The Design of Personalized Multimedia Biographies for Persons with Alzheimer's Disease

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About the Authors
Tira Cohene, author of this position paper and proposed attendee to the Home Technologies to Keep Elders Connected Workshop, is a Master's student of Human-Computer Interaction in the Department of Computer Science, University of Toronto, Canada. She received a double major in Computer Science and Cognitive science from McGill University. Tira has over a year of industry experience in the design and configuration of applications for specialized needs. Currently, she is working with Ron Baecker Ph.D. and Elsa Marziali, Ph.D. on the design of personalized multimedia retrospective life histories for individuals with Alzheimer's disease. She has completed the primary stage of her research, including a composite investigation into Alzheimer's disease, psychosocial intervention methods, memory and cognition, as well as computing and design methods.

Dr. Ron Baecker, co-author of this position paper, is a professor of Computer Science at the University of Toronto. He is also the founder and a professor within the Knowledge Media Design Institute at the University of Toronto. Dr. Baecker is an active researcher, lecturer, and consultant on human-computer interaction and user interface design, user support, software visualization, multimedia, computer-supported cooperative work and learning, the Internet, entrepreneurship and strategic planning in the software industry, and the role of information technology in business. Dr. Baecker is currently leading a research project on human memory devices. The goal of the project is to prototype, design, construct, and evaluate a family of memory devices and prostheses that will assist individuals in a wider range of circumstances in which they are affected by memory loss.

Dr. Elsa Marziali, co-author of this position paper, is the Schipper Chair, Gerontological Social Work Research at the Baycrest Centre for Geriatric Care, and Professor and Director of the Katz Centre, Faculty of Social Work and Medicine (Psychiatry), University of Toronto. Her current research focus is on the development and testing of computer/Internet based supportive interventions for family caregivers of patients with Alzheimer's, stroke or Parkinson's disease. Her past work includes intervention-outcome studies with measures including; therapeutic alliance, social support, stress response, and interpersonal representations.

Research Interests
Although it is not currently possible to reverse the effects of Alzheimer's disease, intervention methods can be invaluable for providing support and enhancing the well-being of the individuals' lives. They can focus on strengthening the memory faculties, providing support for memory capabilities, enhancing one's life in areas where memory loss has caused strains, as well as facilitating the responsibilities of the caretakers. Our goal is to prototype, design, construct, and

evaluate a web based intervention tool for individuals with Alzheimer's, their families, and caregivers.

Symptoms specific to Alzheimer's disease can cause various behavioural effects. Examples of symptoms include memory loss, increased dependency, and changes in personality. These symptoms often lead to behavioural issues. For example, people diagnosed with Alzheimer's disease tend to have high levels of depression, grief, fear, and frustration (Kasl-Godley & Gatz, 2000). These are often coupled with agitation or even a loss of sense of self (Marziali, 2002).

In addition to considering the well-being of the individual who is afflicted with the disease, it becomes important to consider the well-being of their loved ones. The caretaker, who's often a family member, becomes very much affected by the disease as well. In addition to their responsibilities, they must cope with the loss of their family member to the disease. As a result, caregivers frequently suffer from isolation, stress, and depression (Kasl-Godley & Gatz, 2000). Other family members are often affected in similar ways.

Prof. Elsa Marziali, Schippers Chair of Social Work at the Baycrest Centre for Geriatric Care, has begun research on the effects of personalized videotaped retrospective life histories on individuals with Alzheimer's (Marziali, 2002). The video intervention serves to diminish problematic behaviours, in part through reinforcing the individual's positive self-identity. Caregivers and family members collaborate on the filming, editing, and viewing of videos. The film uses visual and auditory stimuli such as themes and props to represent retrospective memories. One of the objectives is to evaluate the individual's mood and agitated behaviours throughout the duration of the project.

In this project, we are extending the research from Marziali to a multimedia platform. The potential of the Internet for intervention and support exceeds the limits of video-based interventions. The web has the benefit of allowing information to be presented in a nonlinear, interactive, and pesonalizeable format. Text, still graphics, as well as media rich visualizations such as animation and video can be combined, based on an individuals reactions and feedback to the media. These benefits can enhance and facilitate the creation, manipulation, and presentation of retrospective life histories.

We are adapting ideas and approaches from multimedia authoring and publishing to the development of tools for creating *multimedia family histories*. We will provide tools for caregivers and family members to work together to assemble, manipulate, and view life histories of individuals with Alzheimer's. The life histories can include video and text narratives, photos, music, family trees, as well as other tools used in reminiscence and life review. Our approach will also allow caregivers and families to contribute material to a growing Internet multimedia library. The media can be delivered via CD and the Internet and viewed by patients, caregivers, families, and friends.

Reminisce and life review intervention methods are known to have both intrapersonal and interpersonal benefits. Researchers report that the intrapersonal benefits include enhanced self-understanding and a sense of personal stability, aid in gaining a sense of meaning to one's life, enhanced ego, and minimized despair (Kasl-Godley & Gatz, 2000). Other researchers have also found that review of past accomplishments promotes competency in individuals (Cook, 1984). In addition, Woods reports that there are significant sentimental and emotional benefits from this intervention method (1994). Some interpersonal benefits suggested by Woods include socialization among friends and family, and leaving a legacy (1994).

Our evaluation will investigate whether recollecting and reinforcing memories of the individual and multimedia family histories could have beneficial effects. In particular, we wish to study effects

such as bringing a sense of well-being or joy to the entire family, enhancing relationships among friends and family, and calming or reducing disruptive behaviour of the individual with Alzheimer's disease. Our project aims to keep individuals connected in the present and future, through the collaborative recollection of past connections.

Appendix

Cook, J.B. (1984). Reminiscing: How it can help confused nursing home residents. *Social Casework: The Journal of Contemporary Social Work* 65, 90–93.

Kasl-Godley, J., Gatz, M. (2000). Psychosocial interventions for individuals with dementia: An integration of theory, therapy, and a clinical understanding of dementia. *Clinical Psychology Review* 20:6, 755-782.

Marziali, E., (2002). Effects of personalized video-taped retrospective life histories on persons with alzheimer's mood and agitated behaviours. Unpublished report.

Woods, B. (1994). Management of memory impairment in older people with dementia. *International Review of Psychiatry* 6, 153–161.