Collaborative Memory Technology for Supporting the Care Network

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Abstract
This position paper outlines the initial steps of a research project that focuses on supporting people with anterograde amnesia and their care groups. The paper presents the idea that memory aids can be viewed as collaborative technologies. The paper also proposes the use of theory as a potential solution to increasing the generalizability of results that may appear to have limited applicability to a specific population. Two theory-related questions are offered for workshop discussion.

Keywords
Cognitive prostheses, memory aids, theory, assistive technology, anterograde amnesia, CSCW

ACM Classification Keywords
K.4.2 [Computers and Society]: Social Issues – Assistive technologies for persons with disabilities.

Background
Our lab at the University of Toronto has been engaged in a major research thrust to design, prototype and evaluate a family of electronic aids to specifically address the needs of people who have cognitive impairments [1]. At the heart of our research has been the vision that such assistive technologies may

ultimately become “prostheses of the mind” to either replace missing cognitive functions or strengthen unaffected capacities in an effort to compensate for what was lost. One branch of our broad research plan is focused on designing memory aids to support people who have anterograde amnesia.

Anterograde amnesia [3] is a selective memory deficit that impairs a person’s ability to store new episodic memories (dated recollection of personal experiences). An example may be what happened during one’s last doctor’s appointment. This memory impairment makes it extremely difficult to learn new facts and events.

Anterograde amnesia can affect anyone -- male or female, young or old. It results from an injury to specific structures of the brain believed to be responsible for memory consolidation. Common causes of anterograde amnesia include oxygen deprivation (for example, from a stroke), certain forms of encephalitis, burst arteries in the brain, tumors, chronic alcoholism, or blows to the head. While the damage to the brain makes it difficult for victims to consolidate new memories, memories prior to injury (that have already been formed) are often left unaffected. So someone who acquires anterograde amnesia later in life may still remember their childhood. At the same time, this deficit does not affect other cognitive functions such as intelligence, communication, decision making, and the ability to implicitly learn habits or procedures. There is currently nothing known that will repair the damage in the brain, but cognitive rehabilitation holds much potential in enabling the recovery of lost function.

Over the past couple of years, I have been working to create and evaluate a memory aid to assist individuals with anterograde amnesia [6]. A key catalyst of this research has been a close collaboration with clinical researchers from the Memory-Link program at the Baycrest Centre for Geriatric Care. Memory-Link is an outpatient service that helps train and support adults having severe memory problems. I worked closely with members from Memory-Link and we adopted a participatory design approach [4]. Six amnesics actively participated in our design team as equal partners, working together to arrive at design decisions by consensus. One challenge that had to be overcome was that whenever we convened to conduct our design sessions, we could not expect everyone to remember what had occurred in previous meetings. It was necessary to adapt several design techniques in order to successfully work with our partners [7]. Together we envisioned, designed, and evaluated the OrientingTool, an application for Palm handheld devices to assist amnesics when disoriented or lost. This particular research project has been instrumental in defining our current research objectives.

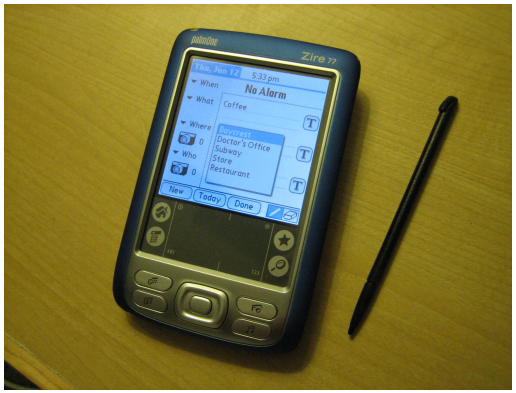

figure 1. Our orientation application running on a PDA.

Memories as Collaborative Processes

For two years I have worked alongside amnesics -- attending memory support groups, and assisting clinicians in memory rehabilitation training at Baycrest. Based on these experiences, I have directly observed that amnesics are deeply supported by their families who not only provide practical, functional, and social support, but provide effective memory support. For example, a spouse will often provide reminders about relevant upcoming appointments. I have also observed family members participating in support group meetings where they share experiences and apply that knowledge in co-developing new compensatory memory strategies.

From these observations it appears that amnesics are not isolated in their struggles against the challenges that result from poor memory. They are part of larger collaborative team that may include a primary caregiver, family members, clinicians, and health care workers. This support group might be viewed as a memory system in itself, as information is encoded, stored, retrieved and transferred between people of the group. However, these processes can be extremely taxing for caregivers, who must devote much energy in remembering appointments for the amnesic, providing reminders when necessary, or acting as an external memory aid on behalf of their loved one when the situation demands.

The goal of my current research program is to develop a “collaborative memory aid” to support such processes of coordination and sharing of information in an amnesic’s care network. This involves two parallel and complementary research tracks.

1. A necessary component of this exploration is to gather evidence of memory as composed of collaborative processes. To this end, I am in the process of conducting fieldwork to gather such data. This involves “shadowing” amnesics and their caregivers as they perform their everyday activities. I would like to assess to what extent such support groups behave as a memory system. I am also interested in finding communication and collaboration breakdowns. This could be followed up by a needs assessment and the development of a technology solution to resolve the breakdowns. Potentially fruitful areas of research include the design approach we choose for this project, the technology we develop, and the evaluation.

2. On a parallel track, I am exploring the importance of theory and conceptual frameworks as a means to conceptualize what we see in the data, or to guide the design of new memory aids. Theoretical constructs that examine the intricacies of how people and technology interact may prove relevant, yet with few exceptions there has been little effort to apply them in practical design. I am currently reviewing theories drawn from a variety of sources, and assessing their value. Two potential theories are Activity Theory and Distributed Cognition [5].

The Role of Theory

There has been little research in CSCW to identify principles that can be generalized across various domains [2]. In fact, this is a major problem that many researchers in the field of assistive technologies face. Researchers struggle to apply knowledge drawn from very specialized populations to their own research that may deal with populations that have different

neurological differences and thereby significantly different needs. This problem is exacerbated by the fact that populations within a “group” have a great deal of variance as well. For example, one amnesic might remember details from a conversation that occurred days ago, whereas another amnesic may have difficulty remembering events occurring only seconds ago.

One solution to this problem of generalizability may be found in the use of theory. Theories focus on particular facets of a problem and will often help abstract key concepts. This may help researchers conceptualize their problems in more general ways.

Questions for the Workshop

Two questions that could lead to interesting topics of discussion at the workshop are:

1. What are the criteria that define a valuable theory for designing cognitive aids?

2. Are there theories from related disciplines that we can borrow (cognitive science, social theory, others?) and if so, are there consistent ways that we can adapt them to our needs?

I am interested in comparing the theoretical and practical approaches of other projects at the workshop, and identifying commonalities that may lead to a unified theoretical framework.

Brief Biography

Mike Wu is a second-year Computer Science doctoral student specializing in Human-Computer Interaction under the supervision of Dr. Ron Baecker at the University of Toronto. Over the past couple of years, Mike has been collaborating with Dr. Brian Richards from Baycrest Centre for Geriatric Care. Mike is currently a member of the Dynamic Graphics Project, a Health Care, Technology, and Place Fellow and a member of the Knowledge Media Design Institute.

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