

# Sharing Personal Identities in Family Contexts

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## ABSTRACT

As people grow older, their personal identities may be “lost” as a result of disease, aging, or death. This loss frequently occurs in a context where family members must care for the affected individual. In our work, we are studying how to design, build, and evaluate a set of technologies which help older adults share their past, present, and future identities. A first line of research is concerned with building and deploying multimedia biographies into the homes of older adults with Alzheimer’s disease or mild cognitive impairment. A second project is concerned with providing seniors with social network information on their mobile phones, and helping them to feel more connected with family and friends. Finally, we are beginning to examine how to help people project their identities into the future. In the context of these three initiatives, we are finding that technology can change the relationship between older adults and their family members in a way that helps to rehabilitate identity.

## Author Keywords

Identity, family, elderly, memory, social networks, self.

## ACM Classification Keywords

H5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

## INTRODUCTION

As the baby boomer generation nears old age, families will increasingly find themselves caring for a loved one who suffers from a loss of personal identity. This loss may stem from neurodegenerative or cardiovascular conditions such as Alzheimer’s disease, vascular dementia, or stroke. It may also occur as a result of institutionalization, wherein an older person is confined to a hospital or residential care facility where little of their previous lifestyle and possessions remain. For example, a recent article in the New York Times notes that upon admittance to most

nursing homes, seniors are permitted to bring only two personal items [5].

This loss of personal identity, coupled with the increasing burden of care placed on family members, can place enormous stress on the relationship between the older adult and their family members. A middle-aged child may find him or herself tending to the physical needs of the older adult, while at the same time realizing that their parent is no longer the same “person” as they once were.

In our research, we are studying how a variety of personalized displays and devices can help older adults maintain or share their personal identities with their families. Formalizing the meaning of the term “personal identity” can be difficult, as it is related to other aspects of self, such as self-concept, self-esteem, and self-expression. For purposes of our investigations, however, we consider identity to be the overarching narrative of an individual’s entire life, including the *past*, *present*, and *future* [3]. In contrast, self-concept and self-esteem are instantaneous constructs, while self-expression is an action wherein the individual shares their personal identity. Accordingly, we organize our projects along themes of past, present, and future.

## SHARING THE PAST WITH MULTIMEDIA BIOGRAPHIES

Our first study, which is currently nearing completion, revolves around building multimedia biographies for seniors with Alzheimer’s disease (AD) or mild cognitive impairment<sup>1</sup> (MCI). The process consists of two major phases: an authoring process, and a viewing process. For the authoring process, we have developed techniques for structuring the life of the participant into temporal or thematic “chapters” (e.g., “childhood” or “My Life in Politics”) [1] (Figure 1). After working with the family to gather, organize, and digitize materials, we produce a DVD of the biography and ask the senior and his or her family to gather and watch the biography together. These representations of the past contain material which may trigger autobiographical memory, and correspondingly provide the senior with a stronger sense of identity [2].

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<sup>1</sup> Mild cognitive impairment is commonly thought to be a precursor or risk condition for developing Alzheimer’s disease [9].



**Figure 1.** Charts used for structuring a biography into chapters.

To date, we have worked with 12 families in order to produce these multimedia biographies. The familial arrangements and stage of pathology have varied considerably (Table 1). In 10 of the 12 cases, the senior lived at home or with a family member. Three worked on their autobiographies alone while 9 worked with their immediate and extended families from to build the biographies.

Family participation varied. Three MCI participants were cognitively intact enough to work on their biographies alone. At the other end of the spectrum, family members had to create the biographies for people with AD. Our research team adapted correspondingly. For the three MCI seniors who built their own biographies, we worked closely with them to produce the biography. In families where the seniors had sons, daughters, and spouses working on the biography, our research team took on a more advisory role.

**Table 1.** Families in the multimedia biographies project.

Participant	Diagnosis	Age	Family
Ms. F	Mid-stage AD	91	2 children
Ms. L	Advanced AD	60	Husband, daughter
Mr. M	Early AD	70	Wife
Ms. N	Early AD	71	Son
Ms. Y	Mid-stage AD	79	3 children
Ms. Z	Mid-stage AD	85	2 children
Mr. A	MCI	82	Wife
Mr. W	MCI	84	Wife
Mr. S	MCI	95	Wife, 5 children
Mr. G	MCI	84	None
Ms. K	MCI	74	None
Ms. P	MCI	79	None

In some cases, the roles changed over time. For example, Ms. L entered our study with early-stage AD but had progressed to advanced AD within a year; her family and our research team had to become more involved as this occurred.

Upon completion of the DVD, members of the family were invited to attend a “world premiere” viewing of the biography. We asked participants and their family members to watch the biography at least once a week. We visited each family 3 months and 6 months after the premiere in order to interview them as they watched the biography. We videotaped the family during each session and transcribed their dialogue and commentary. Each of the transcripts was then analyzed using open coding, and themes emerged from the data.

The heterogeneity of participants and their families challenged us to adapt our approach on a person-by-person basis. As a result, each participant had a slightly different experience, limiting the generalizability of our findings. Even so, qualitative data from interviews and working with the families leaves little doubt that the participating families found this experience meaningful and emotionally rewarding, and helped to change how they saw their loved one. In a similar, offshoot case study using slightly different technologies, gains were observed on formal psychological measures of personal identity, supporting the idea that these family-crafted technologies can, under certain circumstances, help to restore identity [7].

### SHARING IDENTITY IN EVERYDAY SITUATIONS

A large part of one’s day to day personal identity is influenced by relationships with other people, especially family members. However, age-related cognitive decline (including, importantly, forgetting names and personal details) can sometimes interfere with the establishment and maintenance of a strong, positive relationship. Social situations may become stressful opportunities for embarrassment rather than enjoyable, fulfilling experiences. For example, a woman might forget what major her college-aged granddaughter has declared, and feel like a bad grandmother due to her failing memory. As a result, older adults sometimes become reclusive and narrow their social circles. This lack of socialization has been linked to higher risk for mortality in retrospective studies of long-term care [4].

In this project, we are designing a mobile ambient display called Friend Forecaster. Friend Forecaster will act as a tool to help seniors feel more at ease, connected, and involved with their day to day social networks. We have chosen to design this as an ambient mobile phone application based on previous studies we conducted regarding seniors’ needs with reference to mobile phones [6].

Our current design displays serendipitous information about the senior’s social network on the “home” screen of the device (e.g., on a Windows Mobile phone, it appears on the

Today screen). Whenever the senior checks the display, for example, while plugging it in or when placing a call, he or she will stumble across the social network information. To ensure this information is pertinent, we are developing a logic engine which infers the top N contacts most likely to be seen in the next few hours. This list is generated by fusing information from GPS with calendars, contact lists, and location history. Social information may also be entered and reviewed manually (Figure 2).

Before conducting pilot trials with older adults, we conducted pen-and-paper versions of the study with two lab members acting as subjects. Over a period of weeks, the subjects kept track of where they went, who they met, and tagged them with memory cues. Example tags varied, and examples included: bald (physical descriptor), Susan's husband (social role), children's fiction writer (profession), and Mississauga (location). At the end of this exercise, the two subjects reported feeling more connected to their communities and surprised at the number and variety of people they knew. This preliminary and cursory investigation nonetheless suggests that the application domain could impact identity through mediating social ties.

Currently, we are beginning to recruit older adults to participate in pilot trials. Emerging methodological and design hurdles include managing family members, friends, and acquaintances in the same application. It is much more unlikely for a senior to forget her daughter's name than it is for her to forget her hairdresser's name. However, both of these types of people have changing personal details that need to be managed by the system. How to best integrate family members into more general classes of social network applications remains unclear.

Unlike the exploratory design of the multimedia biography studies, in this project we will be using a field experiment with a delayed-intervention control group. This includes psychometric batteries administered to the participant and informant measures collected from family members. Our study design is a field experiment with a delayed-intervention control group, and this has raised issues regarding how to deploy and recover the technology from homes where multiple family members may be residing. We anticipate that participants will be dissatisfied with returning the mobile phone after it becomes a part of their daily familial communication practices, yet must remove the intervention in order to draw conclusions. Despite these challenges, early anecdotal responses from potential participants have been enthusiastic.

### SHARING IDENTITY INTO THE FUTURE

A third component of personal identity consists of the goals, dreams, and concepts of future self that we all hold. Because this aspect of identity has yet to come to pass, it can sometimes be difficult to share with other people or articulate. It may even be that we wish to share our identities with people we will never meet, such as our great-great-grandchildren [8].



**Figure 2.** Friend Forecaster mobile phone data-entry interface.

In this work, still in its infancy, we are beginning to examine how we can design technologies which may help people to better articulate and share the future selves they hope to become, perhaps even beyond death. Clearly family plays a key role in the creation, storage, and retrieval of such identities. We anticipate working closely with families in a participatory design/action research stance, to develop a set of needs and technologies which may help family members share their identities with each other well into the future.

### CONCLUSION

We have discussed a program of research that examines how families and technology can work together to help older adults share their past, present, and future identities. Results from our multimedia biographies work suggests that working with families requires a methodology more flexible and adaptive than traditionally employed in studies of individuals or even within other types of social organizations. Meanwhile, the Friend Forecaster project has begun to highlight challenges associated with conducting randomized field experiments, and with integrating family life into a larger social sphere. At the workshop, and in the future, we hope to continue learning how to design and evaluate technologies which can help families come together to celebrate the unique lives of their members.

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## Author Biographies

Michael Massimi is a Ph.D. candidate in computer science at the University of Toronto and doctoral fellow in the CIHR-sponsored Health Care, Technology, and Place program. His research interests in HCI include understanding how ambient displays impact personal identity, with an emphasis on psychosocial rehabilitation. He earned a Master of Science in computer science from the University of Toronto, and a Bachelor of Science from The College of New Jersey.

Ronald Baecker is Professor of Computer Science, Bell University Laboratories Chair in Human-Computer Interaction, and founder, Director, and Chief Scientist of the Knowledge Media Design Institute at the University of Toronto. Baecker has been named one of the 60 Pioneers of Computer Graphics by ACM SIGGRAPH, has been elected to the CHI (Computers and Human Interaction) Academy by ACM SIGCHI, and has been awarded the Canadian Human Computer Communications Society Achievement Award and the Leadership Award of Merit from the Ontario Research and Innovation Optical Network (ORION). His current research focuses primarily on developing technology for rich media communications over the Internet (see <http://epresence.tv>), and on envisioning, designing, building, and evaluating a family of technological aids to cognition, intended variously for individuals with Alzheimer's disease, Mild Cognitive Impairment, and amnesia, and in some cases for "normally aging senior citizens."