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

Emma Dixon
University of Maryland, College Park,
Maryland, USA
eedixon@umd.edu

Anne Marie Piper
University of California Irvine, Irvine,
California, USA
ampiper@uci.edu

Amanda Lazar
University of Maryland, College Park,
Maryland, USA
lazar@umd.edu

ABSTRACT

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.

CCS CONCEPTS

• **Human-centered computing** → Human computer interaction (HCI); Empirical studies in HCI.

KEYWORDS

Self-management, Dementia, Self-management Technology, Chronic Care, Sociotechnical Systems, Self-determination

1 INTRODUCTION

Self-management is the ability to manage the symptoms, treatments, and lifestyle changes necessary to live with a chronic condition [8, 9, 14, 24, 28, 45]. HCI researchers have studied self-management strategies [24, 48, 71, 72, 95] and designed technologies to support self-management through tracking symptoms and triggers [19, 38, 101]. 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 [54, 76, 79]). The goal is often to facilitate behavior change so that individuals can cease using the self-management technology [53]. But, researchers are beginning to study self-management for progressive medical conditions requiring continued support, such as Multiple Sclerosis [4–6] and Parkinson's Disease [70, 72]. 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 [70–72]. 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 [43, 85, 87], primarily to support adolescents in behavior change (e.g., to regulate emotions and form new communication habits with parents [43, 85]). Yet, cautionary pushback has emerged, pointing out that these interventions require neuro-diverse people to adhere to dominant social practices without considering their wishes [109]. 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 [112], 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" [96]. 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" [10] rather than as social actors in their own lives [15] who are able to establish priorities and make decisions about their daily activities [69, 98]. 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 [93]. 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 [16–18, 56, 65, 93, 94]. This

perspective calls attention to the ways that people often equate a dementia diagnosis with symptoms of someone in the end stages of dementia [10, 67, 92], 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) [57] as well as how to design social interventions to teach people with dementia self-management strategies [23, 66, 67, 77, 78]. Throughout this paper, we anchor on the definition of the self-management of dementia put forth by dementia advocates [96], 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.

2 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.

2.1 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" ([8] cited in [9, 14, 24, 28, 45]). This past work examines technology for self-management for a range of conditions, including rosacea [19], chronic fatigue syndrome [24], arthritis [38], chronic respiratory conditions [95], heart failure [101], and diabetes [54, 76, 90]. Past work has focused on understanding self-management strategies [24, 48, 71, 72, 95], designing tools to identify symptom triggers [19], and tracking activity [101] to provide clinicians with data to personalize care plans [38].

Less research is focused on progressive conditions or neuro-divergent populations. One exception is Ayobi et al.'s work with people with Multiple Sclerosis [4–6]. This research points to the need for self-tracking technologies to be designed for agency and not "persuasion and compliance" [5]. 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 [109]. Another critique of existing approaches to self-management emerged in research studying the self-management practices by people with Parkinson's Disease [70, 72], 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 [29, 70–72, 100]. 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" [71] – a call to which our work responds.

2.2 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) [57]. Barriers to self-management perceived by people with dementia, caregivers, and clinicians include societal stigma of dementia affecting people's ability to self-manage [55], a lack of general public's education about dementia [67], 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 [56, 93]. 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) [55, 67]. 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 [23, 56, 66, 67, 77, 78]. These self-management group interventions have been found to increase people with dementia's self-efficacy [78], confidence [89] and cognitive functioning [44]. People with dementia themselves have published literature since the 1990s advocating for their human rights, agency, and ability to manage their condition [16–18, 65, 93, 94]. Dementia advocacy groups have published informative booklets and programs outlining practical steps people with dementia can take to self-manage their condition [96]. 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.

2.3 Assistive Technology for Dementia

Past research has looked at open technological opportunities to support caregivers and people living with dementia at home [106, 108]. These opportunities typically focus on assisting people with dementia in completing activities of daily living [108, 114]. One area that has been extensively examined is technologies to assist in the task of navigation to prevent individuals from becoming lost [40, 49, 81]. The COGKNOW day navigator [68], 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 [68]. 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.) [75]. 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 [64], brushing teeth, dressing [13], and cooking [107, 110]). 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) [20]. 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 [26].

Past research has also reviewed the assistive technologies currently available to people with dementia [36, 37, 51, 60, 82], finding assistive technology use is driven by [3, 35, 75] and mostly benefits caregivers [3, 34]. 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 [74]. Further, Øksnebjerg et al. report the literature is "lacking a holistic approach to the dynamic interrelationship between technology, user, and context" [74]. 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.

3 METHOD

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

3.1 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. 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 [91] and to yield insights into the potential benefits of technologies that might exist when adopted by a broader audience [116]. 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 [39].

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 [99]. 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 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.

3.2 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.

3.3 Analysis

Our approach to data generation and analysis drew from constructivist grounded theory [22]. 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,

Table 1: 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.

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 [22]. 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 [93]. Similarly, our analysis is shaped by notions of interdependence, which centers people as agents in securing access to resources [12]. 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 [47]. 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 multi-faceted 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" [33]. By representing our informant's views as they were expressed, reacting to their social positioning as people living with dementia in a hyper-cognitive 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 [47].

3.4 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 [111]. 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 [10, 92] that can lead to unwillingness to discuss experiences with researchers [88]. 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 [21]. The recruitment requirement that participants had to use technology regularly may also have led to a relatively younger group of participants [11, 73].

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 [2], 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 [25, 30], institutional barriers to education [59], and stigma consciousness [59]. 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.

4 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.

4.1 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.

4.1.1 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."

4.1.2 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.

4.1.3 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.

4.2 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.

4.2.1 Fitting in and Projecting Normalcy. Dementia is an enormously stigmatized condition [10]. 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.'"

4.2.2 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.

4.2.3 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.

4.3 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.

4.3.1 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.

4.3.2 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.

5 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 [35, 36, 80]. 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 [10, 93]; and a focus on retaining control in a condition where others come in to make decisions [10, 69, 98]. 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.

5.1 Turning to the Future

Self-management technologies for dementia often focus on needs in the moment, such as day planners [68, 75] and reminder systems for task completion [20, 61]. And, self-management systems may be designed to be used until no longer necessary [53]. 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 [50, 84], 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 [62, 83] with dementia who are desperately seeking opportunities to self-manage a condition with so little guidance for living well available [93]. 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., [86]). 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.

5.2 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 [35]. 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 [31]. Another study found people with Fibromyalgia used multiple social media accounts to manage other's perceptions [42], 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 [113, 115] 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 [41]. 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 [109]. 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.

5.3 Principles of Self-determination within Self-management

The dementia advocate definition of self-management as "a person-centred approach in which the individual is empowered and has ownership over the management of their life and condition" [96] 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 [104, 105] 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" [105]. 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 [7, 97], or monitoring technology [102, 103].

Self-determination refers to people acting volitionally – making conscious choices – based on their own will [105]. 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 [63]). 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 [52, 58, 63]. 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 [27], 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 [8] 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 [32, 46, 47], 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'" that would then "allow for gradual disengagement" [53]). The definition of self-management put forth by dementia advocates and Wehmeyer's theorizing of self-determination also align with recent work on interdependence [12], 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 [71, 72].

6 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 neurodivergent 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.

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