

Usable Security for Persons with Alzheimer's Disease

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ABSTRACT

In this position paper, I discuss usable privacy and security issues that arise as a result of assistive technology for persons with Alzheimer's disease or other cognitive impairments. These concepts will be illustrated through a planned project that will investigate how the information needs and interaction abilities of elderly people change as their cognitive abilities decline and how technology can be designed to adapt to this process. The goal of the project is to develop a calendar and reminder system that can be used throughout the phases of cognitive decline, from normal memory loss related to aging, to mild cognitive impairment, to dementia. Beyond presenting the information at a useful granularity and in a usable form, the personal information used by such adaptive technologies must be securely stored, yet remain accessible to users with reduced cognitive abilities.

Categories and Subject Descriptors

K.4.2 [Computers and Society]: Social Issues -*Assistive technologies for persons with disabilities*, K.6.5 [Management of Computing and Information Systems]: Security and Protection

General Terms

Security, Human Factors.

Keywords

Privacy, security, assistive technology, personal information management, cognitive impairment, Alzheimer's disease

1. INTRODUCTION

Assistive technology is growing in scope and many of these technologies capture intimate details about a person's schedule and actions. For example, Autominder [7] models the daily living plans of memory impaired individuals and then reasons about when to issue a reminder and whether or not it is appropriate to do so. Some of the more recent technology is capturing visual information about daily activities and incidents to support people's memory for past, personal events (e.g., Sensecam, as discussed in [9]).

Privacy concerns are often mentioned as being an issue for such technologies. For example, Cheng et al. [2] discuss privacy and security issues in relation to privacy of third parties photographed without their consent and for privacy concerns if others (including

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the legal system) gain access to the vast store of personal information captured by such systems. There are also privacy concerns that arise when the information that has been captured is later interacted with for the purpose of recall, particularly if a speech interface is used. It is these latter two types of privacy and security issues that most interest me: securing the personal data stores against unauthorized access and ensuring privacy during interactions with the system.

It is clear that the privacy and security of such systems needs to be considered during system design and development, particularly for those systems intended to be used outside the relatively safe environment of home. However, even if security procedures are put in place, it is also clear that cognitively impaired users will have difficulty managing their security and privacy. It is difficult enough to motivate users with full cognitive abilities to manage their information [10].

There are several issues with cognitively impaired users, which must be resolved in order to build useably secure assistive technology. We next provide some background about the characteristics of persons with Alzheimer's Disease (PwAD) that impact their interaction abilities. We then discuss our prior work developing requirements for an information device for PwAD [5] and describe our planned research project that will investigate how the information needs and interaction abilities of elderly people change as their cognitive abilities decline and how technology can be designed to adapt to this process. The goal of the project is to develop a calendar and reminder system that can be used throughout the phases of cognitive decline, from normal memory loss related to aging, to mild cognitive impairment, to dementia. It is important that we not only design this assistive technology to provide PwAD with the information they need; but that we also ensure that this detailed personal and identifying information is secure.

2. PwAD INTERACTION CAPABILITIES

As Alzheimer's disease progresses, individuals move through several stages: from the decline in cognitive abilities characteristic of normal aging to mild cognitive impairment (MCI) without dementia, through to the mild, moderate, and severe stages of AD [8]. Severe stage patients are completely dependent upon others and mostly unaware of their surroundings and both recent and lifetime events, so assistive technology are generally not designed for this population. Memory impairment characteristic of normal aging is subjective in nature. Individuals may forget words or names but can generally remember them at a later point in time. Individuals with MCI have an objective memory impairment accompanied by normal general cognitive functioning and no decline in functional abilities that would impact activities of daily

living. Mild and moderate stage Alzheimer's patients have several characteristics that impair their ability to use standard user interface techniques. These include cognitive impairment, declining language abilities and normal effects of aging.

The cognitive impairment impacting mild stage AD patients results in their difficulty handling complex tasks that require sequencing of actions and problems with recent memory, but can be prompted [8]. Those with moderate AD need help with basic activities of daily living (ADLs) [8].

Alzheimer's patients also exhibit declining language abilities [8]. Reading comprehension is typically impaired before auditory comprehension. Mild stage patients may occasionally stammer, substitute words that are similar in meaning, and describe functions of items when they can't recall the name of the item. Moderate phase patients exhibit incomplete sentence structure, have increased difficulty in naming objects, and substitute syllables within words.

Additionally, most Alzheimer's patients are elderly and thus have the normal limitations on their vision and hearing associated with aging. Hand tremors may limit their input abilities with keyboards, mice, and styli, while speech input can be limited by voice tremors and short-term memory limitations. Touch screens have been found to be a viable option for those with dementia [4].

Systems for Alzheimer's patients are often designed to assist the patient without requiring them to initiate the interactions. For example, the ADL Prompter monitors the patient as they complete ADLs and only prompts them when they become stalled [6]. However, PwAD do interact with their caregivers throughout the day and may be capable of initiating some interactions with technology. This ability to interact was apparent in the CIRCA project [4] where a conversation aid initially designed for use by caregivers was instead often interacted with by the participant with dementia

3. ILLUSTRATIVE EXAMPLE

3.1 Adaptive Calendar System for PwAD

We previously evaluated the feasibility of an information appliance with the goal of alleviating repetitive questioning behaviour, a contributing factor to caregiver stress [5]. Interviews were conducted with persons with Alzheimer's and their caregivers to determine the nature of the repetitive questioning behaviour, the information needs of patients, and the interaction abilities of both the patients and the caregivers. We found that an information appliance for Alzheimer's patients has many requirements including the need to satisfy various information needs in a variety of settings. Furthermore, it must meet the changing needs of its users as their cognitive abilities decline and their information needs evolve. PwAD appear to require information that is much richer in detail than those with full cognitive abilities, likely because they cannot use the information as a cue for recall. However, the interaction abilities of this population tightly constrain the device.

It was also clear that such an information appliance will have to virtually eliminate the chance for errors and have only the most basic of interactions. Direct input appears to be feasible, probably in the form of touch. Speech may also be a possibility, but may be

challenging due to their declining language abilities, particularly their difficulty in remembering words.

While we did not expect that the PwAD would be able to use computers, we were surprised at how few device interactions they have in general. Usage of devices such as radios and remote controls was minimal. During discussions with the caregivers, it appeared that much of the PwAD's reluctance to use devices has arisen from bad experiences. It is not so much that the PwAD cannot use the device, as that they are afraid to use it because of past experiences. In contrast, young adults with cognitive disabilities who were already familiar with gameboys and other devices were willing and able to use a handheld device for prompting [1]. Psychological barriers related to complexity and anxiety about technology is common with the elderly [3] and appears to be exacerbated for those with dementia. We believe there may be a better chance of success if a device is introduced during earlier stages of memory decline when the PwAD is more confident of their abilities to interact with devices in general.

Our future research will include elderly adults with normal cognitive functioning and those with mild cognitive impairment to learn more about the types of information these individuals forget or need to keep track of, their current methods of finding and recording this information, and their willingness to use assistive technology. We wish to determine how the information needs and interactions of individuals with AD differ from those in earlier phases of memory decline.

The goal of the project is to develop a calendar and reminder system that can be used throughout the phases of cognitive decline, from normal memory loss related to aging, to mild cognitive impairment, to dementia. Our hope is that a more general solution could adapt to the changing requirements of an elderly individual as their abilities deteriorate. Furthermore, such a system could store the information entered when the users are more cognitively able in order to lessen the input needs during later use. Beyond presenting the information at a useful granularity and in a usable form, the personal information used by such adaptive technologies must be securely stored, yet remain accessible to users with reduced cognitive abilities.

3.2 Privacy and Security Challenges

There will be privacy concerns due to the nature of the information captured by such a device. Such information will likely include a myriad of information including sensitive and personally identifiable data (e.g., contact information, account information, details about medical visits, prescriptions). Rich detail is often omitted in our own calendars (i.e. a note of doctor's visit, 2pm, Tuesday is enough to cue memory); however PwAD need information such as who the appointment is with, what the appointment is for, where they have to meet them, and how they are going to get there [5].

The end result is that we will need to provide some level of access control so that if these devices get lost or stolen, the information will not be easily accessible. However, finding an appropriate authentication mechanism will not be easy. Even solutions as simple as biometric authentication may not be feasible for users with reduced manual dexterity and difficulties initiating tasks.

There may also be privacy concerns as the cognitively impaired user interacts with the device and accesses the data. On a display,

the information may have to be very large in order to be visible to an elderly person, which may subject them to shoulder surfing attacks. If speech interactions and audio responses are utilized, sensitive data may be overheard. The tradeoffs between usability of the system and security of system must be carefully balanced.

4. CONCLUSION

In conclusion, accessible privacy and security is a challenging problem for users with cognitive impairment, including those persons with Alzheimer's Disease. Assistive technology is beginning to afford this population increased independence both within the home and the community; however, the information captured and used by such technology needs to be securely stored. Our future research intends to explore some of the open questions about how to balance the tradeoffs between usability and security for this population.

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