As all of us know, whether we are seven or 77, each of us can have challenging needs when in good health or when we are suffering from any number of ailments. The reality of understanding users is that health issues can color our lives in ways we might never expect. In this issue's forum, Mike Wu discusses the pressing needs of adults with severe memory impairments and what can be done to support them and their families through technology. What this article reminds us is that even when we consider our older or younger users, we must also consider the people that live with them. Their care-givers, whether they be grown-children or parents, can play a critical role in the lives of family members at any age. This forum on life-long interactions celebrates not just one age of user, but all ages working together to make life a little better for all of us. —Allison Druin

Memory Impairment Is a Family Affair

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Amnesia is often used as a cinematic device to advance a movie's plot. Heroes lose their memories after a bump on the head, only to recover them following a subsequent bump. Yet what makes for popcorn-filled summer blockbusters rarely parallels how amnesia is truly experienced.

Before I began designing aids for people with severe memory problems, I couldn't begin to imagine what having amnesia would be like. Everyone forgets things from time to time, but how is having amnesia different? Through working with real people suffering from amnesia, I quickly learned the harsh answer. Amnesia deprives individuals of the ability to remember new information, leading to a profound forgetfulness. A person with amnesia will appear perfectly fine and can carry on an interesting conversation with you, but the next time you see them, they won't remember the conversation—or even who you are. Fortunately, those who suffer from the debilitating effects of amnesia are not alone in their fight against it.

While working in this domain over the past few years, I've been struck by the countless times family members step up to provide support for loved ones suffering from amnesia. Yet breakdowns in this support can be catastrophic. Consider the example of Fred, a man with amnesia who is at a doctor's appointment by himself. When the appointment ends early, Fred does not remember that his daughter intends to pick him up and decides to walk home, not realizing that he does not know the way. Fred then gets lost and his family members find themselves in a situation where it is not just Fred who's grasping for information—they all are.
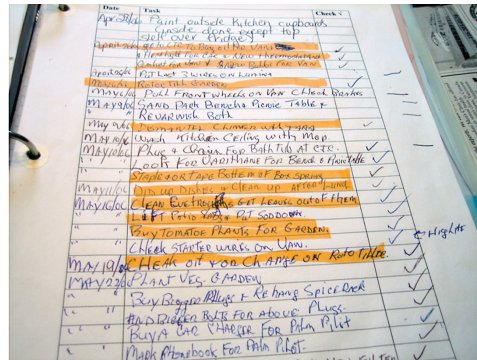
Amnesia

For much of the last century, researchers conceived memory to be a single entity that was either intact or damaged. In the case of a damaged memory, the predominant view was that the patient was untreatable. No one tried to rehabilitate for memory deficits, and there were few services available for sufferers of permanent memory loss. Patients with amnesia often had to deal with the issues on their own.

Two decades ago discoveries in neuroscience and psychology led to a better understanding of amnesia. Amnesia results from an injury to a structure in the brain responsible for processing new memories; this injury can occur following a heart attack, stroke, aneurysm, cyst, or encephalitis.

What is interesting about amnesia is that it does not affect a person's memories before the brain injury, nor does it impair other cognitive abilities such as intellect, problem solving, and communication. Despite this, persons with amnesia have extreme difficulty doing basic things like remembering an appointment. Their inability to recall what they need to do from one moment to the next typically results in their being unable to return to work.

Challenges

There are still very few services for people with severe memory problems, but this is changing.

► A logbook of an individual with amnesia. The spouse highlighted the tasks to indicate which ones she felt were important.

► Everyone participates equally by writing their schedules onto a family calendar.

► A caregiver copies the appointments of her relative into a second day planner and keeps it with her to know what her relative is doing.

Memory-Link is a unique outpatient service offered by Toronto-based Baycrest, a geriatric care center. Memory-Link helps to assess, support, and train the use of memory aids for adults with amnesia. Although they may not be able to recall how, a person with amnesia can acquire new skills (such as riding a bicycle or playing a musical instrument) through painstaking repetition and practice. This is because amnesia spares their procedural memory system.

A number of years ago, I began collaborating with clinical researchers at Memory-Link to design a new memory aid. While working closely with amnesiac clients, I learned that from time to time they completely forgot where they were, who they were with, and what they intended to do. When this happened in public places, it resulted in anxiety and panic—not only for those with the memory problem but also for their family, who worried that their relative would get lost. To address this, I gathered a design team that included persons with amnesia. We developed an orienting tool that enabled users to instantaneously access key information to help them remember where they were going and what they were doing [1]. This tool, like many other external memory aids, was designed for individual use. However, my experiences since the orienting tool suggest that an individual focus is not sufficient. Family members often play a crucial role in the day-to-day functioning of individuals with cognitive deficits.

There are a few memory aids that involve caregivers (e.g., NeuroPage) [2], but they typically facilitate the flow of important information in one direction. Caregivers take on the role of inputting appointments, while persons with cognitive impairments primarily act as recipients of such information. A more powerful vision may be to enable a bidirectional flow of information—also allowing persons with cognitive impairments to actively exchange information they find relevant with their caregivers. Unfortunately, it is hard for designers and practitioners to develop such tools, because not much is known about how families coping with cognitive impairments work together.

**Families Collaborating
to Combat Memory Impairment**
I teamed up with colleagues from my university to carry out a field study of individuals with amnesia and their families [3]. Through observing them in

their natural settings, we found that the families successfully collaborated to combat the memory issues in a number of ways.

• Important information was stored and exchanged between family members and external artifacts. The artifacts served as mechanisms around which family members organized their activities and updated their schedules.

• Even though individual strategies for coping with amnesia involve repetition, I was surprised to see that the entire family was involved in repetitive processes to increase the reliability and availability of information.

• Families succeeded because they worked together very closely, as a unit. For example, family members often kept track of daily events of their relative with amnesia and would provide reminders throughout the day.

While the families succeeded in working together, they faced difficulties because of the memory impairment.

• Primary caregivers reported that they were overwhelmed with the amount of information they needed to manage, such as their own appointments, appointments of the care recipient, medication dosages, and various reminders. This led to increased effort and was a significant burden on caregivers, some of whom gave up full-time employment to make time to perform these activities.

• Family members differed in their opinions about what was important to remember or who should do the work of recording it. This often resulted in important information being left unrecorded.

• The amount of effort required and differences in opinions appeared to evoke high levels of stress in families.

Design Implications for Assistive Technologies

Our findings suggest that new tools that facilitate shared remembering, discussion, and coordination can be useful. Here are several strategies for improving the design of assistive technologies and for facilitating information sharing in families:

1. *Make reliable storage easy and available*

Families frequently accessed and recorded important information, and this needed to be done quickly and reliably. Therefore, recording and access to information must be easy and instantaneous.

2. *Automate redundancy, synchronization, and tight coupling*

Technologies to help families remember together can be useful, but designing collaborative tools for multiple users in multiple locations poses some challenges. Designers should allow users to access information from multiple places, have information from various artificial sources automatically synchronize to maintain accuracy, and enable family members to work together even when they are not in the same place.

3. *Increase awareness of information access and updates*

Families wanted to know when and how other people processed information. It is important for assistive technologies to provide information about whether family members received information and whether they took correct actions upon receiving it.

Presently, families work hard to adapt artifacts not designed with family systems in mind. Hence, rather than just focusing on individual rehabilitation, as designers and practitioners we should shift our focus to the rehabilitation of the entire family system and place our efforts in designing collaborative rehabilitation technologies.

Acknowledgements

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