Memory Aids as Collaboration Technologies

Michael Wu
Department of Computer Science
University of Toronto
40 St George Street, Room 5167
Toronto, Ontario, M5S 3E4
mchi@dgp.toronto.edu

ABSTRACT
Memory aids are typically viewed as prostheses designed to assist an individual in compensating for difficulties in remembering important specific information or in remembering information related to management of their personal lives. However, some of our research with people having amnesia has suggested a fundamentally different view of artifacts designed to aid those with memory impairments. This workshop proposal is based on the notion that memory aids are collaboration technologies that can be designed for memory impaired individuals as well as their caregivers, family, and clinicians.

Keywords
Memory aids, cognitive prostheses, distributed collected practices, collaboration technologies, information sharing, distributed memories, anterograde amnesia.

BACKGROUND
Anterograde amnesia [1] is a memory deficit that impairs an individual’s ability to form and retain new information after a brain injury. Memories formed prior to the brain trauma are more easily recalled, but amnestics have difficulty storing new memories. Though this selective deficit spares other cognitive functions, people with anterograde amnesia have great difficulty managing their lives since they essentially live in the present at all times.

A major issue of concern for amnestics and their families is the problem of disorientation. Even when traveling with caregivers, amnestics are susceptible to feeling lost and disoriented in various settings since they have much difficulty recalling recent events. Such episodes are often accompanied by spikes of anxiety, which can be compounded by the rush of noise and commotion in unfamiliar public settings. In such scenarios, there are few established strategies. If caregivers are present, they often will cue amnestics back to normality, but when amnestics are alone – even temporarily – the end result can be devastating. Some will wait in the area and not leave, some may unsuccessfully think back through the day’s events to try reason what is going on, and others will telephone for police assistance.

A participatory design team [2] involving six amnestics was created with the goal of designing a computer tool to address this problem of disorientation. We adapted the design process to accommodate our unique team. Our participatory design team envisioned the OrientingTool (see Figure 1), a software application for Palm devices that presents situational information (for example, time of day, location, user intentions and goals) to help an amnestic who is lost get back on mental track. We have trained several amnestics how to use our tool and have conducted two user studies to evaluate its effectiveness in ecologically valid contexts. For further details, please see [4]. This exploration into digital memory aids has directly led to our current research into collaborative information sharing and distributed memories.

Figure 1. The OrientingTool running on a Palm Zire 71.

VISION
I am interested in how to support collaborative practices involving the distribution and dissemination of digital memories. This would entail understanding how heterogeneous experiences and memories are exchanged through digital means. Information sharing between members of any community group is an important aspect of Distributed Collective Practices because communication is a necessary component of collaboration.

WORKSHOP ISSUES
I bring an intimate knowledge of a user community that has a need for distributed collaboration technology, but does not currently use any. This presents some interesting perspectives that may draw parallels to other user groups in similar situations. As a first year doctorate student, participation in this workshop would be a valuable experience for me. It would be exceedingly useful to speak to established researchers in this field as I carve out my research goals and directions.
CURRENT RESEARCH DIRECTIONS
Memory aids are typically viewed as prostheses designed to assist an individual in compensating for difficulties in remembering important specific information (such as names, faces, facts, dates, and medications) or in remembering important information related to management of their personal lives (i.e., engaging in planned activities at future target times.). Yet a decade of research on amnestics and their families carried out at Bayerest Centre for Geriatric Care (http://www.bayerest.org/index.html) has suggested a fundamentally different view of artifacts designed to aid those with memory impairments.

An amnestic is typically not an isolated individual struggling against the consequences of his or her disability. Rather he or she is part of a collaborative team that also includes a primary caregiver, members of their family, and sometimes a clinician who provides counseling and access to needed services and medical care. This team can be viewed both as a support system and a system for storing, distributing, and transmitting information of importance between the amnestic and their community. The following examples demonstrate the importance of information transfer in this context:

1. We have observed amnestics and their families collaborating around a large paper-based wall calendar used for marking meetings, tasks, and activities. Everyone in the family adds their activities and a simple glance at this calendar reveals information about the whereabouts of each person throughout the month. This sharing of information enables an amnestic and family to coordinate activities and keep everyone apprised.

2. We have seen that amnestics and their families often share their experiences with other families during support group meetings. This information exchange expands the range of experience of any one individual family and can prompt the development of novel strategies for dealing with the everyday challenges that are common to those with severe memory impairment.

3. In the daily functioning of any family, information frequently becomes outdated and thus updating that information and appraising everyone involved becomes a priority. For example, we have observed a secretary calling an amnestic to inform them of an appointment time change, but due to the amnestic’s memory impairment, this change is not relayed to the caregiver who, remaining unaware of the change, continues through with original plan. This failure of reliable registration and relay of changing information leads to confusion, frustration, and increased stress for the amnestic and family.

These examples suggest that we view memory aids as systems designed to facilitate collaboration among an amnestic, his or her primary caregiver, family members, and clinicians. Few research projects have focused on supporting families and caregivers beyond the memory impaired individual, and the ones that do often are asymmetrical in interactivity and support. For example, while NeuroPage [3] allows caregivers to schedule alarm times for a pager carried by memory-impaired individuals, those individuals have no ability to make modifications themselves in the system. This limits their autonomy and does not allow them to independently shift their activities, or update their caregiver, in accordance with changing circumstances that may be encountered during the day. We propose an interactive collaborative system that comprises of personal portable devices for amnestics and each member of their support groups. Our system will not limit the role of amnestics to only recipients of information, but will enable them to actively share information and become more integrated into the daily flow of activity. Such a system would also enhance the ability of amnestics to share their daily experiences, impressions and reactions in a timely fashion, something amnestics are not currently able to do, and which typically traps them at a constricted level of social interaction. We hypothesize that collaborative sharing of digital memories between amnestics and their network of caregivers, family, and clinicians will enhance the amnestics’ quality of life and enable them to function more autonomously. This in turn, will lead to a decrease in stress and burden for the family. We propose the following research method for testing our hypothesis over a 3-year period.

- Phase 1 (6 months) will consist of field studies to better understand the nature of information that is shared between members of the amnestic community. Interviews will be performed on the target participants to assess stress levels in current practice.
- Phase 2 (12 months) will be spent working with a participatory design team that will include amnestics and their caregivers. This phase will include a series of design iterations while the necessary software applications are developed, tested, and redesigned.
- Phase 3 (18 months) will involve a longitudinal study examining the use of the collaborative system in real contexts. Data will be collected through system logs detailing what information is shared as well how it is used. Every month, surveys of caregiver stress and burden will be conducted. Monthly measures of self-efficacy will be administered to amnestics. Periodic neuropsychological evaluations of memory and cognition will be conducted with the amnestics in order to monitor change, and identify whether improvement observed at the functional level is due to the collaborative system intervention or to unspecified change in the underlying neurological condition. The survey and questionnaire results will be compared to the data collected from the system logs to identify how active engagement in information transfer affects independence, confidence, stress and burden.
Although the proposed intervention will be developed through work with severe amnestics it nonetheless has direct applicability to other populations with less severe memory impairment including Traumatic Brain Injury, Mild Cognitive Impairment, and Normal Aging.

**BIography**

Mike Wu is currently a first year Ph.D. student under the supervision of Dr. Ron Baecker at the University of Toronto. Over the past two years, he has collaborated with Dr. Brian Richards of the Psychology Department at Baycrest Centre for Geriatric Care. In 2004, Mike completed his M.Sc. in Computer Science at the University of Toronto and in 2002 he received a B.Sc. in Computer Science at the University of British Columbia. Mike has interests in assistive technologies, interaction with computational tabletops, and educational games for children.

**REFERENCES**


