Identifying Features and Functions of a Work-management App for Supporting People with Early Onset Dementia/ Mild Cognitive Impairment

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INTRODUCTION

The number of people with early-onset dementia (EOD) and mild cognitive impairment (MCI) is rising rapidly worldwide [1]. A relatively higher age of retirement, as well as medical progressions in diagnosing these conditions are causing the number of employed people with MCI/EOD to increase [2,3]. Both dementia and mild cognitive impairment cause neurological symptoms that can affect a person's memory, thinking, problem-solving, and communication abilities [4,5], skills that are often crucial for task-management in most professional occupations.

Literature suggests that work can promote social well-being, physical health, and cognitive functioning for this population [3]. A study in 2010 showed that a mixture of technology and policy-based solutions were the most used accommodations for supporting individuals with and without disabilities [6]. However, to date, the majority of technology, services, and policies to support dementia and MCI have been centered around supporting the needs of the older population (i.e., above 65 years of age) or late onset dementia (LOD).

Most design efforts for people living with dementia have focused on safety, reminiscence, tracking, and communication with younger family members or caregivers [7,8]. While offering valuable support and having created significant improvements in the living experiences of people with LOD, they do not target work-related support for employed individuals with MCI/EOD. Many of the everyday technologies designed for the general population (e.g., laptops, personal computers, and smartphone applications) are not user-friendly for people with MCI/EOD [9,10]. Designing technologies that support the needs and requirements of this population could increase their options with respect to accessing occupations such as employment as well as empower them in improving their lived experiences post diagnosis.

This research aims to develop a user-centered digital application for work-management tailored to the requirements of people with MCI/EOD. In this paper we aim to answer the following research question: *"what features and functions would support people with MCI/EOD at work?"* To answer this question, we use data derived from interviews with people with MCI/EOD to propose features that will be incorporated into an initial app wireframe for further user testing and analysis.

Keywords: Early onset dementia/mild cognitive impairment; HCI; user-centered design; experience-centered design; user-experience; inclusivity

METHODS

Study design

This two-part study included (i) semi-structured interviews to probe on the experiences, challenges, and self-initiated strategies of people who developed MCI/EOD while employed to overcome challenges related to changes in cognition; and (ii) participatory workspace recreation to probe on technology requirements and identify potential design opportunities to provide support at work. Details about the design of activities during the interview sessions, questions involved, and the rationale behind them can be found in [11].

The interviews consisted of people with MCI/EOD with the presence of a support person if they chose. The participants must have been either (i) currently employed; or (ii) employed less within the last five years. Participants were recruited from the Durham and Waterloo-Wellington regions in Ontario, Canada by contacting local dementia organizations, posting flyers on local businesses' bulletin boards as well as social media and research network newsletters.

Data analysis

Recordings from interviews were transcribed by the members of our research team to ensure the validity and accuracy of data collection [12]. The transcribed recordings were then structured using qualitative analysis

software (NVivo V.12 Pro). After initial data familiarization and scanning of the text, the first author came up with a set of pre-defined codes to use as a template to guide the qualitative analysis process [13]. The codes were continuously updated through systematic theme development and examination [14,15]. While performing a deductive approach to find answers to the research question, we performed an inductive approach to allow for emerging patterns that would help to identify potentially effective features and functions for a digital technology for people with MCI/EOD at work [16].

RESULTS

We interviewed a total of nine participants between the ages of 46-65 (7 current/recent employees with MCI/EOD and 2 caregivers; 3 male/4 female). Interviews were conducted from December 2018 to March 2019 in-person and at the location of the interviewee's choice. The interviews lasted an average of 106 minutes in length. Table 1 shows the demographics of interview participants.

Table 1. Demographic of research participants

Participant ID	Age	Gender	Participant type/ diagnosis	Employment Status	Occupation	Interview type
P1	54	Male	MCI	Employed (seasonal)	Seasonal worker	Interview
P2	57	Female	MCI	Employed (sick leave)	Training coordinator	Interview and participatory session
P3	62	Female	EOD	Employed (full-time)	Customer services coordinator	Interview
P4	46	Male	EOD	Unemployed	Manager in economic development	Interview
P5	46	Female	Caregiver	Employed	Not known	Interview
P6	65	Male	EOD	Retired	Support missionary	Interview
P7	59	Female	EOD	Retired	Healthcare manager	Interview
P8	53	Female	Caregiver	Employed	Accounting consultant	Participatory session
P9	60	Male	EOD	Retired	Electronic diagnostics/ repairs	Participatory session

The heterogeneity of the group in terms of occupation, interests, and daily activities meant that not all challenges, strategies, and other themes were identical for all participants. However, we collected the most common examples of each theme that could be a first answer to the research question. Due to using the coding guide and the research question to guide answers for identifying app features, some themes (e.g., physical pain) were excluded from this analysis, although we continue to acknowledge them as inseparable pieces to the user experience.

Theme I: Work-related challenges

1) Forgetting the starting point of a task; 2) multi-tasking; 3) task re-ordering; 4) concentration; 5) forgetting tasks while performing them; 6) missing tasks; 7) stigma; 8) anxiety and confusion; 9) lack of legal support; 10) irrelevant or limiting workplace accommodations; 11) learning new skills.

Theme II: Effective self-initiated strategies

To overcome the challenges mentioned above, participants named self-initiated strategies [17] they used that helped them to accomplish a task or alleviate/prevent a negative experience of those mentioned above or one in general. These strategies were: 1) Asking trusted individuals (e.g., colleague, job coach, children, or spouse) for help; 2) working from home for better focus, organization, and avoiding stigma; 3) creating cheat sheets of step-by-step task procedures; 4) creating lists of tasks; 5) improving organization and reducing chaos (e.g., having a specific location for everything); 6) note-taking strategies such as color-coding and following a consistent format; 7) delegating (part of) work to colleagues.

Theme III: Technology features that positively impacted usability

During the participatory session, we asked the participants to describe a tool or piece of technology (general or work-related) that they liked and a piece of technology that they disliked. Probing on the reasons for technology usability or lack of it gave us cues about useful features for design. These features include: 1) Minimal need for

navigation (e.g. in Netflix interface); 2) versatility and portability; 3) minimal need for learning how to use; 4) familiar design (e.g. texting cellphone app); 5) minimal need for user input; 6) enabling socialization.

Theme IV: Technology features that negatively impacted usability

Related to liked and disliked technologies mentioned in Theme III: 1) Cluttered interface/button pad (e.g. office printer); 2) Function buttons with faded, worn off, or no labels (e.g. in TV remote control and electrical oven); 3) too many steps for accomplishing tasks.

DISCUSSION

As noted in the Methods section, the number of research participants in this study was limited. Due to the difficulty of recruiting people with MCI/EOD who would be willing to disclose their work challenges, a small sample size for this research was considered appropriate and comparable to similar studies [18]. However, more rounds of user-testing and participatory design sessions with new participants would be needed to increase the possibility for generalizability of results. With the preliminary data, we can make a connection between challenges and self-initiated strategies described by participants and their caregivers, and carefully use them as design suggestions. As a goal of this user-centered research, we aim to develop the wireframe "with" people with MCI/EOD and not only "for" them [19].

The identified challenges (Theme I) guided us toward opportunities where the app can be useful in a work setting. Self-initiated strategies (Theme II) gave us hints as to how to address these challenges in design. Finally, Theme III and Theme IV provided guidance about basic features. Examples of derived features and functions are described below:

1) Mitigate task-related challenges: can be addressed by note-taking, list-making and re-ordering functions. Tasks should include sub-tasks defined by the user themselves for enhanced versatility and consistency of note-taking formatting and vocabulary. The tasks should be displayed in ordered lists, with a user interface suitable for minimizing distraction. For example, proper layout, navigating strategies, and feedback to the user (e.g., displaying an hourglass when the app system is processing) can help users manage attention while interacting with the app.

2) Learning new skills: a note-taking function could help by enabling users to create cheat-sheets within the app. This allows them to document personalized support in a way that makes sense to them. Notes should be easy to find and be flexible for color-coding and re-ordering.

3) Tracking progress through tasks: enabling the user to record and follow the status of each task and sub-task, (e.g., seeing different labels for accomplished and remaining tasks) could help the user continue in-progress tasks, helping to ensure they do not redo/miss a task.

4) Managing team tasks or asking for help: including a sharing function for tasks and/or subtasks could enable socializing and allowing the user to ask questions from their trusted ones when facing a pressure point.

It is important to note that as mentioned by research participants, the familiarity of a technology design profoundly impacts its usability. This can mean that the experiences of individuals reflected in this study can be subjective of their past experiences with similar or different technologies. While understanding the liked and disliked technologies as viewed by our participants helped us find cues about the concept of "familiar design" in this research, this could change in the future as the capabilities and design of technology changes.

CONCLUSION AND FUTURE WORK

We derived results from this study for design cues for designing a wireframe for a workplace-support digital app. This work was the first experimental step to help us understand which main features and functions would be beneficial for a work-management app for individuals with MCI/EOD.

To our knowledge, this is the first research that has included people with MCI/EOD in designing an app to support work-management. With the intention of reducing stigma and fostering inclusion of people with MCI/EOD, we aim to design an app that is usable not only by this population, but by everyone in the workplace who may need to manage their tasks and stay organized.

The next steps involve conducting more participatory design sessions with the same or new participants to (i) develop a wireframe; (ii) gain more targeted and design-led inquiries as we identify usable and non-usable features alongside our research participants; and (iii) to develop a functional prototype for further user-testing.

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