Designing Interactive Life Story Multimedia for a Family Affected by Alzheimer's Disease: A Case Study

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ABSTRACT

In this paper we present a design project involving primary end users who have declining cognitive abilities such as memory, communication, and problem solving. We are designing interactive multimedia with personalized life stories for individuals with Alzheimer's disease. We conducted a case study to discover and address the design challenges for this project. A particular challenge is a limited ability to communicate with the primary end users. In this paper, we present design methods that take this challenge into consideration. Our goal is to contribute insight into designing for users with cognitive disabilities, and to present methodologies that are useful for designers who have a limited ability to interact or communicate with end users.

Author Keywords

User-centered design, design methods, Alzheimer's disease, intervention, reminiscence, multimedia, life stories

ACM Classification Keywords

K.4.2 [Computers Milieux]: Social Issues — Assistive technologies for persons with disabilities, H.5.2. [Information Interfaces and presentation]: User Interfaces – Theory and methods, user-centered design

INTRODUCTION

The human-computer interaction community has researched many methods for communicating with stakeholders and end users in order to conduct user-centered design. Interviews, ethnography, and participatory design involve rich interaction and communication with participants [8,9,12,17]. However, in some design projects there are obstacles that prevent designers from having sufficient interaction or communication with participants. Differing languages, locations, and cultures are examples of such obstacles. In addition, there may be privacy issues that prevent direct communication with end users. In this paper, we shall discuss the case of end users with significantly impaired cognitive abilities.

Impaired cognition affects a range of thinking abilities that are often taken for granted. These lead to communication

and interaction obstacles that make many design methods impractical. Adaptations to these methods can help designers conduct the needed research to gain insight about their users. In this paper we recount our atypical use of research methods in the early design stages of a personalized life story multimedia system for individuals with Alzheimer's disease.

Alzheimer's disease (AD) is a degenerative brain disease that causes the gradual loss of brain cells [1]. This leads to the decline of cognitive abilities such as memory, language, communication, problem solving, reasoning and judgment. As time progresses the severity of the symptoms increases and the disease advances through the early, mid and late stages. The expression of the symptoms can range for each individual and at each stage. AD affects one in ten North Americans above the age of 65, and nearly one half of the population over the age of 85. Due to the aging population, the diagnosis rate is expected to triple by 2050 [1].

Our memories are important because they help shape our experiences, our relationships, and our sense of self. The loss of them can be devastating and can cause changes in personality and behaviour [1,11,14,19]. In addition to these changes, individuals with AD increasingly become dependent on a caregiver for activities of daily living. Thus the caregiver, who is often a family member, is also very much affected by the disease [1,2,4,11].

In order to help cope with these issues, health care communities offer intervention methods, which are forms of non-medicinal treatment or support. They may focus on memory training, memory support, assisting life aspects strained by memory loss, or facilitating the responsibilities of the caregivers. Intervention can enhance the well being of individuals' lives [11,16] and in some cases it can slow down the progress of the disease [18]. Reminiscent therapy is an example of an intervention activity that can reveal and support a person's identity. Even the family can participate and play a major role to support their relative [14,19].

Most intervention technology created for people with cognitive disabilities is designed to make up for cognitive losses [13]. These are often referred to as Assistive Technology for Cognition (ATC). To date, little attention has been given to the development of psychosocial technological interventions. Elders with cognitive decline

can benefit from social support tools, and recent ethnographic research provides insight into the design of such systems [15]. Several intervention technologies focus on supporting the caregiver, such as specialized telephone and video conferencing applications [2,4].

Other related work includes CIRCA (Computer Interactive Reminiscence and Conversation Aid) [7], which explores the effects of interactive multimedia on AD individuals. CIRCA employs generic and non-personalized media to stimulate conversation in reminiscent therapy sessions. We are broadening this research by studying the effects of customized, personal life stories on the overall well being of the individual. A distinguishing research question in our early design is how can we elicit the necessary information and requirements for a personal life story system.

In September 2004 we began a project to create personal life stories for families affected by AD. The project is based on previous work that studies the effects of viewing VHS video life stories [14]. We are conducting the research at the Baycrest Centre for Geriatric Care in Toronto, Canada with a multidisciplinary team of social workers, interaction designers, health care providers and participating families. The multimedia content includes digital video, images, photographs, and audio. Interactive components allow the individual to actively participate with the multimedia.

Our hypothesis is that the intervention technology will provide stimulation while reinforcing the individual's positive self-identity. Our objectives are to evaluate any resulting stimulation from this activity, evaluate the individual's mood and behaviours throughout the duration of the project, and to study the nature of the interaction of the AD participant with the interactive media.

A significant challenge for the user-centered design of our project is our unique user group. Short-term memory loss is one of the most significant symptoms. Other symptoms can hinder communication and interaction with the individual. For example, a mid-stage individual may have difficulty following instructions, making decisions, or recalling words. An additional challenge is accessibility to participants. The researchers were very concerned about disrupting the individual's daily activities, disrupting health care staff, as well as other ethical issues.

In the following section we will describe how these challenges prevented us from conducting user-centered design methods in the way they are intended. We describe how we modified the methods to account for the communication and interaction barriers.

CASE STUDY

Our research goals include:

- To explore life stories and determine how (and if) the stories stimulate a reaction from the participant

- To collect the information and media necessary to tell the life story

- To explore how to encourage and support system interaction via system instructions and input devices

We began with a case study to design the system for a mid-stage AD individual and her family. The participant lives in a long-term care facility. Other stakeholders include the family, friends, health care and mental health providers, and other AD individuals. Throughout the design process the family's input and contributions are very significant.

OUR ETHNOGRAPHIC APPROACH

When the end user's environment is accessible ethnography is an option. Ethnography involves immersion in the users environment and participation in relevant activities [3,9,17]. Unfortunately, immersion can be invasive and ethically questionable for the user population [10]. In our case study ethics, privacy and administrative issues created accessibility barriers to the AD individual. With a moderate amount of access to the AD population at the Baycrest Centre, we conducted ethnographically and ethically informed research. Instead of fully immersing ourselves in the participant's environment we observed individuals in selective activities. They were organized, weekly activities in common spaces with one-hour durations. We interacted with groups ranging from 5 to 35 mid- and late-stage AD individuals. Over a three month period we played bingo, made crafts, joined sing-alongs, and observed meal times. We did not observe individuals privately or visit in personal spaces.

These non-invasive activities gave us insight into the communication needs and abilities of the AD population, including the importance of simplicity, consistency, and minimizing over-stimulation. We used our observations to explore failure free interaction methods and undemanding design paradigms. With these understandings we can leverage the individual's abilities in the system design.

CONTEXTUAL EXPLORATION

In order to elicit the necessary information for a personalized life story system we needed to conduct design methods that would give us an intimate understanding of our participant. We employed principles from contextual inquiry [3] and observed relevant tasks in the participant's natural settings. We conducted a reminiscing session with the individual and the family members. We observed how personal photographs might stimulate the participant. Conducting tasks can be a challenge because they often rely on cognitive abilities. As well, if we highlight declining memories it might frustrate or upset the participant. To cope with this, we focused on exploratory tasks and were sensitive to the participant's abilities and feelings.

We visited with the AD individual in her room at the care facility and let her independently explore a stack of photographs. There were a variety of outcomes to viewing each photograph including positive and negative responses, or no response at all. Some photographs elicited more meaningful conversation than the relatives expected. We

were conscientious to the length of the activity, ending the session as soon as the participant showed signs of distress.

As a result of this contextual exploration we knew that the participant could be meaningfully stimulated by activities involving personal life stories. As well, the range of responses motivated us to design a system in which the participant can control the content that is presented.

INTERVIEWING SECONDARY STAKEHOLDERS

Unfortunately the severity of the disease prevented us from conducting meaningful interviews with the participant. As a work around, we interviewed secondary stakeholders including family members, friends, caregivers, social workers, and recreational therapists.

Researchers warn that interviews can involve assumptions and biases [8]. In our case, life story information came from a perspective other than the end user's. The eldest family stakeholder is twenty years younger than the participant so learning about the individual's early life was a challenge. Despite the drawbacks, interviews are useful in understanding previously unknown needs, disease factors, and life history.

THE PARTICIPATORY DESIGNERS

Participatory design entails active involvement with the end users in the design process, and the end user participation is often considered a prerequisite for good design [12]. However, stakeholders other than end users can provide very valuable input. When designing for persons with disabilities, another group can act as a proxy in the participatory design process [5].

One risk in conducting participatory design with end user surrogates is that there may not be sufficient representation of all of the user's needs and abilities. To foster creativity among the relatives, we created a participatory activity based on 'probes' [6]. Probes are packages of tools that help elicit imaginative and inspirational responses. Our probes included a workbook, forms, notes, and storyboards.
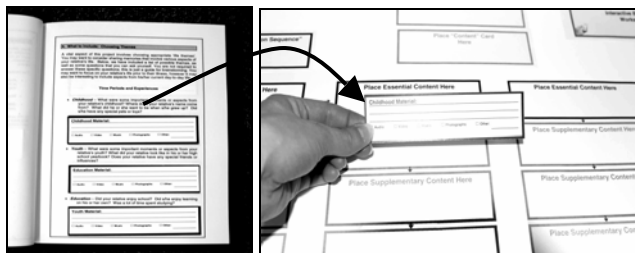

Figure 1. Participatory Workbook and Storyboard

The workbook inspired the family to contribute narratives and collect relevant media. The family completed forms in the workbook and placed the forms on a storyboard (figure 1). They marked up the storyboard with notes, and arranged and rearranged the forms. They made events cohesive by organizing and interconnecting them. The participatory design workplace is shown in figure 2. The completed

storyboard determined the content and interaction flow for the system.

Figure 2. Participatory Design Workplace

The participatory activity led to the elicitation of psychosocial needs. The family members expressed personal growth after discussing difficult memories and feelings. They wanted to make significant contributions and be recognized in this project.

INITIAL PROTOTYPING

We created several prototypes based on our design research. We implemented the multimedia in a DVD format for cost and accessability reasons. We created specialized input devices from remote controls (figure 3). In one prototype, we explore video instruction sequences and a simple single button input device. In another prototype, we explore the ubiquity and metaphor of a photo album as an input device. The participant controls the navigation of the media content by turning the album pages.
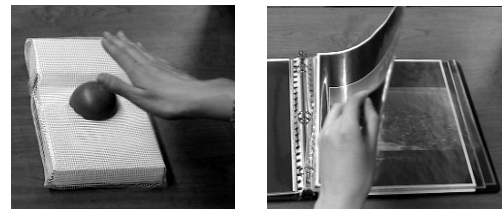

Figure 3. Input Devices

A challenge in presenting our prototype is to maintain the anonymity of our participant. Some demos included the life story of one of our researchers, instead of the participant. By shifting the context of the project we risked eliciting less useful feedback. However, we found that the reactions valuably informed the next iteration of our design, with new metaphors and input methods.

In our first stage of prototyping we tested a subset of the entire life story with several input devices. The participant was delighted and engaged by the multimedia. She interacted with the device after prompting from the family, and needed progressively less prompting throughout. Our next step is to present a broader range of prototypes to the participant and thoroughly study the participant's responses to the interactive multimedia.

CONCLUSION

In this paper we address some of the complex challenges involved in designing an intervention system for people with Alzheimer's disease. We adapted our design methods to account for various communication and interaction barriers. We made use of secondary stakeholders and we were sensitive to the cognitive and psychosocial needs of our participants. With these modifications we were able to meet our research goals. However, we were concerned whether the modifications hindered our ability to collect sufficient and unbiased information.

Although there are risks involved, we suggest that it is not the risks that impede design, but the failure to recognize such risks. For example, had we based our design solely on the results from our interviews, we may have downplayed the first twenty years of the life story of our participant. As a result of being aware of this issue, we made an extra effort to learn about those years and represent them in the life story. Another risk of great concern is the limited ability to make generalizations when designing for a dynamic and degenerating disease.

As the family became more involved in the project, it was more apparent that their needs should not be neglected. It is difficult to anticipate who will be affected most by the system, and who will be the principal end user. There is a significant impact on the family merely by participating in the design process. They share memories, gain perspectives, and create legacies that they themselves will own and use one day. In this project, user-centered design does not just entail focusing on an end user. It involves exploring throughout the entire design process how to provide support and opportunities for all individuals affected by a pervasive disease.

ACKNOWLEDGMENTS

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