Designing Electronic Memory Aids:
A Research Framework

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Abstract

This position paper presents a framework for research on electronic memory aids and other cognitive prostheses and gives examples of projects that illustrate the framework.

Keywords

Cognitive impairments, electronic memory aids, cognitive prostheses, cognitive rehabilitation

ACM Classification Keywords

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

Introduction

Memory is essential for participating in life and in work, for engaging in social interaction, and for preserving health. We need to make appointments and meet deadlines. We must remember names and be able to associate them with faces, and be able to base what we say in a conversation on what has occurred in the recent past. We must remember to take medications and to see doctors on time.

We are most aware of the importance of memory when we forget something that is important. We all have memory lapses; even those with normal memory

struggle to remember names, appointments, facts, numbers, and details of procedures. Although a temporary loss of memory may be inconvenient for individuals having normal abilities, consistent memory loss can disrupt daily activities to the extent that unemployment or social isolation may result.

There are a wide variety of conditions that lead to serious memory impairments. For example, Alzheimer's Disease (AD) and related dementias affected 364,000 Canadians over the age of 65 in 2001; this number is projected to grow to almost 780,000 Canadians by 2031 [2]. Memory deficits are particularly prevalent in the elderly. The U.N. notes that 10% of the population today is over 60, and projects that this will increase to 20% by 2050, and 33% by 2150.

The last 20 years has seen a rapid growth of research on technology for individuals with special needs [4]. Three good examples of this are technology for: the visually-impaired (e.g., reading machines, screen magnifiers, mobility aids); the speech- and hearing-impaired (e.g., hearing aids, closed-captioning systems, and voice recognition and synthesis), and those with motor disabilities (e.g., computer-based systems that enable quadriplegics to communicate through simple motions of individual body parts).

Yet relatively little work has focused on individuals with cognitive impairments in general, and memory disorders in specific. Thus we have embarked on a research program:

- to design, develop, and evaluate prototype cognitive prostheses to aid human memory

- to demonstrate health benefits that such prostheses afford to those with memory impairments.

The Framework

This paper introduces a research framework intended to guide our research, to help us choose opportunities more wisely, to help ensure that each development informs future projects, and to maximize coherence and synergy among various developments. Our conceptual framework for the principled design of electronic memory aids has six dimensions:

- the kind of memory that is impaired, such as reminding, orienting, reminiscing, and recognizing

- the memory disorder or disease category from which participants will be chosen, for example, mild cognitive impairment (MCI), AD, or amnesia

- the ultimate goal of the work, which might be *compensatory*, the memory aid viewed as a prosthesis; or *restorative*, the memory aid viewed as a rehabilitation device; or *preventative*, with the goal of delaying the onset of a disease such as AD;

- who is the primary "user", for example, the person with the memory disorder, the caregiver, the family, the clinician, or some combination of stakeholders

- the design approach used, such as user-centred design (design *for* users) or participatory design (design *with* users)

- the technology employed in the memory aid, for example, laptop computers, DVDs, personal digital assistants, or cell phones.

Examples

For example, one project employed participatory design with amnestics to develop PDA-based software to aid them in avoiding disorientation. The design team consisted of Computer Science M.Sc. student Mike Wu, rehabilitation specialist Dr. Brian Richards, and 6 amnestics [7,8]. Our findings suggest that the resulting new OrientingTool could improve an amnestic's independence and confidence in handling situations that could otherwise cause great anxiety. Yet perhaps the most important achievement in the work is the dramatic demonstration of the ability of individuals with memory disorders to participate actively in designing cognitive prostheses.

A second example project employs user-centred design with the families of individuals afflicted with Alzheimer's Disease to develop DVD-based multimedia to facilitate the reminiscing of personal and family history. The M.Sc. thesis work of Tira Cohene [1] developed a prototype multimedia family biography incorporating photos, videos, music, interviews and narration for an individual in her 90s with mid-stage AD. Family members report strong benefits for both the Alzheimer's individual and family members from regular viewing of the biography.

Benefits of the Framework

The role of the framework becomes evident as one seeks to integrate such individual projects into a coherent research program. For example, consider the concepts of user, participant, or stakeholder. Mike's M.Sc. work suggested that technology should not be viewed as prosthesis for an individual, but as collaboration technology to aid amnestics, caregivers, and family members in together overcoming the affects of the impairment. This is now the theme of his Ph.D. research [6]. Tira's M.Sc. work pointed out the difficulties in mobilizing individual family members to work on multimedia biographies while struggling with the demands of caregiving. This observation motivated directions for Simona Mindy's current M.Sc. work on the collaborative authoring of multimedia scrapbooks.

Perhaps even more interesting is the progression in research goals from compensatory to restorative to preventative. Another current M.Sc. project is that of Mike Massimi [3], who is assembling a participatory design team to develop a context-aware mobile phone to aid senior citizens in remembering names and faces. Mike's short-term goal is prosthetic, e.g., enabling a senior on his or her way to the bridge club to easily review the names and faces of those individuals in his or her social network who play at the club. But a longer-term goal is to imagine how such technology, incorporating also "memory training games", could increase cognitive reserve [5] and thus one's resistance to developing AD. Could the regular use of such tools for cognitive calisthenics slow down the onset of AD[1]? This is indeed an ambitious goal.

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[1] The Religious Orders Study reports: "In a proportional hazards model that controlled for age, sex, and education, a 1-point increase in cognitive activity [on a 5-point scale] was associated with a 33% reduction in risk of AD." (Wilson et al., JAMA 287(6), 2002)

Questions for the Workshop

1) Is this framework helpful to other researchers? How can it be improved? 2) How can we make it easier to form participatory design teams to work in this field?

Biographical Sketch

Ronald Baecker is Professor of Computer Science, Bell Universities Laboratories Chair in Human-Computer Interaction, and founder and Chief Scientist of the Knowledge Media Design Institute at the University of Toronto. He is Principal Investigator of the $5.5 million Canada-wide NSERC Network for Effective Collaboration Technologies through Advanced Research (NECTAR). Ron is also Affiliate Scientist with the Kunin-Lunenfeld Applied Research Unit, Baycrest Centre for Geriatric Care, Toronto; and is currently Visiting Professor, Cognitive Neuroscience Division, Taub Institute, Columbia Univ. College of Physicians and Surgeons.

He has been named one of the 60 Pioneers of Computer Graphics by ACM SIGGRAPH, has been elected to the CHI Academy by ACM SIGCHI, and was recently given the Canadian Human Computer Communications Society Achievement Award. His B.Sc., M.Sc., and Ph.D. are from M.I.T.

Baecker is an active researcher, lecturer, and consultant on human-computer interaction and user interface design, cognitive prostheses, software visualization, multimedia, computer-supported cooperative work and learning, and software entrepreneurship. He has published over 100 papers and articles on topics in these areas, holds two patents, is the author or co-author of four books, and has founded and run two software companies.

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