she critiques them as being "so abstract that a lot of them are meaningless to me." To address the abstractness of many icons, Pr4, an Occupational Therapist, uses "Visual guides like putting a picture of the toilet or the bathroom" on the bathroom door, rather than just the standard icons for bathrooms. Luke, living with vascular dementia, proposes a future device to verbally describe icons to address abstractness "If you were to hover over the icon and there was something on the computer there that could be spoken as to what that icon is."

Other participants with dementia described the need to switch to receiving information auditorily from technology to address surface dyslexia. As Sharon describes, when she reads she "mix[es] up information because something gets crossed in my brain. So, when I look at words the way I used to scan and speed read... I get things wrong." But when she "hear[s] it, and I can see it… I can triangulate the information to be sure I got it right" [Sharon]. Annette, who is living with Alzheimer's disease, explains: "These days, I much prefer to hear what it is I'm doing really. I do emails and everything else, yes, but sometimes I get a little bit muddled" with the written information.

Participants with subjective cognitive decline and mild cognitive impairment also described audio as currently useful, or potential useful in the future, as alternatives to reading text. Alina, describes experiences where she reaches mental fatigue: "I get to the point in the evening where I don't want to look at things. I still have things I'd like to do on my computer. But I can't, my brain is tired... I think that is related to the cognitive strain." At that point, she uses audiobooks rather than printed books or reading eBooks. Margaret, also living with subjective cognitive decline, describes preferring to listen to poems. However, she chose to read the poem text alongside as a way to "try to control" and "maintain" her ability to read because "I don't want to just become where I rely on listening." In this example, Margaret is choosing to read along as a way to stimulate her brain, where people with dementia may no longer have the ability to take in information through reading. When asked if he uses audio functions on his eBook Chris, living with subjective cognitive decline, said that "I just haven't got there yet," indicating that he might see a need for this function in the future if his cognitive changes progress. Everly, living with mild cognitive impairment, describes how she "want[s] something that's going to be able to read to me… I just need something like that [Audible], to do everything to read everything," including everyday things like recipes or how much food to feed her dogs as this is more accessible for her than reading text-based content.

Videos were another way to accommodate difficulty with reading irregular words, by supporting individuals in receiving information auditorily as well as visually without having to read. As Frank describes his preference for "YouTube, how to guides" rather than "try[ing] to read somebody's supposed detailed instructions on how to do something. That might be reams and reams of it, miles and miles of it. Where you can go and look at a 30 second video of it and oh yeah that's it." Similarly, Ben, living with early onset Alzheimer's disease, preferred video "little mini tutorial[s]... where you can actually watch the person do what you need to do. So instead of seeing instructions."

### Auditory and Speech

Participants described auditory changes they experienced that interacted with their technology use, including fluctuating sensitivity to sound, changing speech and language patterns, and perceiving and identifying different sounds. Clinical researchers have identified hearing loss as a possible indicator and risk factor for age-related cognitive changes and dementia [176].

*Fluctuating Sensitivity to Sounds:* Individuals living with dementia experience changes in their sensitivity to sound [181]. For instance, Frank, who is living with mixed vascular dementia and Alzheimer's disease, describes his decreased auditory sensitivity, where "Sometimes I need things louder and louder and louder." The need for louder audio was attributed to the progression of the day as well as "what's been happening in the day [which] will have a massive effect on the speed at which the change takes place" [Frank]. So, "as the day wears on the levels go down and down and down" [Frank] in relation to the amount of activity during the day. Pr13, an Occupational Therapist, suggests to her clients with decreased auditory sensitivity assistive devices such as "a pocket talker or a pocket magnifier so that they can hear music or have conversations." Pr5, a Speech Language Pathologist, describes using an app called "Bla, Bla, Bla" that includes a "face [which] changes as your voice gets louder" for people with dementia who need others to speak more loudly to hold a conversation due to their decreased auditory sensitivity [Pr5]. In other instances, as Frank describes, he can have increased auditory sensitivity where he "can't handle anything."

During conversations, participants reported having difficulty concentrating on the conversation while blocking out other noises from the environment. For example, during the remote interview session with Bill, who is living with dementia with Lewy bodies, he remarked, "I'm working extremely hard trying to stay focused talking to you because right outside the window are these guys doing their things [construction]. And, out of my eye I can see them, but not only that, I can hear them. And, it's really hard for my brain to stay engaged and focused on just you." When interviewing Helen, living with early onset Alzheimer's, in person at a local coffee-shop she explained how "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." This caused Helen's "brain" to be "maxed out," making interacting with the interviewer much more difficult. These environmental conditions "can have a fluctuating effect" [Frank] on auditory sensitivity. As Frank describes: "I can go off to a crowded shopping center... and it's fine. Another time, I can go to exactly the same place, possibly with even less people there and within five minutes I'm so stressed out I need to leave." Further, Frank describes how these fluctuations are “not really predictable” because “I don't know what causes the same thing one day to appear totally different and have a completely different effect on you another day.” In response, Frank sometimes put on headphones on the noise cancelling setting or with music. He sometimes even listens to music while interacting with others: “when I'm having a conversation with somebody, I might just slip the headphone back or the earphones.”

*Changing Speech and Language Patterns*: Participants with dementia described experiencing changes in their verbal communication abilities. For example, Helen, living with early onset Alzheimer’s disease, explained how due to dementia, she started to “stutter severely,” including long “pauses” when she speaks, and “slowness of the speech.” Due to similar changes, Phillip, living with Alzheimer's disease and semantic dementia, now speaks more slowly and has to “stop to think about something” before he says it – a strategy Helen also employs. Phillip describes how his speech pattern changes makes interacting with his voice assistant “aggravating” because “I got to repeat it [what he is asking] three times because it doesn't understand what I'm saying.” For this reason, Phillip proposes his idea for his Google Assistant to recognize who is speaking so that “when I speak, that it allows for more time in between my speaking so it doesn't stop in the middle.”

Some participants appreciated that voice enabled smart devices make it so that voice commands could be in natural language – using “our simple language” [Frank], where “If I don't say it exactly correctly, she can still figure it out” [Sharon]. Other participants experienced difficulty with forming commands for voice enabled smart home devices. For example, Annette, who heavily uses a Google Assistant, reported increased difficulty using syntax that matches the system's requirements, making it difficult to use Google Assistant because "the commands must be asked in a certain way because otherwise she's not understanding what I'm trying to say." Frank and Linda, living with mixed vascular dementia/Alzheimer's disease and major neuro-cognitive impairment respectively, compared voice assistants and favored Google Assistant because it is "the best listener" [Linda]: "Alexa... is too specific with its vocabulary… Google [voice assistant] is a bit more forgiving. And for somebody with dementia... That's critical" [Frank]. Pr11, a Memory Care Activities Coordinator, indicated that in later stages, people can be supported in prompting commands that could be understood by the voice assistants: "we have a script that says, "To turn on light say this. To turn off light say this."

*Perceiving and Identifying Different Sounds:* Some people with dementia experience auditory agnosia, which is impairments in sound perception and identification for select types of sounds without any clinical hearing dysfunction [122]. For example, researchers have documented people with dementia's difficulty recognizing sounds that are not words [39,109,119,120]. Frank, living with mixed vascular dementia and Alzheimer's disease, describes how the "musical" sounds that different apps make "wouldn't register." In response, he's used an app (Zedge) so that "absolutely every kind of notification, I've changed to have an audible word that tells me what it is." So, when he gets a WhatsApp message his phone will audibly notify him by saying "WhatsApp."

In other instances, people with dementia may experience difficulty perceiving and identifying sounds in the form of “word deafness,” where individuals have difficulty comprehending spoken information [139,153,235]. For example, David, who is living with vascular dementia, describes how he now has trouble interpreting information from others when they talk: “for myself… every 8 words you miss like 3 to 4 of those.” Similarly, Phillip describes “when you talk to me. I don't even get everything... I literally have to piece together in my mind what you're saying and try to kind of make sense of it because I'm not getting every single word that you're telling me.” He elaborates, “that's just a disease. I mean, I used to be such a good listener.” Joseph, living with mild cognitive impairment, describes situations where “if I'm in a store and someone is explaining something to me going too fast... I got in the habit I'd say, ‘Could you slow down a little bit? I have Alzheimer's.’ or ‘I've got some cognitive issues. Could you slow down a little bit?.’” This difficulty with listening transfers to the use of Google Assistant, where he needs it to speak, “slower in speed when it talks” [Phillip]. He suggests, “set[ting] it up to have a dementia mode. So under dementia mode, you can set the delay of speaking.” Linda, living with major neuro-cognitive impairment, also suggested voice enabled smart speakers speak “slower” and “pronounce better” what they are saying. Pr19, a Dementia Care Educator, emphasizes the importance that voice interactive technologies are “sensitive enough to be able to slow down and if the person says, "Can you repeat that?"” rather than requiring the person with dementia to ask the device to slow down.

Healthcare professionals described modifying the way they interact with people with dementia when they experience difficulty with comprehension of verbal communication due to the progression of the condition. Pr2, an Occupational Therapist, describes how her interactions with people change: where she “starts out primarily just verbal and fades into needing some visual, maybe tactile, and then more tactile in the end [stages].” This is because “if you just say move your right hand this way, they may not know what that means” [Pr2] because they may no longer understand words. Often this is because as people progress with dementia “verbal, it gets lost, they stop understanding verbal things sometimes” [Pr3]. Some healthcare professionals take people’s inability to understand words to mean their clients can’t hear them. However, Pr12, a Gerontologist Consultant, noted how it’s “not necessarily louder; you don't have to always rely on noise” to get your point across. Instead, when people with dementia exhibit difficulty understanding verbal communication, Pr3, an Occupational Therapist, described how “they really need the physical prompts versus the verbal prompts.” This could include physically motioning the actions they would like someone with dementia to follow or mirror to complete a task. Pr3 describes this as “do[ing] a lot of miming… most people I worked with really the physical miming prompts rather than the verbal.” For example, Pr8, a Lifestyle Director, explained that with shuffleboard, “You’d have to put it in front of them and make the motion of pushing the puck so that they could do it. Every time it was their turn.” In these instances, the healthcare professional would be “mirroring them or standing in front of them and actually physically motioning what to do” [Pr8]. Pr2, an Occupational Therapist, described utilizing a virtual reality simulation to give people visual feedback on how well they were mirroring the physical movement. Pr2 explains, “if people have trouble just following verbal instructions, there was a way to put on the screen an image of them moving. It was like a mirror image so they could then see what they were doing was reflected back to them."

### Dexterity

People with age-related cognitive changes can experience changes in dexterity or fine motor ability which are unique to the experiences of "normal aging" [99,237]. Dyspraxia, a condition which partially limits motor function [103] was described by participants. For example, David and Annette, living with vascular dementia and Alzheimer's disease respectively, explained their difficulty "getting dressed" due to dexterity changes: "I'm no longer able to do zip up buttons and fiddly garments" [Annette]. Healthcare professionals in our study even use dexterity and tactile skills as determinants of progression of dementia, with Pr3 using a "box and blocks" test that involves sorting blocks quickly. Though changes in dexterity due to aging are not unique to those living with dementia. As Peter, living with subjective cognitive decline, describes how precise or accurate movements were increasingly difficult to accomplish: "I sometimes hit something which I'm not expecting to." In activities composed of "slight" movements, like unloading the dishwasher and "taking out the glass or the cup" he sometimes "hit[s] the edge of the countertop" because of disruptions in his dexterity and tactile abilities .

Participants described a variety of dexterity changes that made using technology challenging. This included difficulty with mice, trackpads, and keyboards while using their computer. When using a mouse was difficult, Pr6, an Activities Service Supervisor, suggests "a laptop would be better for them to use" because they could use the trackpad. But, some people, such as Phillip, prefer desktops with a mouse because “I have trouble with laptops. I have trouble coordinating the mouse [through the trackpad] using my finger.” Still others described difficulties with computer keyboards due to “massive pains in my hands” because of a medication, which makes typing on a keyboard difficult [Arthur] or other comorbidities which caused “a tremor” [Pr13].

Touchscreens require some precise motor movements or selection between options that can be close together, which were challenging for some participants. Frank found sliding a button on his phone to answer a call difficult due to the precision and sustained movement required. When using his phone, Phillip often “send[s] them the text by accident rather than call them, you know, because I hit the wrong thing.” Peter experienced something similar, explaining how he “minimize[s] composing” emails and surfing online using his phone because he hits “two keys at same time” or “the wrong key.” Because of the challenges he encounters with precisely typing on his phone, he chooses to only surf or send emails on his computer where he can utilize the keyboard. Phillip, living with Alzheimer's disease and semantic dementia, explained the interplay of memory and dexterity required to operate touchscreens and how this was impacted by his changing abilities: “And I don't remember how to do the right amount of pressure and feel to do the swipe.” In contrast, Ted, living with subjective cognitive decline, said “I've learned how hard and long to press a button to make it actually work most the time.”

In response to the mismatch between dexterity abilities and what was required to operate the touch-screen devices successfully, participants switched to larger devices (Arthur and Phillip), and envisioned solutions like a single press physical button in a consistent location for their phone (Phillip) or auditory input to answer the phone rather than swiping ("then I haven't got to touch anything" Frank). As Sharon, living with vascular microangiopathy, noted her desire for a computer to "alternate between modes of inquiry" by "use[ing] a linguistic and touch interface" where one could visually use icons, tactilely press on the screen, and have an audio interface, so that someone wouldn't have to rely solely on interact with the device through touch.

#### Proprioception

Participants described changes in proprioception or their ability to move their bodies, which affected their daily lives, including fluctuations in motor memory, and changes in balance.

*Fluctuations in Motor Memory:* Pr3, an Occupational Therapist, describes how over time, someone with dementia's ability to do tasks changes "because they lose that motor memory and they just lose the memory portion of how to perform those tasks at times." In these instances, one strategy healthcare professionals use is to physically move their clients bodies in the motion of the activity, where the client would then be able to follow the motion on their own. Healthcare professionals described using Teepa Snow's (a Dementia Care Educator [350]) "hand-over-hand guiding" (also known as hand-under-hand) where "I'm moving her body for her in a way" to provide "tactile" interactions [Pr3] "use[ing] the person's hand so they're not surprised" [Pr18]. Pr8 described an application of hand-under-hand where one of her clients with dementia "was struggling" to complete a coloring activity "and they loved to color." So, Pr8 "put the pencil in their hand and put my hand over their hand

and color[ed] with them until they started doing it themselves.” Though Pr8 does elaborate that their ability to color is “all short-term as well. It doesn't last as long.” The goal of using body movement is to “make the most of somebody’s procedural memory. Which is preserved longer into the disease process” [Pr5].

A second strategy healthcare professionals used is to provide physical objects as embodied cues to spark motor memory. For example, utilizing objects from “somebody’s previous profession or routine” is one way to access procedural memory [Pr5]. So, “if somebody was an electrician, I might engage them in activities where they’re sorting the little tiny wire caps that they would have used in their profession as opposed to a stay at home mom, a homemaker, who I might engage in clipping coupons or something of that nature.” As another example, Pr12, a Gerontologist Consultant, shared:

> “we put the Wii on and one of the ladies I read in her background that she had played tennis… All of a sudden this woman got out of her wheelchair, got the typical tennis stance because she was a lifetime tennis player and started swinging the Wii [remote] with the tennis racket. We used the Nerf attachments that you can put on so it looked like a tennis racket and started playing tennis. It was beautiful… she actually got up and played like a professional tennis player."

Participants living with dementia also described utilizing physical objects as embodied cues to help them in their daily lives. For example, though Helen uses a complex reminder system with her Google Calendar on her phone, she explains how sometimes she has to use a “physical post-it note” which she “will physically keep it in my hand” as a “tactile reminder” of where she is going when she leaves her house. Although the post-it note is one example of an embodied cue, Helen takes embodied cues one step further by “either stick[ing] it [the post-it note] on the purse” or “on the phone” which are the two items she has ingrained in her routine to take as she leaves the house. Thus she “makes sure it [the post-it note] goes with me.” She described how “even sticking the post it note on the door doesn't work. There has to be something to force me to touch it” in order for the embodied cue of the post-it note to be effective [Helen]. In these instances, people in the earlier stages of dementia may experience changes in ability to engage in many everyday activities of daily living. But by utilizing objects and routines they know well they are able to surface procedural motor memories and continue to participate in everyday activities.

The key to the embodied cueing strategy was finding objects that facilitated ingrained motor movements. For example, embodied cueing with technology only works “if the person was a technology user, like I often think when I get older and experience dementia perhaps a telephone with a calendar is going to be the habit or routine that I am used to. If you're talking about my mom, her technology is a television with a remote control” [Pr5]. When there isn’t a match between embodied cues and ingrained behaviors this can “make them a little bit more confused” [Pr4]. For instance, having clients “sign off on the home health tablets with their finger” where “they're looking for the pen and they're trying to give us their finger back thinking it's the pen” because “they're not used to that technology” [Pr4]. To sign a document with their finger was not a motor movement that was ingrained in their everyday procedural memory prior to dementia.

*Fluctuations in Balance:* People with dementia may experience unique changes in balance [99]. For example, Bill, living with dementia with Lewy bodies, explains how he cannot drive anymore “because I have my balance issues.” Changes in balance can fluctuate throughout the day, where Andrew, living with Alzheimer's disease and vascular dementia, described how: at “8:30 this morning, there was there wouldn't be no way for this to take place because I was in a very, very thick fog where I was not able to get words out… [and] my balance was off.” However, by the afternoon when the interview was scheduled his balance had changed again and had gone back to normal. Pr3, an Occupational Therapist, describes how balance can fluctuate from day to day: “every day is going to be different. If mom got up yesterday and walked beautifully to the bathroom and you guys had a great day, it might not be that way tomorrow.” “Balance assessment[s]” are even included in “cognitive assessments” given by healthcare professionals, where they “check how someone does getting up, turning around, eyes closed, eyes open” as well as “assess[ing] someone's strength or range of motion” to check the progression of the condition over time [Pr2]. Pr2, an Occupational Therapist, used virtual reality to assess motor ability, asking patients to perform a series of movements: “Move your arm up, reach this way, move that way, lean this way or step to the side.” While patients were doing these tasks, the computer would assess how precise these movements were and provide Pr2 with real-time feedback.

Healthcare professionals used various accommodation strategies for their clients with dementia experiencing changes in balance. For example, Pr11, a Memory Care Activities Coordinator, utilizes Alexa with her clients with difficulty balancing to turn on and off the lights because this can "be so much easier than them trying to stand up, causing more fall risk and leading to hospitalization." Pr2 tries to include exercises that "not only support someone's goals and strength and whatever they're working on but also can be enjoyable to someone." For example, she uses "a little set of flowers, so people can garden if they want to at least get their upper body going, [and] work on balance" [Pr2]. Taking a similar approach focusing on enjoyment, Pr8, a Lifestyle Director, has found "Dancing... If you stood someone up, even if they had trouble with balance they could dance and walk to the music where ordinarily they couldn't." In other instances, healthcare professionals had to focus on more functional activities of daily living and working with ingrained procedural memory. For example, Pr3 describes how "recently I had a lady with multiple cognitive diagnoses, so when you interplay those together it's always a mixed bag... so this particular lady just was not able to get up and really move to the bathroom safely." When Pr3 tried to implement a new "route to the bathroom that I deemed as safer" this client would not use it. So, Pr3 "put grab bars everywhere she put her hands" on her typical route to the bathroom to support her "patterns, instead of trying to break them."

Smell

Clinicians have documented the unique changes[5] in olfaction (smell) that people with age-related cognitive changes experience [5,208,250]. Regardless, healthcare professionals in our study point to smell as one of the remaining ways to engage the senses of people with even in "the very end stage dementia" [Pr2]. As Pr2, an occupational therapist, described "the only thing I could do with them is like we had this sensory bin and we have different scents and aromas that they could smell." Specifically one of her clients "who had really just looked like she was not engaged in anything. She suddenly would smell something and she would look up and make eye contact and smile" [Pr2]. Similarly, Pr6, an Activities Service Supervisor, uses "sensory stimulation" through "scents or lotions, hand massages, that kind of thing" to engage with "residents who are unable to verbalize." Pr7 and Pr8, an Activities Director and Lifestyle Director respectively, utilize flower arranging activities for the tactile and scent engagement but also as a way to "bring back memories... You know a flower for happy occasions. Even though it could have been sad occasions, it's something that will trigger, mostly a good memory" [Pr8]. In other instances, Pr8 described, "put[ting] on a pot of soup in a crockpot and just the aroma of the food would help increase their appetite" and provide a stimulating experience. Aromatherapy was used by some healthcare professionals as an engaging sensory experience because "when they breathe it in, they don't have to do anything your body knows what to do. It just reacts." This instinctive reaction to Aromatherapy was used by Pr11, a Memory Care Activities Coordinator, when "someone who, let's just

[5] Clinicians have documented a correlation in olfactory changes with age-related cognitive changes.

say they're in Hospice care they're at their end stage. One of the things we can have Google Assistant to play music, to set some Aromatherapy for them to set the scene with the lights… So, that would help advance the quality of life for that individual going through that last journey of life." Healthcare professionals were the only group of participants to describe changes in olfactory ability. All instances were described in relation to provide engaging or enjoyable experiences for those in the very end-stages of dementia.

*Discussion*

Our analysis of interviews with fifteen people with mild to moderate dementia, two people with mild cognitive impairment, five people with subjective cognitive decline and nineteen healthcare professionals describes how sensory changes experienced by people with a range of age-related cognitive changes affect technology use. Clinical studies have demonstrated each of the sensory changes participants in this study described: visual [34,242,264,289], auditory [39,109,120,121,139,153,181,235], dexterity [99,103,237], proprioception [99,103,237], and olfaction [5,101,208,250]. Therefore, the contribution of our work is not to surface these sensory changes, but to bridge the clinical research with the body of research aiming to design technologies that are accessible and useful for people experiencing age-related cognitive changes. The present paper takes a step back from our previous paper [79], which focused on the technological accommodation strategies people with dementia and healthcare professionals use to overcome challenges with technology use due to sensory changes, to provide an understanding of the effects of sensory changes people with age-related cognitive changes experience on technology use. Below, we first discuss each of these sensory changes and ways to leverage optimal modes of sensory interaction for accessible technology use with existing and emerging technologies. Finally, we discuss how accessible sensory stimulation may change across the spectrum of age-related cognitive changes.

### Interacting with Technology Using the Senses

Participants described changes to vision like lowered visual acuity, color perception, and surface dyslexia which affected reading, texting, and finding documents, resembling those described in the clinical literature [242,264]. For visual changes, participants benefited from changing font size, as well as from existing accessibility features that have been designed for people with visual impairments, such as utilizing voice to text dictation or voice recording messages (as noted in our previous work [79]). Participants also emphasized how changes in color perception made it important for technology to include adjustable color, intensity of brightness, and color contrast on their devices [79]. Some participants used the attention-drawing properties of color, along with conventions of meaning assigned to different colors, to accommodate cognitive changes. For example, they color coded tasks of a digital calendar, using red to signal urgency [Helen]. We can also learn from the barriers and workarounds participants described such as, difficulty selecting something from a cluster of items, needing everything for a task to be visible at one time, as well as from their experiences with surface dyslexia. Designers may attempt tactics such as leveraging visuospatial organization and split screens to keep all documents for a task visible at one time, as well as simplifying text phrases, using images or short video tutorials instead of or in addition to words, and utilizing auditory read-aloud settings either independently or to “triangulate” auditory information with written information.

Though auditory interaction was described by many participants as their preferred mode, some participants described experiencing fluctuating sensitivity to sound – as described in the clinical literature [181] – meaning in some instances they needed increased volume and in others they needed to utilize noise canceling headphones to block out all sound. Other participants described difficulty perceiving and identifying sounds. Clinical research shows people can experience this in the form of “word deafness” [139,153,235] or in the form of difficulty distinguishing musical tones [108,131], which can affect the way audible notifications on devices are perceived by users with more significant age-related cognitive changes, such as dementia. This work also has implications for the design of voice enabled smart speakers, as some people with age-related cognitive changes may need smart speakers to speak “slower” and “pronounce better” if they are experiencing “word deafness.” Additionally, participants describe changes in speech and language which affects their use of voice enabled smart-speakers. For example, some participants described developing a stutter and experiencing slowed speech. To accommodate these changes, participants describe wanting voice enabled smart speakers to be able to adjust based on the auditory and speech needs of the user. Though the nuanced needs of users with dementia and age-related cognitive changes in voice interactions with technology is a topic beginning to be investigated [51], further work is needed in this area.

Dexterity changes, as described in the clinical literature [99,103,237], affected touchscreen use as these devices require precise motor movements for selection between options and the use of the right amount of pressure, which was challenging for some of our participants. These findings provide a more nuanced understanding that advances previous work [90,143,305,334] on the effects of dexterity changes people experience on the accessibility of touchscreen devices and how they imagine future accommodations. To accommodate their dexterity changes, some participants switched to larger devices. Others envisioned solutions like a single press physical button in a consistent location for their phone or utilizing auditory input to answer the phone rather than swiping. Previous work with people with dementia has shown the effectiveness of auto-snap on touchscreen devices as one accommodation for dexterity changes [334]. Further work is needed to expand our understanding of future technical adaptations to address dexterity changes for people experiencing age-related cognitive changes.

Similar to Guan et al.'s work [111], our findings point to the usefulness of miming actions for people with dementia to mirror when people are no longer able to understand verbal communication. This finding supports Bouvier, Hinz, and Schmidt's concept of a "virtual coach in a mirror" for people with dementia [38]. This finding also provides further justification for extending research efforts in Augmented Reality (as in [14,340]) and XBOX Kinect (as in [86]) as our findings demonstrate the potential of these tools to provide accessible sensory prompting when verbal interactions become less accessible. Additionally, with changes in proprioception, participants described the importance of motor movement to trigger procedural memory. This finding points to the potential of using technology to prompt motor movement. For example, future work should consider testing the use of haptic gloves [200] to prompt motor movements for people with dementia.

With the changes in balance that people with dementia experience [99], this opens up new opportunities for voice enabled smart speakers to facilitate everyday tasks such as turning on and off devices without having to stand up, which could put someone in jeopardy of falling and hurting themselves. However, this brings up debates over agency vs safety in dementia technology design [78,127,129,159,281], which are of critical importance for technology designers in this space to consider.

Our findings also indicate using physical objects as embodied cues to spark motor memory for people with dementia. This finding links efforts to designing accessible interfaces for dementia with the extensive research designing for embodied interactions with people with dementia [28,84,160,206,324,326]. For example, one participant described using a Nerf tennis racket attachment to their Wii remote to engage with a client. This person primarily uses a wheelchair due to changes in physical abilities. However, when the client touched what looked and felt like a tennis racket, they were able to stand up and play Wii Tennis because they were prompted with a personally meaningful embodied cue. This finding implies the potential of including embodied cues in virtual environments (as in [150]), but specifically to facilitate exercise and movement for people with dementia and mild cognitive impairment (as in [91,203,317–319]). This finding also points to the potential for designing Internet of Things environments, providing embodied cues through a sense of touch with familiar objects that are interconnected with technical environments for use by people with dementia.

Embodied cues were also used to assist with focus and comprehension for people in the mild to moderate stages of dementia, such as described by Helen's use of Post-it notes as "tactile reminder[s]" for assistance with navigation. In particular, the permanence and continuous presence of physical objects appear to be beneficial (as noted in our previous work [79]). Uhlig et al.'s concept of designing digitally augmented everyday reminder objects to "break down and communicate complex information via sensory input and output" [308] serves as inspiration for future work that aims to provide embodied reminders for people with dementia. At the same time, it is key to consider how embodied cues are only useful if the object held meaning or was a part of daily routines for someone before they developed dementia.

Smell also changes as a result of dementia [5,101,208,250]. Participants described using aromatherapy, the smell of slow cooking food, and sensory bins to engage with people in the most severe stages of dementia. In these instances, smell actually facilitated reminiscence and positive feelings. This finding points to the potential of incorporating smell into multi-sensory environmental therapy for people with dementia [62] and including the use of smell in combination with virtual reality [24,236] to support reminiscence and enjoyment for people with dementia.

#### Accessible Sensory Interaction Across the Spectrum of Age-related Cognitive Changes

In this section we provide preliminary evidence for accessible sensory interactions with technology for a range of age-related cognitive changes, as described by participants in our study. Our intention is to support HCI researchers and technology designers in investigating a continuum of accessible sensory interactions for people with age-related cognitive changes and thus be better equipped to design adjustable, multi-modal devices to adapt to a range of abilities and changes in abilities. Further we intend to help researchers and technology designers distinguish between sensory changes people with different age-related cognitive changes may experience, which can assist in designing for more targeted groups of end-users with age-related cognitive changes. These distinctions will also assist technology designer and developers in making technologies adaptable with the progression of age-related cognitive changes, which is particularly useful when considering the often unique changes in ability each individual with dementia can experience.

Participants with subjective cognitive decline, mild cognitive impairment, and mild to moderate dementia described how visual changes they experienced affected their interactions with technology. For example, many participants described having to use voice to text due to changes in visual acuity or auditorily listening to text-based information be read aloud to accommodate surface dyslexia or mental fatigue. In addition, healthcare professionals noted how verbal communication and interaction is best for people in the very mild stages of dementia. Participants across the range of age-related cognitive changes also described their increased difficulty with dexterity, specifically with fine-motor skills required for using touchscreen devices and computers. To accommodate changes in dexterity participants described their desire for a single button system or always using voice to interact with their devices. Based on these findings we posit that verbal interactions with technology may be more accessible for some people with more mild age-related cognitive changes, such as subjective cognitive decline, mild cognitive impairment and mild dementia.

Participants in our study living with mild cognitive impairment, mild to moderate dementia and healthcare professionals described changes in speech and language patterns, such as developing a stutter, slowed speech, and word deafness, which affected people's ability to interact with others and technologies through verbal communication. When these verbal and auditory changes occurred, participants noted the use of visual stimulations as the next best mode of interaction. As one healthcare professional noted, her interactions with clients start with primarily verbal interactions and as her clients progress she uses more visual interactions [Pr2]. But not all forms of visual stimulation were considered equal. As several participants described, written information was more difficult for people to understand than visual images (e.g., Bill, Sharon, Pr17). Healthcare professionals also described how color perception changes for people shifting from the mild to moderate stages of dementia [Pr3]. Though providing visual prompts through miming and asking people to mirror their actions was one strategy that healthcare professionals described when verbal or auditory interaction was less accessible.

When visual prompting became less accessible, people with dementia and healthcare professionals described using embodied cues (e.g., Helen's sticky notes) or for those who were in the more advanced stages of dementia interacting using hand-over-hand prompting (Pr8's coloring exercise). Specifically, healthcare professionals described the use of more tactile or physical interactions in the end stages of the condition rather than visual or verbal, such as in the example Pr12 gave of the woman who was a life-long tennis player. This is an especially accessible form of interaction for those in the later stages of dementia as these embodied cues may spark procedural or motor memories which are preserved much longer into the progression of dementia. Though, when designing technical interactions triggered by embodied cues for those in the later stages of dementia it is important to consider changes in balance that people may experience which could make certain activities, such as playing Wii tennis, difficult and potentially hazardous.

Interacting using ones sense of smell was only described when participants referred to people who were in the very last stages of dementia who were approaching end of life. For example, one healthcare professional even associated sensory prompting through aroma therapy with Hospice care for people with dementia in their last days of life. Therefore, based on these findings, we posit technical interventions which include interactions with users sense of smell may be particularly useful for interacting with those in the latest stages of dementia. Though, clinical research has shown odor identification can be more difficult for people with Alzheimer's disease, vascular dementia [5,208,250] and mild cognitive impairment [101]. Future work is needed to investigate the olfactory abilities that remain, the potential of technical interactions which utilize the sense of smell for people with various types of dementia as well as across the spectrum of age-related cognitive changes.

Although our findings provide some evidence for accessible sensory interactions for people with different age-related cognition changes, our findings also demonstrate instances where participants' visual, auditory, and proprioception abilities fluctuate day to day or even throughout a day. Thus, accessible sensory interaction may fluctuate within a day or even within an hour. With this understanding of the fluctuations of the condition and the wide variety of ability changes, we urge future researchers to conduct longitudinal studies with people with various age-related cognitive changes to better understand how sensory abilities change over time and how these sensory changes affect technology use. Future work in this area should also consider systematically testing different sensory modes of interactions with technology to better understand how to provide accessible interactions with technology for those experiencing age-related cognitive changes.

It's particularly important for future research to investigate the varying effects on the sensory ability changes people experience with different types of dementia [99,108,131,240,243]. While we provide an overview of these sensory changes, this paper doesn't comprehensively break down sensory changes by different types of dementia (e.g., dementia with Lewy bodies, vascular dementia, Alzheimer's disease, etc.). One direction for future work in HCI is linking specific accessibility features and building accessibility profiles for each of the different types of dementia. Though we recognize dementia is complex and even those with the same type of dementia may experience differences in sensory changes, this mapping would help technology designers and developers to make adaptable and customizable accessibility options to accommodate the spectrum of sensory changes with dementia.

### *Conclusion*

This work provides a first step towards bridging the gap between the clinical literature describing sensory changes due to age-related cognitive changes and understanding how these sensory changes effect technology use. Through interviews with people with subjective cognitive decline, mild cognitive impairment, mild to moderate dementia, and healthcare professionals who work with people with dementia, findings from this study describe how changes in visual, auditory, dexterity, proprioception, and olfactory abilities effect engagement with technology. Together these findings demonstrate ways to leverage optimal modes of sensory interaction for accessible technology use with existing and emerging technologies. Finally, these findings provide preliminary evidence for accessible sensory interactions with technology across a spectrum of age-related cognitive changes.

# Chapter 4: The Role of Sensory Changes in Everyday Technology use by People with Mild to Moderate Dementia

This chapter appears in the proceedings of the 2020 Conference on Computers and Accessibility: Dixon, Emma, and Amanda Lazar. "The Role of Sensory Changes in Everyday Technology Use by People with Mild to Moderate Dementia." In *The 22nd International ACM SIGACCESS Conference on Computers and Accessibility*, 1–12. ASSETS '20. New York, NY, USA: Association for Computing Machinery, 2020. https://doi.org/10.1145/3373625.3417000.

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.

*Introduction*

The World Health Organization describes dementia as “one of the major causes of disability and dependency among older adults” [342]. Dementia is typically described as a condition which involves cognitive decline and affects domains such as memory, thinking, comprehension, learning capacity, language and judgment [344]. Based on this understanding of dementia, it is not surprising that most technology focuses on cognitive support through task assistance [30,53,82,129,199,204,233,327,328] or memory enhancement [14,213,311].

A body of work distinct from the literature on cognitive support focuses on technology for sensory stimulation for people with dementia [205,207,324–326]. 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” [67]. Sensory stimulation has been a method used for many years to engage people with dementia, often in the later stages [64], in meaningful sensory activities [46]. 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 [91,92,96,205,207,325]. 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 [11,158,213,267].

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 [194].

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 [133]. 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 [133]. 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.

## *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.

### 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 [342] – 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 [107,173,194,257], as well as projected mega trends for future assistive technology in dementia [346]. Past research has looked at hinderances and difficulties with technologies [227,228,251], as well as the reasons or purposes for technology adoption by people in the early stages of dementia [227]. 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 [133], 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 [13,105,106]. 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 [105]. Similarly, Arntzen found that technology's integration with everyday life was typically dependent on the caregiver's willingness to engage with the technology [13]. 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.

### 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 [6]. Similarly, the COGKNOW day navigator [213], 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 [327,328] or preventing individuals from becoming lost [129,168,255]. 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 [199] and cooking [76,233]. 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 [53,187].

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.

### Technologies Designed for Sensory Engagement

People living with dementia experience complex sensory changes that differ from the normal process of aging [133,219]. These changes differ according to the stage of dementia [5]. In HCI, most sensory stimulation technologies are designed for those in the later stages of dementia living in care facilities [91,92,96,205,207,325], though recent work reflects a shift to designing multi-sensory technologies for those in early stages [126,128,132]. 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 [327] and basic tasks such as handwashing [199]). 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 [167]. Researchers in HCI have designed technologies to facilitate the enjoyment of music, including supporting musical creativity [90,253] and the control of music choices [272]. 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 [4,110]. 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 [136], gesture-based technology combined with virtual worlds [150,277], or tangible objects with multimedia engagement [134]. Recent work continues to use multisensory prompts to provide enriching experienced but has moved away from reminiscence as the end goal [91,126].

Multi-sensory technologies have also been designed to provide enriching experiences by facilitating communication and reducing social isolation. Systems such as Printer Pal [96] or Photostroller [102] 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 [128,161,333]. 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 [128]. This work is inspired by multi-sensory environmental therapy, which uses multi-sensory stimulation rooms (e.g., [280]) to provide relaxing, enriching engagement for people with dementia [254,265,287].

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 [142]. 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.

## *Method*

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

### 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[6] and regular use of

[6] All participants self-reported a clinical diagnosis of dementia including the specific type of dementia they were diagnosed with (e.g., Alzheimer's disease, Vascular dementia, etc.). Participants were also asked to self-report their clinically diagnosed stage of dementia.

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 [286]. 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 [348]. 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 [307]. All

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When participants with dementia did not know their clinically diagnosed stage, we asked them to self-assess their stage of dementia at the time of the study based on the categories we drew from the US Center of Disease Control and Prevention and National Institute of Aging's function-based stage classification [220,221,305]. These categories included subjective cognitive decline, mild cognitive impairment, mild, moderate, and advanced dementia as well as vignettes of functional changes associated with each of these categories (see [217,218,298]). Each category was read to participants where they indicated which best fit their functional abilities. Function-based stage classifications is a particularly relevant measure to technology use, as it indicates one's ability to carry out daily activities and tasks.

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.

### 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 4 below for more detail on participants age, ethnicity, country, gender, and type of dementia.

*Table 4 Chapter 4 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 |

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 5 for a summary of each practitioner's age, ethnicity, country of practice, occupation, and years of experience.

*Table 5 Chapter 4 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 |

Analysis

We took a constructivist grounded theory approach to analyze the interview data [56]. 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 [56]. 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 [292]. We support the use of technology to facilitate interdependence [27] and self-management [148]; enabling people to take an active stance in their own health and well-being through supportive decision making and recovery-focused approaches [18,57]. 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 [160].

### 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 [342]. 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 [25,291], making them unwilling to discuss their experiences with researchers [279]. 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 [55]. 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 [8]. Researchers have suggested several barriers in research recruitment of different ethnic groups including education level [192], stigma consciousness [192], and lack of trust in researchers [74,89]. 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.

*Findings*

Dementia affects engagement in everyday activities [138,156,256]. 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., [194,213]), 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.

### 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.

### 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.

### 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 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.”

### 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.”

*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.

### Intentional Sensory Stimulation

To date, most technologies for dementia target comprehension through simplification [11,158,213,267]. 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 [177], 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.

*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 [51].

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 [28,84,160,205,324,326]. 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" [308] serves as inspiration for future work that aims to provide embodied reminders for people with dementia.

*Limiting Sensory Input to Enhance Engagement:* Past work has indicated that technology can be a source of overstimulation [177]. 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 [318], as well as increase in reminiscence [273] and quality of life for people with dementia [272,316]. 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 [100]. 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 [215], as reported in past work in HCI where a mix of soundscapes played together was overwhelming for people with dementia [132].

### 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 [30,110,138,194,223,282]. 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 [220]. However, what is less clear is how to design personalized technology in a way that is scalable, rather than custom built devices (as in [96,126,158,207,325]). 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 [148]. Caregivers are typically expected to play the primary role in customizing the "the look and feel" of a device for people with dementia [198,223,241]. 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., [314,315]) 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 [322]. 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 [78].

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 [322], 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 [248], or Deaf people who often find it difficult to read long passages of text-based online content [63]. 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 [248] and Chung et al.'s text augmentation system for Deaf people that converts complex sentences in long online articles into simple sentences [63]. 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 [129,168,327,328]. 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 [183]. Further work is needed to understand the depth of the intertwined nature of emotions and utilization of technology.

*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.

# Chapter 5: Mobile Phone Use by People with Mild to Moderate Dementia: Uncovering Challenges and Identifying Opportunities

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With the rising usage of mobile phones by people with mild dementia, and the documented barriers to technology use that exist for people with dementia, there is an open opportunity to study the specifics of mobile phone use by people with dementia. In this work we provide a first step towards filling this gap through an interview study with fourteen people with mild to moderate dementia. Our analysis yields insights into mobile phone use by people with mild to moderate dementia, challenges they experience with mobile phone use, and their ideas to address these challenges. Based on these findings, we discuss design opportunities to help achieve more accessible and supportive technology use for people with dementia. Our work opens up new opportunities for the design of systems focused on augmenting and enhancing the abilities of people with dementia.

## *Introduction*

Over the past decade, smartphone use has steadily increased world-wide [239,284]. Smartphones are becoming increasingly central to participation in society, from mundane tasks such as viewing restaurant menus to vital purposes such as dual authentication to access email.

Dementia is a condition which involves changes in cognition and affects the ability to engage in daily tasks and activities [218]. Dementia is typically progressive, with people in more mild stages of dementia experiencing less changes to their functioning than those in more advanced stages [218]. Many everyday technologies are not designed to meet the access needs of individuals with dementia [79,98,105,106,228]. At the same time, research shows a trend towards greater mobile phone use by people with mild cognitive impairment and mild dementia, with almost half using smartphones [117,155]. The rising usage of mobile phones and the documented barriers that exist lead to the opportunity to study the specifics of mobile phone use by people with dementia. This usage, as well as barriers to use, are key to understand in order to design apps and features that are useful and accessible for people with dementia. In this study we address the following research questions:

1. For what purposes do people with dementia use their mobile phones?
2. What challenges, if any, exist with mobile phone use?
3. What opportunities do people with dementia envision to support them when they encounter challenges with their mobile phone use?

Through semi-structured interviews with fourteen people with mild to moderate dementia, we learned that individuals used mobile phones in everyday life not only to accommodate changes in cognitive ability and emotional regulation, but also to stay productive and manage their health. We uncovered three major challenges with mobile phone use: 1) navigating to apps and features; 2) task execution in moments of high stress, fatigue, and time pressure, and 3) re-learning task flows after updates and upgrades. To address these challenges, participants described ideal interactions with mobile phones, including customizable user interfaces, activity-based customization, proactive technology assistance, and extended modalities for voice-based interactions.

Based on these findings, our work makes four primary contributions to the literature. First, this paper provides an empirical account of how fourteen people with mild to moderate dementia use mobile phones and the challenges they face with mobile phone use. Second, it describes participants' ideas to address challenges with mobile phone use, demonstrating the considerable creativity of people with dementia in generating ideas for future technologies. Third, abstracting from participants' ideas for future more accessible interactions with mobile phones, this paper discusses design opportunities to help achieve more accessible and supportive technology use for people with dementia. Finally, this work opens up new opportunities for the design of systems focused on augmenting and enhancing the abilities of people with dementia.

### *Related Work*

The following section describes research on mobile phone use by neurodiverse users. Following this, we describe research on barriers to general technology use for people with dementia as well the provision of technical support when people with dementia experience challenges with technology use.

Mobile Phone Use by Neurodiverse Users

Researchers have begun to investigate how neurodiverse users, such as those living with traumatic brain injury, Down syndrome, and autism use mobile phones. For example, researchers have found individuals with traumatic brain injury heavily relied on their phones for reminders out of concern for forgetting upcoming events and that they only used limited features as the more advanced features, which may have been of use, were considered too complex [60]. Research with individuals with developmental disabilities broadly, including people with Down syndrome, autism and other unspecified developmental disabilities, found that mobile phones played a key role in safety [72], increasing independence [72], providing entertainment [163], social connectedness [72,163], and reminders and scheduling support [73]. Researchers have noted specific phone features which can be barriers for individuals with developmental disabilities (e.g., small buttons and complex menus [72]), as well as how features can be better designed to support neurodiverse users (e.g., large buttons, icons with titles, and a single level menu structure for individuals with traumatic brain injury [216]).

Past researchers have designed and developed prototype apps for tablets and mobile phones to support people across the stages of dementia (e.g., to promote safe walking with GPS tracking on mobile devices [129,169,327,328]). Apps have also been designed to support self-care and health management by people with mild dementia [113,146,148]. Much of this past work focuses on the design and evaluation of new prototype applications to support users with mild to moderate dementia in important aspects of life. Given the increasing number of people with mild dementia now using mobile phones in their daily lives [117,155], there is an opportunity to understand how to design for people with dementia from another angle: by studying existing use.

### Barriers to Technology Use by People with Dementia

Past research has identified barriers that people living with mild to moderate dementia experience with technology use, such as the cost of devices [152], ethical issues [112,152], attitudinal aspects [112,152,251], condition-related challenges [112,152,185,228,259], and technology-related challenges [112,152,228].

In regards to specific attitudinal aspects, researchers have argued that people with dementia face difficulties with using technology due to low digital self-efficacy (belief in one's capacity to execute technology-related tasks) [12,112,228,230]. Two studies compared digital self-efficacy of people with mild dementia to older adults without dementia, finding participants with mild dementia perceived using technology to be more difficult than participants of the same age [185,259]. This low digital self-efficacy may impact the uptake of new, potentially useful devices [48].

This low digital self-efficacy may be due, at least in part, to changes that dementia brings which include memory, sensitivity to stress, orientation to place and time, and interpreting and understanding information [228]. Past work investigating barriers to technology use largely focuses on cognitive challenges [112,152,185,228,259]. Though researchers have also described the unique changes to sensory abilities that can cause barriers to technology, such as changes in speech patterns and language patterns and difficulty identifying different sounds [77]. In addition, researchers have pointed to how the progressive nature of the condition affects technology use [112,152,251].

Past research has also investigated difficulties people living with dementia experience due to the design of various technologies, such as websites [98,123,151], devices for in-home monitoring and support [33,35,48,52], and computers and cell phones [228]. These difficulties include challenges with familiarity [48], conspicuous devices [48,52], and complex interfaces [113,123,151]. Unlike past work with other neurodiverse users [61,72,163] little work has investigated the accessibility of mobile phones for people with mild to moderate dementia. One exception reports difficulty some tech-savvy participants with mild to moderate dementia have typing on their mobile phone due to small key size and identifying notification ringtones and sounds [79]. With this limited understanding of the technologically-related challenges people with mild to moderate dementia experience, in this work, we set out to investigate the specific barriers people with mild to moderate have with mobile phone use. Understanding these barriers is essential to designing future systems to provide the necessary technical assistance to combat these barriers..

### Technical Support for People with Dementia

With the challenges that people with dementia face with technology use, research to date has largely discussed ways informal caregivers can provide technical assistance [70,106,147,148,193,212,223,251,267]. Past work found that while assistance from others can be useful, it was not always desirable by people with dementia, with individuals going to great lengths to avoid assistance from other people to avoid burdening loved ones and to avoid others taking away tasks that they had difficulty with [80]. Some participants in this study suggested that technical assistance mediated by technology may be more desirable than human assistance. Researchers have proposed one alternative to provide necessary technical assistance without relying on caregivers - automatic personalization (e.g., [314,315]) in combination with AI to determine instances when an individual may need assistance and automatically provide this assistance or make suggestions according to the perceived need [79]. Although this past work suggests alternative solutions to provide technical support to people with dementia, researchers have not yet investigated how people living with mild to moderate dementia envision the provision of technical support. In this work, we investigate the perspectives of people with mild to moderate dementia on the optimal provision of technical support when challenges arise with mobile phone use and future opportunities for technological support.

### *Methods*

To understand how people with mild to moderate dementia are using mobile phones (RQ1), the specific challenges they have with mobile phone use (RQ2), and opportunities for technology to support people with dementia when they encounter these challenges (RQ3), we conducted semi-structured interviews with fourteen people with mild to moderate dementia. Below, we present our approach to recruitment, procedures for data collection, participant demographics, analytic approach, and limitations.

### Recruitment

Participants with mild to moderate dementia were recruited through convenience sampling and snow-ball sampling. The first author reached out to 20 potential participants with a brief email describing the study and the eligibility criteria. People were eligible to participate in the study if they self-reported a clinical diagnosis of mild to moderate dementia, owned a mobile phone, and used their mobile phone daily. Seventeen potential participants responded to the email from the first author expressing interest in participating in the study. Three of these potential participants who initially showed interest in participating in the study were not comfortable with the interview being recorded and therefore chose not to participate. The other fourteen potential participants consented to participate electronically, and completed a demographics questionnaire. Aligning with best practices when working with people with mild to moderate dementia [124] as well as legal and ethical best practices in some countries [164,300], we assumed participants' capacity to consent. Although people in the mild to moderate stages of dementia can experience changes in cognitive ability [218], they are generally able to participate independently in research studies [124]. All interviews were conducted remotely in November and December of 2021.

### Procedures

We conducted remote, semi-structured video interviews that were split into two segments of questions. The first segment focused on participants present mobile phone use and any challenges they experienced. The second segment focused on opportunities for future mobile device interactions. This is in response to Lewis, Sullivan, and Hoehl's call to include individuals with cognitive disabilities in the design and development of future more accessible mobile phones [165]. Speculative futuring in the dementia space has primarily used co-design methods, where people with dementia use sketching and paper prototyping to ideate future technologies [168]. Due to changes in dexterity, other researchers have sketched participants' design ideas as participants describe them, with the participants actively critiquing the designs being drawn [37]. However, researchers have found these low-fidelity prototyping methods are not always effective for people with dementia who sometimes prefer to verbally describe their design ideas over sketching [81]. For this reason, in the second section, we first asked participants to verbally describe their ideas to accommodate the challenges disclosed during the first section of the interview. We used ideas participants shared in earlier interviews to engage later participants in discussions about future mobile phone use.

Past work has also shown how using high-fidelity prototypes helps participants with mild to moderate dementia grasp abstract concepts even with changes in abstract thinking ability [81,125]. For this reason, after participants had shared their ideas for future technologies, we used a publicly available Android smartphone application as a technology probe [137], to inspire participants to think of new kinds of technology to support their needs and desires. This app was chosen as the technology probe because it was designed for neurodiverse users with cognitive disabilities to provide a simplified user interface with customizable buttons which enable multi-step tasks with a single click (see Figure 1). We demonstrated some functions of the technology probe which we believed may be of specific use to people with dementia, such as providing directions, making phone calls to specific people, using smart-home devices, and opening specific YouTube Channels. See Figure 1 for a visual of the mobile phone home screen demonstrated during the interview as the technology probe.

The semi-structured nature of the interview allowed us to ask further probing questions to pursue topics guided by the informants themselves. Following each interview, participants received a $75 gift card as an incentive. Interviews ranged from 47 to 67 minutes (average = 54 minutes). The interviews were audio and video recorded, resulting in 13 hours and 27 minutes of data. We provide the full study protocol, including interview questions, in the supplementary materials.

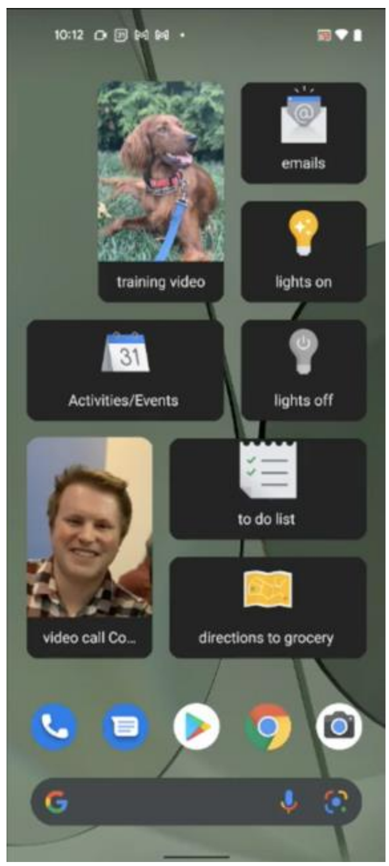


*Figure 1 An Android phone home screen showing customizable single click buttons for common multi-step tasks specific to the individual. Customizations include personalized images, labels, and sizing.* .

Participants

The research team conducted 14 semi-structured interviews with people with mild to moderate dementia. This aligns with the average sample sizes for remote interview studies [49]. Table 6 provides more information on participant demographics and mobile phone use. All participants were familiar with voice-assistants and some of their functionality. All participants resided in the U.S. with one participant, Miranda, residing in Canada. Throughout the paper we use pseudonyms for participants.

*Table 6: Chapter 5 Participant Demographics*

| **Pseudonym** | **Gender** | **Age group** | **Education** | **Racial or Ethnic Group** | **Mobile Phone Operating System** | **Regularly received assists from others with mobile phone use** |
|---|---|---|---|---|---|---|
| **Thomas** | Man | 55-64 | Bachelor's degree | White | iOS | Yes |
| **Elenora** | Woman | 55-64 | Master's degree | White | Android | No |
| **Kim** | Woman | 45-54 | Bachelor's degree | Black or African American | iOS | No |
| **Tristen** | Man | 65-74 | Some college credit, no degree | White | Android | Yes |
| **Sylvia** | Woman | 55-64 | Some college credit, no degree | Black or African American | Android | No |
| **Preston** | Man | 55-64 | Some college credit, no degree | White | Android | No |
| **Miranda** | Woman | 55-64 | Some college credit, no degree | White | iOS | Yes |
| **Kennith** | Man | 65-74 | Some college credit, no degree | White | iOS | Yes |
| **Tina** | Woman | 65-74 | Master's degree | White | iOS | No |

| | | | | | | |
|---|---|---|---|---|---|---|
| **Malcolm** | Man | 55-64 | Master's degree | White | iOS | Yes |
| **Josslyn** | Woman | 65-74 | Some college credit, no degree | White | Android | No |
| **Hall** | Man | 65-74 | High school diploma or the equivalent | White | iOS | Yes |
| **Alecia** | Woman | 55-64 | Some college credit, no degree | White | Android | No |
| **Sabella** | Woman | 55-64 | Some college credit, no degree | Black or African American | iOS | Yes |

Analysis

We used a thematic analysis approach to analyze the interview data [41]. To become familiar with the data, the first author verified computer-generated interview transcripts from audio recorded interviews. The first author then coded each transcript to generate initial codes. The first author grouped initial codes into potential themes and went back through all interview transcripts to gather quotes relevant to those themes. The research team reviewed and discussed themes to ensure that they were relevant to the codes and quotes extracted. The first author created a thematic map, grouping themes under each of the three research questions of the study. The names of the themes within the thematic map were then refined to more clearly describe the findings in each section. Finally, the research team selected the most vivid and compelling examples that related back to the research questions to include in this report.

Limitations

This work has demographic limitations. First, most participants (10/14) most likely had early onset dementia, representing 9% of dementia cases world-wide [1]. This relatively younger group of participants may be overrepresented in our research due to the contacts we recruited from and the recruitment material language: "we'll discuss how you use your mobile phone in daily life, any challenges you have with mobile phone use, and your ideas for ways to make technology use easier for you." As one study showed, technophilia - high enthusiasm for new technologies - was associated with lower age of people with dementia [117]. The second demographic limitation is the lack of people of color. With research showing a higher prevalence of dementia in non-white people [9] and only three participants identifying as Black or African American, these demographics were underrepresented in our sample. The third demographic limitation is that participants resided primarily in the United States. Findings from this study are therefore limited in terms of geographic and cultural settings, which affect healthcare access, socioeconomic status, and network device coverage.

This study was also limited by the one-hour semi-structured interview method, which was chosen to minimize the time commitment and amount of work required of participants. This choice limited the scope of the data collected, as opposed to a longitudinal study design which could provide several weeks for participants to report on mobile phone use and future ideas. Further, we choose to conduct interviews, not co-design sessions, as past work has demonstrated that some people with dementia may experience difficulty sharing sketches over video-conference calls [81]. Instead, we relied on participants' verbal explanation of their future ideas, where a UX Designer on our team later illustrated these ideas in Figma to include in this report

### *Findings*

Through our interviews we learned of the reliance, desire and interest participants with dementia had with their mobile phones and the individually meaningful activities they used their mobile phones for. Even with the heavy use of and reliance on their mobile phones, we also uncovered challenges participants had with navigating to apps and features; time pressure, high stress and fatigue affecting task execution; and difficulty re-learning task flows after updates and upgrades. To address these challenges participants outlined their ideal interactions with mobile phones, providing opportunities for the design of more accessible mobile phone interactions for people with dementia. Below we elaborate on each of these findings.

#### Mobile Phone Use

All participants described their reliance on their mobile phone, emphasizing how they "can't live without this phone" [Malcolm]. Further, mobile phones enhanced participants' quality of life, as they described them as "their best and most famous friend" [Kennith] and their "brain" [Thomas, Tristen, Preston]. Most participants described their reliance on the mobile phone to support "memory issues" [Thomas] they experienced affecting their executive functioning skills, leading Kennith to refer to his mobile phone as "the way I cope with my daily existence." Their reliance on the phone for scheduling and reminders of everyday activities resulted in several participants sharing the adage: “if it’s [an activity or event] not on the phone, it’s not going to happen” [Preston]. Other participants used their phones as a security measure for moments when they struggled to remember where they were. As Hall described, the phone is “something that I have to have with me all the time if I go someplace. That way, [Hall’s wife] can keep track of me and/or call me, or I can call them. So, it's a safety catch for me.”

Participants described their use of their mobile phones for diverse and individually meaningful activities. They described their use of apps for social media, navigation, online shopping, mobile banking, reading the news, listening to music, games, entertainment, productivity, and health management. Please see the appendix for the full list of apps participants reported using. This list does not represent all uses of the mobile phone by participants, only those that participants were able to recall during the interview. Participants’ specific uses of their mobile phones for purposeful work and health management were particularly interesting and unexpected. Therefore, we describe them further below.

*Mobile Phones Facilitating Purposeful Work and Connection*: Many participants described the difficulty they had after receiving a dementia diagnosis and subsequent retirement. Malcolm described his experience as feeling like there “was such a void in my life… I have to be busy. I don't sit around much because I feel if I sit around, I'm not productive and I like to be productive.” Participants described ways that their “phone is the key factor” in “keeping myself pretty busy” [Tina]. All participants described the importance of their calendar to support general productivity through connecting with others and keeping track of daily tasks. A few participants described productivity in relation to helping others through advocacy work. As Miranda described "I do a lot of one-on-one support things with other people with dementia. So quite often I do video calls on my phone with someone who is in need."

Still others worked on more social and creative activities, which they considered to be purposeful part-time jobs. For example, Thomas works part-time as a freelance court reporter. Sylvia "use[s] my phone a lot on Facebook live… I show people how to make natural herbal lip balm, and I tape the whole thing." Malcolm started to co-host a podcast, which he posts online from his phone. He explained how his podcast "is sort of my salvation. It's the thing that without it I think I would probably be very depressed because it's the one thing that I so look forward to" [Malcolm]. Staying productive through these various methods was as much about enjoyment for participants as it was about "keep[ing] my brain active" through "something to prepare for... I do it all pro bono, but it's that little job that I have. It is purposeful work, and it keeps me going" [Malcolm].

Participants used their mobile phones to support general productivity, meaningful hobbies, and for more creative activities - all providing purposeful work for participants.

*Mobile Phones Making Health Management Easier*: Participants also described using their phones for health management activities. For example, some participants used their phone for medication reminders, asking Siri to "remind me to take my medication every day at 7:00. So, I use that feature and it's extremely helpful with making sure I take my medication" [Kim]. For Miranda these medication reminders included specific days and dates because “I often struggle with what day we're on, what the day and date is,” which is important for specific medications she takes.

Participants described how valuable it was to be able to use apps on their phone to keep track of medical results [Josslyn, Sabella] and to collect medical data [Thomas]. Thomas, who is living with type 2 diabetes, demonstrated his use of his “glucose monitor, which I use with my phone” where all he has to do is place the phone up to his left triceps to check his blood sugar. This data is then uploaded to the cloud so physicians can access this information, sparing Thomas from “hav[ing] to stick my finger all the time. They were just able to share the data and see on a day-to-day, hour-to-hour way all my blood sugar.”

The phone was also used for recalling medical information during doctor’s visits. Elenora described how during doctor’s visits they “always ask the same standard information about your medications and surgeries and all this stuff. And I can just pull it up on my phone… and I can share it with the doctors” [Elenora]. This included notes on her phone with “specific links to my prescription list document my supplements document” [Elenora].

Participants also described how valuable the phone is to call emergency medical services. For instance, when Miranda’s “phone is upended or shaken too severely, it will send out an SOS[7] and they will actually come on and say, ‘are you

[7] SOS is an internationally recognized signal of distress in radio code used especially by ships calling for help.

okay? Do you need help?'" In addition to this feature, Miranda has used her phone "to Call 911[8] to have an ambulance come for me."

Participants used their mobile phones for medication reminders, keeping track of medical results, collecting medical data, to recall medical information during doctor's appointments and to be able to call 911 in emergency medical situations

### Challenges with Mobile Phone Use

Although participants described their reliance on their mobile phones and used their phones for a variety of individually meaningful activities, they also described the challenges they had with navigation, task execution, and relearning changed interfaces after updates and upgrades.

*Difficulty Navigating to Apps and Features:* Participants described experiencing challenges with navigating to apps and features on their mobile phone. Thomas described this as "maneuvering through the phone" where "as it becomes more useful I think it can become more challenging because there's more stuff squeezed in there and finding it all and maneuvering through it all can be a challenge."

Participants often knew exactly what they wanted to find on their mobile phone but had difficulty "sift[ing] through the vast amount of information… zoom[ing] down into it" to get to what they were looking for [Thomas]. For example, several participants described their difficulty with "navigating the contact lists" in high stress environments [Miranda]. Elenora, who lives alone and whose emergency

[8] 911 is a phone number used in North America to contact emergency services.

contacts live in another state, described her experience “when I was in the hospital and I was trying to message those two people to let them know what was up. And I couldn't remember their names. You’d think I'd remember the names of my best friends and power of attorney people, but oh, no, not with dementia on board… So, I literally had to scroll through my contacts list until the name finally rang a bell.”

Although this strategy worked for Elenora, Preston described how “A lot of people with dementia would forget to scroll. They would think I only can see what's on that page… Somebody with dementia that gets overwhelmed or finally realizes they're lost. All a sudden your anxiety is so high. It's like, ‘Where do I make a phone call? Where's the number?’” We can understand this example through the lens of affordances - an interaction element that tells us what we can do with it [68][Norman, 1999]. Affordances are binary - they either exist or they don’t - and contextual, meaning if we cannot perceive or understand an affordance because of our situation, it does not exist. In the example Preston describes where high anxiety makes scrolling to find a phone number in his address book challenging. For Preston, there is no identifiable indication of how to interact with the phone in those moments, though Preston is able to understand how to do this in other contexts when he is less anxious.

In other instances, participants described difficulty navigation to specific applications and content on their mobile phones. For example, Kim enjoys cooking and described how she will often “save the recipe on the social media platform that I’m on. And then when it’s later on, it’s time to cook, I don’t know where it is cuz some stuff might be on YouTube, some stuff might be on Facebook, some on

TikTok… it could be anywhere and just getting back to it.” Similarly, Sabella described an instance when her daughter

> “made a post about me on her Snapchat… it was a beautiful post about living with dementia and how she feels about me living with dementia. And so, I was trying to go back to find it to save it and I just could not understand the concept of doing that... I wanted it so bad, but I just couldn't figure out how to do it [get back to the Snapchat post]. So, I lost it which was the most frustrating for me.”

Participants described difficulty with navigating to apps and features due to the amount of information available on their phone and challenges with remembering where items were saved on their phone.

*Time Pressure, High Stress and Fatigue Impairing Task Execution*: The challenge here was not in understanding what steps are necessary to complete tasks but in executing the necessary steps to complete tasks with precision (i.e., the Gulf of Execution [222]). This challenge was primarily described in instances of time pressure or when participants experienced moments of high stress and fatigue.

Participants described feeling time pressure for tasks, which made them more difficult to execute with precision. For example, when inputting calendar events on their mobile phone, participants described experiencing “the pressure of the person that you're doing business with kind of standing there going ‘Why is this so hard for you?’” [Alecia] as well as the “people behind you” in line [Josslyn]. In some instances, this time pressure can lead to the event not “get[ting] on the calendar and

I'm thinking, I thought I did it. And I think I'm missing that last click" [Josslyn]. In other instances, this time pressure led to participants having inputting the exact month and time of events correctly, therefore scheduling events "in the wrong month" and consequently "show[ing] up at wrong appointments at the wrong time because I've screwed them up" [Alecia].

Participants also described challenges with executing tasks in moments of high stress and fatigue. For example, Elenora described a "time when I was very cognitively exhausted and I was waiting for a specific bus to come home. And it was delayed." Although Elenora was able to check on her phone to see the bus was delayed, she "didn't have the cognitive wherewithal to figure anything else out," meaning use her phone to search for other alternative ways to get home. Similarly, Thomas described being "in a situation where our brains aren't working right" where he was "looking at this map of these train stations and it's just not making any sense. And all I could think of was the train somehow jumped the tracks into a different line and they'd taken me to the wrong place."

In these instances of high stress and fatigue, participants were either not willing to ask for help from other people or had difficulty communicating with others. Elenora described how in these moments "I'm certainly not going to ask a stranger on the street because when you get in a fog like that, as friendly as I tend to be and willing to ask for help, when I'm that deep in the fog, I really enclose in on myself." Thomas was willing to ask for help, but when he "asked the conductor, he was very gruff, and made me feel stupid… and look[ed] at me like I was crazy" but his directions just were "not computing to me." In this instance, Thomas called his husband who drove to pick him up, describing how "people with challenges need the ability to reach out to a human even more than" other people.

Participants also described high stress interactions with voice-based systems which impaired them from executing tasks on their mobile phone. For example, Malcolm describes using his bank's interactive voice response system regularly to pay his bills. However, these systems do not always understand Malcolm where the system will say "I didn't hear you." This could be due to changes in speech patterns that people with dementia experience [211,243] such as slowed speech, a developed stutter, and greater pauses between words. Preston posits this may be in part due to participants asking "question[s] and say[ing] the wrong word or the wrong adjective sometimes by mistake" [Preston]. In these instances, Malcolm then responds by "yelling and screaming because they don't hear my voice," which led to "a very high level of frustration… and I end up hanging up the phone because it's horrible." This example shows that execution of tasks on mobile phones may be impaired due to voice assistants not understanding their verbal commands.

Participants described challenges with executing tasks on their mobile phones when under time pressure and in moments of high stress and fatigue, such as after a long day trying to navigate home or when interacting with mobile phone voice-based systems.

*Difficulty Re-learning Task Flows After Updates and Upgrades*: Similar to past work [144], participants expressed the challenge it was to re-learn tasks flows after updates and upgrades because "this is the new path I have to go through to do the things that I'm used to doing. I'm not to the point where I can't do it, but it definitely can give me pause when a program changes or updates" [Thomas]. For Tristen, upgrades were difficult because "nobody gives you instructions that these are the changes that have taken place. It just happens on the phone." He explained that "sometimes I get very anxious and frustrated, when changes [updates] take place." Notably, participants did not describe barriers with updates and upgrades in relation to WCAG violations [323]. Instead these barriers were more so due to the change itself, rather than the substance of the change, as well as the fact that these changes are not explicitly called by the system.

Several participants expressed fear over upgrading their phones to a newer version. Tina described how she has "always kind of updated or upgraded as needed. But now with my Alzheimer's, I think that if I got another phone that had more fancy things that might make it more difficult… I don't try to start all over again and get a whole brand-new phone" because she was "afraid I'm gonna mess up and then it'll screw up my brain." Malcolm shared this fear: "it's a five-year-old [phone]. I'm afraid to get a new phone because I'm afraid I'm not going to know how to use all of this stuff. So, I keep the phone. It works fine."

Participants also described not wanting to switch the operating system they used because of the difficulty they experienced with learning new systems. Josslyn explained that when she retired "I just kept [previous operating system] because I knew how to use it and I didn't want to have to relearn everything." One participant, Preston, intentionally got a new phone with a larger screen and memory "with the hopes I probably never have to get a new phone again" as he plans for this phone to last him the rest of his phone use.

Updated, upgraded or switched operating systems of their mobile phones complicated discovery for participants, forcing them to re-learn mobile phone skills, which led to frustration and fear for some participants.

### Participants' Ideas to Address Challenges with Mobile Phone Use

In this section we describe participants' ideas to address challenges with mobile phone use, including customizable user interfaces, activity-based customization, proactive technology assistance, and extended use of voice-based interactions. These design opportunities are based on feedback provided during the speculative design portion of the interview, where participants first articulated their ideal interactions with mobile phones and then saw the technology probe demonstration.

*Customizable User Interfaces on Mobile Phones:* Participants wanted to customize the size of apps and the icons so that they could more easily recognize icons and navigate their mobile phones. For example, Thomas wanted "to sort of mold the device to what you need." Molding the device included making app icons that are "recognizable… easy for me to identify, even when I'm at my worst with my brain fog with my dementia" [Miranda]. This also included "hide[ing] all those other things that we don't use or don't want" [Miranda] and placing only the most used "app[s] on the home screen" [Thomas]. Malcom describes how he needs "less options. I don't need 90% of the things [apps]… Because I think that's where I have problems, when there's a lot of options. Limit the options so I'm not searching for things."

Participants also wanted a pre-specified easy version of their phone rather than having to make user interface customizations themselves. Josslyn proposed the idea of being able to "choose an easy format" where modifications were "set for you" making the phone similar to "these phones advertised for seniors with the simplicity things." Though when asked if she had considered buying and using one of these phones, Josslyn explained how she would prefer "just a simplified version of my phone" because this is what she is familiar with, relating back to the challenges with re-learning task flows after updates and upgrades.

*Activity-based Customization on Mobile Phones:* Participants also described their need to bundle common activities - meaning to create specific categories of activities - and store these bundles in distinct, easily identifiable places. For example, Josslyn described how she "had to have it [her calendar] compartmentalized" where she "save[s] it [her phone calendar] for doctor's appointments, or hair appointments or something that I'm leaving the house for. Not just like to remember to do the laundry… routine things are put on the paper calendar." Josslyn made this modification to her calendar use after her diagnosis as she described "when I worked I had all that" on her phone calendar, "but once I had to simplify my life that's how I simplified it - paper calendar, phone calendar."

This idea of bundling common activities and storing them in distinct places was applied to several envisioned futures for mobile phone use. First, after seeing the technology probe could make a phone call using a single click button to a pre-specified individual (a common feature on devices geared towards older adults and people with dementia [213,278]), Tina described her desire for a "my tribe" button to “push the button that would have the name and the phone number of those seven people that are in my tribe so that I don't have to look it up” in her contacts (see mockup of this idea created by our research team in Figure 2). This suggestion includes bundling a group of common activities into a sub-menu.

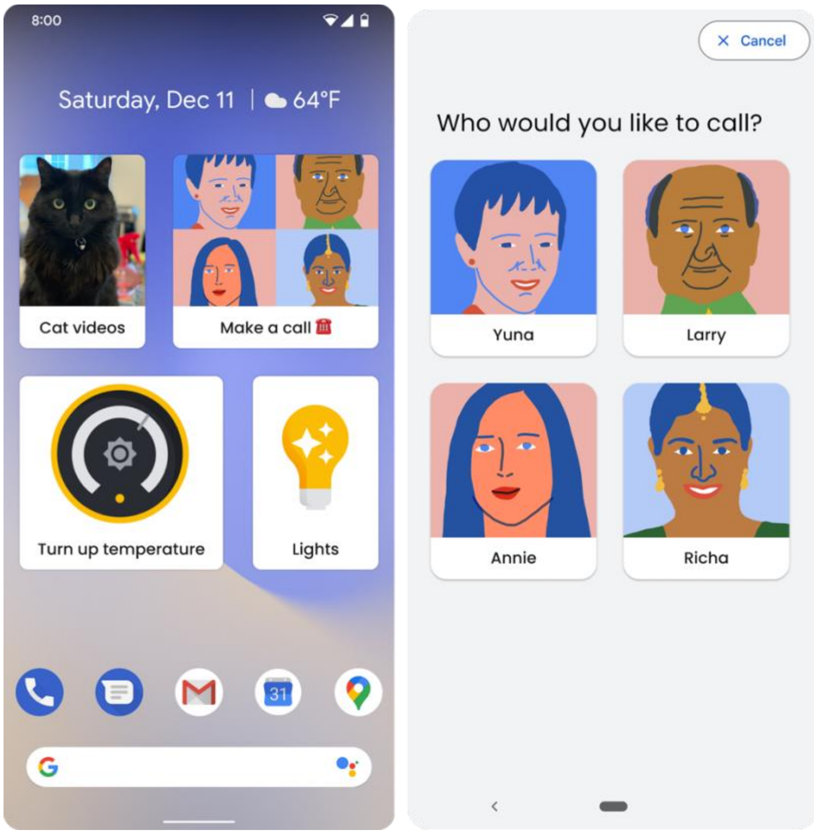


*Figure 2 Mockup of nested shortcuts to make a call to a group of people that an individual pre-specifies.*

In another example of activity-based customization by bundling common activities, one participant, Sylvia, described her desire to present voice-assistants as support for specific aspects of life. For example, Sylvia wanted her phone to “have five buttons” each with a different “personal assistant… one is for doctor's appointments. One is to help you with the grocery store. One is to [remind you to] take medication.” Practically this would be one voice-assistant (e.g., Alexa, Google Assistant, Siri) but presented as different types of assistants to help with different bundled aspects of their life. We found this concept compelling, and so proposed it in later interviews to get other participants' feedback. This idea was well received, with several participants proposing different personal assistance (e.g., life coach assistant to support chores [Alecia, Josslyn], and a technical support [Kennith]).

Participants described their desire to have activity-based customization by bundling common activities and storing these bundles in distinct, easily identifiable places.

*Proactive Technology Assistance on Mobile Phones:* Participants also described their desire for more proactive technology, where their mobile phones take some action on their behalf without them asking for this assistance. For instance, Sylvia described her desire for a single button, that when pushed, enabled a personal assistant that could help her during doctor's visits by "advocat[ing] for me" by "asking [questions] for me" if she forgets to ask them. Sylvia also wanted the personal assistant to tape her conversations with her doctor, because "if I can record it then I can play it back," supporting her memory changes. In later interviews, we used Sylvia's idea to probe other participants' perception of the line between helpful and disconcerting with this kind of assistance from mobile phones. Tina described her perspective: "I don't think it's creepy because you're making the choice to tell [the system] to start filming [recording]… It's not like she [the system] knows you just got into the doctor's office and now automatically the microphone's going to show up." However, Sabella surfaced a legitimate concern: "the thing about the button [to activate the personal assistant] is you have to remember to tell the button to do it [provide assistance]." Because memory can be increasingly challenging for people with dementia, Tina later concluded: “I think[s] there's going to be a time where we really need all those crazy voices [voice assistants] kind of helping us” without being prompted.

In addition to wanting more proactive assistance in doctor’s visits, participants also described how they would like their phone to track their activities on their mobile phone to play a part in sustaining their relationships. Participants wanted their phone to help them respond to others and initiate social interactions with others - tasks that were becoming increasingly difficult. For example, Alecia wanted her phone to be “snooping in your text” to then remind you “‘hey, you haven't checked in on or checked up on so and so since such and such’.” Though Alecia describes how it would be important for the system to be “synced to your text” rather than social media in order to only be tracking those more active social connections. Figure 3 demonstrates a mockup created by our research team of one potential interaction with proactive technical support to provide social reminders.

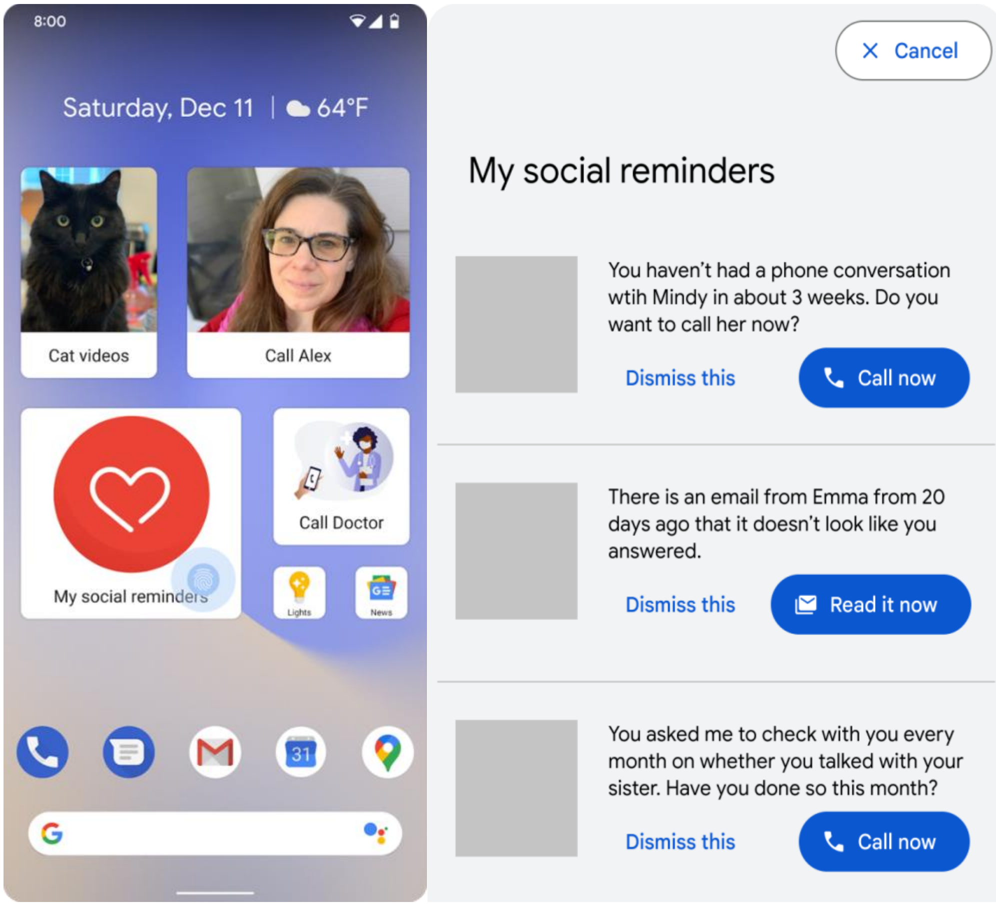


*Figure 3 Mockup of proactive technology assistance through an automated social reminder systems.*

One participant, Preston, proposed another instance when tracking mobile phone use to provide proactive technology assistance may be useful: in identifying unused but potentially useful features (e.g., a stylus). For example, Preston proposed the phone could identify: "'Hey, he really hasn't used that stylus pen. Maybe we should send him another opportunity.'" and then provide "a tutorial" of how to use that feature. When this idea was presented to participants in later interviews it was well received.

Participants also wanted their phone to provide more proactive assistance by learning and automating routine uses of their phone. For example, participants described using specific intervals of reminders for every calendar event: "it's always two days before the event, one day before the event, one hour before the event, and maybe 15 or 20 minutes before the event, and then a five-minute reminder" [Preston]. Preston wanted his phone to be "smart enough to realize, I'm doing the same reminders every time. There should be an option where I can just say, 'use your common reminders'." Sabella wanted to completely automate the process of inputting calendar events so that "when you call to say 'Sabella, I'm going to set us up a Zoom for so and so' and it automatically just kind of records it in some little strange way and it sets it on the calendar right then… Not for me to do it [input a calendar invite] but its own self."

Proactive assistance could also take the form of voice-assistants providing more structured prompts in a conversational style to help people execute tasks on their phone in moments of high stress and fatigue. For example, Elenora wanted to be able to

> "tell my phone while I'm out: 'I'm confused' or 'I'm not sure where to go.' Then it could start asking me questions. Not, 'Do you want to do this?' But literally ask me questions to help me figure out what it is I'm trying to even do. And, I could just say 'I'm trying to get home' and it could say, 'Well, there's all kinds of ways. What do you prefer? Want to go home the fastest way? The easiest way? The cheapest way?' And then I can just pick one."

This system would allow Elenora to "interact with it in a more natural language… almost have a conversation with the system." This example reflects the challenges of balancing 100% open-ended conversation with structured prompting (as previous work with older adults has highlighted [42]). In our findings, participants describe their need for structured prompting but in a more conversational style and for voice-assistants to understand less structured responses.

Participants described their desire for more proactive technology assistance through unprompted assistance, more in-depth tracking of their mobile phone use, and automating routine tasks.

*Extending Voice-based Interactions with Mobile Phones:* Participants described their desire to use voice-based interaction to address challenges with navigating their phone. For instance, Tina wanted to just be able to speak to her preferred social media app to have it search for pictures of her and her daughter on vacation rather than having to scroll through her past posts to find the album. Many participants described their desire to “click on the calendar [app] and use your voice and say, ‘doctor's appointment, this date, this time’” and have it add an event [Josslyn]. Figure 4 provides an example of adding a calendar event using voice-based interactions with Google Assistant on the mobile phone, which also takes into consideration more proactive technology assistance. Participants also wanted to search for content across apps [Elenora, Josslyn, Alecia, Sabella, Kim, Preston] (e.g., saved recipes on different social media apps [Kim], social connections with people [Thomas]). Preston wanted to “name your phone, which would then turn it on like Alexa” when you spoke its name.

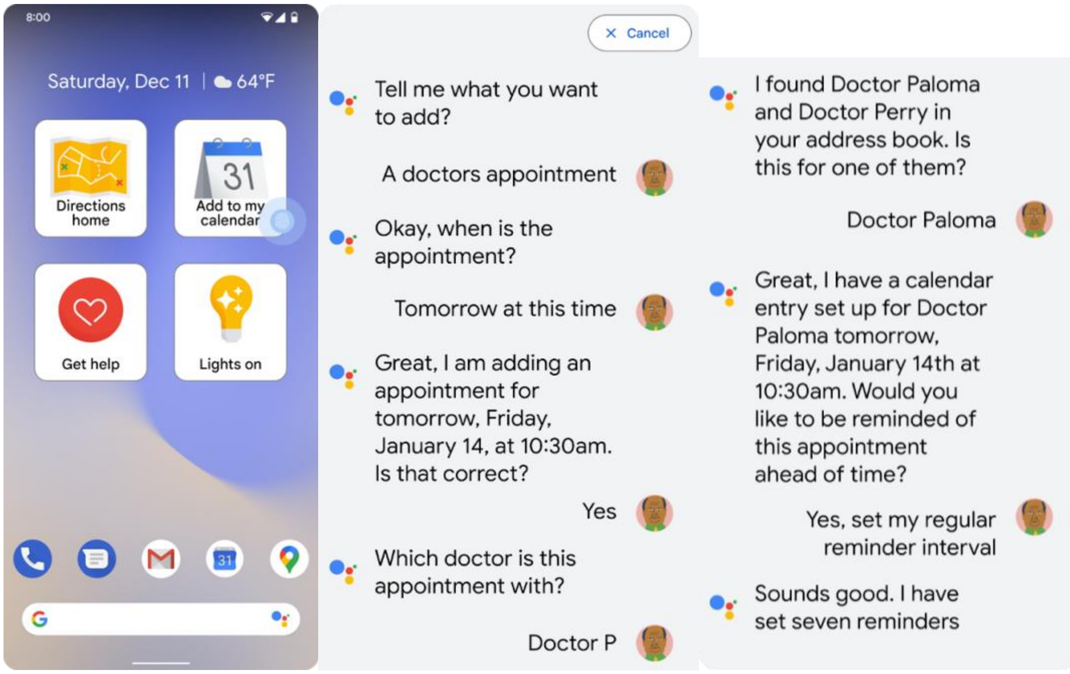


*Figure 4 Mockup of adding a calendar event using voice-based interactions with Google Assistant on a mobile phone, including proactive technology assistance with reminder intervals.*

Several participants described needing an avatar in combination with a voice-based virtual assistant on their mobile phone to help with attention. For instance, Malcolm described how “I don’t like people talking to me over the phone, it’s difficult for me. This [points at the video conference call camera] is easier.” Preston describes this as “a dual connection because you're connecting with your eyes and your ears, whereas if my screen is gone, we've only got one connection and that's just listening.” Preston believes this dual connection would help to “draw you in and you're going to pay more attention than a voice that's just randomly talking.” Because of this need for a dual connection, participants described the need for voice-based interactions on their phone to have an “artificial person” or “an android person” [Preston]. Sylvia described wanting to personalize her virtual assistant by having “an animated person” where “I can pick his voice. I can pick the culture. Like, it'll probably be a person of color.” She explained this concept by relating to “the Wii game you can describe your person… You can pick the hair, you pick the glasses, the voice, the outfit. I would like to pick my virtual assistant" [Sylvia].

Participants also described clear lines for acceptable use of avatars with virtual assistants for people with dementia, relating back to the uncanny valley effect [203]. Preston notes that the system needs to make it clear that "it's not a real person" by having "in the background saying 'You're speaking to Robby the Robot' something that is displayed. So that they know this person isn't real because for some people they could get confused." One participant, Alecia, was open to support from avatars in combination with virtual assistants as long as it remained two dimensional where any physical or three-dimensional robots were considered "scary" and "going over the top."

Even with the enthusiasm of many participants about extending voice-based interactions with their mobile phone, several participants also noted the importance of providing human assistance in high stress or time sensitive instances where voice assistants were not understanding them: "there are times when we just need, particularly people with cognitive challenges, need the ability to reach out and touch another person. Especially if we're in a situation where our brains aren't working right" [Thomas]. Similarly, Miranda describes how she "prefers person-centered help" especially "when you're talking to an artificial intelligence [about] anything more complex." Though she elaborates "that doesn't mean that I don't think things like [voice assistants] aren't good. But I think within those [having] the ability to easily access an actual person is also important" [Miranda].

Participants described their desire to extend the capabilities of voice-based interactions by: facilitating voice-based interactions within and across apps; using avatars in combination with voice assistants to support attention and further personalization; and providing access to human assistance in instances when voice assistants did not understand them.

*Discussion*

Through interviews with fourteen people with mild to moderate dementia, we address each of our three research questions. First, we investigated how people with mild to moderate dementia use their mobile phones, finding they use a range of apps for: navigation, mobile shopping, online banking, games, social media, news, entertainment, communication, connection, productivity, and health management. These findings take a first step towards filling an empirical gap in the literature by detailing some ways people with mild to moderate dementia use their mobile phones. Because past research in the development of mobile apps for people with dementia have primarily focused on designing apps to improve memory [113] or for GPS tracking to assist in navigation [129,168,327,328], we also intentionally highlight two common activities on mobile phones, productivity and health management, in need of further research and development.

Second, we investigated the pain points and barriers to completing tasks on mobile phones that people with mild to moderate dementia experience. We uncovered challenges with: 1) navigating to apps and features; 2) task execution in moments of high stress, fatigue, and time pressure, and 3) re-learning task flows after updates and upgrades. These findings expand on past work on barriers tech-savvy people with mild to moderate dementia have with typing on their mobile phone due to small key size and difficulty identifying the notification ringtones and sounds [79] by providing a more thorough examination of the barriers people with mild to moderate dementia experience with mobile phone use.

Addressing our third research question concerning opportunities for technology to support people with dementia when they encounter challenges with their mobile phones, we uncover four design opportunities based on participants envisioned future interactions with mobile phones: customizing for accessibility, activity-based customization, proactive technology assistance, and extended modalities for voice-based interactions. These findings demonstrate the considerable creativity of people with dementia in generating ideas for future technologies.

Many of these ideas incorporate AI and automation to support more accessible interactions with mobile phones for people with dementia. This provides a different perspective from past work in AI and dementia, which has primarily focused on ways AI could be used to detect and monitor the progress of dementia [29,116,263,294,295,303], in smart home environments to support care partners in monitoring the activities of individuals with dementia [10,58,68,175,234], or to support therapy [36,50,301]. Therefore, our work opens up new opportunities for the design of future AI systems to support the abilities of people with dementia, as in ability-based design [339].

In the remainder of the discussion, we describe design opportunities to support individuals with progressive disabilities and tensions with automation for people with dementia.

One contribution of this work is taking a first step towards understanding how to design for access needs for a group of neurodiverse users that experience progressive changes in ability, going beyond the traditional binary representation of disability. For instance, our findings demonstrate the importance of adaptive user interfaces to minimize navigation of mobile phone use, which can become increasingly difficult for people with dementia as they progress with the condition. Our findings also demonstrate the importance of providing increasingly proactive technological support for people with dementia as they progress with the condition. In the following section we discuss each of these directions for future design.

*Adaptive User Interfaces for Progressive Changes in Ability:* Participants described their need to have customizable home screens to minimize their challenges with navigation, including adjustable app sizes and personalizable icons (aligning with guidance from the WCAG Cognitive Accessibility Task Force) [323]. Importantly, participants did not want to use simplified phones made for older users out of concern for having to learn how to use a new system. Instead, they wanted their phone to adapt with them as they experienced changes due to the progression of dementia which affected their mobile phone use. These findings indicate familiarity with the user-interface was more important than the simplicity of the interface.

One potential future direction is to use temporal dimensions for adaptive user-interfaces for people with dementia, building off of previous work on ephemeral adaptations - where only the most used menu items are displayed abruptly and then all other menu items gradually fade in [94]. In the case of mobile phone accessibility for people with dementia, it may be necessary for the less used apps to gradually fade out and no longer be displayed due to changes in visual ability with the progression of the condition, including selecting an object from a visually busy environment [34,289]. To be clear, we are not advocating for systems that strip away functions of a device to the bare minimum due to the inability of people with dementia to understand complex functions of devices (as in past work [11,48,123,151,171,213,267]). Rather, we are proposing systems which display the most used features in a way that is easy for people with mild to moderate dementia to navigate to, while still providing access to less used features if/when they want them.

Another potential future direction is the design of adaptable systems in combination with activity-centric thinking [20], which shifts away from traditional application-centric computing and towards human goal-oriented activities, cutting across systems boundaries [20]. Participants wanted their user interfaces to bundle common activities and store these bundles in distinct, easily identifiable places. For instance, participants bundled their calendars by type of activity (e.g., in-home activities vs. out of the house activities). Adapting user interfaces to reflect bundles of common activities may be one way to make systems more accessible to people with dementia as they experience progressive changes in ability.

These are just two examples of potential areas to explore in future work on adaptive user interfaces to support people with dementia. There is room for much further exploration concerning adaptive user-interfaces to support more accessible interactions with technology for people with progressive changes in ability.

*Proactive Technological Support*: One way to provide more proactive technological support is through context-aware computing. Participants described the need for their phone to recognize their location as well as their conversational partner (as in the TalkAbout System for people with Aphasia [145]) to assist them in executing tasks in moments of high stress and fatigue. This assistance could be provided through context-aware prompting for tasks, as in [53,54] which provided prompts for users with cognitive impairments to complete tasks. Though, as participants in our study mentioned, there may come a time with the progression of the condition where prompting will not be enough and the system will need to provide more active assistance. For example, assistance could be provided automatically when the system recognized the context the person with dementia was in (e.g., in a doctor's appointment speaking with their doctor). One participant even wanted their mobile phones to listen into their phone conversations to automatically add calendar events as they were confirmed during phone calls, as in past work [178,179]. Future systems should consider utilizing context-aware computing to provide more active support to people with dementia.

Another way proactive technological support could be provided is through tracking technology use. For example, several participants described their desire for their phone to monitor their text and emails to prompt them to respond to and initiate social interactions with others. Participants also wanted their mobile phones to track what features they used and propose new or previously unused features that may be helpful to them based on their historic phone usage. Current systems provide nudges and notifications for new features, walking interested users through how to use a system once as further reminders are assumed to be unhelpful and annoying to users. Our findings suggest that for people with dementia they may need to be reminded about features more than once, due to the progressive nature of the condition and their changes in memory overtime. Future systems could integrate more proactive technological support (e.g., context-aware proactive smart-speakers [249,331,332]) by highlighting potentially useful features and providing regular reminders of these features if they begin to go unused.

### Tensions with Automation for People with Dementia

Participants described extensive future applications for automation, surfacing tensions with autonomy specifically who would be in control of initiating support, the person or the system. For instance, participants in our study described ways that automation could be used to improve their task execution on their mobile phones, centering their own role in completing the task (e.g., having a button where they could prompt voice assistants). This may be one solution to the concern of some people with dementia in past work towards receiving support from AI to assist with managing their daily life out of concern for the loss of autonomy [80]. However, participants also described how with the progression of the condition, they will need systems to eventually act autonomously to perform tasks on their behalf (e.g., start audio recording in doctor's visits). Participants described these progressive changes in abilities due to the condition necessitates less autonomy with technology to support them to continue to be active in everyday activities (e.g., attending doctor's visits independently).

In our work, participants also described instances where their reliance on technology negatively affected them. For example, participants described how moments of intense brain fog can render technology assistance useless (e.g., when navigating), requiring them to reach out to another person for support. These findings suggest future systems should be designed to keep humans in-the-loop (as proposed in [275]) around users with dementia to provide support when necessary. For example, future systems could sense frustration or negative emotion from voice interactions, and then automatically connect the user to human assistance, potentially a loved one.

We recognize that this is not a full investigation of all possible tensions that may arise with automation for people with dementia (e.g., privacy, trust, explain-ability). Further work is needed to investigate these tensions and ways for designers, developers, and researchers to better navigate these tensions.

### *Conclusion*

This work details ways people with mild to moderate dementia use their mobile phones surfaced through an analysis of interviews with fourteen people with mild to moderate dementia. Findings from this study showed three major challenges with mobile phone use: 1) navigating to apps and features; 2) task execution in moments of time pressure, high stress and fatigue, and 3) re-learning task flows after updates and upgrades. To address these challenges participants described their ideal interactions with their mobile phones, which included customizing for accessibility, activity-based customization, proactive technology assistance, and extended modalities for voice-based interactions. This paper contributes to the literature by 1) providing an empirical account of how fourteen people with mild to moderate dementia use mobile phones and the challenges they face with mobile phone use; 2) demonstrating the considerable creativity of people with dementia in generating ideas for future technologies; 3) uncovering design opportunities to help achieve more accessible mobile phone use for people with dementia; and 4) providing new directions for the design of future systems to augment and enhance the abilities of people with dementia. With the pervasive use of mobile phones in our society, these findings will help researchers and creators of technology design environments that assure societal inclusion [130] for people with mild to moderate dementia.

# Chapter 6: Conclusion

## Overview

The objective of this research was to understand how participants living with mild to moderate dementia in this dissertation use technology, the barriers to technology use they experience, ways they work to overcome these barriers with commercially available technology, and how they envision future technological support to prolong their technology use. I focus on people living with mild to moderate dementia who use technology regularly as a way to discover issues that may be exacerbated or even impossible to overcome for less technology savvy users and to yield insights into the potential benefits of technologies that might exist when adopted by a broader audience.

In the first paper of this dissertation, I examine every day technology use by tech-savvy individuals in the mild to moderate stages of dementia. In this study I describe how technology savvy participants with mild to moderate dementia utilize intricate socio-technical systems they have designed to support the management of their daily lives and condition. I discuss the considerations these participants took when designing these systems, including designing for: future changes in ability, the social world around them, and maintaining control.

In the second paper of this dissertation, I describe the sensory barriers to technology use people with age-related cognitive changes can experience. In this work I discuss ways the unique sensory changes people with dementia experience can cause barriers to technology that overlap and also contrast with the barriers experienced by people with typical age-related sensory changes. In describing the spectrum of sensory changes that people with age-related cognitive changes experience, I also describe ways technology may be adjustable to adapt to a range of abilities and changes in abilities.

In the third paper of this dissertation, I describe the adaptations participants in my dissertation with lived and professional experience with dementia make to commercially available systems to meet the changing accessibility needs of people with dementia. Findings from this study also revealed the limits to technology adaptability that may lead to the cessation of technology use for some people living with dementia.

In the fourth and final paper of this dissertation, I investigate mobile phone use by people with mild to moderate dementia, the challenges they have with mobile phone use, and their ideas to address these challenges. I discuss the barriers people living with mild to moderate dementia experience with navigating their phone, task execution, and relearning changed interfaces after updates and upgrades. To address these challenges participants described their ideal interactions with their mobile phones, opening up new design opportunities for people with mild to moderate dementia. Abstracted from participants ideas, I discuss opportunities for future systems to provide better support to people with mild to moderate dementia as they encounter challenges with technology use.

## Contributions

Below, I detail my contributions and the literature that I expand upon through my dissertation work.

### Expanding our understanding of the barriers to technology use and opportunities to address these barriers

Past work has largely attributed barriers to technology use to the cognitive changes people with dementia experience [194,213] and less work understands the barriers to technology use people with dementia experience due to the design of technology [229]. In this dissertation, I expand on past work by describing ways technology is not always built to match the changing sensory, cognitive, and motor abilities of people with dementia (Chapters 3, 4 and 5). With this more in-depth understanding of some barriers people with mild to moderate dementia may experience with technology use, my work opens up a variety of design opportunities to address these barriers.

### Positioning dementia technology research within the accessibility literature

Past work in understanding technology use for people with dementia has largely been concentrated in the health and gerontology literature [105,228,229,232,233]. Although researchers in HCI are increasingly focusing on the design of more accessible technologies for use by people with dementia [68,75,112,133,214], this dissertation takes steps towards positioning dementia technology research within the accessibility literature. Chapter 3 takes steps towards bridging the clinical research on sensory changes with the body of research aiming to design technologies that are accessible and useful for people experiencing age-related cognitive changes. Specifically, Chapter 3 contributes to the HCI literature by describing how accessible sensory stimulation may change across the spectrum of age-related cognitive changes. Chapter 4 describes ways some people with dementia are using existing accessibility settings, designed for other disability populations, to adjust devices to meet their changing accessibility needs. Further, Chapters 4 and 5 describe similarities between accessibility needs of people with dementia and those of people from other disability populations. Positioning dementia technology research within the accessibility literature opens up new opportunities for researchers in the accessibility field to test existing AT and design new AT for people with dementia and older adults with age-related cognitive changes.

#### Demonstrating the necessity of adaptable systems

Past work has primarily designed systems for use by people in distinct stages of dementia [96,127,159,207,330]. In this dissertation, I demonstrate the necessity of systems to be adaptable to the changing needs of people with dementia over longer periods of time (Chapters 2 and 5) with the progression of the condition, as well as with day-to-day or hour-to-hour fluctuations in ability (Chapters 3 and 4). Further, Chapters 4 and 5 provide directions for future work to develop and test adaptable systems using AI.

#### Recognizing the technical proficiency, creativity, and innovation of people with dementia

Previous work has largely described people with mild to moderate dementia as unable to use technology or apathetic towards technology use [13,105,106]. In this dissertation, I demonstrate how some people with dementia are capable technology consumers (Chapters 2, 4 and 5), inventive creators of technology systems to manage their condition (Chapter 2), and innovative in generating ideas for future technologies to meet their changing needs (Chapter 5). Therefore, the findings of these studies necessitate a shift in the way researchers, designers and developers think about and approach the design of future systems for people with dementia. This shift entails moving away from the deficit narrative, which focuses on designing technologies to monitor the "behaviors" of people with dementia [10,58,68,175,234], and towards the design of systems focused on augmenting and enhancing the abilities of individuals living with dementia as they progress with the condition.

## Crosscutting Tensions

In this section, I detail the most salient tensions which emerged across the four studies in this dissertation and potential ways to mitigate these tensions in the design of future systems.

### The interplay between sensory and cognitive changes

In Studies 2 and 3, there is a focus on sensory changes experienced by people with dementia and ways technologies are not always designed to accommodate these changes. I make a distinction between sensory and cognitive changes in order to highlight the full breadth of changes that people with dementia may experience [218], as past work has primarily focused on designing technology to support cognitive changes in the form memory enhancement [14,213,311] and reasoning [30,53,82,129,199,204,233,327,328]. But many of the changes described by participants included an interplay of both sensory and cognitive changes. For example, participants described difficulty reading on devices due to color contrast, spacing, and font type as well as acquired dyslexia (Study 2) and using auditory stimulation in the form of music to support focus (Study 3). Due to this interplay, the distinction between cognitive and sensory changes and their implications for technology use is difficult to tease apart. One potentially fruitful way for future work to navigate this tension between sensory and cognitive changes people with dementia experience would be to focus instead on neurodiversity – different cognitive and perceptual capabilities than what is normative [65] – and investigate ways these differences may affect (both negatively and positively) various aspects of everyday functioning [69]. In addition, future accessibility guidelines [140] could better incorporate the experiences of people with dementia, and other neurodiverse populations, by creating guidelines that incorporate the interplay between physical, sensory and cognitive changes which can affect technology use.

#### User versus system control

In Study 1, when asked to describe the considerations they took before including technologies within their self-management systems, some participants with dementia described their concerns for maintaining control and autonomy when using voice-assistants (Study 1). Yet in Studies 2, 3, and 4 in this dissertation, many of these same participants described using voice-assistants on a regular basis – though with some accessibility barriers. This surfaces a tension between an ideal world and the reality of living with dementia, a progressive neurological condition. For example, in an ideal world participant wanted to have full control over when a device (e.g., a voice-assistant) performs an action on their behalf and wanted to avoid any devices that didn't offer full user control (Study 1). In reality, with the progressive changes people experience with dementia, the benefits of utilizing technologies (e.g, voice-assistants) to continue to participate in daily life as they wish make them a necessity

(Studies 3, 4). And, participants recognized they may not be able to remain in full control of their device as they progressed with the condition (Study 4). To navigate this tension, future systems could be designed with an emphasis on human-system collaboration with adjustable levels of control between the user and the system [275]. For example, future systems could provide progressively more prompting and assistance as users with dementia need it due to the progression of the condition.

### Familiarity versus Adaptivity

Another tension that emerged throughout this dissertation was the need for systems to be adaptive to the changing needs of participants (Studies 3 and 4) and the need for interactions with technology to be familiar or routine (Studies 1 and 4). Here it was not that participants did not want their devices to adapt to be more usable or accessible to their needs, as Studies 1 and 3 describe ways people with dementia were themselves making adaptations to their devices. The challenge was with learning new interaction patterns that result from adaptations (Study 4), where there comes a point in the progression of the condition that learning how to follow new task flows is more difficult (Study 1). One potential way for future systems to navigate this tension is for systems to explicitly call out any changes made, and provide access to comprehensive technical support in the form of short, detailed training videos or access to a technical support person.

### Older adults technology needs compared to people with dementia

Several of the challenges with technology that participants with dementia in this dissertation described overlap with challenges with technology use past work has reported older adults experiencing. For example, the need for structured prompting from voice-assistants (Study 4 and [42]); and a deep sense of frustration when technology does not work for them (Studies 3, 4 and [23]). Although these user groups may share common difficulties with technology, it is important to not equate the experiences of people with dementia to the experiences of neurotypical older adults. As described in detail in the background section in Study 2, people with dementia experience unique changes from those experienced by neurotypical older adults that affect their daily life and activities [218]. Yet, even with these differences, most people living with dementia may also identify as older adults, which makes disentangling the effects of these different experiences on technology use more difficult. Therefore, we propose one way to mitigate these tensions moving forward is to take an intersectional approach to the design of future systems, where "various dimensions of identify coalesce inseparably and relate to the conditions of one's surroundings" [66,269].

Limitations and Tradeoffs

In addition to their contributions, each paper has several limitations, which are described in detail in their subsequent chapters. One cross-cutting limitation is the use of one-hour semi-structured interviews for all four studies included in this dissertation.  This method was chosen in order to minimize the time commitment and amount of work required of participants. This choice limited the scope of the data collected, as opposed to a longitudinal study design (e.g., diary or ethnographic studies) which could provide several weeks for participants to report on technology use, barriers to use, accommodation strategies, and ideas for future interventions. I also chose to conduct individual interviews rather than focus groups, as past work with older adults has shown, when ideating new technologies in focus groups, participants were designing for an ambiguous, stereotypical older adult rather than ideating based on their own needs [244]. Future work should consider using focus groups to further fleshing out ideas participants shared in individual interviews throughout this dissertation, as this may result in valuable insights and iterations to these design ideas.

A second cross-cutting limitation of this dissertation is that data collection for all four studies was conducted almost entirely using remote methods, due in-part to restrictions on gathering with the COVID-19 pandemic as well as the geographic location of participants. I had to rely on verbal explanations of technology use and barriers to use, because observation of technology use was difficult to conduct remotely. Therefore, my work provides an account of participants perceptions towards technology use more than empirical account of technology use. Additionally, I chose to rely on verbal explanations of future technology ideas, as in my past work people with dementia experienced difficulty with sharing sketches over video-conference calls [81]. Therefore, illustrations of participants design ideas were developed by my research collaborators and may not precisely capture what participants envisioned. Further, although this dissertation proposes new directions for the design of technologies for people with dementia, no prototypes were developed.

This dissertation also included overlapping participants, where interview data from one-hour, in-depth, semi-structured interviews with 17 people with dementia, 5 people with subjective cognitive decline, and 19 health-care professionals were analyzed with different research questions for Study 1, Study 2, and Study 3. In Study 4, 7 new participants with dementia were recruited, meaning the other 7 participants also participated in the previous studies. Together there were 48 unique people who participated in this dissertation resulting in four research papers. This small sample size demonstrates the rapport and trust developed between myself and the study participants to collect such in-depth interview data. One major draw-back of this small sample is that it limits the generalizability of the findings to the larger population of people living with dementia.

## Opportunities for Future Work

Below I outline several areas of future work that my dissertation points to:

### Designing technologies that utilize sensory engagement to support everyday life

My dissertation opens up new directions for the design of technologies which are more accessible to people's changing sensory abilities. For example, In Chapter 3 I uncover the importance of motor movement to trigger procedural memory for people with dementia. This finding points to the potential of using emerging technologies (e.g., the haptic gloves [200]) to prompt motor movement. In Chapter 4, I discuss ways to leverage optimal modes of sensory interaction for accessible technology use with existing and emerging technologies (e.g., embodied reminders as in [312]) and the potential utility of music to support tasks and engagement with everyday activities. Future participatory design studies are needed to flesh out these initial design ideas and understand ways that embodied and sensorial focused technologies could be used to support everyday life for people in the early stages of dementia.

### Making IoT systems more accessible for less tech-savvy people with dementia

In Chapter 2, very technologically savvy individuals with dementia described ways they personalized their IoT devices within their home to work for their unique needs. Though many of the accommodations in Chapter 2 may be useful for a broader audience of individuals with dementia, further work is needed to understand how to make the setup and personalize of these IoT systems more accessible to less tech-savvy users with dementia.

### Identifying the tensions of utilizing automation to support people with dementia

There is also a need to further investigate tensions with the design of systems that utilize AI to support people with dementia. Although many participants throughout this dissertation were optimistic to and described using automation regularly, largely through mobile phones or smart-speakers, participants also expressed concerns for remaining in control of their life when receiving support from AI (Chapter 2). Further, in Chapter 5, I described tensions with autonomy with automation due to the progression of the condition necessitating less autonomy with technology to support people with dementia to remain active in everyday activities. Much further work is needed to identify other possible tensions that may arise with utilizing AI in the design of systems for people with dementia and to ideate ways for designers, developers, and researchers to better navigate these tensions.

Concluding Remarks

In this dissertation, I present papers that expand our understanding of everyday technology use and ways to improve its accessibility for people with mild to moderate dementia. The findings from these studies demonstrate how people with dementia are capable technology consumers, inventive creators of technology systems to manage their condition, and innovative in generating ideas for future technologies to meet their changing needs. Therefore, this work opens up new directions for the design of future systems for people with dementia that focus on augmenting and enhancing the abilities of individuals living with dementia as they progress with the condition.

# Appendices

## Appendix A: Supplementary Material - Interview Protocol for Participants with Dementia used in Study 1, Study 2, and Study 3

Introduction

Thank you for participating in our study. The goal of this study is to learn about the technologies you use and what you think about them. This will help us make technologies more enjoyable and useful for people with dementia.

The study will involve four stages that we will go through today:

1) First, I will ask you questions concerning the technologies you currently use to manage your day to day life and to engage in meaningful activities.
2) Second, I will ask you to show me the technologies that you use. I may ask you to show me how you use these technologies as you would normally.
3) Third, I'll ask you questions concerning the ways you manage your health and wellbeing.
4) Finally, if we have time, I will ask your thoughts on some future technologies that you might find useful and about your formerly used technologies.

The whole study session should take up to an hour. Your data will be kept anonymous. You have the right to stop participating in the study, for any reason, at any time. We will be audio/video recording the interview. For the video recording, your face will not be captured and we do not intend to take identifiable images of you. Before we begin the interview, we need to complete a consent form and a basic demographic form.

**Questions related to current use of ICT:**

1. I'd like to hear about your general attitude towards technology?
2. Can you tell me some of the technologies you use regularly
3. I'm going to go in depth on some of these to understand your motivations and experiences using them, and also how dementia affects people's experiences of using technology. Are there any of these you think would be interesting to talk about?
4. Can you walk me through a recent time that you used this technology? [follow up questions below ]
    a. How did you feel?
    b. What did you like about this experience (visual, audible, tangible, functional)?
    c. Follow up: can you tell me more?

d. Can you tell me about anything you liked about the technology at that time?
e. What need was this technology meeting for you? (e.g. contact, reminders)
    i. How well did this technology meet your needs?
    ii. Can you think of any ways the technology might be improved to better meet your needs?
f. How often do you use this technology? (e.g. once a week, once a day, hourly, etc.)
    i. Is the use you described to me typical of how you use it?
g. Is the use you described to me similar to how you used it when you first started using it?
    i. If no: In what ways has this changed?
h. What about changes you've experienced with your dementia? Do these affect your use of the technology?
    i. Do you find it works better for you certain times than others?
    ii. (If yes:) How does your use change if you are having, for example, a sensory challenge?
        1. How do you know if you are having sensory challenges?
    iii. Now we will shift gears a little bit and think about using technology in the broader social context. Have you helped anyone use this technology, or has anyone else ever helped you use it?
        1. If someone else helps them:
            a. How do they help?
            b. How do you let them know if you need help?

We know that people experience variability in terms of what they are able to do over time or from day to day. We want to understand if there are any changes that you make to the technology to make it easier to use for yourself.

1. Is there a way you adjust the technology?
2. How do you decide when you need to adjust it?
3. Who determines the level of cognitive ability to set the technology to?

Now, is this something you'd be able to show me over video-call?

- Can you walk me through how you use it?
- How do you know what to do next?
- How do you feel using this?
- Why did you decide to do that?
- Do you ever have trouble with this part? What do you do about that?

- How did you learn to do this?
- Have you always done this that way?
- Do you usually do that this way or is there a different way you normally do it?
- Is this the way the device was designed to be used? If not: how did you modify it? Who modified it?

**Questions related to self-management strategies:**

1. With many conditions, there is research on how people "self-manage," or how they take care of their health and wellbeing. For example, people have studied the way people with diabetes make sure they have the right blood sugar. With dementia, this is a newer idea. We are interested in understanding what the concept of "self-management" might mean in dementia.
    a. Do you have any thoughts on that idea?
    b. Do you have a good word to describe this or should we use "self management"?
    c. What is your experience with your own self management?
        i. Can you tell me about some of the areas of your life that you self-manage?
        ii. How is technology involved in all this?
        iii. How did you start to use this/find this technology?
        iv. Are other people involved in your self-management of this area or technology use? How?
2. Now we are going to hone in on the idea of information to help you self-manage. In diabetes, this might be learning what foods best to avoid. What kind of information is important in dementia for self-management?
    a. Can you tell me about a recent time when you needed information to help you self-manage?
    If useful:
        i. What activity were you doing?
        ii. What information were you looking for?
        iii. Where were you?
        iv. Who was with you?
    b. What type of information do you need regularly?
    c. How do you obtain the needed information?
        i. How is this information presented?
        ii. What do you like about this medium?
        iii. What do you dislike about this medium?
        iv. What is your level of trust on the information given by this medium?

v. Are there any functions this medium does not do that you wish it did?

d. How urgent is your informational needs?
e. How often do you need information to self-manage? [ hourly, daily, weekly, etc. ]
f. If not information, are there other things you need to help manage your daily routine?
   If yes:
   i. What are those things?
   ii. How does [ whatever they mention ] help you manage your routine?
   iii. How often do they use it?

Is there anything else you wanted to add in regards to self-management?

**Questions related to future ICT:**

1. Is there anything you want to be able to do with a technology but can't?
   If yes:
   a. What would you like to do but cannot?
   b. Why do you want to do those things?
   c. What is prohibiting you now from doing those things?

We have one idea for a design that came out of our past work. Before going ahead and making this thing, we want to make sure it is useful. We are really interested in hearing your feedback, even (and especially) if there are any parts that don't seem like they make sense or would work for you!

*Figure 5 Storyboard demonstrated to participants in Study 1, 2, and 3 protocol*

*Show and explain the storyboard: if over video conference, screen-share with them. Otherwise, hand them the printed copy.*

2. What are your thoughts on a technology that would take into account awareness and measure changes in its users and its environment and then change interfaces to accommodate these changes?
    a. What is your perception of the usefulness of this type of technology for people with dementia?
    b. Do you see any potential problems with this technology?

**Questions related to formerly used technology:**

1. Are there any technologies you used to use to provide meaningful or enjoyable activities but you no longer use?
   If yes:
    a. Why did you stop using this technology?

b. What aspects of the technology did you not like (visual, audible, tangible, functional)?
c. What need did that technology fill?
d. What do you now do to meet that need?
e. Where did you use this technology (e.g. in your home, mobile, adult day care, in a group setting)?
f. How often did you use this technology? (e.g. once a week, once a day, hourly, etc.)
g. Did your cognitive changes factor in to you no longer using this ICT?
    i. If yes: Can you explain how this happened?
h. Did you look for other technologies similar to this technology which you used to use?
    i. If yes: Where did you find this technology?

2. Where do you go to find new technologies? (e.g. searching online, practitioner recommended, etc.)

**End of the Study**

# Appendix B: Supplementary Material - Interview Protocol for Practitioners used in Study 2 and Study 3

**Introduction**
Thank you for choosing to participate in our research study. We are researchers in the Human-Computer Interaction Lab at the University of Maryland, College Park. The objective of this study is to understand from the perspectives of practitioners, the usefulness of current Information Communication Technology (ICT) for cognitively disabilities people. Your participation will help us understand the current state of technology and how to design systems to make life more enjoyable for people who are currently limited by cognitive disability.

The study will involve an interview where I will ask you about the types of support you currently use to engage people with dementia with their environment and your professional strategies to encourage engagement in everyday activities. I will also ask you questions concerning your recommendations of ICT for people with dementia. If time permits, I will show you a list of different currently available technologies and ask your perception of the usefulness of these technologies.

The whole study session should take up to one hour with the option of an additional 30 minutes for more extended questions. Your data will be kept anonymous. You have the right to stop participating in the study for any reason and at any time. We will be audio recording. Before we begin the interview, we need to complete a consent form and a basic demographic form.

**General questions:**

1. Can you tell me a little bit about what you do? [e.g. as an occupational therapist…]
2. Can you tell me how long and in what capacity you have worked with people with dementia?

**Questions related to professional strategies**

1. Can you tell me about some of the meaningful activities you support people with dementia in?
2. Can you take me through a recent time you worked with someone with dementia to support a meaningful activity and what this looked like?
3. Can you tell me about the strategies you used to help them engage in this activity?
    a. If strategy example does not include technology: Do you have any strategies that involve technology?

    b. Why were you working with this person on this activity in the first place?
    c. What were they struggling with?

[Talk about how our field is concerned with making things accessible to people with different abilities]

4. Can you tell me about strategies you use to make [the same activity as before] accessible to people with dementia? (e.g. visible: large fonts, arrangements, colors; auditory: make sure there aren't other conversations going on at the same time, music; tangible: use soft fabrics, tangible buttons)
    a. Is there a way you deliver prompts or verbal information to make it more accessible to people with dementia?
5. Do you use different strategies for different people with dementia? Can you give me some examples? [probe for: stage of dementia, context of specific activity, person's personal interests or social context]
6. While you're working with a person with dementia do you find it important to be aware of their cognitive ability?
    a. How do you assess their cognitive abilities?
    b. Is this something you reassess? (e.g. weekly, daily, hourly, during the activity etc.)?
    c. How often do you see changes in their cognitive ability? (e.g. days, minutes)
    d. Can you give me an example of how you changed an activity for the same person whose cognitive abilities seemed to change suddenly?
    e. Can you give me an example of how you changed an activity for someone whose cognitive abilities changed over time?
7. Are there any activities that you used to support but don't anymore, or do less now than you used to?
    a. If yes: can you tell me about why this changed? (e.g. physical changes, time limitations)
    b. If yes to do less now: Are there ways that you have modified these formerly used activities so that people can still engage in them?
8. How do you decide on what activities you will do with a person with dementia during a session?
9. How do you assess the individual's level of engagement with their activity?
    a. Can you give me an example of how this looks with different people you work with?
10. Do you ever notice challenges relating to staying focused on activities?
    a. If yes: What are some strategies that you use to keep people focused?

11. How do you assess whether someone is enjoying or not enjoying an activity?
12. Is there a certain time of day that you find better to engage people with dementia in activities, in general?
    a. If yes: why is this time better to engage them than others?
13. How do you decide on the length of time of an activity?
14. How do you wrap up an activity? Are there things you do at the end to signal to the participants that the activity is over?

**Questions Related to Information Communication Technology**

Reminder: ICT includes all technological devices, enabled by internet or wireless, which allow people to interact with the digital world.

15. Do you recommend technology to people with dementia for in home use? [e.g. a phone, a stove sensor, alexa]
    a. If no: why not recommend these technologies?
    b. If yes:
        i. What technology do you recommend to majority of people with dementia?
            1. What are the primary functions of this technology?
        ii. Are these technologies for their enjoyment or for practicalities such as safety, navigation, or caregivers use?
        iii. What are your criteria for recommending certain technologies before others?
        iv. Are there any attributes of an individual or their cognitive ability that you take into considerations before recommending a device?
        v. Are these technologies [ fill in technology they recommend ] adjustable to different levels of cognitive ability?
16. Are there any technologies that you used to recommend but don't anymore, or do less now than you used to?
    a. If yes: can you tell me why this changed?
17. Do you use technologies in your practice to engage participants in activities strictly for enjoyment?
18. Have you used a technology in a way that you feel is unique and different from the intended purpose? (e.g. to measure size, to feel texture)
    a. Request to take pictures of technology.
19. Are there ways that you have modified technologies so that people with dementia can still engage with them? For what purpose did you make these modifications? (e.g. ease of use, visual aesthetics)
20. Is there anything you want to be able to do with the technology but can't?

    a. If yes: why would you make those changes?
21. How do you find or hear about new technologies that you recommend? Are there ways you search for it?

**End of the study, if all questions to this point have been answered and the one hour commitment is up.**

- Thank the participant for their time.
- Ask participants if they would be willing to participate in a further 30 minute session with additional questions.
- If yes, go to the additional questions section.
- If no, fill out participant payment form.

[Not all participants completed this section.]

**Additional Questions-Time Permitting**

Show practitioners the GPII Unified Listings and search for current technologies for people with dementia. If video conferencing, screen share with the participant. The Unified Listing is a central database that stores information about assistive technology solutions and access features in mainstream products.

Let them search for something that is applicable to their work.

22. What is your perception of the usefulness of the Unified Listing?
23. How can you imagine using this?
24. Is there anyway in which you would modify the Unified Listing?
25. What is your perception of the usefulness of the Unified Listing for people with dementia?
26. Would you make any modifications to the Unified Listing to make it more accessible for people with dementia?

**End of the Study**

# Appendix C: Supplementary Material - Study Protocol used in Study 4

**Semi-structured Interviews with People with Dementia**

**Introductions (<5 min)**

**Understanding Daily Mobile Phone Use (5-10min)**

- During a typical day, can you describe how you use your mobile phone?
- Do you use an iPhone or an Android?
- How often do you use your mobile phone?
- What tasks do you typically use your mobile phone for?
- Are there anyways that your mobile phone use has changed over time? (*probe here for pre-cognitive changes and post-cognitive changes)*

**Barriers to Mobile Phone Use (15min)**

- Have you ever experienced any challenges or difficulties with using your mobile phone? If so, can you explain? [another way to ask this: Are there activities or tasks you wish you could complete on your mobile device, but cannot due to device or access constraints?]
    - What do you think was/is the cause of these difficulties? (*probe here for specific cognitive domains or changes in cognition that make mobile phone use more difficult now than before*).
    - How often do you experience this particular difficulty with your mobile phone?
    - How did this challenge impact your use of your mobile phone? (*e.g., did you stop using that feature, figure out a work-around, get frustrated and throw your phone*)
    - Do you have any strategies you used/use to overcome this difficulty? (*e.g., changing the magnification, getting help from a friend or family member*)
        - Are there ways you would like to improve this strategy? Do you have ideas for future accommodations that would work better for you then how you are currently addressing this difficulty?

- Do you experience any other challenges with your mobile phone?
    - Go through same questions as above

**Open Exploration (15min+)**

So we've talked about your current use of your mobile phone but let's transition to thinking about how in an ideal world your mobile phone would work.

- In an ideal world how would you want to interact with your mobile phone and why? (e.g., completely through voice, though one click buttons, through gaze and eye tracking)
- How would you prefer to get technical help with your mobile device? This could even be things you wish you had but the technology doesn't exist yet.
- How do you feel about other people providing technical assistance with your mobile device?
    - Does it affect how you feel if these are people you know versus people who are helping you through a technology help center?
- How do you feel about automating tasks that are more challenging with your mobile device?
    - Show Action blocks here and the phone call or messaging feature.
    - What is your first impression of Action Blocks?
    - Do you think this would be a useful tool for you? Why or why not?
    - Are there certain contexts where Action Blocks might be more useful for you than in others? Alternative wording: "Can you describe a scenario where using Action Blocks could be helpful?"
    - What problems (or potential problems) do you see in Action Blocks?
    - Do you have any improvement ideas for Action Blocks?
    - Are there sets of tasks or macro level tasks that would be useful for you? For example, if you had a grocery pick-up application and you had to look up directions to go to the grocery store and then share your ETA with the people who are delivering the groceries to your car this could be one button.
- Have you ever experienced artificial intelligence (AI) providing assistance in your daily life (e.g., calling the bank or a hospital or using smart speakers to help you)?
    - How would you feel about AI providing technical assistance with your mobile device?
- If you had to rank which of these you felt most comfortable receiving help from, how would you rank them (people, automation, or AI) and why?

**Wrap Up (<5min)**

- Any final thoughts you'd like to share with us?
- Thank participants for their time and feedback.

# Appendix D: Table of Apps and Features from Participants Self-reported Mobile Phone Usage From Study 4

*Table 7 Appendix D: Table of Apps and Features from Participants Self-reported Mobile Phone Usage From Study 4*

| Type of App or Feature | App or Feature | Participants who Reported Using that App or Feature | Number of Participants |
|---|---|---|---|
| **Social Media** | Facebook | Thomas, Elenora, Kim, Tristen, Sylvia, Kennith, Tina, Malcolm, Josslyn, Hall, Alecia | 11 |
| | YouTube | Sylvia, Preston, Kennith, Hall | 4 |
| | Instagram | Elenora, Tina | 2 |
| | SnapChat | Alecia, Sabella | 2 |
| | TikTok | Sabella | 1 |
| | LinkedIn | Thomas | 1 |
| | Twitter | Thomas | 1 |
| **Navigation** | Waze | Tristen, Kennith, Malcolm | 3 |
| | Google Maps | Elenora, Hall | 2 |
| | Apple Maps | Thomas | 1 |
| | Life360 | Thomas | 1 |
| | Uber | Elenora | 1 |
| | Lift | Elenora | 1 |
| | Unspecified | Kim, Miranda | 2 |
| **Online Shopping** | Amazon | Kim, Josslyn, Alecia | 3 |
| | Sams App | Kim | 1 |
| | Ebay | Alecia | 1 |
| **Mobile Banking** | Capital One App | Elenora | 1 |
| | Apple Wallet | Thomas | 1 |
| | Venmo | Alecia | 1 |
| | unspecified | Kim, Tristen, Sylvia, Sabella | 4 |
| **News** | BBC | Malcolm | 1 |
| | CNN | Malcolm | 1 |
| | Fox | Malcolm | 1 |
| | NPR | Malcolm | 1 |
| | unspecified | Josslyn, Hall | 2 |
| **Music** | Pandora | Elenora, Hall | 2 |
| | Shazam | Alecia | 1 |
| | unspecified | Thomas, Tristen, Tina, Alecia, Sabella | 5 |
| **Communication** | Email | Thomas, Elenora, Tristen, Sylvia, Miranda, Tina, Malcolm, Josslyn, Sabella | 9 |
| | phone calls | Kim, Tristen, Preston, Kennith, Josslyn, Hall, Sabella | 7 |
| | Messenger | Kim, Kennith, Tina, Malcolm, Hall, Sabella | 6 |
| | SMS | Tristen, Sylvia, Preston, Josslyn, Alecia | 5 |
| | FaceTime | Miranda, Tina, Malcolm, Sabella | 4 |
| | Zoom | Sylvia, Alecia | 2 |
| | Google Meet | Miranda | 1 |
| | Evite | Kennith | 1 |
| | Blogs | Tina | 1 |
| | WhatsApp | Elenora | 1 |
| **Games** | Words with Friends | Kennith | 1 |
| | Solitaire | Hall | 1 |
| | memory games | Sabella | 1 |
| | unspecified | Kim, Alecia | 2 |

| Type of App or Feature | App or Feature | Participants who Reported Using that App or Feature | Number of Participants |
|---|---|---|---|
| **Entertainment** | Photos | Thomas, Elenora, Sylvia, Preston, Hall, Alecia | 6 |
| | Audible | Kim, Hall, Alecia | 3 |
| | Bible app | Kim, Hall | 2 |
| | Deer Cast | Hall | 1 |
| | Apple TV | Sabella | 1 |
| | Planter - Garden Planner app | Kim | 1 |
| | ESPN | Hall | 1 |
| | Frameo | Alecia | 1 |
| | GoFan | Hall | 1 |
| | E-books | Thomas | 1 |
| **Productivity** | Reminders | Thomas, Elenora, Tristen, Sylvia, Miranda, Malcolm, Josslyn, Hall | 8 |
| | Google Search | Preston, Miranda, Kennith, Tina, Malcolm, Josslyn, Sabella | 7 |
| | Calendar | Thomas, Kim, Preston, Kennith, Tina, Hall, Alecia | 7 |
| | Google Calendar | Elenora, Tristen, Sylvia, Miranda, Malcolm, Josslyn | 6 |
| | Calculator | Thomas, Elenora, Kim, Alecia | 4 |
| | Weather | Kim, Tina, Hall, Alecia | 4 |
| | KeepNote | Elenora, Sylvia, Alecia | 3 |
| | Clock | Elenora, Tristen, Alecia | 3 |
| | Google Workspace | Thomas, Sylvia | 2 |
| | Timer | Kim | 1 |
| | Notes | Kim | 1 |
| | Outlook | Alecia | 1 |
| | Evernote | Elenora | 1 |
| | Flashlight | Thomas | 1 |
| **Health Management** | Fitbit | Alecia | 1 |
| | pharmacy apps unspecified | Kim | 1 |
| | patient portals | Sabella | 1 |
| | glucose monitoring app | Elenora | 1 |
| | fall detection apps | Miranda | 1 |

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