

An Interactive Multimedia System for Monitoring the Progressive Decline of Memory in Alzheimer's Patients

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Abstract. This paper describes an assistive technology designed for longitudinal monitoring of memory decline for people with Alzheimer's Disease (AD). While there are systems designed for rehabilitation of people with AD, supporting caregivers, and psychosocial intervention, there is a lack in technology support that provides quantitative measures of progressive memory decline that can assist physicians in clinical settings. An interactive autobiographical memory repository of images and sound recordings was developed to facilitate measuring memory recall and recognition. The system functionality and the user-centered design approach of involving geriatric psychiatry specialists and caregivers are described.

Keywords: Alzheimer's Disease, Memory Decline, Caregivers, Elders, User-Centered Design, Caregiver Burden.

1 Introduction

Accelerated cognitive decline and memory loss is a concern for rapidly aging populations. One of the most common reasons of memory loss is Alzheimer's Disease (AD), a neurological disorder which is an irreversible progressive form of Dementia affecting memory, cognition, and behavior [2]. Prevalence is growing worldwide affecting many facets of life. In Saudi Arabia alone, 50000 people were estimated to have been diagnosed with AD [9]. AD is also considered to be the sixth main cause of death in the United States [10]. An equal number of caregivers are affected who support People with AD (PwAD) with their physical needs of aging and episodic memory impairments. In 2008, there was an estimate for AD that 9.9 million caregivers provide 8.5 billion hours of care at a cost of \$94 billion in the US [1]. Caregivers are often a spouse or a close relative of PwAD, and are considered the second or hidden victim of AD. Caregivers' burden lies in the challenge of assisting PwAD physically and mentally, while at the same time trying to keeping track of progressive decline in cognitive abilities in interventional therapy.

Recent research has suggested that earlier diagnosis facilitates earlier treatment of the disease, when medications have been shown to be most effective [8]. A challenge

resides in monitoring memory loss at the onset of AD symptoms and for patients with Mild Cognitive Impairment (MCI). Recently, there has been increasing interest in the design and development of assistive technologies for PwAD. While this research serves the purpose of providing solutions for people who need them (e.g. individuals with AD, their caregivers, physicians), it also gives researchers opportunities to investigate and learn from people with AD whose requirements challenge the extent of designers' and developers' understandings [6]. Of particular interest to our current work are research studies examining technology solutions for people with AD that have been shown to be effective in facilitation social interaction and eliciting memory cues. Systems have been designed for early diagnosis, rehabilitation of AD patients [10], supporting caregivers [1][6], assisting them with their daily lives [4], and intervention [8]. Clinicians involved in the caring for people with AD often find it difficult to assess memory decline based on caregivers' anecdotal evidence. This has led to the question of whether technology can assist physicians in accurately keeping track of accelerated memory decline. Zplay has been recently introduced for clinical and home use, which facilitates monitoring; however, longitudinal monitoring still relies on subjective or manual recording, which does not involve direct interaction between PwAD and the system [8]. The need for supporting physicians in monitoring decline of memory abilities signals opportunities for technology development. This has motivated us for developing "Monitoring Memory Streams", which is a software program aimed to help caregivers and physicians with that process. The inadequate understanding of the needs of users in this context has entailed adopting a User-Centered Design (UCD) approach for iterative needs assessments and evaluation of prototypes. Monitoring the accelerated decline in memory for patients with AD is a challenge in home settings. In clinical settings, physicians rely on neuropsychological measures. Longitudinal data is difficult to ascertain due to the challenge in eliciting accurate reports described by caregivers. A better understanding of how clinicians measure memory decline can help identify opportunities for technology to help this process and consequently reduce the burden on the caregivers.

Reminiscence Therapy (RT) is a common psychosocial intervention for people with AD. RT involves eliciting memories with tangible objects such as photographs or artifacts. Evidence suggests that having PwAD engage in activities that are cognitively stimulating can slow down the rate of decline in cognitive abilities [1]. Multimedia that can be readily recognized by PwAD such as photos with faces of people familiar to PwAD or places of interest are often advocated in RT [8]. A better understanding of effective conversational prostheses and what visual and auditory stimuli are effective in triggering memories of past experiences can help improve the functionality of a monitoring system in assessing recognition rates over extended periods and consequently provide objective measures of decline.

The aim of this project is to develop a system for monitoring the decline in memory for people with AD. The hypothesis is that a monitoring system used regularly by PwAD can help provide an accurate measure of cognitive abilities over long periods of time between clinical visits, decrease caregiver burden, by automatically keeping track of recognition rates of visual images and auditory cues. In this paper, we first present an overview of the system that we developed for monitoring memory decline of people with AD. Following that, we discuss our user-centered design approach in the design

and development of the system. Finally, we make some concluding remarks and discuss future work.

2 Monitoring Memory Streams: System Overview

Our Monitoring Memory Streams system provides a technology solution for measuring memory decline for PwAD. The system includes customization features for caregivers to build a personalized photo and audio repository of four categories; namely people, places, events, and objects for the AD individual. Categories are based on psychological models of autobiographical memory [4], and have been applied in the context of assistive technologies for people with episodic memory impairment [1]. This is facilitated by populating the photo database with pictures of the AD individual's relatives, friends, familiar places and surrounding objects, and the audio database with sound recordings of the people who are close and familiar to them.

Recognition tests are designed by clinicians to measure the progressive decline of memory for PwAD with customized reporting. The system is intended to be used as a catalyst for facilitating interactions between caregivers and PwAD. Caregivers use the system with PwAD in recognition drills designed as activities similar to browsing photo albums, while the system keeps track of recognition rates of images and audio clips automatically over periods extending between clinic visits. The system generates reports of performance-tracking for enabling the specialists to monitor the memory decline or stability of PwAD. The system is implemented on a touch-pad portable device featuring direct manipulation interaction types with reduced complexity in which functionality is not hidden in menu structures. Evidence exists demonstrating that touch screens are effective interaction types for people with dementia [3]. The system reduces the burden on caregivers in long-term monitoring of PwAD by serving as a catalyst for facilitating a joint activity between caregivers and PwAD in relaxed home settings. Once an individual is diagnosed with AD, subjects are able to work on the interactive drills at home with caregivers. In clinic visits, memory decline can be examined in 3 to 6 month intervals depending on the stage of the AD. This system also facilitates examining the impact of medication on PwAD's ability to respond or recognize people, places, objects or events in the multimedia drills as compared to other treatments. Systems that use personalized artifacts for PwAD have been shown to be promising in reminiscence therapy [4]; however, these have been criticized for burdening caregivers with collecting media. This issue has been addressed in our system by minimizing caregiver involvement to the initial setup stage. The system has a default test specifications, which can be customized by clinicians to match each PwAD's needs. The tests' results are stored and customized reports can be generated for the specialists' use.

3 User Centered Design

The system was developed with a UCD approach arising from the need expressed by physicians and caregivers of PwAD for a way of facilitating the monitoring process of accelerated memory decline for long periods between clinic visits. Physicians and

caregivers were involved as informants in the design and the development of the system, to provide insights into measures of cognitive decline to identify system functionality, and the needs of our targeted user population. Development of prototypes was carried out iteratively, with the input of a geriatric psychologist, neurologist, and caregivers throughout. Indirect involvement of PwAD was considered in early stages of the project due to the difficulties known to exist in eliciting requirements directly from PwAD [6]; however direct involvement of PwAD is planned for later stages of iterative prototyping and in the longitudinal trials of the monitoring system. In specifying the context of use for Monitoring Memory Streams, it was evident that our problem involves users who require specific design considerations that avoid complexity and over-stimulation and who have memory recollection issues, and is targeting specialists in the medical field. As designers and developers, a key challenge for us was to develop a system for people who have different life experience from our own.

The main cycle of work was comprised of four activities. First, specifying the context of use in both clinic and home environments with three categories of users (i.e. specialists, PwAD and their caregivers). Second, specifying requirements involved examining software designed for RT and assistive technologies for PwAD as well as conducting requirements discovery sessions with specialists in fields such as geriatrics, psychiatry, and neurology. Caregivers of PwAD were involved as design informants to elicit insights into their cognitive and interaction needs. Third, producing design solutions involved iterative prototyping in two stages. First, the low fidelity prototype was designed using paper-based sketch formatted interface and was assessed by a neurologist. Second, a high-fidelity prototype comprised of an interactive application running on an iPad was examined by a geriatric psychiatrist. Cognitive walkthroughs of the design were conducted with the geriatric psychiatrist and refinement of measures and interaction design were revised accordingly.

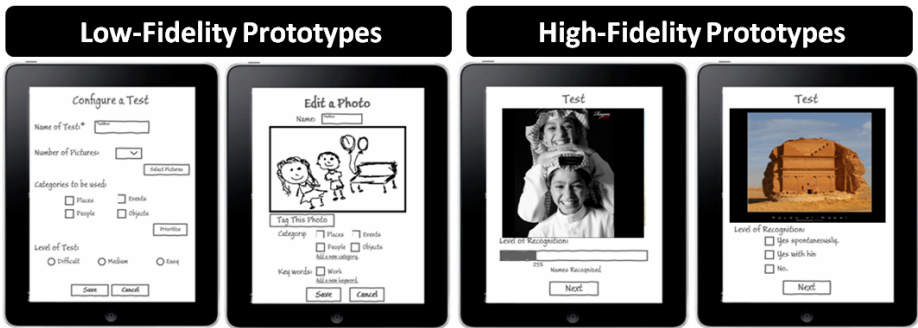


Fig. 1. Prototypes used in requirements discovery sessions with physicians

4 Conclusion

This project has presented a technology solution for healthcare practitioners for the purpose of monitoring memory decline of people with AD. The UCD approach

adopted in this project extends our understanding of how a monitoring system can be designed to meet the needs of clinicians and caregivers. At the stage of writing this paper, we have implemented the design and will evaluate it with our target user population in a longitudinal study.

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