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Memories of a Life: A Design Case Study for Alzheimer's Disease

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12.1 Introduction

Technology can be a powerful support tool, leveraging media in order to enhance the lives of individuals affected by disabilities. Unfortunately, the design of this technology can be a complex and challenging process. In this chapter we present research in which we are designing interactive multimedia life stories for families affected by Alzheimer's disease (AD). AD is a degenerative brain disease that causes the deterioration of cognitive abilities such as memory, language, communication, reasoning, and judgment (Alzheimer's Association, 2005). 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. Currently, there is no cure for the disease, however, there are ways in which the symptoms can be treated.

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 behavior (Kasl-Godley and Gatz, 2000; Woods, 2001; Alzheimer's Association, 2005). In addition, individuals with AD become increasingly 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 (Kasl-Godley and Gatz, 2000; Czaja and Rubert, 2002; Alzheimer's Association, 2005). Nearly half of individuals over the age of 85 show symptoms of AD (Alzheimer's Association, 2005). As a result, it is becoming increasingly important to provide social support for the many people who are affected by this pervasive and complex disease.

In order to help cope with these issues, health care communities offer intervention methods. 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 (Kasl-Godley and Gatz, 2000; Spector *et al.*, 2003) and can in some cases slow down the progress of the disease (Wilson *et al.*, 2002). Reminiscence 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 (Woods, 2001; Marziali, 2003).

Intervention technology refers to technology that provides support or other nonmedicinal treatment. Most intervention technology is designed to help individuals perform everyday activities, such as memory aids or planning tools (LoPresti *et al.*, 2004). To date, little attention has been given to the design of technological tools for social support. Elders with cognitive decline can benefit from social support tools, and recent ethnographic research provides insight into the design of such systems (Morris *et al.*, 2004). Several intervention technologies focus on supporting the caregiver, such as specialized telephone and video conferencing applications (Czaja and Rubert, 2002; Marziali, 2003). Few intervention technologies focus on psychosocial support for the patient.

In September 2004 we began a project to create digital personal life stories for families affected by AD. The project is based on a previous pilot study involving nondigital life stories. Researchers created and presented a VHS video life story to an AD individual (Marziali, 2004). The work from the VHS pilot study has inspired the project to create digital life stories, which began with the case study described in this chapter. The digital multimedia content includes digital video, images, photographs, and audio. Interactive components allow the individual to actively participate with the multimedia. We are conducting this research at Baycrest in Toronto, Canada with a multidisciplinary team of social workers, interaction designers, health care providers, and participating families.

Our goal is to understand how interactive reminiscent media can play a role in intervention for families affected by AD. Our hypothesis is that the intervention technology will provide stimulation while reinforcing the individual's positive self-identity. In the first year of our research we (i) investigated and documented the process of creating interactive multimedia life stories, (ii) investigated potential effects that the intervention may have, and (iii) explored how to encourage and support system interaction via system instructions, navigation, and input methods.

In this project we have experienced many challenges for the user-centered design of our system. A significant challenge is our unique user group, and the ability to communicate and interact with them. Short-term memory loss is one of the most significant symptoms of AD. However, other symptoms can also hinder communication and interaction with the individual. For example, a mid-stage individual may have difficulty following instructions, making decisions, or recalling words.

A second 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 concerns. Issues such as cognitive decline in the user population and limited access to participants have great impacts on the entire design processes for our system.

A third challenge is to meet the needs of our broad range of stakeholders. The term 'stakeholder' refers to anyone who is affected by the system. In our case this includes relatives, friends, and health care providers. We need to meet each group's differing needs, abilities, and roles in this project. Not only is it a challenge to meet the needs of all of our stakeholders, it is also a challenge keeping stakeholders involved in the process.

Given these challenges, how can we elicit the necessary information and requirements to tell the story of someone's life in a stimulating and interactive way? In this chapter we begin to answer these questions based on our experiences from an exploratory case study. We begin with a brief discussion on related background research. While assistive technology for cognition is promising, much more development is required, particularly for assistive technology for psychosocial support.

We discuss our needs and requirements analysis process and how we had to modify several common design methodologies to address the challenges. We iteratively designed, prototyped, and tested the multimedia life story system with one participant with AD as well as secondary stakeholders. We describe our preliminary findings, and suggest that interactive participation has the potential to be stimulating, empowering, and trigger reminiscence in a different manner than noninteractive participation in intervention reminiscence activities. We also discuss our lessons learned from the project. Since this exploratory case study does not consider the long-term effects on a large sample size, we do not intend to broadly generalize our results. However, we do intend to inspire further research in related areas. For a more detailed description of the work described in this chapter, see Cohene (2005).

12.2 **Background**

Memory loss is often associated with aging or age-related conditions such as dementia or AD. The Alzheimer's Association defines AD as an irreversible progressive disorder that causes the gradual loss of brain cells (2005). AD is the most common form of dementia, a term used to describe various diseases or conditions involving the progressive deterioration of brain tissue and the related cognitive faculties (Zec, 1993). Dementia can occur in conditions aside from AD including senility, cerebrovascular disease, Huntington's disease, Parkinson's disease, and Pick's disease (Burns and Zaudig, 2002).

Alzheimer's is known for its high frequency in the aging population. According to reports conducted by the Alzheimer's Association (2005), one in ten people over the age of 65, and nearly half of those over the age of 85 show symptoms of AD in North America. Due to the aging population, the diagnosis rate is expected to triple by 2050 (Alzheimer's Association, 2005). The worldwide incidence is projected to grow from a current level of 18 million to 34 million by 2025. The worldwide incidence of dementia may grow to 42 million by 2020 (Ferri *et al.*, 2005).

Although AD often has strong associations with memory loss, it is important to recognize all of the symptoms of cognitive degeneration. Common symptoms indicated by Alzheimer's Association (2005) include a gradual loss of memory, problems with reasoning or judgment, disorientation, difficulty in learning, loss of language skills, and a decline in the ability to perform routine tasks. The memory loss is more severe for short-term memory and prospective memory. The AD symptoms express themselves more severely as the disease progresses through early, mid, and late stages. Table 12.1 gives examples of how these symptoms might be expressed. More

***Table 12.1** Symptoms of Alzheimer's disease (adapted from the Alzheimer's Association, 2005)*

Symptom	For example, a person may:
Memory loss	Repeat stories or questions Have trouble recalling familiar people, things, or recent activities Frequently misplace objects
Problems with reasoning or judgment	Have difficulty performing or prioritizing common tasks Be unable to follow directions Rely on others to make decisions or answer questions
Disorientation	Get disoriented about time, people, and places Become lost in familiar places, wandering frequently
Difficulty in learning	Be unable to think clearly
Loss of language skills	Have difficulty in speaking, reading, or writing
Decline in ability to perform routine tasks	Forget how to cook, perform routine chores, or play cards Have difficulty brushing teeth, combing hair, or making a bed
Changes in behavior	Experience high levels of grief, fear, confusion, or mood swings

information on AD and each of the stages of the disease is available from the Alzheimer's Association (2005).

When an individual begins to experience cognitive loss there may be various behavioral consequences. They may experience changes in personality, a lesser sense of self, or a loss of independence (Kasl-Godley and Gatz, 2000). This can lead to symptoms such as high levels of depression, grief, fear, and frustration, all of which have a significant impact on the well-being of the individual.

In order to deal with both the cognitive and behavioral symptoms, health care professionals may provide various medicinal treatments. Nondrug intervention approaches such as support and training can also help decrease the symptoms of AD and dementia. Health care providers offer various coping strategies and tips (The Alzheimer Journey, 1998; Alzheimer's Association, 2005). For example, experts suggest maintaining meaningful activities that focus on the individual's remaining abilities and help the person feel active and empowered.

The term 'intervention' refers to the specific application of techniques intended to change knowledge, attitudes, beliefs, or behaviors (Eprevco, 2005). Psychosocial interventions refer to therapy and techniques designed to enhance an individual's well-being. Each intervention method may have specific goals, such as to activate memories, strengthen intact abilities, alleviate distress, facilitate coping, or enhance behaviors. Examples of intervention methods include memory training, support groups, reminiscence and life review, psychodynamic approaches, reality orientation, and cognitive and behavioral therapy.

Reminiscence and life review therapy aims to improve an individual's well-being by bringing past experiences and unresolved conflicts into awareness (Woods *et al.*, 1992). Examples include telling stories, using photographs and memorabilia as prompts, creating autobiographies, creating scrapbooks, or going on pilgrimages and reunions. Despite the many potential benefits of conducting life story work, formal studies to date have not shown empirically significant results in terms of specific benefits (Spector *et al.*, 1999). Despite this, they do show slight interpersonal and intrapersonal benefits (Baines *et al.*, 1987; Kasl-Godley and Gatz, 2000). The reported interpersonal benefits include enhanced caregiver–patient relationship, socializing with others, and leaving a legacy (Baines *et al.*, 1987; Woods, 1994). These benefits are especially useful for individuals with moderate stage AD. Reported intrapersonal enhancements include self-awareness, personal stability, and life meaning. These benefits are more common among individuals with mild impairment (Kasl-Godley and Gatz, 2000).

It is particularly important for AD individuals to be able to support and maintain their personal identity. Reminiscent activities provide a means for defining and supporting one's personhood, which may help deter negative behavioral symptoms (Tobin, 1999). Life stories have many interesting factors that contribute to the individual's identity. Although the participant may not recall all of the life stories, some may evoke recognition or reminiscence. The experience may elicit different responses such as joy or discomfort. They may offer new perspectives, or help make lives seem more coherent or continuous. Some of the content may prompt rare thoughts or additional support in comparison to everyday activities. The stories can also affect others by providing a legacy, a vehicle for communication, or a shared experience. They may also involve difficulties, such as unpleasant memories or feelings.

In 2003, Dr Elsa Marziali, Schipper Chair in Gerontological Social Work at Baycrest, began research on the effects of personalized video life histories on individuals with AD and their caregivers and families (Marziali, 2004). The hypothesis is that the video intervention may provide stimulation, provide distraction from negative stimuli, reinforce the individual's positive self-identity, and diminish problematic behaviors. In addition, potential outcomes for the caregiver include relief from stress, frustration, and reduction in caregiver burden.

The researchers conducted a pilot study, creating the life story video intervention for one mid-stage AD participant. We call this the VHS pilot study. Caregivers and family members collaborated on the filming, editing, and viewing of their relative's life story. The VHS video included interviews, photographs, as well as other prompts and cues such as visual and auditory stimuli to represent retrospective memories. The story progressed through the participant's life, including milestones, relationships, and personal interests. Unfortunately, the researchers were unable to measure any significant positive results from the VHS pilot study. Yet they saw the need for more research to learn how to maximize the positive outcomes for both the patient and family.

Assistive Technology for Cognition, or ATC (LoPresti *et al.*, 2004), refers to technological interventions that assist people with cognitive and neuropsychological disabilities. In most ATC projects, the assistance is geared toward the rehabilitation of performing everyday activities. One of the major benefits claimed for ATC is that of increasing the individual's independence, since they are less likely to rely on others to recall things or perform tasks. ATC are also known as 'cognitive prosthetics' or 'cognitive orthoses' (LoPresti *et al.*, 2004). For a review on ATC designed for individuals with various cognitive impairments, such as memory aids or planning devices, see LoPresti *et al.* (2004).

ATC can be designed for individuals who are affected by dementia, but not afflicted with it. AD impacts both the people with the disease and the people who interact with them. Almost 90% of people with AD receive home care by a family member

(Alzheimer's Association, 2005). Studies show that caregivers often neglect their own health and well-being as a result of the stress of caregiving (Czaja and Rubert, 2002). Many older individuals are socially isolated due to a shrinking network of family and friends (Morris *et al.*, 2003). Many caregivers also cannot leave their ill spouses unattended (Marziali, 2003). Studies confirm that caregivers feel isolated and experience high levels of depression and anxiety (Haley *et al.*, 1995). Support networks are invaluable for providing communication, compassion, advice, and consolation.

Examples of ATC support networks include the Telephone-Linked Care system and the Caring for Others project. The Telephone-Linked Care (TLC) system links a telephone to an Alzheimer's communication and information network. The TLC system facilitates access for caregivers to resources and information (REACH, 2003) through dedicated voicemail services, teleconferencing family therapy sessions, and teleconferencing discussion groups. Caring for Others (CFO) is a web-based support tool for seniors who care for their spouses with dementia (Marziali *et al.*, 2005, in press; Marziali and Donahue, in press). The CFO site is a portal for access to information, training, and videoconference support groups. Both the TLC and CFO systems offer a wide range of benefits (Czaja and Rubert, 2002; Marziali *et al.*, 2005) including enhancing communication, managing the stress and burden of caregiving, and reducing the amount of resources in comparison to face-to-face intervention.

At this time, there does not exist substantial development in psychosocial ATC designed for the AD individual as the end user. One exception is CIRCA (Computer Interactive Reminiscence and Conversation Aid), which explores the effects of interactive multimedia on AD individuals (Gowans *et al.*, 2004). A goal of CIRCA is to stimulate conversation in reminiscent therapy sessions. The project uses a database of audio, video, animation, and QuickTime VR media content with a touchscreen interface. The media is not personalized for each participant and can therefore be presented to all participants. For an image of the CIRCA system see Figure 10.2 (p. 306). The media are displayed on a touchscreen with menu items including alternative themes, media choices, and navigation. Their studies show that the system provides a mechanism for eliciting more natural, less repetitive, and sometimes entirely new responses from the participants in reminiscent therapy sessions (Gowans *et al.*, 2004). A particularly significant finding from this work is that many participants were able to interact and operate the system themselves, even though it was initially designed to be used with the aid of a therapist.

The researchers decided not to use personalized content from individual participants because it involves several risks (Gowans *et al.*, 2004). In the health care environment, researchers must maintain participant privacy and restrict public access to personal data. There is also a risk of upsetting participants by emphasizing their forgotten memories and their cognitive deficit. In CIRCA, the researchers are able to support communication without the use of personal data. Although it is risky and requires more customization for each participant, using personalized information (such as in the case of Marziali's VHS life story work) may have powerful benefits including being more stimulating and meaningful for both the participant and the relatives.

12.3 How this Project Helps the Targeted User Population

In this project we wish to support an individual's personhood through a technological intervention. We are creating personalized multimedia systems. We believe that an intervention method that reinforces a self-identity can have positive effects for both the individual and the family caregiver. For example, the activity may bring a sense of well-being or even joy to the entire family. It may have calming effects, or may reduce disruptive behavior for the individual suffering from AD.

Inspired by the VHS pilot study, we were interested in learning how we could maximize the positive outcomes for both the patient and family. We saw the potential for using technology and interactive multimedia in this research and decided to create digital life stories. In order to obtain the information necessary for the successful conduct of a large-scale research project, we began the digital multimedia research with an exploratory case study. This case study is the focus of this chapter.

Similar to the VHS pilot study, one of our research objectives is to investigate if and how recollecting and reinforcing memories of the individual and family history could have beneficial effects for both the participant and her family. In comparison to the VHS pilot study, we were also interested in exploring how to encourage and support system interaction via system instructions, navigation, and input methods.

With technology and multimedia, the life story activity can become interactive. It can be an active event involving participation and varied presentation formats. In comparison, VHS videos are restricted to a linear nondynamic presentation format. Digital video can be presented nonlinearly, opening up new possibilities for storytelling and sharing experiences. For example, the person viewing the biography can be given the option to select the particular stories that he or she would like view at that time. This interaction may help promote a positive and stimulating experience, potentially more stimulating than viewing noninteractive linear life stories. Contributing to the reminiscent activity may even promote empowerment through feelings of control and value. The media can stimulate many senses including sight, sound and even touch with opportunities to physically participate. This multi-modal sensory stimulation may also add to the effects of viewing the life stories. In addition, the participant's responses to the opportunities to interact will offer an additional variable to observe and measure.

The first participating family consists of a 91-year-old female participant, Laura, with mid-stage AD, living in a long-term care facility. To maintain the participants' anonymity all names have been changed. Laura moved from South Africa to Canada at the age of 86 to be with her two daughters and was diagnosed with AD one year later. The two daughters are both very much active in this project. Cathy and Margaret are in their mid-sixties, work full time, and have families and grandchildren of their own.

12.4 **How this Project was Developed**

To pursue the exploratory case study, we began with a user needs and requirements analysis process. We obtained initial insights by conducting extensive research on the disease, memory and cognitive loss, intervention methods, digital storytelling, and previous ATC research. We then employed common user-centered design methodologies including ethnography, interviews, contextual exploration, participatory design, and iterative prototyping. However, because of limitations in our ability to communicate with an AD individual we had to make adaptations to these methods. We introduce our atypical use of research methods in Cohene *et al.* (2005), and provide additional information in this chapter.

When the end user's environment is accessible, ethnography can be an excellent means of learning about the stakeholders and their needs. Ethnography involves immersion in the users environment and participation in relevant activities (Suchman, 1987; Hughes *et al.*, 1993; Beyer and Holtzblatt, 1998). We had a limited amount of accessibility to AD individuals at Baycrest due to participant health conditions, ethics, privacy, and administrative issues. Given that we had a moderate amount of access, we conducted research that was inspired by ethnography but limited by these conditions. We call this moderated ethnographic research. We interacted with groups of individuals in moderated recreational therapy activities. The groups ranged from 5 to 35 mid- and late-stage AD individuals, and were moderated by health care staff and several volunteers. Over a 3-month period we played games, made crafts, joined sing-alongs, and observed meal times. In comparison to traditional ethnographic research, we did not observe individuals privately or visit participants in their personal spaces.

These noninvasive activities gave us insight into the communication needs and abilities of the AD population. Instead of merely focusing on the disabilities due to cognitive decline, we also made many observations related to the intact abilities.

Many individuals are able to react to instructions and respond to activities, such as a game of bingo. However, the abilities range among individuals and even among day-to-day interactions. There is also a wide range and complexity within the individual's own abilities. For example, even though the person may mark squares on the bingo card, they may not become aware they have won a game.

Observations such as these have stressed the importance of simplicity, consistency, and minimizing over-stimulation. These principles can be applied to the multimedia life story content as well as the interactive design. With these understandings we can leverage the individual's abilities in the system design.

Unfortunately, the severity of the disease prevented us from conducting meaningful interviews with the participant. In order to elicit as much information as possible we interviewed and consulted with many secondary stakeholders. We consulted experts from the Baycrest health care staff including social workers and recreational therapists. We also conducted interviews with members of a spousal caregiver support group. We then spoke with experts outside of the Baycrest community including representatives of the Toronto Alzheimer's Society, colleagues researching other ATC projects, ethnographers, and life story authors. These interviews contributed a general understanding of the AD individual's capabilities and potential limitations in their ability to interact with the communication provided by the life story presentation. It also helped determine general life story content, themes, and media that could be included to create a stimulating experience, listed in Table 12.2.

Personal content and specific needs were determined in the following stage, in collaboration with the participating family. We conducted interviews with Laura's relatives, particularly with her daughters, Cathy and Margaret, in order to collect the necessary information to tell the life stories. We presented a workbook to introduce

Table 12.2 *Life categories and life themes*

Time periods and experiences	Personhood	Interests and accomplishments	Social factors
Childhood Youth	Personality Values, Religion, Spirituality	Achievements, Strengths Culture, Languages	Family Friends
Education Profession Middle age Life today	Rituals Health history Losses, Tragedy	Hobbies Leisure activities	Social history Celebrations Community

the family to the research project called the Family Workbook. The Family Workbook aimed to foster a discussion on the project goals and the potential benefits of reminiscing through life stories.

We used this opportunity to elicit the most important goals from the family, including personal project outcomes that were the most meaningful to them. One of the goals in collecting the information necessary to tell a life story is to collect information other than lifetime events or milestones. In addition to important events such as graduations and births, we wanted to convey characteristics, habits, and values in the life story content. We call all of this information a life theme. In order to help the family elicit appropriate life themes, we asked questions to prompt the elicitation of stories regarding each life category and theme in Table 12.2. For example, the 'Time Periods' section in the Family Workbook began with several questions aimed at prompting life stories for the participant's childhood.

The Family Workbook essentially acted as an open-ended questionnaire with 21 life theme prompts, as well as details on user goals, media content preferences, and other requirements. As a result of this questionnaire, the relatives filled out 15 life theme sections and we gathered an immense amount of data about lifetime milestones, day-to-day life, and the participant's personality. For example, Cathy and Margaret told stories about entertaining guests in their home, recalling the scent of their mother's perfume, and being tucked into bed at night. These stories may help trigger emotions related to memories of frequently experienced moments.

The Family Workbook played a major role in the elicitation process for the life story system design. Based on the interviews and consultations with the secondary stakeholders, none of the relatives or health care providers expressed confidence that a mid-stage AD individual would be able to physically interact with the life story system. This is despite their universal support for the project. In the next stage we met with the participant at the long-term care facility in order to learn how we could support and promote system interaction.

In order to elicit the necessary information for a personalized life story system we needed to carry out design methods that would give us an intimate understanding of our participant. We employed principles from contextual inquiry (Beyer and Holtzblatt, 1998) and observed relevant tasks in the participant's natural settings. 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 failure-free exploratory tasks and we were sensitive to the participant's abilities and feelings. We call this contextual exploration.

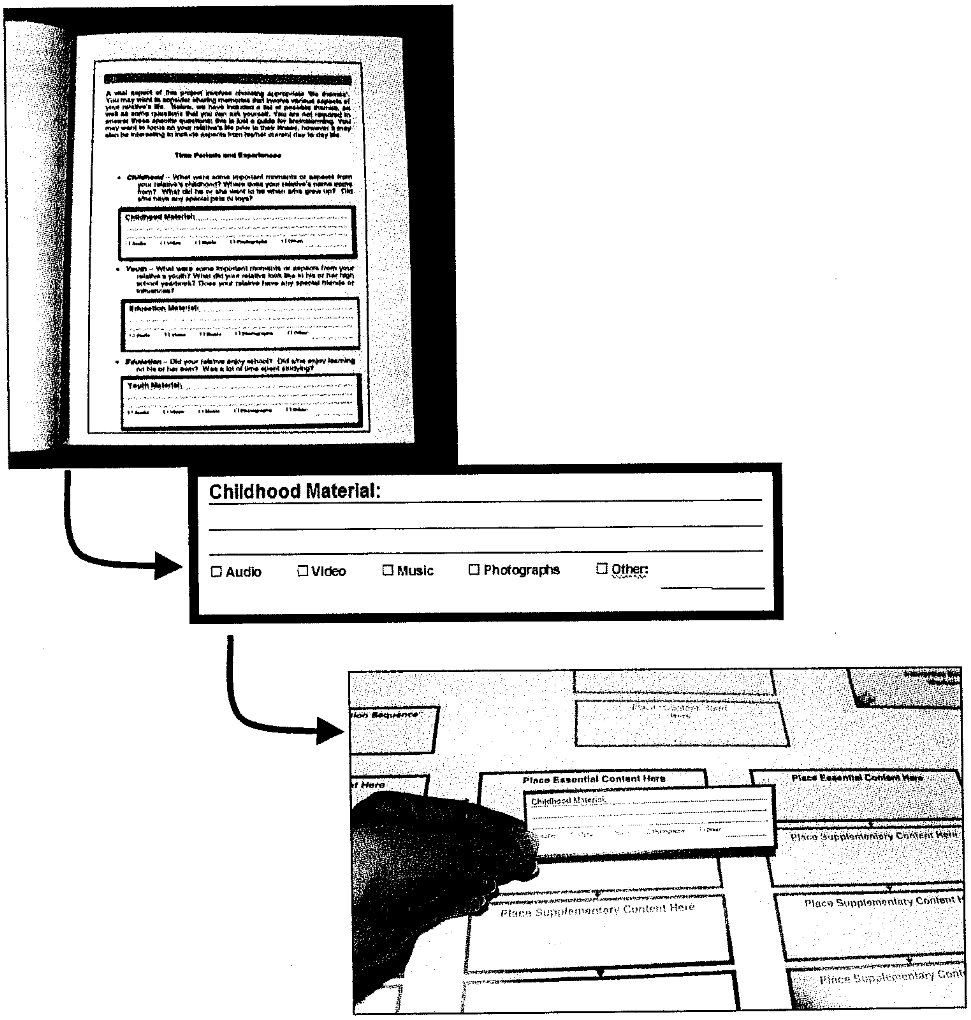
We visited Laura in her room at the care facility and conducted a reminiscing session with her relatives in order to learn how personal photographs might stimulate her.

First, Laura independently explored a stack of photographs. There were a variety of outcomes to viewing each photograph including positive and negative responses, or no response at all. For example, Laura enjoyed looking at photographs of some people but not others, regardless of their relation to her. Some photographs elicited more meaningful conversation than the relatives expected. They were quite surprised that she recalled names of several old friends and enjoyed reminiscing about her home town. When we presented two photographs to Laura, and asked her which she preferred, she responded with a smile, and did not answer the question. As mentioned, it is common for mid-stage AD individuals to have difficulty making decisions.

We also considered some other activities aside from browsing photographs. The relatives were surprised to find that Laura could still physically demonstrate how to stand in a position from her sporting career. She could also play certain card games, a favorite and common activity throughout her life. We demonstrated to Laura how to turn off the television, however, after some time she could not recall how to turn it off on her own. Throughout these activities we also noticed some communication difficulties. For example, Laura sometimes used incorrect words to describe items. Throughout the contextual exploration the social workers were conscientious to the length of the activity, and we ended sessions if the participant showed any signs of possible distress such as discomfort, confusion, or irritation.

As a result of this contextual exploration we uncovered many requirements specific to our participant. Although she was unable to follow instructions from a short time prior, she maintained a significant amount of procedural memory for activities that occurred often throughout her life. We also learned that the participant could be meaningfully stimulated by activities involving personal life stories. Since we observed a range of responses from the participant, we learned how we could design the system to maximize the amount of positively stimulating content, while minimizing the amount of negatively stimulating content. At the same time, we suspected that the participant might respond differently from one day to another. This motivated us to design a system in which the participant would be able to control the content that is presented in the life story multimedia.

In participatory design there is active involvement with the end users in the design process, and the end user participation is often considered a prerequisite for good design (Kensing and Blomberg, 1998). However, stakeholders other than end users can also provide very valuable input. When designing for a user group that includes persons with disabilities, another group can act as a proxy in the participatory design process (Fischer and Sullivan, 2002). To foster creativity among the relatives, we created a participatory activity based on 'probes' (Gaver *et al.*, 1999). Probes are packages of tools that help elicit imaginative and inspirational responses. Our probes



Childhood Material:

☐ Audio ☐ Video ☐ Music ☐ Photographs ☐ Other:

Figure 12.1 Participatory workbook and storyboard.

included a workbook (previously discussed), life theme cards, a storyboard, script forms, sticky notes, and clear plastic bags.

As mentioned, the Family Workbook introduced the family to the research project. The sections that could be filled out were actually removable cards. A sample card is shown in Figure 12.1. The cards were lined with adhesive reusable glue, similar to the glue on 'Post-It' notes.

Once the relatives completed the card forms in the workbook, they were able to place all of the cards on a storyboard. The storyboard included rectangular blocks stating 'Place [content] here,' where 'content' referred to specific card forms from the workbook, including project goals, multimedia content preferences (such as music, photographs, or videos), and life story content. The cards were arranged in a flow chart to represent the relationships between different life stories. Since the multimedia life story system is interactive, the content does not need to be presented to the viewer in a linear manner. Depending on the response from the viewer, the life story sequence can change. Therefore, it was essential that we understand the relationships between each story and establish navigation sequences for the life story content.

The red line in Figure 12.2 traces a path along the introduction content, essential life story content, and the conclusion content. We asked the relatives to determine the

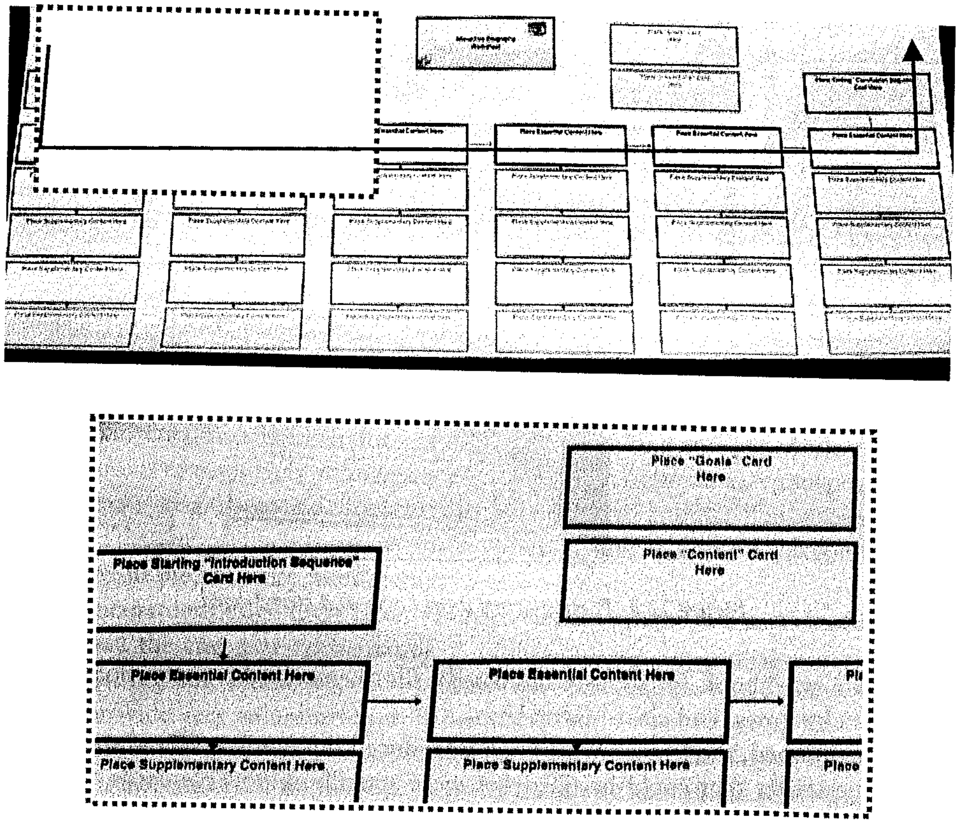


Figure 12.2 The storyboard navigation and enlarged view.

most important life stories theme cards and place them in the essential spots, in an order that was meaningful to them. We limited the number of spaces to six cards, forcing the relatives to prioritize the stories. We also asked them to place less essential stories (that we called supplementary content) below one of the six essential life stories.

Together with the relatives, we arranged and rearranged the cards, and marked up the storyboard with notes. We continued organizing and interconnecting the cards until they represented cohesive stories. A section of the completed storyboard is shown in Figure 12.3.

Corresponding to each life theme card, the family filled out a form to write down an interview script. The script form included space for describing the story, listing the related media (e.g. specific photographs), and describing information on the media (e.g. names of people in photographs). We then placed the scripts with their related photographs and memorabilia in clear plastic bags. We used these bags as kits for

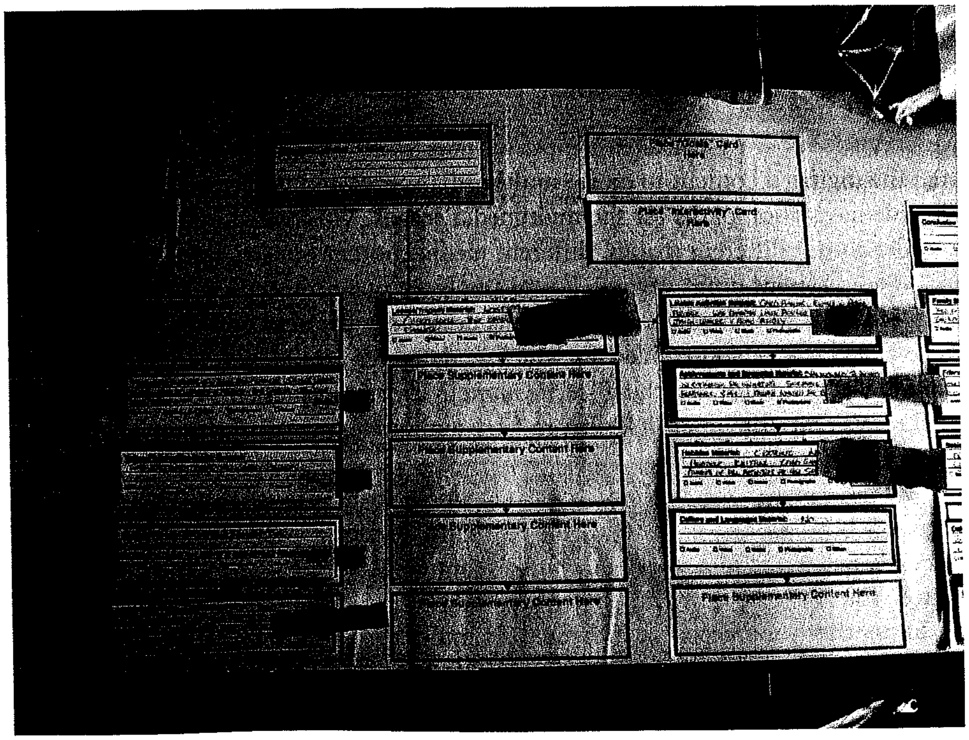


Figure 12.3 The completed participatory design storyboard.

creating each scene of the life stories. We interviewed the relatives on camera, photographed memorabilia, scanned family photos, digitized home videos, and collected music.

We developed a conceptual model based on the results of the requirements and needs analysis. To test the conceptual model we developed some prototypes using rapid prototyping methods such as paper prototypes and HTML. We then iteratively modified our design concept with further prototypes that we presented to secondary stakeholders. At this stage we addressed challenges in our design process such as maintaining the anonymity of our participant while trying to elicit feedback from colleagues, health care providers, and other stakeholders. In order to ensure this, several 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 design metaphors and input methods (such as photo albums and television channels).

In the next iteration, we developed prototypes on the platform of the deliverable system. We decided to make the multimedia in a DVD format because DVD players are less expensive than PCs, DVDs can be easily shared and distributed, and our designers could easily customize the DVD navigation sequences to fit the life stories. We created our own specialized input devices from standard remote controls. We used the digitized content to create multimedia scenes and implemented a number of possible navigation paths for the multimedia scenes. We created multiple prototypes in order to test different stories, different media content (music, video, photographs, etc.), and different input devices. For example, in one prototype we interspersed life story scenes with video-based instructions describing the next options. Between each scene there was a short video in which a daughter would say, 'Hi mom, it's me [*name*], did you enjoy watching [*scene name*]? If you did press the button, otherwise we'll move on to other stories.' Figure 12.4 outlines a portion of the navigation path for this particular prototype.

We rewired the DVD remote control and replaced the small buttons with one large soft button (Figure 12.5a). If the participant pressed the button, the DVD automatically navigated to a story with similar content. If the participant did not press the button, the DVD automatically navigated to a story with different content.

In another prototype, we presented an interactive photo album. Each page contained one photograph corresponding to a life story scene. As the participant turned the pages of the album the corresponding life story appeared on the television monitor (Figure 12.5b). In this prototype we hoped to explore the metaphor of a photo album and the implicit control of the multimedia.

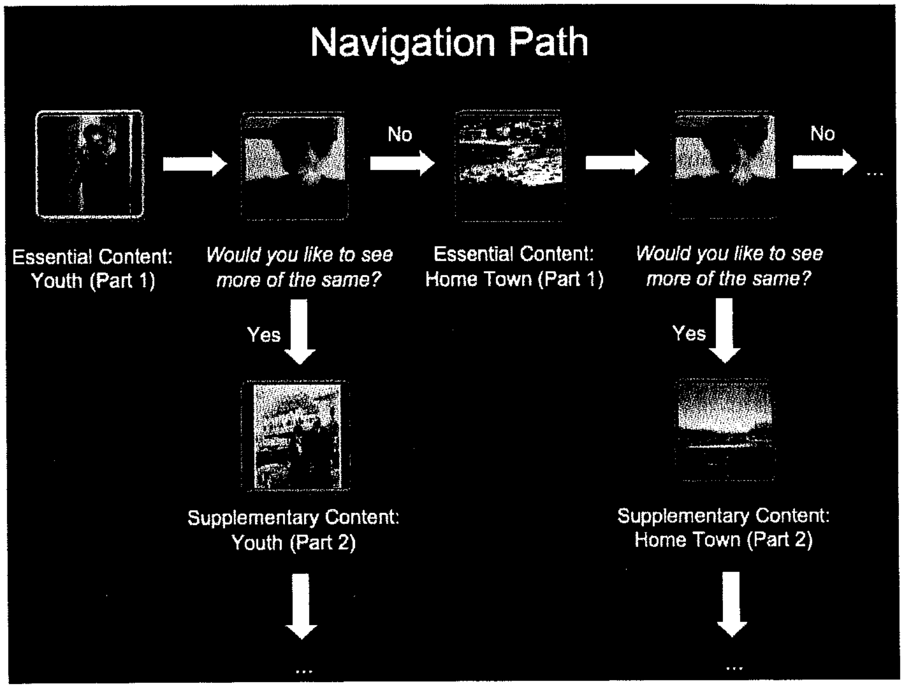


Figure 12.4 *Navigation path for one of the prototypes.*

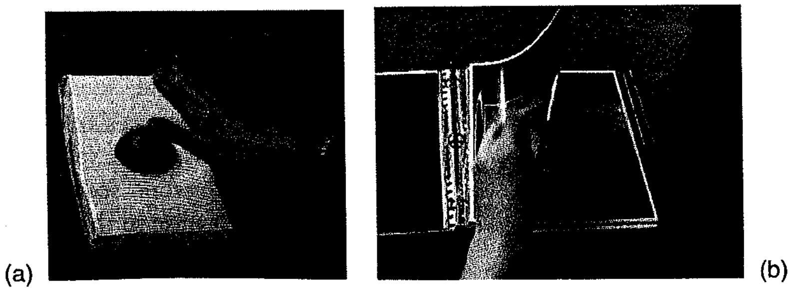


Figure 12.5 *(a, b) Two input devices.*

12.5 How this Project was Evaluated for Usability and Appropriateness

As discussed, this exploratory case study was conducted with one participant in order to uncover and inspire further research in this area. We evaluated the usability and desirability of the interactive life story multimedia specifically for our participant and her family. Although we cannot generalize our results to the entire Alzheimer's community, we believe that the results provide groundwork for future research.

We hoped to learn how Laura was stimulated by the multimedia and how to optimize the stimulation for her. We had many questions for this case study. Would Laura interact with the life stories (for example, by pressing the button or turning the pages)? Would she make verbal comments about the stories? Would the comments be relevant and meaningful? And how would the family respond?

We presented the life story multimedia to the participant and her relatives and conducted post-study interviews with relatives. We tested and iterated the prototypes with our participant in eight trials over the course of 4 weeks and filmed her reactions. Laura watched the presentations under various conditions such as on different days and with different guests in her room. We found that she responded more positively and enthusiastically to particular life stories, media content, and input methods. For example, we found that the interactive photo album was too cognitively demanding because it involved diverting attention from the photo album to the television monitor. Laura was only able to concentrate on one form of media at a time, losing the benefit of the other. As a result, Laura was less responsive to this prototype so we did not continue testing and iterating on it. Based on Laura's reactions throughout the trials we made several other minor (but significant) enhancements to the multimedia and the remote control.

Overall, Laura was delighted and engaged by the multimedia. In response to some scenes Laura made comments such as 'Lovely!' 'Look at this!' and 'Not bad, eh?' However, in response to other scenes she consistently made few or no comments. We determined that the reason for this difference was not just the content but also the format and quality of the content. Our intention was to provide meaningful, clear, and comprehensible information. However, after observing Laura's responses to the life stories we were able to isolate several problematic areas. Some footage was too vague while other scenes were too busy. We realized that certain scenes might have been too linguistically complex or over-stimulating. In response to this we edited the content by slowing down the speed of the footage, adding short pauses between sentences and scenes, and deleting nonessential material. We also created more scenes focusing on music and visuals as opposed to conversations. We interspersed the videos with meaningful, clear, and colorful photos to add to the visual stimulation. We also focused on salient aspects of photographs using various editing techniques. After making these changes we presented the stories and found that Laura made more meaningful verbal responses to the content. In addition to comments such as 'Lovely' and 'Look at this!' Laura made more comments regarding specific people, items, or memories. She said things like 'That's in [home town],' 'That was a good day,' and 'You ever hear from them?'

Despite being engaged by the life stories, Laura did not initially respond to the video instruction sequences by pressing the single button remote control. After viewing several instruction sequences, and receiving additional prompting from her family, Laura pressed the button. At one point she stated, 'Don't forget, got to press the button.' We noted the points in time when the family would provide additional support and edited the videos to include additional prompts and cues for pressing the button. For example, after showing the scene of the relative giving instructions, we presented an image of the remote control and caused a 'beep' to emit from the remote in Laura's hand. We also redesigned the remote control to be more ergonomic (Figure 12.6). We made it smaller so that it could fit better in her hands and covered it in softer fabric. In the next iterations of testing we found that Laura held onto the remote with more enthusiasm and pressed the button with less prompting from others.

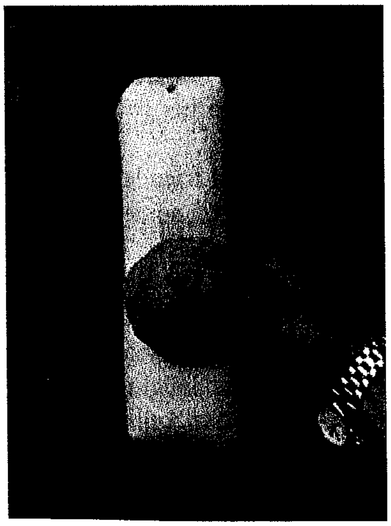


***Figure 12.6** Redesigned remote control.*

She pressed the button at nearly every opportunity, and in once case she did not press the button and mentioned that she would prefer to lie down.

As we iterated through the multimedia designs we found that Laura responded more often and more meaningfully to the life stories. Although there are many variables to consider, we were inspired by Laura's increasingly positive reactions and hope that these are indicative of improvements in the design. As a baseline, we presented the same life stories in a linear noninteractive version of the life stories (such as viewing linear VHS films) in order to gauge and compare her responses to a passive, noninteractive activity. Interestingly, Laura's responses to these presentations did not result in as many verbal responses nor as many meaningful responses.

We also saw how the entire process impacted the relatives. The relatives seemed initially frustrated by watching their relative reminisce. At times, they seemed disappointed when Laura could not recall specific memories. However, in retrospect they reacted positively to this collaborative activity. They were interested in seeing Laura reminisce, communicate, and react to the activities. After the first reminiscing activity, a daughter wrote in a letter:

> . . . I hadn't realized how much pleasure seeing these photos would give her . . . [Yet] she didn't know my name and that we were her daughters . . . I saw that different things can trigger her memory, and obviously [her] career lit a spark. So hopefully seeing some video of earlier times will light something up for her, and she'll enjoy those memories. What a thrill that would be.

In the 3-month follow-up interviews with Cathy and Margaret, we asked the daughters whether they observed any changes in Laura's behavior outside of the viewing sessions. One daughter mentioned that Laura was more likely to use people's names and less likely to ask to return to her room, on the days that she viewed the life story.

We also learned how the family and friends are affected by participating in this project. In our project, we hypothesized some potential benefits for the relatives including leaving a legacy, gaining perspective, enhancing generational bonds, sharing experiences, and communicating. In the follow-up interview, the daughters voluntarily discussed every one of these aspects. Both daughters asked for additional copies of the life stories, to distribute to each of their own children.

In a 6-month follow-up interview the daughters mentioned that their mother continues to watch the life stories between 2 to 5 times per week. Laura watches the noninteractive version because it's significantly longer and does not require as much supervision. They find that their mother is able to stay focused on the life stories, whereas in other activities she often appears distracted. Based on her reactions, they feel that she enjoys the stories and finds them fulfilling:

But maybe this is something that just – when she saw it – unlocked it for her, or if it was just luck that day that the words came back to her I don't know. But I think bringing the family all the time up to her in front of her the whole time – it keeps her happy. And that to me is the greatest benefit of it all. Is that she's happy.

The stories also provide a legacy of memories:

And even now to see the pleasure that she gets from the video and to see her enjoyment. I mean for us this is going to be something that we're going to treasure . . . and we've given copies to all the grandchildren and hopefully that they're going to treasure.

And they have helped shed new perspectives on coping:

Before [the project] I think I just got all upset when she said garbled things and I couldn't work out what she's saying. And maybe now I've become more tuned in.

I've also learned now how to cope with it . . . I'm learning to cope in different ways . . . So I think this whole project and everything has been a wonderful experience for us to – but also to help the family really.

The relatives gained perspective and expressed personal growth regarding managing their own feelings and responding to their mothers disease. One daughter even expressed how the stories helped her see positive qualities that she acquired from her mother. In addition, both greatly appreciated the opportunity to share experiences and communicate. In the large-scale study we will further explore the persistent effects of this project, such as more attentive and calm behavior throughout the day.

12.6 Lessons Learned and Guidelines

We analyzed the results of the study in order to suggest design guidelines and enhancements for the main study.

12.6.1 An AD Population Requires New Design Methodologies

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. In addition, ethics and administrative issues can prevent practitioners from conducting design methods as they are intended. We adapted traditional methods in order to conduct our research so we could gain insight about our stakeholders. We made use of many secondary stakeholders during the interviewing and participatory design activities. During the ethnographic and contextual inquiry activities, we were sensitive to the cognitive and psychosocial needs of our participants. Despite challenges in being able to communicate and interact with our AD participant, we were able to elicit needs and requirements by making adaptations to our design methods.

12.6.2 An AD Population Requires New Design Principles

One of our goals has been to learn more about the needs of the user population when designing psychosocial ATC. Based on our case study results, we have begun to uncover some additional design principles for Laura that may also be useful for other cognitively impaired users. Examples include:

- Appealing to a range of cognitive processes and modalities.
- Supporting tasks at lower levels.

In our testing we saw how different multimedia content can evoke different reactions from our participant. Many guidelines from AD research suggest the importance of communicating clearly. However, it can be very difficult to anticipate the communication needs of each individual. Through iterative testing and design with Laura we were able to isolate specific factors in the multimedia design that would support clear communication. In particular, by appealing to different cognitive processes and modalities we were able to support a more stimulating experience.

We learned that the multimedia should include as much meaningful content as possible and appeal to a range of cognitive processes such as communication, recognition, imagery, and music. Drawing upon a larger range of cognitive process will ideally enhance the ability to stimulate the participant. The content should appeal to a range of senses, including physical touch, such as something soft to hold on to. The factors that require cognitive functioning should be seamless and minimize distractions.

Prompts are very important and can be used to support tasks. A task, such as pressing a button, may seem straightforward for a noncognitively impaired person. However, this task may be much more complex for and individual with a cognitive disability. In the example of pressing the button, the participant needs to:

1. Focus on the video instruction.
2. Comprehend the instruction.
3. Make a decision based on the instruction.
4. Locate the button.
5. Recall the instruction.
6. Associate the instruction with the button.

7. Physically push the button.
8. Focus on the video.

When we break down the tasks to these lower levels, we can better see how to support the interaction through the system design. For example, going from steps 3 to 4 involves redirecting attention from the monitor to the input device. One way in which we facilitated this was by providing an audio cue in the input device, to attract the participant's attention. This form of task analysis has helped us support complex tasks.

12.6.3 AD Participants can Interact with Multimedia

One of our objectives in this feasibility study has been to support and encourage system interaction through system instructions, navigation and input devices. In relation to this, a major research question has been will the participant press the button? When we began this project, the AD experts from our interviews and consultations, as well as the relatives, did not believe that the participant would physically interact with the system (i.e. by pressing the button). We were aware that the participant could press a button on a remote control only after precise, persistent guidance and prompting from another person.

Our goal was to implement a system that would provide precise and persistent guidance, and provide the opportunity to express her preferences in viewing the life stories. Social workers and relatives believed that the cognitive skills used in these activities could not be transferred to an interactive technical medium. In our feasibility study, we began with the assumption that interaction could be possible. We found that Laura was positively stimulated by the content on the new medium of an interactive multimedia platform. Remarkably, Laura did in fact press the button! Although we could not discern whether she interacted based on a cognitive decision involving reasoning and judgment, or whether she interacted based on the instructions and prompting alone, we now know that she was capable of interacting by responding to prompts and cues.

12.6.4 Active Participation is more Stimulating than Passive Participation

In our testing we saw how different types of activities can evoke different reactions from our participant. As we iterated through the designs and enhanced the life story multimedia we saw a growth in positive responses from our participant. We believe that the design of the interactive device can either impede or facilitate the effects of the intervention activity. It is possible that our earlier designs relied more on the diminishing cognitive abilities, resulting in an activity that was too complex or distracting. However, in later iterations we redesigned the multimedia to better meet the special needs of our participant and we saw positive results.

In addition, taking part in the passive noninteractive presentation had a different effect on Laura than participating with the interactive life story system. We found that Laura expressed more meaningful responses when viewing the interactive life story systems, in comparison to the linear noninteractive presentations. She showed more interest (through her body language and facial expressions) when she had the remote control in her hands. One possible explanation for this is that the interactive activity is empowering. We believe that further research should explore whether interactive stimulation affects the participant's ability to communicate meaningfully.

In our hypothesis, we proposed that active participation might be empowering because it promotes feelings of control and value. Prior to conducting this study, we believed that being able to make a decision to control the presentation would be empowering. However, this assumed that the individual could make the cognitive decision, a process that requires reasoning and judgment. In this study, we were at times unsure whether Laura pressed the button as a result of the decision (to see more scenes, or to skip scenes) or from the prompting. It is possible that when the participant interacted successfully, she was merely responding to the instructions without using any reasoning or judgment. Despite the uncertainty of whether the participant was making the decision, we believe that the act of participating itself was empowering for several reasons. First, the interaction added a sense of control to the activity. Even if she was at times unable to make a cognitive decision, the participant was aware of her responsibility and control over the activity. This is particularly evident from her comment, 'Don't forget, got to press the button.' In addition, the activity added physical stimulation through touch and motion. Another factor is that this activity evoked support and positive responses from her family. We believe that these observations inspire further research on interactive psychosocial support tools as an empowering and stimulating activity.

12.6.5 **Different Stakeholders Experience Different Effects**

As the family became more involved in the project, it became apparent that their needs (though different from their relative's needs) should be addressed throughout the project. It could be clinically contraindicated to focus purely on one stakeholder or one end user, since this project touches the lives of many people. Having a clinician who is trained to work with AD patients and their families throughout the development and evaluation of the project was essential for monitoring possible clinical issues that could arise and that would need to be dealt with from a clinical perspective. We also addressed the needs of the relatives through the participatory design process and encouraged the family to share memories and gain perspectives. We also distributed copies of the life story, providing legacies that they themselves can view with their mother or their own families. In this project, user-centered design involves exploring how to provide support and opportunities, throughout the entire design process, for all individuals affected by AD.

12.7 Current Status and Future Directions

We are now in the process of conducting the large-scale research project. Our goals are to (i) study life story multimedia with 12 participants over a period of 24 months, and (ii) research methods for scaling the design process. With more participants we will be able to further test our hypotheses. As we create more life stories we hope to learn how to better scale the project to require less time and resources so that more people can benefit from similar projects. The development and evaluation of effects of the large-scale research project is based on this initial project. The follow up strategies are more structured and have longer durations. In addition, we are asking the families to show the videos at specific intervals and to record their observation of the AD patient's response over a period of a year.

We have now produced two additional digital life histories, and have three more underway. A second family was recruited after the conclusion of our active work with Laura and her daughters. The new participant, Michael, was an 87-year-old man diagnosed with mid-stage AD (names have been changed to maintain the participants' anonymity). Unfortunately, Michael passed away before our project completed, and we were only able to complete an abbreviated 10-minute version. Despite this unfortunate event, we gained important experience and knowledge from working with Michael and his family. We refined our research methods that were developed during our work with Laura and we investigated the impact of including Michael in the design process.

Although we could not conduct structured interviews with Michael, we found that Michael could provide valuable input by being present for the interviews with his relatives. He showed enthusiasm, preferences, and at times he made contributions to conversations. Although the nature of this interaction will be limited as AD progresses, this input can valuably guide the production process, possibly resulting in a more stimulating biography.

We were also able to streamline the design process from the initial project by developing templates and creating semi-customized life stories. When possible, we are also encouraging the relatives to take on larger roles by working with the digital media and focusing more on photographs and music (since video requires more resources). When relatives review and organize the media themselves the development process becomes more efficient and reduces the multimedia editing time. These are just a few of the improvements that we are investigating for this research.

We also created an interactive biography for an individual with vascular dementia. Preliminary findings suggest the result was well received; the participant made numerous positive comments while watching the DVD, and made attempts to interact with the system. Unfortunately, follow-up proved difficult because family circumstances made it impossible to guarantee regular showing of the biography.

We believe that this program has the potential to benefit individuals afflicted with a wide variety of cognitive impairments. Hence future research may include individuals afflicted with other types of dementia, as well as earlier stages of AD and mild cognitive impairment (MCI), and may explore a system that is controlled by different stakeholders. More complex interaction methods may be possible in these cases. Such methods would allow researchers to explore the impact of new variables such as early prevention. Further, researchers can study correlations between the effects of media and different behavioral effects, and use this information to enhance the intervention activity. For example, if a participant is feeling agitated, we can present specific content that is known to manage agitated behaviors.

12.8 Implications for Designers, Researchers, Policymakers, and Participants

12.8.1 The Research is Extremely Resource-Intensive

Conducting the case study requires resources such as intricate recruiting, various research and development, and ongoing production costs. For example, the case study required 6 weeks of ethical review, as well as a variety of technical equipment and software. In addition to these one-time resources, the case study included approximately 200 hours of research and development, and 10 gigabytes of storage space.

12.8.2 This Research is Very Emotionally Intensive

This project has been emotionally intensive for both the stakeholders and researchers. Recruiting families took at least 3, and up to 8 weeks because many families who are coping with the loss of a relative do not feel that they have the time or emotional stamina needed to participate in this project. Even after completing the life stories, the participating relatives continue to experience the many effects of taking part in the project. In addition, this research exemplifies the value of working in multidisciplinary teams, since each researcher is contributing valuable work. In particular, it is essential that social workers are present to provide expertise and professional guidance. They can help the team understand the emotional implications while monitoring possible issues that could need clinical attention.

12.8.3 The Project should be Accessible but Practical

As the number of participants increases it becomes import to be able to manage and streamline the project. It is unlikely that a health care system would have the resources to replicate this approach with AD families and patients. Similarly, not many families can afford to have this project conducted for their relative. Creating a technological product is a great option. However, this is likely to require more commitment, time, multimedia equipment, and computer skills from the family. In addition, the streamlined method should include a social worker to ensure support and value for the relatives. We intend to develop several practical resources to help conduct life story development, such as producing a guidebook for developing the life stories in a simplified form. The book could be geared toward families with children or grandchildren who have computer skills and could deal with digital information readily.

12.8.4 Standards for Evaluations of Interventions are Needed

We also believe that the research community may need to modify and develop standards for evaluations of intervention methods. Normally, large-scale clinical studies are required for showing validity and value. Unfortunately, large-scale studies are not currently possible for these types of research projects. Despite this we aim to conduct research on intervention technologies that can impact the health care community.

12.9 Conclusion

We have designed interactive life story multimedia for families affected by AD. By employing user-centered design principles we have explored how to encourage and support system interaction, particularly through our application of modified design methodologies and new design principles. We have shown that a mid-stage AD individual can interact with multimedia. However, participant interaction is dependent on a number of factors, including the state of the disease and the design of the system.

We discussed several factors that affected the design in our case study, such as simplicity, stimulation, and active participation. We believe that many individuals will benefit from the empowerment offered by participating in this project and interacting with the media. We also believe that creating more effective designs of psychosocial ATC may lead to enhanced intervention programs. This case study also offers an exciting foundation for future research on the interactive life story multimedia project, as well as other related future work. For example, researchers can study the power of interacting and actively participating during reminiscent intervention activities with families affected by AD.

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