Exploring Future Personalization Opportunities in Technologies used by Older Adults with Mild to Moderate Dementia

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Abstract

Technologies for aging are a growing market. These technologies have significant potential to support individuals whose cognitive changes can make everyday activities challenging. However, the adoption and use of these technologies by people with dementia (PwD) remain poor, indicating potential accessibility and usability issues. Such barriers limit PwD's ability to contribute to the digital economy and fully engage with society. Personalization, which aligns technology with someone's unique needs and preferences, may address these issues. We used mixed methods with ten people with mild to moderate dementia to explore how previous ways to personalize (i.e., Windows OS built-in features and settings) and newer personalization applications (i.e., Morphic) might reveal future opportunities for personalization features in technology for aging. This study contributes fifteen design considerations, which, if implemented, may increase the involvement of PwD in the digital economy and society.[1]

Keywords: Dementia, Personalization, Digital Economy, Disability, Cognitive Accessibility

1. Introduction

Older Americans (50+) contribute so much to the gross domestic product ($8.3 trillion) that if they were a country, they would have the third largest economy in the world (Terrell, 2019). Over 55 million people live with dementia worldwide (Gauthier et al., 2021). As such, people with dementia (PwD) represent a significant population segment of older adults that may be under-engaged consumers and contributors to the digital economy. The aging-in-place technology market alone is estimated to grow from $7.1 to $13.5 trillion by 2030 (Schroeder, 2020). Living with dementia in the US brings added expense that alters *how* PwD spend (Terrell, 2019).

Often citing motivations to offset costs of care, developers increasingly look towards technology to support PwD's activities of daily living. Systems range from activity tracking, supporting mobility and cognition, monitoring changes in health, rehabilitation, recording health information, staying connected with others, and leisure activities (Asghar, Cang & Yu, 2015). Despite this surge in research developing technologies specifically for PwD over the past decade, user adoption and usage remain low (Gibson et al., 2016). Poor adoption and non-use of technology often signal accessibility and usability barriers, limiting PwD's ability to participate fully in an increasingly digital society.

Past work suggests personalization as "a key feature" in technology designed for PwD that may address some of the barriers that PwD face when using technology (Meiland et al., 2017). Personalization uses someone's unique needs or preferences to create an individualized presentation of content or services in a way they can understand and interact with it (Lewis & Treviranus, 2013). Our research seeks to answer the question: How can personalization features support the technology needs and preferences of people with dementia?

To answer this question, we supplemented a usability study with semi-structured interviews to allow ten people, who reported having mild to moderate

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dementia, to reflect upon personalization opportunities after using the built-in accessibility and ease of use features in Windows OS and Morphic, a software developed to help people discover and change these settings. This study contributes fifteen design considerations for future technology and personalization features intended to be used by PwD. Generated from our participants' lived experiences with dementia and with technology, these heuristics signal ways that accessible, adaptive personalization features might better support PwD's unique abilities and preferences in their user experiences by reducing their cognitive load. Implementing these design considerations in future technologies may further expand the market and the purchasing power of PwD and facilitate their contributions to the digital economy and society.

2. Background

Dementia is an umbrella term for conditions that can impact a person's behavior, mood, perception, cognition, motor and sensory functioning beyond what is typically expected to occur as we age (WHO, 2012). Dementia can change a person's ability to remember, problem-solve, understand, learn new things, process language, make judgments, orient themselves, and perform everyday tasks (WHO, 2012). Even people diagnosed with the same type of dementia may experience variability in their cognitive, sensory, and motor abilities (WHO, 2012). The progression of dementia can also be highly variable both between and within individuals (Melis, Haaksma, & Muniz-Terrera, 2019).

These changes directly impact the ability of PwD to use technology. Past research has identified difficulties with "identifying, interpreting and knowing how to respond to information from technology" (Nygård, & Starkhammar, 2007) and changes in fine motor ability affecting touch screen and keyboard usage (Burns et al., 2008. Dixon, Anderson, & Lazar, 2022). Finding and using personalization features can be challenging for less technologically savvy users, as they require technical knowledge beyond typical everyday use (Kerkhof et al., 2019). PwD often cannot fully realize technology's potential due to confusion when using technologies, uncertainty with its functional aspects, and how to apply these aspects to their activities (Nygård, & Starkhammar, 2007). Furthermore, technologies offer little guidance during error recovery as the information is both difficult to interpret and understand (Nygård, & Starkhammar, 2007).

Cognitive load also directly affects PwD's use of technology. Cognitive load theory posits that people have a limited amount of working memory during tasks (Sweller 2011). Activities like *learning* a new system or using a system that becomes unfamiliar to the individual because of the effects of dementia require more working memory from the individual. Working memory has limited capacity and relies upon short-term memory and information processing–all of which can be negatively affected by dementia. Working memory is also critical to people's mental models of systems (i.e., how they think a system works and how it can be interacted with). Previous work found that inaccessible technology, such as an interface with too many options, can increase PwD's cognitive load (Freeman et al. 2005). This suggests an opportunity for personalization features to reduce the cognitive load when using technology required by PwD by better aligning systems to their unique accessibility needs.

2.1 Personalization

Personalization has ties with several theoretical frameworks aimed at tailoring systems to their needs or preferences. Adaptive and Plastic UI often use personalization features to improve the usability and accessibility of systems (Miraz et al., 2021). Meta-design, a conceptual framework for technology customization, maintains that experts who design technology will inevitably create a gap between themselves and the non-expert using the system because designing and developing technology for the unknowable future of every person, who, in turn, has their own unique use-cases, abilities, and activities, cannot possibly be anticipated (Fischer & Giaccardi 2006). For meta-design, personalization fills this gap by encouraging flexible features that end-users can adapt to their unknown future needs.

While guidelines exist for technology design for PwD (Mäki & Topo, 2009), the variability across PwD and their fluctuating individual abilities are often cited as barriers to a "one size fits all" approach (Dixon, Anderson, & Lazar, 2022. Meiland et al., 2017) and limits the effectiveness of existing universal usability guidelines. This suggests that creating sustainable technology for PwD needs to: 1) be customizable to their unique preferences and 2) adapt to changing technology needs as the condition progresses (Dixon, Anderson, & Lazar, 2022. Meiland et al., 2017).

Given the heterogeneity and variability of abilities of individuals with different types of dementia and the barriers they face when using technology, personalization is one way to address these issues. Past research has worked to design technologies that can personalize the look and feel and align personal preferences and abilities with specific features and types of apps (Kerkhof et al., 2019). Unfortunately, even though systems often have customizable, built-in accessibility and ease of use features, these settings can be difficult to find and configure, particularly if a rapid shift in ability occurs. Enabling PwD to quickly and easily configure accessibility and ease of use settings to meet the moment's needs can dramatically impact their ability to use a system.

2.2 People with Dementia as Consumers & Contributors to the Digital Economy

People with dementia do not stop being consumers. Instead, how they spend their money adapts to their circumstances. Spending patterns shift from typical consumer behavior to dementia-related expenses, such as medical (i.e., doctor visits, medications) and non-medical costs (i.e., activities of daily living, caregiving, assisted living) (Cantarero-Prieto et al., 2020).

Indirect, dementia-related costs can also impact the workforce, such as losing skilled workers or *paid* work due to inaccessible workplaces and technologies (CEBR, 2019). Working-age caregivers may also leave the workforce to provide full-time care. Caregivers, who remain employed, often report having to reduce work hours and losses in their productivity while at work (CEBR, 2019).

Furthermore, PwD are also contributors to the digital economy. People with mild to moderate dementia can continue working, volunteering, and producing content with appropriate support. For example, the Dementia Alliance International is an organization led by PwD (DAI, 2022). Dementia Diaries produce content by PwD (2022).

2.3 Barriers to Participation in Digital Society

PwD also face other barriers to their full participation in a digital society stemming from a technology adoption gap. One reason for this gap may be the lack of involvement of PwD during the technology evaluation. Much previous work has focused on supporting caregivers or monitoring PwD (Gibson et al., 2016). Many technologies have been designed and developed with informal caregivers rather than directly involving PwD (Gibson et al., 2019).

Further complicating the matter is the lack of *independent* involvement during technology development. Since technology use does not always occur under the supervision of a caregiver, designing and evaluating systems using proxies (i.e., informal caregivers) or dyads cannot account for instances of actual, independent use by people with early-stage dementia. This tendency is problematic and may result in the non-use of technologies due to PwD being uninterested or incapable of using the device (Gibson et al., 2019). As such, our study gathered *direct* feedback from PwD *independent* of caregivers.

Furthermore, resolving accessibility barriers improves a system beyond monetary ROI. Accessible products benefit people with disabilities and mainstream users (Bias & Mayhew, 2005). Accessible technology reduces costs and improves usability, customer retention, social welfare, justice, and employment (Bias & Mayhew, 2005). The sustainable technology movement suggests that technology designed for longevity (i.e., designed for long-term use, accessible and usable) may also have ecological benefits by minimizing waste (Bates et al., 2015). Systems not directly evaluated by PwD independent of caregivers may be more at risk for costly, post-deployment revisions, poor usability, and inaccessible features, potentially resulting in low adoption and non-use by PwD.

3. Method

Our mixed methods study was conducted remotely as the COVID-19 pandemic prevented in-person data collection at the time. Unlike an industry usability study, where the goal is to determine which design (or system) results in better performance, we used the format of a usability study. After using the personalization settings in both Windows and an early version of the personalization application, Morphic, participants reflected upon potential opportunities for future personalization features specific to the PwD during semi-structured interviews.

3.1 The Evaluated Software

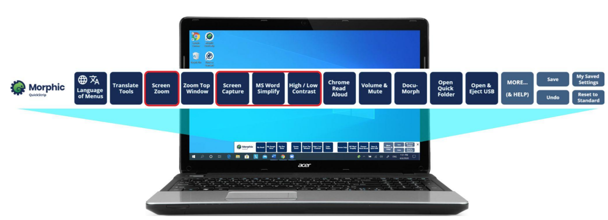

Figure 1. Morphic QuickStrip

Morphic began as a university research project that became commercially available with a non-profit a year after this study ended. Morphic was developed to help people—with and without disabilities—discover and change accessibility and ease of use settings and features that can be difficult to find (Vanderheiden et al., 2020). The Morphic "QuickStrip" is a series of buttons. In this study, participants used the buttons which facilitated: zooming the entire screen, capturing an image of the screen, changing the contrast, and accessing a simplified Microsoft Word toolbar.

3.2 Recruitment

We recruited participants through networks (e.g., large dementia organizations) and snowball sampling. To be eligible, participants needed to self-report a medical diagnosis of any type of dementia, be in the early stages of dementia (i.e., mild to moderate dementia), and use technology in their daily lives.

3.3 Participants

Ten participants are sufficient when working with disability populations, as long as they meet precise inclusion criteria (e.g., a specific stage of a specific disability, technical skill level, etc.) (Lazar, Feng & Hochheiser, 2017). We refer to study participants using the pseudonyms: Spencer, Ronda, Hugo, Luke, Camilla, Max, Renee, Fraser, Sebastian, and Felix.

All participants reported being in the mild stages of dementia except for Fraser, who reported being in the moderate stage. Participants reported having different types of dementia: Alzheimer's disease (n=5), vascular dementia (n=2), a combination of Alzheimer's and vascular dementia (n=2), and an unknown type of dementia (n=1). Participants' average age was 65 years old (58-73). Participants also took part in one of three study methods: installation (n=4), remote access (n=2), and modified think-aloud (n=4). All participants reported being retired or medically unable to work, except for Sebastian, who was employed part-time. All participants were either familiar with or regularly used Windows. However, a few participants verbalized a preference for Apple products.

3.4 Procedures

Before the COVID-19 pandemic, we completed a pilot study (n=4 in-person and n=1 remote) to refine our study procedures and tasks. The main study did not include the pilot study participants. Following the pilot study, we conducted our main study remotely.

Medical professionals often use screening tools, such as the MMSE/MOCA, to track changes in cognition (Siqueira, 2019). However, as non-medical professionals, we recorded the functional capacity that participants self-reported using the NIH's function-based stage classification, which may be more relevant for usability testing (NIA, 2017). Prior to each remote study session, we screened participants to assess their ability to consent using the UC Davis Alzheimer's Disease Center procedures (2002). All participants provided informed consent to participate in the study, followed by a short demographics survey.

Participants used one of three remote methods to take part in the study: Installation (i.e., Morphic was installed directly on to the participant's computer), Remote Access (i.e., participants took remote control of a researcher's computer that already had Morphic installed on it), and Modified Think-Aloud (i.e., participants viewed the researcher's computer using Zoom and verbally dictated the exact actions for the researcher to perform on their behalf). Wood et al. detail their novel Remote Access and Modified Think-Aloud methods (Wood et al., 2021).

Some of our participants did not have access to a stable internet connection, the latest technology, or would have had to permanently alter the familiarity of their computer to participate (i.e., updating the OS). Out of respect to their circumstances, we chose these novel methods over traditional remote summative methods, which would have excluded them from research. Secondly, as familiarity is critical to PwD's ability to use digital systems (Boger, Taati, & Mihailidis, 2016), rigorously following traditional remote summative usability study methods could have harmed our participants. Instead, we offered participants a choice between more accessible methods to facilitate more inclusive research practice. We found no performance or time-based differences between any of the flexible study methods used during the tasks.

Tasks were designed to encourage the exploration of personalization features that participants may not have had previous knowledge of. Tasks also varied in terms of complexity and ambiguity. Additionally, some tasks could be solved using personalization features only (Tasks 1 & 3), while others required shifting between more than one application (Tasks 2 & 4). Tasks were designed to highlight areas of user experiences that might benefit from personalization or were opportunities for future features that might better support PwD's use of technology.

- **Task 1:** Adjust the system-wide magnification of the entire screen.
- **Task 2:** Find directions online to a specific location and then take and save a screenshot of the directions to the desktop.

- **Task 3:** Change the contrast settings to a high contrast dark theme.
- **Task 4:** Find Microsoft Word's Immersive Reader accessibility tab and use the Line Focus feature to isolate lines of text and the Read Aloud feature to highlight and read aloud the content to the participant.

Each session lasted, on average, just under two hours (1.5-2.75). The usability study session consisted of two blocks of the same four tasks. For the first block of tasks, participants used the built-in Windows features to complete the tasks. Then, participants were introduced to the Morphic QuickStrip, given a brief overview of its functionality, and then attempted to complete the same four tasks while using Morphic. Given that PwD have never previously evaluated Morphic, we were concerned about the potential stress, increased mental effort, and its effects on our participants when trying something completely new *first*. For these reasons, we chose to prioritize the welfare of our participants over strict adherence to traditional experimental study design. After each block, participants filled out a System Usability Scale (SUS) and took part in a semi-structured interview to reflect upon their personalization experiences with each tool.

Two researchers were virtually present for all sessions. Each session was audio and video recorded. Using Otter.ai, we transcribed, verified the transcriptions were correct and analyzed ~19 hours of recordings. Following each study, participants received a $40 Amazon gift card. The university's Institutional Review Board approved all study procedures.

3.5 Analysis

Using thematic analysis, we first familiarized ourselves with the data (Braun & Clarke, 2006). We generated initial codes by open coding all ten transcripts. The first and second authors organized the codes by major themes into a preliminary codebook. The other authors reviewed and clarified the codebook definitions. To refine the names and definitions of each theme in the codebook, each transcript was then focus-coded again by two other authors using the refined codebook. Any discrepancies between coding was discussed as a team. This process resulted in the qualitative findings described in this paper.

We also analyzed the screen-captured recordings from the sessions to understand participants' help-seeking behaviors when they seemed especially stuck or frustrated. As recommended by best practice, we recorded four types of researcher interventions employed during the usability tasks (Sauro, 2017):

- **Type 1:** The researcher reminded participants that they could read the task again to re-familiarize themselves with the objective(s) of the task OR they could consider using a different strategy. Researchers did not suggest what kind of strategy they could try.
- **Type 2:** Researchers asked open-ended questions, like "What are you trying to do right now?"
- **Type 3:** Researchers asked more action-oriented questions like: "Would you rather do X or Y or Z?" to limit the number of potential actions that participants could take.
- **Type 4:** Researchers asked if they would like directions to complete the task and then outlined the specific steps for completion.

We recorded these researcher interventions to participants' help-seeking behaviors to highlight potential future accessibility features that might benefit PwD's use of technology and minimize any negative impacts on self-efficacy when the tasks were challenging.

4. Results

Every participant attempted to complete every task. While the tasks were intended to scale in difficulty (i.e., easy, intermediate, hard), the data suggested that some tasks were harder than anticipated. Participants were more successful at completing the first and third tasks. However, a review of the video data indicated that participants found the second and fourth more challenging. Difficulties primarily stemmed from moment-to-moment shifts in abilities, navigational barriers, and challenges managing multiple application windows. Below, we report on future technologies and personalization features that may better support the changing abilities of PwD and may reduce the cognitive load when systems customize according to their unique needs and preferences.

4.2.1 Reduce Complexity. Many participants described barriers to systems when they seemed too complex. Some participants reported personalizing or wanting to personalize technology to address changes in their technical abilities, which many linked to changes in their cognition. Spencer had difficulty "remember[ing] how to do things [on his current devices], even though I used to know how to do it in the past." While Spencer "used to be able to fix computers and program them," technology use became too "complex for me anymore." Felix attributed his decreased computer use "entirely because of this

Alzheimer's diagnosis that I have. It's [computer use] just, it's too damn complicated.”

Camilla asserted, “For most of us with dementia, Windows tend to [be] too hard... Because of the complexity of it’s trying to get you to multitask.” Participants struggled most with tasks that required multiple applications and managing more than one window. Renee recalled, “I can never do any of that.” Participants [Ronda, Hugo, Max] appreciated simplified computer use by reducing the need to navigate deeply into their computers to find specific programs or features. Ronda shared, “[Morphic]'s super simplistic as opposed to digging around in settings.”

4.2.2 More Progressive Disclosure Features. PwD can experience confusion from too many options (Gowans et al., 2004. Kerkhof et al., 2019). Perceptions of system complexity may similarly stem from feelings of being overwhelmed and anxious when presented with an abundance of choices. Several participants wanted more *progressive disclosure* features (Nielsen, 2006). Requested progressive disclosure features included: limiting the initial number of button options presented to the user and personalizing the number of layers or how “deep” they have to navigate to access a larger set of options or features.

Felix and Max described how reducing the layers deep they needed to go to find what they were looking for could make searching easier. Camilla explained how she would like “choices” when organizing functions, including deciding which main buttons were visible and which were hidden under specific drop-down menus.

Although participants wanted to minimize the number of buttons visible at one time, they still wanted access to other personalization options. Participants suggested ways that these two needs could be balanced. Luke suggested the system provide “a down arrow or something that would give me more options” when he wanted to see them. Spencer suggested that future systems should track and auto-populate buttons for those tasks a user completed most frequently as well as automatically group "the ones that are most useful at the top [and] a second grouping [for] things that you do” less often.

4.2.3 Pin Where Content & Applications Are. Several participants reflected that they regularly experienced difficulty navigating systems and searching for content: “I can't stand when I can't find something” [Renee].

Participants reported an increased difficulty remembering where they had saved documents on their computers. Sebastian suggested a “Where’d It Go?” button, which helps search activities based on recently opened documents. Participants struggled to recall exact keywords during a search. They wanted future systems to better support language-based recall issues during search and information-seeking activities.

Some participants personalized how they organized applications on their phones or computers to make content more easily discoverable to them. Because, as Max put it, without organization, “it's an absolute nightmare. Because there’s just crap everywhere... you have to go through about 10 screens, looking at every stupid icon until you can find what you want.”

Others also reported wanting to pin an application’s location, so they always know where to look for support. Hugo used fixed locations to minimize the need to search: “if I don't have [the link] in the same place, every time I start on something, it just takes me too long to search for it.” Participants also saved links to specific websites, such as Amazon and YouTube, that they often visited on their desktop to “be able to go there faster” [Ronda] and to “cut down on the anxiousness and the frustration” of searching for links [Hugo]. This suggests that repeated, mental mapping of content pinned to specific locations may enable PwD’s ability to find and navigate content, actions, and systems more easily.

Future studies can investigate how to manage and scale larger quantities of pins using the personalized organizational methods suggested by participants, such as frequency of use, recency of use, saved in a particular order, or grouped according to task or type.

4.2.4 Support Sensory Changes. Feelings of complexity as well as difficulty finding and navigating content may also stem, in part, from barriers caused by sensory changes (Dixon, Anderson, & Lazar, 2022). Participants often described these changes in terms of how they affected them (i.e., feelings of being overwhelmed, confused, and distracted). “When we switch[ed] to Morphic, I felt much better” because “the way you have it set up on the bottom, this toolbar, it is easier for me... less distractions” [Luke]. Sebastian shared, “I just become very overwhelmed when I have options... I look at the buttons down there ,and it's like, whoa, what do they all mean?” Luke likewise reported that too many options are “overwhelming on the brain... Less options [would be] better.”

Participants also wanted to personalize the appearance of buttons, including typeface, font size, button sizes, and color to reduce eyestrain and make content more distinct and easier to scan. Color coding could help them to visually organize by topic or preference; "because right now I look at everything, and it's sort of all coming together" [Luke].

4.2.5 Protect Familiarity. Technology may seem more complex and difficult for PwD to use, in part, because the design is different from what they are familiar with or prefer. Personalizing the look-and-feel of systems may help maintain a familiar technical environment. Past research used retro designs to create a more familiar technical environment for users with dementia (Gowans et al., 2004). Similarly, Spencer's daughter personalized the color scheme, lettering, and "the little icons," of his desktop to look like Windows95, despite running the most up-to-date OS version. Unfortunately, major system updates often removed or broke his personalization changes. "Every time they make one of these changes [updates]. I gotta get her [his daughter] to go back in or try to finagle it to make it look like the old platform [Windows '95]" (Spencer).

4.2.6 Save Preferred Interaction & Design Patterns. Participants had varied preferences for interaction and design patterns. Spencer used primarily keyboard shortcuts to complete tasks (e.g., screenshots). He elaborated by saying, "if you've used the product [Windows] before, it's [Morphic] going to complicate matters" because he would now need to learn and remember what the Morphic buttons do. He continued, it's "hard enough for me to remember how to do things [keyboard short-cuts]." No other participants used keyboard shortcuts or preferred Windows.

Others wanted interaction and design patterns to emulate their preferred device: a smartphone. Felix organized applications by frequency of use, putting "all the stuff that I use most of the time right on the front" ("first screen") of his phone. Similarly, Renee kept "all those [related apps on her phone] put in one box". Max believed that emulating mobile-first design patterns could also mitigate distraction. His "strong suggestion would be to find a way to have that [Morphic] as the only thing on the screen so that there aren't any other buttons or distractions." In other words, Max wanted only one application displayed at a time with no other menu bars or short-cut icons visible on the desktop, much like a smartphone.

4.2.7 Customize Naming Convention. Several participants described how the labels of the buttons on the Morphic QuickStrip as unintuitive, and even "misleading" [Hugo]. For example, participants had different definitions of "contrast" [Renee, Spencer]. Some participants did not understand what a label meant (e.g., "screen snip" [Sebastian], "OneDrive" [Fraser, Luke, Ronda], and "MS Word Simplify" [Max]). For this reason, multiple people wanted to personalize Morphic button names. This suggests that participants may benefit from systems that better align with their personal meaning, associations, and understanding of words and language.

Participants also struggled during tasks that used ambiguous language or different words, meanings, or associations more than they expected (Tasks 2 & 4). This suggests that word associations may be especially critical to adoption, and this population may benefit from the personalization of terminology.

4.2.8 Save Objectives & History of Actions. After reflecting upon the researcher interventions used when they exhibited help-seeking behavior (detailed in section 3.5), participants reported wanting a "What's My Objective" button. Sebastian described how "I would be able to come up with that objective, and then save it. Or it would like say steps as to what I need to do to get to that [objective]," much like Spencer's "cheat sheet" of how to do common actions. Participants also wanted a single button to "shorten that task. Or [suggest] another route" to complete a task. In this way, the system would create simple instructions to accomplish an objective. Luke suggested this walkthrough guidance could be similar to Microsoft Office's "wizard I think it is, it sort of walks you through it [how to use their products]."

5. Discussion

This research has several implications for technology design and PwD's role within an increasingly digital society and economy. First, the design considerations (described in section 5.1) for future personalization systems, features, and other technologies for aging may reduce condition-specific barriers for PwD. As such, technology personalization may support and positively impact the everyday lives of PwD in several ways.

When technology does not align with someone with dementia's unique functional abilities, the individual must problem-solve and determine workarounds in a system that is not accessible to them, increasing the mental effort necessary during use. Our study results suggest that personalization might lessen the cognitive load required by PwD as they use technology by more closely aligning the accessibility of the system to the variable changes they experience with their attention, sensory and information processing abilities, and working memory. Personalized technology aligned to the individual may also lead to more intuitive user experiences.

Personalization features could further reduce cognitive load by increasing the levels of perceived familiarity with systems. Personalization for familiarity could leverage existing mental models stored in their long-term memory. As a result, less working memory (i.e., short-term memory) would be needed to learn or re-learn systems when functional abilities shift or their condition progresses. As we saw when Spencer's computer personalization emulated the Windows95 OS, personalization for familiarity could assist PwD in using newer technologies. It might also reduce feelings of disruption when system updates occur, which was stressful for several participants.

Furthermore, personalized systems may reduce caregiver effort by relegating some activities for daily living to technology. This may, as a result, foster greater independence and autonomy for PwD. By creating more accessible and usable technology for PwD, personalization might better support their technical knowledge and digital literacy skills and mitigate adoption barriers. As a result, personalized technology using accessibility and usability features and the design recommendations described may reduce costs associated with adoption barriers and other post-development-related costs.

Personalization may also support more sustainable technology production for PwD. Spencer, the participant who had the most personalized computer, was also the most loyal to their existing systems. This tendency may indicate that personalized systems might encourage greater customer retention and loyalty to products that support such features. As a result, personalization may reduce wasted R&D time and resources as well as physical waste from producing unused products and devices by PwD.

Additionally, this work has broader implications for the field of HCI. The personalization features described in this paper may benefit other highly heterogeneous populations, such as people with other conditions affecting their cognition (e.g., brain injury, aphasia, substance-induced cognitive impairment, amnesia) or intellectual and developmental disabilities. This study adds to the body of research that demonstrates how the independent involvement of PwD in research and technology development can benefit not only the wider digital economy, but also potentially increases PwD's engagement with digital society through personalization.

Finally, this work has several theoretical implications for personalization-related bodies of literature aimed at minimizing the novice-expert design gap. Meta-Design, Adaptive, and Plastic UI all seek to lessen the novice-expert divide between end-users and expert designers by enabling people to adjust their user experiences using either manual or automatic customization features that better align with their needs or preferences. Our study suggests that one use case not yet covered by any of these theories is the variable future (immediate, near, and far) needs and preferences of PwD, which can change from hour to hour, day to day, and as their condition progresses. As such, future features aimed at reducing the novice-expert divide caused by differences between user needs and system design also need to include intelligent flexibility to adapt to the variable changes that abilities may occur in people, such as those with dementia. Finally, our study builds upon previous cognitive load theory research (Freeman et al. 2005) by contributing 15 design considerations that may make systems and features more accessible to PwD by reducing their mental effort and drawing upon features and functionality that leverages stronger mental models stored in long-term memory via familiarity.

5.1 Design Considerations: Future Technology and Personalization Features

1. Avoid designs that require PwD to multi-task or manage multiple windows. Too much multi-tasking can distract, frustrate, or overwhelm PwD. (4.2.1)
2. Avoid simplification design techniques used in "elderware," which may trigger feelings of otherness and stigma in PwD who are familiar with technology and modern UI trends. (4.2.1)
3. Incorporate progressive disclosure features to support PwD's ability to navigate systems, perform actions, and make choices. (4.2.2)
4. Searching by keyword should automatically include similar words (e.g., mom, mother) or synonyms (e.g., parent) to better support PwD's language recall abilities. (4.2.3.)
5. Design for familiarity by supporting PwD's ability to leverage existing technical skills and knowledge stored in their long-term memory. (4.2.5)
6. As many of our participants verbalized their preference for their smartphones over computers or tablets, mobile-first design patterns and personalization features could reflect this preference. It may also reduce

perceptions of complexity and simplify multi-tasking and the management of multiple applications simultaneously. (4.2.6)

7. Include definitions of how a word is being used to translate the designer's meaning of a label, which may improve comprehension. (4.2.7)
8. Include a “What are you trying to do?” feature with several buttons that can either be automatically performed or guide the user step-by-step. Button options should be based on context, reference past user behaviors or previous actions, and be relevant to their current activity. (4.2.8)
9. To minimize PwD getting caught in a feedback loop of actions, let PwD track and view their actions as a "history" so they can see what worked and what didn’t. (4.2.8)
10. To facilitate quick, easy access to commonly used or searched for documents, features, or actions, let PwD pin UI elements to specific locations on their screen, within an application, or on the desktop. (4.2.3)
11. Let PwD personalize styling options to visually organize and group content to better support fluctuations in their sensory abilities. (4.2.4)
12. To improve the accessibility of reading content, let PwD personalize how text and content are presented to them (i.e., spacing, highlighting, when it is triggered, etc.). (4.2.4)
13. Protect the familiarity of user experiences by having these personalized settings persist even after an OS update occurs. (4.2.5)
14. Leverage the benefits of familiarity by offering the choice between newer design patterns and older, legacy versions of system presentation (UI) and interaction patterns (UX). (4.2.6)
15. Allow PwD to personalize how elements are named to better align with personal meaning and understandings. Ensure original names are visible and/or easily accessible. (4.2.7)

5.2 Limitations

This study used non-experimental strategies (i.e., a usability study without counterbalancing) to stimulate participant reflection during interviews rather than following an experimental or quasi-experimental study design. As each block took roughly an hour, we chose not to counterbalance the order of task blocks to minimize potential stress and mental effort in our participants by beginning the tasks using more familiar systems (i.e., Windows OS). The decision to protect our participants rather than the experiment’s design, however, may limit the strengths of our findings due to possible learning effects.

6. Conclusion

Personalization has been suggested to make technology use more accessible for people with dementia because of the variability between individuals and their fluctuating abilities (Meiland et al., 2017). Using mixed methods, ten participants explored the accessibility and usability features in Windows’ OS and a newer personalization application, Morphic, to reflect upon future opportunities for technology personalization specific to PwD.

We contribute fifteen design considerations to improve the accessibility and usability of future personalization systems and features intended to be used by individuals with dementia. While future research needs to evaluate these considerations to provide more concrete design recommendations, implementing these contributions may support the abilities of PwD to be more engaged with an increasingly digital society. Personalization may also increase the market potential and purchasing power of PwD via personalized, accessible, and usable technologies. Finally, personalized technology may also promote sustainable technology development of systems intended to be used by heterogeneous populations, such as PwD, by better aligning with their preferences and abilities.

7. References

Asghar, I., Cang, S., & Yu, H. (2015). A systematic mapping study on assitive technologies for people with dementia. In *2015 9th International Conference on Software, Knowledge, Information Management and Applications (SKIMA)* (pp. 1-8). IEEE.

Bates, O., Hazas, M., Friday, A., Morley, J., & Clear, A. K. (2014). Towards an holistic view of the energy and environmental impacts of domestic media and IT. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (pp. 1173-1182).

Bias, R. G., & Mayhew, D. J. (Eds.). (2005). *Cost-justifying usability: An update for the Internet age*. Elsevier.

Boger, J., Taati, B., & Mihailidis, A. (2016). Interdisciplinary development of manual and automated product usability assessments for older adults with dementia: Lessons learned. *Disability and Rehabilitation: Assistive Technology*, *11*(7), 581-587.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, *3*(2), 77-101.

Burns, W. P., Nugent, C. D., McCullagh, P. J., Zheng, H., Finlay, D. D., Davies, R. J., ... & Black, N. D. (2008). Personalisation and configuration of assistive technologies. In *2008 30th Annual International Conference of the IEEE Engineering in Medicine and Biology Society* (pp. 3304-3307). IEEE.

Cantarero-Prieto, D., Leon, P. L., Blazquez-Fernandez, C., Juan, P. S., & Cobo, C. S. (2020). The economic cost of dementia: a systematic review. *Dementia*, *19*(8), 2637-2657.

Centre for Economics and Business Research (CEBR). (2019). *The economic cost of dementia to English businesses – 2019 update. A report for Alzheimer's Society*.

Dementia Alliance International. (2022). DAA. https://www.dementiaallianceinternational.org/

Dementia Diaries. (2022). Innovation in Dementia. https://dementiadiaries.org/

Dixon, E., Anderson, J., & Lazar, A. (2022). Understanding How Sensory Changes Experienced by Individuals with a Range of Age-Related Cognitive Changes can Effect Technology Use. *ACM Transactions on Accessible Computing*. 15(2), 33.

Gauthier, S., Rosa-Neto, P., Morais, J.A., & Webster, C. (2021). *World Alzheimer Report 2021: Journey through the diagnosis of dementia.* Alzheimer's Disease International.

Gibson, G., Dickinson, C., Brittain, K., & Robinson, L. (2019). Personalisation, customisation and bricolage: how people with dementia and their families make assistive technology work for them. *Ageing & Society*, *39*(11), 2502-2519.

Gibson, G., Newton, L., Pritchard, G., Finch, T., Brittain, K., & Robinson, L. (2016). The provision of assistive technology products and services for people with dementia in the United Kingdom. *Dementia*, *15*(4), 681-701.

Gowans, G., Campbell, J., Alm, N., Dye, R., Astell, A., & Ellis, M. (2004). Designing a multimedia conversation aid for reminiscence therapy in dementia care environments. In *CHI'04 Extended Abstracts on Human Factors in Computing Systems* (pp. 825-836).

Fischer, G., & Giaccardi, E. (2006). Meta-design: A framework for the future of end-user development. In *End user development* (pp. 427-457).

Freeman, E. D., Clare, L., Savitch, N., Royan, L., Litherland, R., & Lindsay, M. (2005). Improving website accessibility for people with early-stage dementia: a preliminary investigation. *Aging & mental health*, *9*(5), 442-448.

Kerkhof, Y., Pelgrum-Keurhorst, M., Mangiaracina, F., Bergsma, A., Vrauwdeunt, G., Graff, M., & Dröes, R. M. (2019). User-participatory development of FindMyApps; a tool to help people with mild dementia find supportive apps for self-management and meaningful activities. *Digital health,* 5, 1-19.

Lazar, J., Feng J.H., and Hochheiser, H. (2017). *Research Methods in Human-Computer Interaction.* Elsevier Science & Technology/Morgan Kaufmann, Cambridge, MA. 504-509.

Lewis, C., & Treviranus, J. (2013). Public policy and the global public inclusive infrastructure project. *interactions*, 20(5), 62-66.

Mäki, O. & Topo, P. (2009). User needs and user requirements of people with dementia: Multimedia application for entertainment. *Dementia, design and technology: Time to get involved,* 61-75.

Meiland, F., Innes, A., Mountain, G., Robinson, L., van der Roest, H., García-Casal, J. A., ... & Franco-Martin, M. (2017). Technologies to support community-dwelling persons with dementia: a position paper on issues regarding development, usability, effectiveness and cost-effectiveness, deployment, and ethics. *JMIR rehabilitation and assistive technologies*, 4(1), e6376.

Melis, R. J., Haaksma, M. L., & Muniz-Terrera, G. (2019). Understanding and predicting the longitudinal course of dementia. *Current opinion in psychiatry*, 32(2), 123.

Miraz, M. H., Ali, M., & Excell, P. S. (2021). Adaptive user interfaces and universal usability through plasticity of user interface design. *Computer Science Review*, *40*, 100363.

National Institute on Aging (NIA). 2017. Symptoms & Diagnosis of Alzheimer's Disease. What Are the Signs of Alzheimer's Disease?

Nielsen, J. (2006). Progressive Disclosure. www.nngroup.com/articles/progressive-disclosure

Nygård, L., & Starkhammar, S. (2007). The use of everyday technology by people with dementia living alone: Mapping out the difficulties. *Aging & mental health*, 11(2), 144-155.

Sauro, J. (2017). When to Provide Assistance in a Usability Test. *Measuring U*.measuringu.com/usability-assistance/

Schroeder, B. (2020). *This Marketplace Is Over $7 Trillion And Rising—7 New Products & Services This Consumer Will Need From Future Entrepreneurs*. Forbes.

Siqueira, G. S., Hagemann, P. D. M., Coelho, D. D. S., Santos, F. H. D., & Bertolucci, P. H. (2019). Can MoCA and MMSE be interchangeable cognitive screening tools? A systematic review. *The Gerontologist*, 59(6), e743-e763.

Sweller, J. (2011). Cognitive load theory. In *Psychology of learning and motivation* (Vol. 55, pp. 37-76).

Terrell, K. (2019). *Americans 50 and Older Would Be World's Third-Largest Economy, AARP Study Finds.* AARP.

UC Davis Alzheimer's Disease Center. (2002). Policy and Procedures for Assessing Capacity To Consent for Research.

Vanderheiden, G., Lazar, J., Jordan, J. B., Ding, Y., & Wood, R. E. (2020, April). Morphic: Auto-Personalization on a Global Scale. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems* (pp. 1-12).

Wood, R., Dixon, E., Elsayed-Ali, S., Shokeen, E., Lazar, A., & Lazar, J. (2021). Investigating Best Practices for Remote Summative Usability Testing with People with Mild to Moderate Dementia. *ACM Transactions on Accessible Computing (TACCESS)*, *14*(3), 1-26.

World Health Organization (WHO). (2012). Dementia: a public health priority. *World Health Organization.*