Collaborating to Remember: A Distributed Cognition Account of Families Coping with Memory Impairments

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ABSTRACT

Individuals with cognitive deficits and their families are prime examples of collaborative "systems" that seek to perform everyday tasks together. Yet there has been little investigation into how these families communicate and coordinate in basic tasks like remembering appointments. In this paper we take a distributed cognition approach to studying ten families struggling with amnesia through nonparticipant observation and interviews. Our data show that the families work closely together as cognitive systems that must compensate for memory volatility in one of the members. We explore our participants' strategies for overcoming these difficulties and present lessons for the design of assistive technologies, highlighting the need for redundancy, easy and frequent synchronization, and awareness of updates. We conclude with implications for distributed cognition theory.

Author Keywords

Amnesia, family, collaboration, exploratory study, design, assistive technology, distributed cognition, theory.

ACM Classification Keywords

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

INTRODUCTION

Cognitive disabilities can occur in people of all ages, and involve impairments related to memory, attention, language and problem solving. Recently, there has been increasing interest among CHI researchers in the development of assistive technologies for people with autism [11], aphasia [1, 24], dementia [8, 23], amnesia [12, 14, 39] and other cognitive impairments [2, 25]. Such research plays the dual

role of seeking solutions for those who need them while simultaneously giving researchers the opportunity to study and learn from individuals whose unique cognitive needs challenge the boundaries of our understanding [28].

Most rehabilitation technologies to date, particularly with regard to memory disorders, have focused on restoring independence to those who are disabled [36]. Such systems allow individuals to track data such as future appointments [18] or contextual information to avoid losing the train of thought during an activity [39]. Given developers' focus on independence and individual rehabilitation, they have not considered the role of caregivers and other family members in the life of the person with the disability.

Yet our experience suggests that, even where rehabilitative technologies are in use by people with memory impairments, caregivers and families still play a crucial and integral role in the day-to-day functioning of these individuals. 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 needs more information about events as they unfold – they all do.

This experience is consistent with prior research suggesting that families often bear much of the responsibility for caregiving [6, 33], and that the adoption, use, and maintenance of assistive technologies often become a family responsibility as well [5].

Nonetheless, there have been few studies [10] of how families work together to provide care for individuals with cognitive disabilities. In the paper that follows, we present a study of ten families of persons with amnesia (PwAs). We draw on Hutchins' theory of distributed cognition (DC) [15] to argue that families of PwAs function as unique cognitive systems in accomplishing day-to-day tasks, and that it is this entire system that should be the focus of rehabilitative technology. This novel approach highlights the need for redundancy, easy and frequent synchronization, and awareness of updates in rehabilitative technologies.

BACKGROUND AND RELATED WORK

Amnesia and its Treatment

Amnesia can affect anyone – male or female, young or old. It results from an injury to specific brain structures responsible for memory processing. Common causes of amnesia include oxygen deprivation (e.g. following a heart attack), strokes, some forms of encephalitis, tumors, chronic alcoholism, or blows to the head.

Anterograde amnesia [4] refers to difficulty in consciously remembering activities and events that occur following damage to the memory systems. The extent and severity of these impairments to conscious recollection differs between individuals, depending on the location of the brain injury. Typically the knowledge base and skill sets acquired prior to injury are largely preserved. Amnesia is also characterized by preserved intellectual, problem solving and procedural memory abilities.

Procedural memory [34] refers to the ability to learn new skills and associations based on prior experiences without the conscious recollection of the experiences. Procedural memory forms the basis of our ability to acquire skills and habits that require repeated practice (e.g., swimming, touch typing). This memory system can form the basis of rehabilitation techniques that focus on learning skills needed for using memory aids such as a daily planner.

Cognitive Rehabilitation

Common compensatory strategies for amnesia are focused on supporting individual memory and include: using a memory notebook to schedule daily events, writing on pieces of paper and placing them around the home as reminders of important tasks, and repeating routines and procedures. While most of these are individual strategies for the person with the memory impairment, family members are often heavily involved in training, testing, and refining the techniques. As well, individuals with memory impairments often ask family members to remind them of important information.

Technology has also been used to combat a range of memory-related conditions. Over the past decade, a number of researchers and clinicians have had success designing and using technology to assist with memory deficits/losses [3, 12, 14]. Electronic memory aids such as personal digital assistants (PDAs) and pagers were used to meet the scheduling needs of PwAs [12, 18]. Kapur et al. [17] reviewed mechanical memory aids (e.g., pillboxes) and computer-based memory aids for patients with non-progressive brain injury and those with mild to moderate memory deficits. LoPresti et al. [22] surveyed low-tech and computer-based technological interventions for cognitively impaired individuals.

These projects focused on tools for individual rehabilitation, but individuals with cognitive impairments do not live in isolation. Their families are heavily involved in their rehabilitation. For example, many of the user studies described in the papers above required the help of family members. These family members integrated the cognitive aids into the lives of those with impairments, trained them to use the devices in real settings, provided support for the devices when they failed, and evaluated their effectiveness during longitudinal studies.

Wilson et al [38] describe a case study of a PwA who developed a sophisticated system of external memory aids (paper, alarms, etc.) over ten years to help him compensate for his memory. While the family members of this person did not participate in the daily operation of the system, they helped refine it. Oddy and Cogan [29] followed this work and observed in their own case study that the family played an important role in providing "emotional support" and "active and long-term help in devising, tailoring and monitoring compensatory strategies." A number of computational memory aids are explicitly designed to involve family caregivers, but these typically rely on family members for explicit input and instructions, rather than dynamic coordination and shared remembering. NeuroPage [12] is a pager system for assisting memory-impaired individuals in remembering appointments and tasks, such as taking medication. A caregiver uses a desktop computer to input prompting times and textual messages that are transmitted to the wearer of the pager at appropriate times. MAPS [2] is a guided prompting system that supports diminished executive and memory functions by providing verbal and pictorial prompts to a cognitively-impaired user. A caregiver uses a web browser to create various support scripts that are then shown on a client's PDA. MEMOS [35] is designed for memory-impaired patients with head injury. A therapist or caregiver uses a central server to supervise actions of the patient when he/she is outside. Memojog [26] is similar to MEMOS, but is designed specifically for memory-impaired older adults to support memory for prospective tasks. Memojog is composed of a PDA and a web-accessible database. The user, caregiver, or care professional can make changes to the users' schedule through the system. There are also coordinating tools for families of cognitively intact individuals [31], such as the calendar system LINC [27]. These tools differ from the above designs in that they are designed for the entire family and any member can access it.

We believe that improving rehabilitative technologies beyond the "caregiver as input" model requires a more subtle understanding of the complex interaction and coordination that occurs among family members as they help a PwA in living life day-to-day. Distributed cognition, described in the next section, provides a theoretical lens for exploring these processes.

Theoretical Framework: Distributed Cognition

In his theory of distributed cognition, Hutchins [15] uses the examples of navigators on a ship's bridge and pilots in a cockpit [16] to make the fundamental argument that cognition in these environments does not just occur within

the minds of individuals. Rather, it occurs in "cognitive systems" that involve multiple memory storage and processing units that are both humans and artifacts. These are then used by the system to accomplish specific goals, such as flying a plane [16] or steering a ship [15].

Distributed cognition (DC) helps explain how people use artifacts and work together to solve complex problems, paying particular attention to:

- *How knowledge is accessed and shared* [32]. Information in a cognitive system is encoded into representations and stored into artifacts that can facilitate sharing. For example, in navigating a ship Hutchins [15] talks about how information pertaining to where the ship is located relative to known landmarks is written into a logbook by the bearing taker for sharing with the plotter.

- *How communication occurs as the activity progresses.* Communication is a key aspect of a DC system. Representations that need to be communicated between members are propagated to other members or artifacts in the system. For example, the logbook described above is read by a plotter, who then carries out another part of the navigation process by calibrating a tool according to the data. [30]

- *How distributed units coordinate*. Another key aspect of DC is how members of the system are coordinated with one another. Hutchins [15] describes how a ship steers into a harbor by the coordinated activities of multiple people and artifacts working together to plot a fix. No one individual can be said to be navigating the ship. Rather, it is a complex coordinated activity that involves team members carrying out simple individual tasks that, when combined, help to locate the ship and where it is headed. [30]

We argue that the families of PwAs that we observed are also representative of cognitive systems. In our case, the goal of the system is to enable the PwA to lead a reasonably normal life, by ensuring that they remember appointments, have meaningful personal relationships, take necessary medications, perform household chores, and so forth.

DC presents a model of how we might expect such a family to behave when providing day-to-day support. For example, we would expect task-related information to be stored in various locations, both human and artificial. We would also expect frequent communication and coordination among family members, in which information is periodically shared and updated. As we will illustrate below, we saw substantial evidence of families behaving as cognitive systems. This systemic approach allows us to suggest novel design recommendations that are likely to substantially improve assistive technology design.

Moreover, the families we studied provide a unique environment for studying DC in action. Unlike Hutchins' navigators and pilots or Halverson's air traffic controllers

[9], the cognitive systems we studied all had a human memory component that was known to be volatile and could not be replaced by a more reliable component, as might be the case in a workplace or artificial memory system. Thus, studying this extreme situation [28] will allow us to preliminarily explore the potential impact of memory volatility on cognitive systems more broadly.

RESEARCH CONTEXT AND METHOD

The present study has been preceded by over a decade of work by researchers from the Memory-Link program at Baycrest, a major research and clinical setting working with senior citizens. Memory-Link is an outpatient service that supports adults who have severe memory problems, focusing on developing and training use of compensatory strategies by tapping into preserved memory systems (i.e., procedural memory).

Participants

Subjects and families were recruited from Memory-Link and were trained or were currently training to use Palm Zire 72s. Our study began with five such families who had been living with amnesia and were involved with Memory-Link for several years. To diversify our sample, we recruited additional families who were new to the program (see Table 1). By the time we observed the tenth family, our primary analysis showed that new observations were not adding significantly to our themes. and so we stopped collecting data. Our participants with amnesia were all male. We tried to recruit female PwAs but were unable to do so. Pseudonyms are used in this paper to preserve our informants' anonymity.

Case	Participants Observed	Year of Injury	Years in Memory-Link
1	Mark, Jane (spouse*), Bell (daughter)	1987	5
2	Charles, Linda (spouse*)	2002	3
3	Keith, Anna (spouse*)	2001	3
4	Stuart, Lily (ex-spouse*) Heather (health care worker)	2002	4
5	Peter, Sarah (spouse*), Emily (daughter), mother	2004	1
6	Alan, Claire (spouse*), two daughters	2004	0
7	Jacob, Eva (sister*)	1992	0
8	John, Tessa (spouse*), health care worker, mother-in-law, nephew	2004	0
9	Donald, Judy (spouse*), son, daughter	2005	0
10	Eric, Nancy (spouse*)	2005	1

Table 1. Overview of our participants. The first person listed in each case has amnesia. Asterisks denote primary caregivers.

Data Gathering

Detailed interviews or questionnaires alone are unsuitable for our participants with memory impairments because they have difficulty reporting on their experiences. Thus in addition to semi-structured and freeform interviews, the first author carried out nonparticipant observations [7]. We chose this method in order to avoid self-reported data, which could be compromised due to memory difficulties or caregiving stress [10].

Nonparticipant observation also allowed us to document processes that PwAs and their families might not be personally aware of. We were able to observe spontaneous events as they unfolded. Observations were carried out in an overt manner with full agreement of our participants, who were encouraged to proceed with their daily activities in a normal fashion. While participants may have been made slightly uncomfortable by the presence of an observer at first, there was no evidence to suggest that they modified their behavior in the long term.

Hour-long interviews were conducted prior to and following each group's participation in the study in which the PwA and their primary caregiver were interviewed together. Pre-interviews involved questions derived from our research questions. Post-interviews were freeform and used to clarify observations.

Families were observed between November 2005 and September 2006. Typically, we spent 2-3 days and 4-7 hours per day observing each family. In total, we conducted roughly 121 hours of observation that involved 31 people interacting in significant ways. We wrote 138 pages of field notes and took 331 photos of artifacts and environments.

Analysis

DC provides a lens through which we can understand how a group of individuals accomplishes complex tasks. In our case, we take the family to be the cognitive system and performing activities of daily living to be the complex task. Every day, a PwA must deal with errands, chores, tasks and appointments that must be remembered and tracked. These must be remembered to ensure they occur on time. They must also be tracked to ensure that they were completed for medical reasons (e.g., the doctor needs to know that proper doses of medication was taken during the month) or for later reflection or sharing with others. However, human memory volatility makes this difficult.

As information and memory are distributed over people, over artifacts, and over time, we focused our analysis on the complex interactions and information exchange between our study participants and external artifacts. We applied an open coding method but paid particular attention to the important elements of distributed cognition outlined in the theoretical framework section: how knowledge is accessed and shared, how communication occurs, and how coordination is achieved. We also looked at evidence of memory volatility impacting the cognitive system. By being

immersed in the lives of our participants, we developed domain expertise that helped to guide our analysis. At this stage of the project, we decided to start with a coarse-grained level of analysis. We found that this was sufficient in providing evidence that families coping with amnesia act as cognitive systems.

In the next section, we present our results, arguing first that the families worked together as cognitive systems, and then exploring the impact of memory volatility on these systems.

RESULTS

Families Functioning as Cognitive Systems

The first issue we sought to address in analyzing our data was the extent to which the families we observed constitute cognitive systems in the way Hutchins describes in DC. Despite the impaired persons' use of assistive technologies designed largely for individual usage, we saw substantial evidence in all of the families we studied that they were actually working together quite closely.

Information Storage and Access

As DC would predict, information was indeed stored and exchanged between human minds and external artifacts. Some of these artifacts were computer-based and some were not, but all of them were utilized for storing important information that was needed for everyday living. The families appeared to rely on less volatile memory sources, which tended to be artifacts rather than human memories. We briefly discuss two artifacts that the families incorporated into their lives: wall calendars and handheld PDA cameras.

Wall calendars were used by 6 of 10 families to plan and view prospective appointments (cases 1, 2, 3, 5, 7 and 8). The calendars were placed in high-traffic locations in the home, typically the kitchen. The one- to two- month view enabled coordination and awareness of upcoming activities within the family. The effort that families put into collaborative calendaring was surprising because we believed that the calendaring needs of the PwA would be met by the calendar application that ran on their PDA, which they have been trained to use on daily basis. What is interesting here is not how or where information is stored in the artifact itself, but that this artifact was being used by the group to manage information shared among people. In contrast, prior research on family calendars has shown that typical families have one person who assumes the role of primary scheduler [27].

Case 5: As an example of how these artifacts were used, Peter (the PwA), Sarah, and Emily updated their wall calendar by individually adding their events to the schedule (see Figure 1). The notes are colour-coded: red for personal events (e.g., work, taking the pet to the veterinarian, hockey game), and blue strictly for Peter's personal appointments. Planning was often done together, which was important because Emily's work afforded her some flexibility in choosing which days to keep free to help her father.
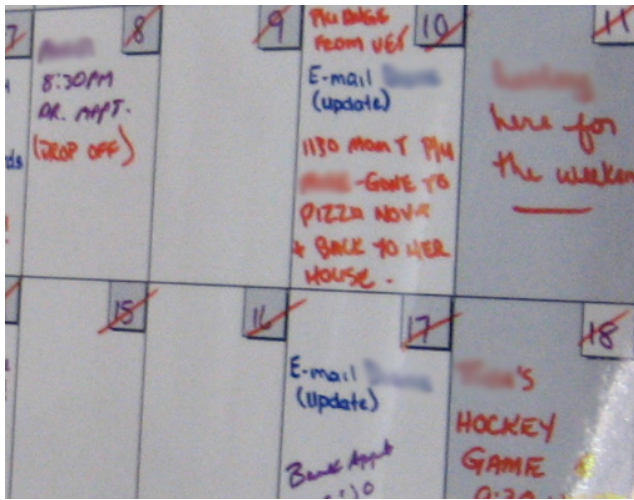
Figure 1. The activities on Case 5's wall calendar are written by various family members. They are colour-coded: red for general activities and blue for Peter's activities. Names have been blurred to preserve anonymity.

In 6 of the 10 cases, the PwA used the built-in camera of their Zire 72. These participants took photos of people and objects and showed them to others to supplement their recollections and also to help trigger their memories, as the following pair of examples show.

Case 3: Keith used his PDA to take photos of his new dog and his daughter skating. He learned by himself to move images taken with his digital camera onto his handheld device. Keith shares these photos with his brother and sister-in-law as well as his friends to tell stories.

Case 10: Using his PDA, Eric took a photo of a couch that he saw at the mall that he wanted to show his wife. He also annotated the photo and sketched the price so that he would not forget. Another time, he took a photo of his bathroom sink drain that he wanted to replace. He brought it to the hardware store and presented it to a sales associate who was then able to identify what he needed.

Redundancy in Information and Communication

Many individual coping strategies for amnesia stress the importance of repetition because of intact procedural memory in PwAs. However, rather than individual repetition, we saw that the entire family system was involved in repeating various processes. These redundant processes were used to increase the reliability of information exchange in the family as well as increase the availability of information.

A significant amount of the verbal information exchanged between PwAs and their families was redundant. In large part, this was because the PwAs would forget information and ask for it from their caregivers. As a result, there was a constant updating, checking, changing, and negotiating of upcoming appointments throughout the day. In fact, families often quickly switched from casual conversation to

sharing redundant information and then back to casual conversation.

Redundancy provided additional avenues for the PwAs to acquire information, thus improving chances that critical information will be remembered or retrieved when necessary. For example, we saw once in Case 5 that a simple piece of paper was used in combination with a phone message. Despite the fact that Peter, the PwA, was asleep, Sarah, his wife, wanted to tell him something. She left a paper note on the dining room table, which was their designated message passing location, and also followed up later in the day by calling home from work to leave a message on the answering machine. Thus, there were two ways that Peter could get the message and the redundancy therefore improved the probability that he would get the information.

Similarly, we saw evidence of redundancy being used to improve ready access to information. Important information was often replicated in multiple external aids so that information could be accessed more easily. For example, while the wall calendar kept shared events relevant to the entire family, these events were often replicated in paper-based planners for family members and in the PDAs for PwAs. This allowed them to access the calendar information from outside the home through their external aids. In fact, Claire (case 6) went so far as to keep old calendars of the past two years (i.e., old appointments) and doctor's cards (i.e., phone numbers) in her purse.

In one of the families (case 1), Jane coordinated her PDA with a paper-based wall calendar at home to ensure that her shared family data is current. She also maintained a copy of her husband's appointments in her device, which was similar to what the primary caregivers from cases 6, 8 and 9 did. In these cases, caregivers copied the PwA's appointment schedule into a paper-based day planner that they carried around. Such information was said to be important because it provided a level of awareness of where the PwA was at various times of the day.

It is interesting to note that in cases 2 and 3, the primary caregiver owned a PDA but did not use the device, mentioning that it took too much time to enter data.

All families, however, saw the need to synchronize information, and either communicated immediately as new information arose, or through weekly meetings (cases 1 and 2). As well, some caregivers accessed artifacts owned by the PwAs to check for new appointments and information that might have been added during the course of their days. As is evident from these descriptions, redundancy to ensure ready access to information required substantial effort.

Coordination Processes

The groups we observed succeeded because they worked very closely together as a unit. For example, members of each group were aware of the daily events of the PwA and would provide reminders to him about those events along

the day. They planned their schedules together and also shared information via artifacts such as photos, photocopies, and notes. We discuss two examples: collaborative planning and running errands.

In all families where the primary caregivers lived in the same household as the PwA (all cases but 4 and 7), collaborative planning of appointments was observed. The discussion surrounding these appointments revolved around ideal timeslots and the availability of family members to help with various tasks or transportation. An example of this interaction follows.

Case 1: After Mark checked messages on the answering machine, Jane reminded him to call George in order to reschedule their lunch meeting.

> Jane: You can have lunch Thursday with [your friend].
> Mark: No I can't… I have something (takes out PDA).
> Jane: Yes you can. You have a meeting but it'll be done at 12.
> Mark: (after checking PDA) Ok (calls his friend, speaks with him, puts phone down and updates PDA)
> Mark: (quickly, to Jane) Wait a minute, wait a minute. Jane starts speaking but is interrupted)
> Mark: Wait a minute. (Jane patiently waits 5-10 seconds while Mark finishes)

From a distributed cognition standpoint, there are two particularly interesting things happening in this conversation that make it clear that this planning activity involves a system of individuals, and that this occurs regularly. First is the tightly coupled interaction between Mark and Jane that occurs immediately before and after Mark's interactions with the phone and his handheld device. Second is the quick switching between use of human and artificial memory sources.

Many of these collaborative planning activities were structured to provide early awareness to all members of appointments (e.g., meetings with a doctor) and then provide more detailed information when relevant (e.g., scheduling to determine who can provide transportation).

Another example of tightly coupled action between PwAs and their caregivers was errand-running. This occurred in cases 1 and 5 and at a frequency of once every 1-2 days. Typically, this involved the caregiver driving the PwA to various locations so that important tasks could be completed. The caregivers drove in both cases and the conversations in the car often involved discussion of the tasks at hand, as well as updating each other about events in their lives. Here is an edited excerpt from the field notes of this kind of interaction, again from Mark and Jane.

> *11:40am:* Driving in car: Jane updates Mark on things going on in daughter's life.
> *12:00pm:* At the bank: As Jane parks car, Mark writes in his PDA that Jane is waiting in car outside. Mark goes by himself to do his banking.
> *12:15pm:* At the drug store: Jane tells Mark about radio broadcast and politics. Jane tells Mark she's going to shop for something. Mark asks what they are buying.

> *12:25pm:* Driving in car: Mark asks "So now what are we doing?" Jane explains that they're going to post office to weigh an item.

Two things are particularly interesting in this interaction. First is the level of detail that must be remembered, as when Mark writes in his PDA that Jane is waiting for him outside the bank. Second is the frequency and ease with which they switch between task-based information (e.g., reminders, updates, etc.) and casual conversation, suggesting that the practices have become ingrained in their daily activities.

We have seen substantial evidence suggesting that the families we observed were behaving as cognitive systems. We now turn to the question of how human volatility impacts these systems.

Impacts of Memory Volatility on the Cognitive System
The families we observed experienced stress and tension not ordinarily seen in cognitive systems due to the volatility of the memory of the PwA in each case. While the families were generally able to accomplish their goals successfully using the tactics we described above, they often had difficulty in doing so, due to three specific factors: 1) additional effort was required, 2) priorities were misaligned and coordination was difficult, and 3) stress was magnified.

Amount of Effort Required
While the work of remembering and reminding was shared by all members of the caregiving system, caregivers often bore a significant burden. Family members constantly provided reminders of events and people, kept track of the location of important objects, and helped organize the lives of the PwAs. These activities occurred throughout the day and dominated many conversations. The fact that redundant processes were used meant that extra work was required (e.g., repeating things that were said to the PwAs, triple checking that an important note was received).

Also, redundant information was often stored in different artifacts, and these sometimes needed to be synchronized. Synchronization was often a time-consuming process, as is shown in the following example.

Case 8: While John wrote into his journal, Tessa sat on the sofa and spent 20 minutes updating one of the calendars in the home before a phone call interrupted her.

> John: What are you working on baby?
> Tessa: Calendar. The calendar for the bedroom, then I have to transfer it over. (After 10 minutes Tessa goes to the fridge with her calendar to see if she missed any appointments on the fridge calendar. She sees a note on the fridge)
> Tessa: Ok, this (reading note) "[health care worker] 4pm", is this Wednesday or the Wednesday past? Did she make another appointment with you? Do you remember? She had a Wednesday appointment and it just passed. I'm wondering if she booked another appointment.
> John: Oh I think it's for this coming Wednesday. There was no room on the calendar [for me to write it].

Tessa: Oh, ok. Well she marked you for Tuesday already (referring to another upcoming appointment)
John: Write down her phone number on there just in case, that way if things don't work out you can call her.

In this example, updating the calendar required some work in checking multiple memories (John's memory, fridge calendar, fridge notes). Furthermore, the information on the note was unclear and John did not seem sure himself, leading to additional work that Tessa would need to do to confirm the appointment.

Caregivers of all families reported that they were overwhelmed with the amount of information that they needed to manage, such as taking care of their own schedules, the schedules of the care recipient, medication dosages and reminders, or medical information that the health professionals needed to be aware of. The primary caregiver needed to give up their full-time employment in several cases (1, 2, 6 and 8) to free up their time so that they could perform these activities.

Differences in Information/Task Prioritization

While it is common for individuals in groups to have different opinions and priorities, we found this to be particularly problematic in some of the families we studied. In particular, problems stemmed from differences in what was perceived to be important information that should be recorded or remembered, or in who should do the recording or remembering.

Case 2: Linda claimed that Charles writes "lots of useless things in his Palm like how many times the dog pooped during walks." Charles kept these notes mostly for himself as a running diary. Linda often suggested that he look back at his notes to remember what he has done. However, he did not do this on a regular basis, perhaps because his notes were fairly detailed. Linda does not read Charles' notes, but said that she would like to hear more about how his day went. He does not share as much as he did before his aneurysm due to his memory lapses. As Charles becomes more independent Linda has fewer cues and knows less about how he is doing. This is important information that she would like to know.

Such situations often led to information being left unrecorded, which could have had significant consequences for the family. The differences also created conflict between members of the group when deciding how to handle the situations.

Case 10: Nancy wanted Eric to report details about his seizures to his doctor but did not trust Eric to accurately do so because he had forgotten important details in the past. Eric did not record information when he was not feeling well and Nancy was not always around to record the details herself, so important information was missed and not relayed to the doctor.

Stress, Tension, and Frustration

The amount of effort required and the misalignment of priorities appeared to evoke high levels of stress in families. In fact, caregivers reported that managing information such as appointments, medications, and reminders on daily basis was a very stressful part of their lives.

All primary caregivers reported that dealing with memory issues was extremely taxing. They devoted a great deal of time and energy to providing reminders and cues when necessary. The amount of work added stress to the caregiver, which may have negatively impacted a couple of the families in the long-term. Two of the ten spouses in our study divorced their husbands with amnesia several years post-injury (one divorce happened many years before our study and the other happened after). We were sensitive to the personal nature of these decisions and did not ask for specific reasons, but it is certainly possible that this was related to the stresses involved with the spouses suddenly being cast into a caregiving role in which they needed to give up their employment and devote much of their energies to taking care of someone full-time (see [20] for a study on divorce rates after brain injuries).

Sometimes stress led to tense events during the day when priorities were misaligned. For example, stress can be rooted in spontaneous planning by the PwA. The PwA has difficulty remembering their family members' appointments and may decide to perform tasks that require their help (e.g., for transportation). When these plans conflict with the family members' schedules, family members will rearrange their day to accommodate, but this can be a frustrating and laborious job. Stress was evident in other situations as well.

Case 1: After a meeting between Mark, Bell, and a lawyer, Mark left the office before Bell. However, after saying goodbye to the lawyer, Bell did not see Mark outside the office and began to worry. She searched the hallways to no avail. Finally, she found Mark in an adjacent office retrieving a book. Bell was visibly upset and scolded Mark, "You have to tell me where you go! ...I'll put you on a leash!" He looked surprised as he himself had not yet realized that he had wandered off. Mark replied in a serious tone, "I forgot you were with me." This episode showed that a great deal of tension could have been avoided by a small information update, and that caregivers need to be constantly aware of the activities of the PwA and his whereabouts when outside the home.

Case 9: Rising stress led to a very emotional experience between Donald and his wife and children. Donald recounts that his son lectured him about his memory and mentions that ever since that incident, any mention of his health really stirs up things in his family. Judy explained that it has been hard on everyone and provides a different interpretation, "[He] thinks [our son] is telling him off... he's not. [Our son] is trying to explain things. They all looked up to father for help. Now, it's almost like

reversed." This frustrating experience may be more related to Donald's lack of awareness of his deficit. Donald feels that there is nothing wrong with him and that his memory has always been bad, so he cannot tell the difference between pre- and post-injury. However, based on his experiences with his family he does see that something is not quite right and comments, "Sometimes I wonder if I wasn't happier if I was a lot sicker. It'd be a lot easier to rationalize."

DISCUSSION

Despite these difficulties imposed by amnesia, the family caregiving systems we observed were still able to accomplish their goals by using the tactics we described above. In this section we describe design and theoretical implications of our DC approach to the problem of cognitive rehabilitation.

Design Implications

We saw extensive evidence of families working very hard together to adapt technologies that were not designed with cognitive systems in mind. Our findings suggest several strategies for improving the design of assistive technologies, and possibly for improving information sharing in families more broadly.

Make reliable storage easy and available

We saw many cases where information needed to be recorded quickly and reliably for easy access later by multiple individuals. In some cases, as when Mark had to write down where Jane was waiting for him, a PDA or camera was the best way to address this. In other cases, however, as when Eric failed to record information about his seizures because it was too difficult, it was not. Given the frequency with which we saw our participants access this information and its importance in their lives, recording and access must be easy and instantaneous.

When designing for PwAs, memory aids should facilitate the storage of details at the time of the event or immediately afterwards, since recalling details after a delayed interval can be problematic for individuals with severe memory problems. One way to ease the storage of information at the time of the event is to support the capture of rich media types like photographs or video. There are numerous projects demonstrating the benefits of easy capture such as SenseCam [14], a retrospective memory aid that captures a digital record of the wearer's day that includes images and sensor logs. The PDA cameras we described accomplish some of this, but sensors and video could augment this substantially.

Automate redundancy, synchronization, and tight coupling

While many existing assistive technologies appear to focus on rehabilitating an individual's memory or restoring their independence, our observations suggest that technologies designed to help families remember together may be more useful and effective. Design for multiple users in multiple locations raises a number of challenges.

It is important to make it easy to check or browse information from multiple places, such as multiple wall calendars or personal PDAs. Designs should allow users to make frequent updates to stored information, but these updates should involve some sort of "checks and balances" system to prevent significant confusion on the part of PwAs. Designs could, for example, support automated cross-checking of information such that it automatically synchronizes information from various artificial sources to maintain accuracy. In automating support for these processes, designers must be careful, however, not to eliminate the important coordination processes that redundancy facilitates – only the extra effort. Automation would save human effort.

In addition, tight coupling of action such as the scheduling of conversation we observed between Jane and Mark could be accomplished even when they are not physically together. This could be supported by, for example, allowing one family member to "suggest" activities that could be approved by another member.

Increase awareness of information access and updates

Many families wanted to know when and how information is processed by others in the system (e.g., whether they received the information, whether they took the correct actions with regards to the information). Designs should therefore incorporate awareness of who makes "read" and "write" actions on information stored in the system and when they do.

For families coping with amnesia, this might be accomplished by having technology track how information flows from artifact to person and vice versa for various activities that need to be done by the family system. The information could then be presented to family members on a handheld device or PC visualized in some way, perhaps using something similar to the "edit wear and read wear" visualization technique [13] that displays history of author and reader interactions with a document in an abstracted graphical form. This would provide awareness of access and update activities to members of the family.

Theoretical Implications

While we used DC primarily as a lens with which to view the collaborative activities of families of PwAs, we also had the opportunity to study a unique type of cognitive system. This perspective gives us some insight that allows us to derive some preliminary implications for DC, though more research is clearly needed to fully explore these ideas.

Prior DC research has explored memory failures in pilots and air traffic controllers [9, 16]. This research does address system reliability and uses redundancy to help reduce the number of errors. However, there is an implicit assumption in DC that no one memory source is more likely to fail than

any another. DC does not explicitly account for the degree of volatility in a memory source, only that it exists. Our study illustrates a very profound volatility beyond those mentioned in previous research and this is the key issue in our domain that separates family systems coping with amnesia from other systems. If we can identify unreliable sources in a given system and account for them theoretically, the reliability of the entire system can be improved. While our results showed that the families we observed were robust cognitive systems that coped with the volatility of memory through a variety of strategies, we also saw that this was difficult and stressful for the families.

Our findings suggest that the reliability of human components in a cognitive system can impact stress and affect relationships between all members of that system. While this may not be surprising, we must consider the importance of personal relationships in effective communication, coordination and information sharing [19], which are the very foundations of DC. This is particularly true when it is not possible to remove or replace the component known to be volatile, as is the case with the families we studied. This suggests that the role of relationships in DC (e.g., how the cognitive system is affected by stress, power, feelings of resentment) deserves more careful study. Past research in work environments also advocates incorporating social, cultural and organizational factors into the cognitive framework [9]. However, work domains involve formal relationships between coworkers where role expectations and norms may be clearer than informal relationships in the home where roles are often poorly defined. The focus on the role of relationships is perhaps more important in home settings because individuals may be particularly sensitive where disabilities (or the perception there of) are concerned.

Our insights have arisen from our studying of scenarios with known volatility, which simplified what we were observing. However, all memory is imperfect and there are various degrees of imperfection. Therefore, our observations may be pertinent to many other settings beyond amnesia. For example, this may impact prior research on how persons with Alzheimer's Disease manage their informational needs with family caregivers [10].

LIMITATIONS

All of our participants with memory impairments were male due to difficulties in recruitment. It would be valuable to compare our results with families having female PwAs.

Our results are an interpretation by the first author and thus subjective. Yet the third author who is a clinician for the PwAs independently verified that the facts reported were consistent with what he observed himself from his interactions and years of history with his clients. We also recruited a volunteer to observe four support group meetings at Baycrest and thereafter assist in our analysis of field data. She confirmed that our interpretations were consistent with hers.

The presence of the researcher may have changed the behaviour of our study participants. On the other hand, the researcher strove to maintain non-participant status. The majority of interactions did not actively involve the researcher and the dynamics of the interaction did not appear to be significantly altered. Our interview data tended to confirm this.

CONCLUSION AND FUTURE WORK

We presented a study of ten families coping with amnesia. Our results showed that they worked together as cognitive systems yet were affected by the memory volatility of the PwA. We discussed design implications for assistive technology and theoretical implications for distributed cognition. At the stage of writing this paper, we have designed a collaborative memory aid to support PwAs and their families. Our design has been informed by findings from this study. We are implementing this design and will evaluate it in a longitudinal study.

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