Aging with Multiple Sclerosis
Inclusive Universal Design (UD) Guidelines for Mobile User Interfaces

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1 RESEARCH PROBLEM

The number of older adults with multiple sclerosis (MS) is increasing because of the rising life expectancy of people with MS and the growing population of older adults (Minden et al., 2004). As a result, 14% of people with MS are now over the age of 65 (Minden et al., 2004). However, there is a lack of MS research targeted to older adults (Finlayson, 2002).

MS does not reduce life expectancy unless the disability that results from the disease is severe (Weinshenker, 1995). Approximately 10% to 15% of people with MS develop severe disability (Minden, 1993), which suggests that the vast majority of will live as long as their age peers (Finlayson, 2002). Thus, people aging with MS will deal with changes in life related to aging in addition to managing disability as a result of MS (Finlayson, 2002).

The most common MS symptoms reported by older adults are similar to those reported by younger adults, including pain (Stern, 2005), fatigue, problems with balance, and weakness (Finlayson, 2002). However, research has shown a significant individual variability in the relationship between duration of illness and physical functioning, which leads to a conclusion that older adults with MS are more physically disabled than younger adults (DiLorenzo et al., 2004). In addition, MS has overlapping symptoms with physical effects of aging, including decline in muscle strength, problems with balance, weakness, fatigue, reduced sensation, vision impairments, alterations in bowel/bladder function, cognitive impairment (Stern et al., 2010), osteoporosis and sleep disturbances (Fleming and Pollak, 2005). In one study, 80% of people with MS reported that their physical health limited their daily activities and caused them to accomplish less than they wanted (Minden et al., 2004).

To overcome barriers to daily activities that result from functional limitations and non-supportive environments, many older adults with MS have adopted assistive devices (Minden et al. 2004). Use of assistive devices with proper social supports can enhance older adults' perceptions of their degree of mobility and independence, thus impacting their overall wellbeing (Finlayson and van Denend, 2003). More recently, many mobile technologies have been developed that integrate assistive and information technologies thus providing better solutions for older adults and people with disabilities (Harris, 2010). However, many older adults and those with MS in particular, have many usability problems with current mobile technologies (Harris, 2010).

Unfortunately, there is a lack of literature on needs and concerns of people aging with MS (Finlayson, 2002) to inform the design of mobile technologies. Moreover, there is a dearth of literature on the design of user interfaces and corresponding guidelines for people with MS, specifically those aging with this mobility-affecting chronic disease.

Universal design (UD) considers designing products and interfaces usable by all people, to the greatest extent possible, "without the need for adaptation or specialized design" (Mace, 1988). UD promotes usable design by the greatest number of people, including older adults and disabled people. It addresses wide range of limitations and combinations of limitations one might have (2013). Furthermore, Design for Aging (DfA) focuses on the aspects of aging that limit the use of user interfaces (UIs) (Nichols et al., 2006), as well as features of UI design that assist older users with age-associated limitations (i.e. memory, cognitive, hearing, visual, dexterity, and physical impairments) (Zajicek, 2001). The abilities of older adults can change over time (Sanford, 2012). DfA successfully tackles the problems they have with UIs by meeting the needs and abilities of older adults throughout their lifetime (Fisk et al., 2012). Based on UD approach, Universal Usability (UU) makes information and communication technology usable and accessible by

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all people, with and without disabilities (Meiselwitz et al., 2010). UU was defined as "having more than 90% of all households as successful users of information and communications services at least once a week" (Shneiderman, 2004). In addition, mobile design guidelines and recommendations were developed for general population to assist future development of mobile technologies.

Similarly, the population of people aging with MS is diverse in ranges and combinations of functional limitations. Moreover, their abilities not only change over time, but can vary from day to day or within a day. As a result, existing design guidelines that focus on singular and static limitations are less effective for users with multiple limitations and constantly changing abilities (Kascak et al., 2014). Most importantly, design that accommodates variability and combinations of limitations would not only help the design of mobile technologies for people with MS but all users.

2 OUTLINE OF OBJECTIVES

This research contributes to the state-of-knowledge about design for people aging with MS and provides a comprehensive set of design guidelines for the mobile user interfaces for users through the analysis of data from usability studies of three mobile applications. More specifically, it focuses on refinement of inclusive UD guidelines for mobile user interfaces for older adults, which were based on UD, DfA, UU, and mobile design guidelines (Kascak et al. 2014) through the inclusion of users aging with MS.

In our research, we are specifically focusing on older adults, defined here as people of ages 60 and more. Specific aims of the research are to specify design characteristics based on the inclusive UD guidelines and test those characteristics with older adults with MS using three mobile applications. Design characteristics will be tested using the performance measures. The purpose of the usability testing of three mobile applications is to analyse the data gathered from older adults with MS in order to inform the inclusive mobile design guidelines for people aging with MS. Usability testing of the three applications will provide recommendations for design of apps for people aging with MS.

Furthermore, inclusive UD guidelines will inform the design of the health recording mobile application for people aging with MS.

3 STATE OF THE ART

The number of mobile applications designed for people with MS is very limited. There are only several of these applications available to this group of users. These primarily focus on providing basic information about latest research news and practical tips on health, nutrition, and fitness, self-recording of medication adherence and health status, journal data-management, customized injection reminder, connecting to healthcare providers to share the data, and tremor tracking.

Multiple Sclerosis Association of America (MSAA) released a mobile phone application, My MS Manager, for individuals with MS and their care providers (2012). The app offers tools for disease activity self-reporting, storing medical information, creating charts and reports for treatments, moods, and symptoms, reminder settings, links to educational materials from MSAA, and connecting to healthcare providers to share the progress and reports. Similarly, SymTrack was designed to provide health self-reporting tool, which stores the data, reports and shares the charts with healthcare providers (2014b). myBETAapp is an app designed specifically for scheduling, tracking, and recording the treatment with a prescription medicine BETASERON (interferon beta-1b) (2015c). MS self offers a journal for self-reporting the moods, thoughts, and health data, which can be later accessed and shared with the healthcare team, helpful health-related information, and achievements for using the app (2015b). Momentum, the National MS Society magazine, provides an interactive mobile application, which includes stories about people living with MS, expert opinions, reports on current events, MS advocacy and recent advances in MS research (2015a). MS Journal is an injection reminder tool for individuals with MS and their caregivers (2014a).

Researchers were working on the apps that track tremor for people with MS (Joundi et al., 2011, Carignan et al., 2015, Delano et al., 2011, Daneault et al., 2012). Daneault et al. (2012) demonstrated that mobile phones can be used as a standalone platform to assess tremor and perform clinical evaluations. Joundi et al. (2011) used the iPhone accelerometer, through the iSeismo app interface for earthquake tracking, to quickly assess the tremor frequency. Carignan (2015) developed the smartphone application as a standalone platform to assess tremor. However, these research projects were intended for use in the clinical setting, not for the constant tremor tracking on individuals with MS.

Delano et al. (2011) were developing an application to be used with the ubiquitous devices to collect data on hand and arm tremors and send the results to healthcare providers. This app was developed for individuals with MS and their caregivers to track the tremor, as well as for physicians to remotely monitor the degree of disability, progression, and medication response of people with tremor-related conditions. Additionally, the app offered a social component to let people share experiences, pictures, and information.

In addition to a small number of interactive mobile applications available for individuals with MS, there is a lack of these applications for people aging with this chronic disease.

4 METHODOLOGY

4.1 Participants

Three studies will be conducted with two groups of participants. One group will be formed out of older adults, ages 60 and more, without functional limitations and the other one will be a group of older adults with MS. The number and types of impairments will be reported.

4.2 Mobile Applications

Mobile applications were selected for testing based on their use by either older adults or people with MS. First, a cognitive gaming app developed by the GA Tech Rehabilitation Engineering Research Center on Technologies for Successful Aging with Disability was selected as it was specifically designed for older adults with disabilities. Second, My MS Manager was selected as it is a mobile application designed specifically for people with MS by Multiple Sclerosis Association of America (MSAA) (2012). Finally, Candy Crush Saga was chosen as it is a popular gaming app that has reportedly been used by millions of older adults (2014).

4.3 Experiment Setting

Testing will be performed in a controlled environment at the GA Tech Center for Assistive Technology and Environmental Access (CATEA) Usability Lab, which will provide an equivalent environment across users. GoPro Hero 3+ Black edition cameras will be used for recording the usability studies. The cameras are connected to large screen LCD monitors for real-time observation by the researchers. Three mobile applications will be used on a Microsoft Surface using Windows 8, with a 10.6 inch screen and 1366p x 768p screen resolution.

4.4 Measures

4.4.1 Demographics and Background

Participant data on functional status and familiarity with mobile applications will be collected through self-reported assessments in addition to demographic data.

4.4.2 Outcome Measures

Think Aloud protocol will be administered during the testing. Participants will be given the tasks, which will test specific design characteristics. These design characteristics match the inclusive UD guidelines for the purpose of informing the design guidelines for interactive mobile interfaces to include older adults with MS.

The post-study questionnaire will consist of the SUS questionnaire (Sauro and Lewis, 2012), the satisfaction questionnaire, and the open-ended questions regarding the participants' experiences and difficulties with the applications.

4.5 Procedures

Participants will complete the demographic and background questionnaire. Order of the three mobile applications will be counterbalanced across the participants. They will be informed to use Think Aloud protocol.

Participants will be asked to use the three apps to perform the tasks that will test specific design characteristics, matched with the inclusive UD guidelines. Following the completion of tasks for each application, the post-study questionnaire will be administered.

4.6 Analysis

Paired t-test will be used to report within group statistical differences, and t-test on independent means will compare across the groups statistical differences. Differences in performance data across the groups will assess the usability and the level of universality of the apps.

5 EXPECTED OUTCOME

This research is an attempt to contribute to the literature on needs and wants of people aging with MS that interact with mobile technology. Results of the three studies will inform the inclusive mobile design guidelines for older adults to include people aging with MS. In addition, we will provide recommendations for design of future mobile applications for older adults with MS. The expected outcome of my PhD Thesis is the comprehensive integrated set of mobile design guidelines for people aging with MS that would be a complete design tool for new mobile applications as well as an evaluation tool and performance measure of the applications based on these guidelines.

Moreover, guidelines will inform the design of the health recording mobile application for people that age with MS.

6 STAGE OF THE RESEARCH

The research is in the beginning stage of gathering the literature on people aging with MS and existing mobile technologies developed for the population of people with MS, compiling the information regarding the three mobile applications that will be used for usability testing, and preparing the usability testing with the three mobile applications. It is grounded in the previous research of mobile technologies for older adults and the set of inclusive design guidelines for older adults for the purpose of including people that age with MS.

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