

User Experience Design for Persons Living With Dementia- Current Methods and Experimental Experience

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Abstract—Persons Living With Dementia (PLWD) present both a challenge and opportunity for ambient monitoring within smart homes. Persons Living With Dementia could benefit greatly from smart home technologies that monitor their well being and enable them to live at home longer. This potential has not been fully realized, partly because of the difficulty in creating interfaces that individuals with dementia can interpret and use. User experience design and user centred design aim to produce technology that is intuitive and accessible to target users. While traditional user experience design methods are difficult to carry out with Persons Living With Dementia, they can be adapted to better suit this population. By involving the families of Persons Living With Dementia in the design process, adapting the prototyping process, and encouraging empathy on the part of designers, smart home technology for ambient monitoring can be developed for Persons Living With Dementia in an inclusive way. The paper presents results from research projects where Persons Living With Dementia and those with less severe mild cognitive impairment have engaged with technology user interfaces. The results show that users were much more successful with simpler interfaces such as a touch screen over mouse and keyboard. They were also more successful with concepts that drew on early learnings. Our results also show that Persons Living With Dementia that experience night time wandering, can be supported with visual and audio cues from a supportive smart home system. This is a new user interface model for interaction with smart home systems that will require the involvement of PLWD in the design process.

Keywords—Ambient monitoring; Dementia; User Experience Design; Supportive Smart Home.

I. INTRODUCTION

Dementia is a progressive disease of the brain causing cognitive decline and resulting in an impaired performance of activities of daily living. Some of the cognitive domains affected by dementia include memory, language, and abstract thinking. PLWD, especially moderate or severe dementia, require constant supervision, placing a significant burden on caregivers who are often close relatives. PLWD may struggle with independent living as a result of their cognitive difficulties and many caregivers opt to place loved ones in care homes when overwhelmed by the responsibilities associated with caring for an individual with dementia. Remote assessment and support using in-home technology are a potential avenue to allow PLWD to live at home longer by alleviating a

caregiver's responsibilities [1][2]. A variety of projects have been undertaken in an effort to integrate home assessment into the lives of PLWD [3][4].

Projects, such as the AGE-WELL SAM³ (Sensors and Analytics to Monitor Mobility and Memory) collaboration between Bruyère Research Institute and Hospital, Carleton University and AGE-WELL NCE Inc., seek to facilitate life at home for Persons Living With Dementia using technology based solutions. The process of designing supportive ambient assessment solutions for PLWD is challenging due to the cognitive impairments of the target users [5]. The classic User Experience Design (UXD) pipeline includes the end user in most parts of the design process through interviews and testing which are used to gather insights into how to improve a product's usability.

In this paper, we discuss the current best practices for UXD for PLWD according to previous work in the field. In Section II, we discuss current best practices in designing for PLWD. Section II, A covers working with the families of PLWD to facilitate the UXD process. Section II B, covers adaptations that have been made to prototyping methods for use with PLWD. Section II C, covers the role of empathy in designing for PLWD as well as methods that have been used to leverage it. We also outline the challenges and insights we have gathered from past development of user interfaces for PLWD in Section III. In Section III A, we outline an experiment using word search and sudoku games. In Section III B, we cover an experiment where PLWD played whack-a-mole on a digital tablet. In Section III C, we go over an experiment where we had older adults, some with PLWD, use a balance tracker. In Section III D, we discuss a project where we designed and tested a system to reduce nighttime wandering in PLWD. In Section IV we outline a framework for future UXD for continuing work within the AGE-WELL SAM³ collaboration in section IV. In Section IV A, we list some rules for designing PLWD-friendly interfaces. In Section IV B, we summarize the importance of prototyping and iterative design in designing for PLWD. Finally, we present discuss possibilities for further work in Section V.

II. CURRENT BEST PRACTICES

Don Norman, who coined the term User Experience, described the process as “think(ing) through all of the stages of a product or service, from initial intentions through final reflections, from first usage to help, service, and maintenance. Make them all work together seamlessly” [6]. Current best practice methods in user experience include integrating the end user in the design process early and often. Iterative prototyping is one of the most common methods used to involve end users. It consists of the production of multiple prototypes with increasing fidelity, each influenced by the testing of the previous prototype with a sample of end users. For example, an initial prototype of a phone application might consist of a series of paper cutouts representing the various screens of the application. The end user must be able to interpret the paper cutouts for what they represent, which requires abstract thinking.

When working with PLWD, traditional user experience methods must be adapted to better suit the cognitive difficulties this group of end users experiences. The impairment in abstract thinking in PLWD makes traditional prototype testing difficult [7]. In prior work, groups of older adults with low digital literacy and moderate to advanced cognitive impairment were involved in the prototyping of a TV remote [8]. The group of participants in the study represent one of the more impaired subgroups of PLWD. They had “little to no experience with digital technology” [8] and most had an educational level equivalent to 4th grade.

When afflicted with dementia, an individual’s memory deteriorates starting with short term memory and eventually affecting more long term memory. Individuals with both significantly progressed dementia and very little education represent a group with significant cognitive impairments. There is emerging evidence that education has some protective effects against dementia, so this group with low education would be doubly challenged, for instance in the development of mental maps. The remote controls the participants designed during the prototyping exercise researchers led “would not have been fully functional, and the participants had difficulties or were unable to describe or explain their designs” [8]. This type of challenge is common when trying to include PLWD in the design process and has led to the adaptation of traditional UXD methods. Though there has been limited work in adapting design methods for PLWD, a few strategies have emerged.

A. Working with families of PLWD to facilitate UXD

PLWD often live with their families who act as informal caregivers. The bulk of the caregiving responsibility often falls on the spouse or a child of the PLWD [1][2]. These caregivers are familiar to the PLWD and are familiar with the challenges the PLWD faces. Because of this insight, they have frequently either assisted PLWD in communicating with researchers and designers or acted as a stand-in for the interests of their loved ones. Previous projects have had caregivers in the long term care home where the study was held assist the PLWD with prototyping activities when they were unable to grasp what was required of them [8].

In other work, families were used as units for participation in the design of a board game [9]. The families presented their opinions together, allowing the families to assist the PLWD in communicating their thoughts. Including caregivers

when designing for PLWD is useful because they communicate more easily with researchers. However, it is important to recognize the distinction in the experiences of the PLWD and the experiences of the caregiver. While the caregiver may have empathy for the individual with dementia they care for, they cannot have the same perspective. Relying solely on caregivers to inform development can lead to missing important insights on the part of the end user.

B. Adapting Prototype Methods for PLWD

Through trial and error, researchers have found ways of adapting traditional prototyping methods to make them accessible to Persons Living With Dementia. The prototypes themselves can be made more accessible by being explicit and higher fidelity in order to reduce the amount of abstract thinking PLWD must engage in. Persons Living With Dementia also can find themselves unable to describe their thoughts and feelings about a prototype to researchers. One study found that in spite of moderate to severe cognitive impairment, PLWD are able to engage in discussion about photographs [8]. In this study, participants were asked to use various paper “components” to make paper prototypes of remotes. The participants found this task difficult and were unable to explain what their prototypes represented. Despite the difficulties PLWD found in creating traditional prototypes in this study, they found discussing photographs natural. While the prototypes in the study were abstracted (the researchers used paper to represent different pieces of a television remote), photographs require very little abstraction on the part of PLWD to make them interpretable. A later study used photographs as a discussion tool for individuals with dementia to express their feelings about their circumstances [10]. PLWD often find it difficult to recall specific words to describe their situation. The photographs helped prompt them and communicate their state of mind to the researchers.

Another method that has been used to aid in vocabulary recall is a modified semantic differential, “a scaling tool which has been used frequently for measuring social attitudes, particularly in the fields of linguistics and social psychology” [11]. Semantic differentials usually involve subjects choosing a number to represent a level of intensity for a particular characteristic. A modified version has been used with PLWD, allowing the individual with dementia to select from a variety of adjectives on cards and place them on scales of ‘a little bit’, ‘rather’, or ‘very’ [9]. This simplified version of the scale was interpretable to the PLWD and every participant was able to use it in spite of varying levels of cognitive impairment. These two methods present themselves as ways to facilitate discussion about prototypes when PLWD find it difficult to produce criticism unprompted.

C. Empathy as a Design Strategy

Designers and researchers are often able bodied and neurotypical, and have not had experiences similar to those of PLWD. “Young and healthy design team members often find it difficult to collaborate with users who have different abilities from them and live in difficult situations” [10]. Empathy has been posited as a strategy to bridge this gap in experiences. “In empathic design, designers attempt to get closer to the users’ experiences and circumstances” [10]. In empathic co-design, one researcher is able to impart insights from meetings

with PLWD to the rest of their team. This is done through a variety of exercises that encourages team members to consider the perspective and experiences of PLWD. One activity explored is a role-play exercise where the design team re-enacts scenes with some team members acting as individuals with dementia. After the exercise there was discussion to encourage participants to relate the role-play to their own experiences, particularly emotions associated with the frustrations of living with dementia.

A project detailing the design of assistive technology for PLWD highlighted the utility of empathy on the part of designers [12]. A few designers had consistent contact with PLWD and deliberated with them over design choices. This relationship fostered empathy in the “point of contact” for the individuals with dementia and a deeper understanding of their life experiences. Empathy lends itself well to personally tailored designs. While not always feasible, tailoring designs specifically for individuals can be empowering for PLWD. Researchers personally tailored two tracking devices to help participants’ families locate them should they become lost. One participant remarked “they did not want to have to carry a device that made them ’feel disabled’” [12]. This sentiment reflects the importance of empathy in preserving the personhood and dignity of Persons Living With Dementia.

Another method to help researchers understand the lives of PLWD is the “diary interview method,” where participants keep a diary that outlines their daily activities for a period of time. While this method would be impractical for individuals with advanced dementia, it can be an effective way to bridge the gap between the experiences of researchers, designers, and PLWD. One project involved the collection of diary interviews with PLWD involved in dementia activism [13]. In the diaries, participants explained what was and wasn’t difficult for them and expressed feelings of frustration and helplessness. They were able to do so at their own pace, encouraged to record their thoughts daily but not required to. The easy-going nature of this method lends itself well to PLWD who become frustrated with their inability to express themselves in conversation. “The diary interview method, when modified, can engage people with dementia as equal partners in the data-gathering process” [13], and gathering qualitative data on the lives of PLWD in this manner could provide researchers with significant insights.

III. INSIGHTS FROM PREVIOUS WORK

Previous collaborations between Bruyère Research Institute and Hospital and Carleton University have focused on the development of technology to longitudinally assess the cognitive decline of PLWD. While formal User Experience Methods were not used, insights into how PLWD interact with interfaces were gleaned.

A. Word Search and Sudoku Computer Games

We designed two simple computer games to measure the cognitive impairment of PLWD. The first game was a word search game, shown in Figure 1. The second was a sudoku game, shown in Figure 2 [14].

Eleven participants played the games over a six month period and their results for speed, performance, errors, and hints used were measured and tabulated. For the word search game, the user interface was shown on a computer screen and users interacted with the game using a mouse and clicking

to highlight letters. Some users understood the game easily, likely because of the similarity to physical pen and paper word search games they have experienced for many years. Some participants had difficulty associating the movements they made with their mouse to the movement of the cursor on the screen. Clicking the mouse was not always cognitively associated with the ability to select a letter on the screen. Some additionally felt the need or desire to watch their hand, which led them to ignore the screen.

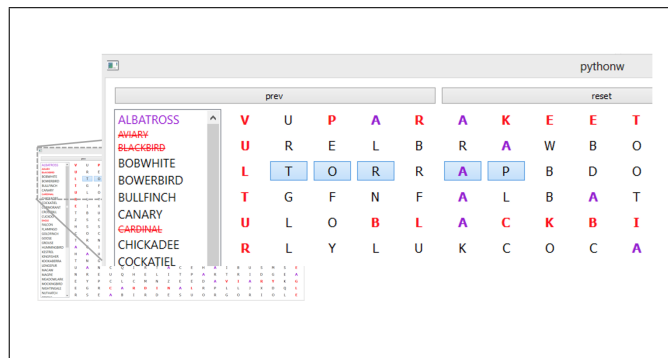


Figure 1. The word search game interface [14].

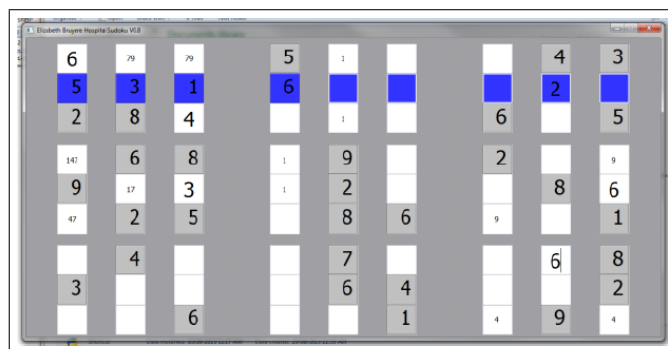


Figure 2. The sudoku game interface [14].

Participants’ prior experience with sudoku was more limited than their experience with word search type games. The visual interface in the game was also dissimilar to what you might encounter in the physical world. As a result, they demonstrated less interest and had less success playing it. In addition, the interface was significantly more complex. Participants not only had to navigate to the cell they wanted to interact with and click on it to engage with it, they also needed to use a keyboard to enter the numerical value they wanted to use and hit enter to confirm the value they chose. In spite of these challenges, some participants were able to successfully play the game. Relabeling keys, such as the “enter” key, helped some participants better understand how to use the keyboard in relation to the game.

B. Wack-a-mole Tablet Game

In another study, we presented twelve PLWD with a whack-a-mole game and their performance was measured “to determine the potential for a game-based instrument to provide an indication of cognitive change and to study the suitability of game-based techniques with patients” [15]. Based on our prior work, we chose wack-a-mole, a game that users would be likely to have early life experiences with. We also chose a



Figure 3. The whack-a-mole game interface [15].

touch-screen interface, as users in our previous work had struggled with the mouse and keyboard setup. Visually, the interface was similar to what participants may have seen at fairgrounds in their childhood, with near photographic renderings of the elements, shown in Figure 3.

To add some additional challenge, we added “bunnies” to the game, which participants were supposed to avoid hitting. It has been conventionally accepted that PLWD do not learn new information because of impairments to episodic memory, however, the results of the study indicate that PLWD can learn an interface and a game. Several participants’ results improved not only within sessions but also between weekly sessions. “Analysis of the results indicates that they improve their play over the first few weeks and then eventually are able to achieve a steady level of play. This indicates that participants are showing an ability to learn the game,” and its interface [15]. The participants even understood that they should hit the moles and avoid hitting the bunnies. The possibility that PLWD can learn an interface over time is a hopeful one, suggesting that even if an interface initially presents a struggle to users with dementia it may eventually be learned.

C. Balance and Cognitive Decline

We have also done work using more traditional digital interfaces not specifically designed for PLWD. In a study done using the Biodex Balance System™ shown in Figure 4, we tracked the balance of older adults [16]. The Biodex Balance System™ was designed with generally physically and mentally well users in mind. For example, it is used to evaluate the balance of high performance athletes after a concussion. The system’s interface consists of a plate participants stand on and a screen that presents the participant with information on their body position and motion using a dot representing their centre of pressure overlaid on a target.

Users were positioned so that the dot aligns with the center of the target and then asked not to move and to keep the dot at the center of the target. Because the participants had dementia, “reminding them to keep their feet in exactly the same position [was] not always effective” [16], and they would often shift their position even between the initial positioning and the actual test. This indicates that they may not have made the connection between the movement of the dot on the screen and their shifting of their centre of pressure, similar to how some users playing the word search game did not understand

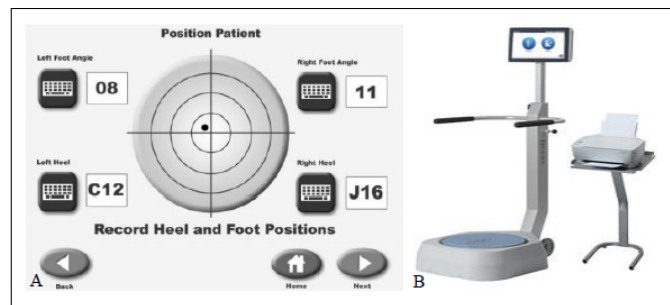


Figure 4. The Biodex Balance System™ [16]

the association between the movement of their mouse and the movement of the cursor on the screen. A modified interface for the balance system may have helped the participants stay in place and resulted in more accurate readings. For instance, outlines of feet on the board may have helped remind PLWD that they were not to move their feet. More research in this area is required to know how best this interface could be adapted.

D. Nighttime Wandering

Our most recent effort has been the design and testing of a system to aid in the reduction of nighttime wandering and its impacts. Nighttime wandering is a common expression of dementia symptoms in those with advanced cognitive decline. It consists of the PLWD awakening at night and finding themselves disoriented, sometimes leading them to leave the home [17][18]. Our smart home solution consisted of a pressure mat embedded in the bed of the participant which is linked to a smart speaker and smart lights. This is a marked break from previous interfaces used in studies by PLWD, which have been much more conventional, using a screen that users interact with. Our interface for this project has no explicit interface for users to interact with, it instead reacts to activities that users might not instinctively understand to be connected to an interface.

When the participant got out of bed at night, the pressure mat in their bed would trigger a series of lights leading to the bathroom, “as bathroom need is typically the cause for waking during the night hours” [17][18]. If the participants strayed away further into another room an audio message was triggered telling the participant that it is nighttime and they should return to their bed. The message was typically in the voice of caregivers, a choice made after consulting families about what would suit them best. Fifteen individuals participated in the study, dyads consisting of a Person Living With Dementia and a caretaker. Because of the advanced nature of the cognitive decline of individuals who exhibit nighttime wandering behavior, it is possible that they interpreted the message as actually being their caregiver speaking. We found this system effective both in convincing the PLWD to return to bed and in alleviating the stress caregivers felt about the nighttime wandering of their loved ones. Future work could explore how variations in the design of the audio and light interfaces change the efficacy of the system.

IV. FRAMEWORK FOR UXD FOR PLWD

A. “Rules of thumb” for PLWD-Friendly Interfaces

Heuristics for the design of PLWD-Friendly interfaces can be drawn from expert knowledge on the condition, as well as

previous work on interfaces from PLWD. Outlines on how user interfaces should be adapted based on expert knowledge of the condition have been created. The initial impacts of dementia are on the cognitive domains such as memory, orientation, and abstract thinking, however more advanced forms of dementia also affect visuo-spatial skills [19]. These outlines emphasize the difficulty in designing “one size fits all” interfaces, and the importance of making solutions that can be scaled to fit the progressive nature of dementia [20]. As their dementia progresses, the individual may need adjustments made to suit their more limited abilities [21]. While any interface designed for PLWD should be user tested, we have compiled a list of “rules of thumb” to use in initial designs for PLWD:

- **Large font size**
As a general rule, larger font sizes are easier to read, although “care should be taken that the font is not increased to the point where scrollable windows are required” [19].
- **Clear Navigation**
PLWD are easily disoriented and may be lost trying to navigate scrollable windows and other interfaces. The location of the user within the structure of a product should be clear at all times.
- **Reduce hidden affordances**
PLWD often have difficulty associating elements with actions that can be taken. For instance, PLWD found using the touch-screen we used for the wack-a-mole game easier than the mouse and keyboard with the word search game, in part because they had difficulty associating the movements of their mouse with the movement of the cursor on the screen. Interfaces should be designed in a way that PLWD understand how they can interact with what they see.
- **Accommodate limited motor skills**
Complex motor movements can also be difficult for PLWD, so interfaces that do not require advanced motor skill are preferable. In our work using the Biodex Balance System™ we asked participants not to move, which is a motor skill they found difficult. While this may have been due in part to memory, discomfort with maintaining their position may also have played a role [22] [23].
- **Avoid the need for information recall**
Problems with short term memory can make information recall difficult for PLWD. Reiterating information across multiple parts of the interface or separating it into smaller, easier to remember chunks, are possible alternatives [20].
- **Provide Hints**
In our prior work with PLWD, we found the inclusion of a hint function to be useful to PLWD. Providing them with information when confused is important. PLWD should always have some form of support system to help them orient themselves [20]. The simple hints we provided in the word search game were used, but those given in the sudoku game were largely ignored. It is possible that the display method used in the sudoku game was too complex and so users did not understand that hints were available.

- **Avoid Iconography**
PLWD struggle with abstract thinking. Using icons to indicate important information can be problematic because PLWD may not associate it with what it indicates correctly, and may not learn the association over time.

Overall, interfaces for PLWD should be characterizable as “structured,” and “simple” [24].

B. Prototyping and Iterative Design

The rules above cannot replace testing and iterative design, where designers and engineers engage with stakeholders during the development of a product. The particulars of dementia mean that the best designs for PLWD may be designs that designers find counter-intuitive. These may only be discovered through the testing of a wide variety of possibilities [25]. This necessitates the involvement of PLWD in the iterative design process. The adapted prototyping methods discussed above may be appropriate for some populations with dementia. In the case of severe dementia, teams may need an alternative way to connect with their end user. Teams could consult with less impaired PLWD to gain an understanding of how they view and interact with the world. Alternatively, family caregivers can be consulted or aid PLWD in communicating with researchers, as discussed in Best Practices. Whatever the method, it is crucial that individuals with dementia are involved in the design process when they are the ultimate end users of any piece of technology.

V. DISCUSSION AND CONCLUSION

While it can be difficult, PLWD can be integrated into the UXD process. By using adapted prototyping methods, design heuristics, and involving caregivers in discussions, designers and researchers can gain insights into the lives of PLWD and how the products they are creating can best serve them. Our past work with PLWD has highlighted the difficulties they encounter when interacting with interfaces the cognitively able would consider obvious. Limitations in memory, orientation, and abstract thinking are all barriers for PLWD when trying to use interfaces. The future of the AGE-WELL SAM³ collaboration will include further work on non-traditional visual user interfaces, interfaces in non-visual modalities such as audio interfaces, and multi-modal interfaces such as the one implemented in our nighttime wandering project. The limited work done in these areas will necessitate further research into how non-traditional interfaces can be made less abstract and more interpretable to PLWD to allow communication of richer and perhaps more complex supportive cues and messages.

Testing interfaces in the prototype stage is crucial to identifying problems PLWD encounter while using them. By using the framework outlined in this paper, we will be able to make more stringent efforts at accessible and adaptable technological solutions for individuals living with dementia.

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