Participatory Design of an Orientation Aid for Amnesics

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ABSTRACT
We present the participatory design and evaluation of an orientation aid for individuals who have anterograde amnesia. Our design team included six amnesics who have extreme difficulty storing new memories. We describe the methods we used to enable the participation of individuals with such severe cognitive impairments. Through this process, we have conceived, designed, and developed the OrientingTool, a software application for Personal Digital Assistants that can be used by amnesics to orient themselves when feeling lost or disoriented. Two complementary studies were conducted to evaluate the effectiveness of this tool in ecologically valid contexts. Our findings suggest that the OrientingTool can improve an amnesic's independence and confidence in managing situations when disoriented, and that participatory design may be productively used with participants who have significant cognitive disabilities.

Author Keywords
Participatory design, anterograde amnesia, users with disabilities, assistive technologies, orientation aids, cognitive prosthetics, Personal Digital Assistants.

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

INTRODUCTION
Anterograde amnesia [7] is a memory deficit that impairs an individual's ability to form and retain new information following a brain injury. Memories formed prior to the brain trauma are more easily recalled. Though this selective deficit spares other cognitive functions, people with anterograde amnesia have great difficulty managing their lives because of their difficulties in retaining information relevant to their day-to-day lives.

A major issue of concern for amnesics and their families is the problem of disorientation. Even when traveling with caregivers, amnesics are susceptible to feeling lost and disoriented in various settings because of their difficulty in recalling recent events. Such episodes are typically accompanied by anxiety and panic, often compounded by the rush of noise and commotion in unfamiliar public settings. Amnesic individuals have few established strategies for dealing with such scenarios. If caregivers are present, they often will cue the amnesic back to normality by telling them the details of the current situation, but when amnesics are alone – even temporarily – the end result can be devastating. Because they have difficulty thinking back through the day's events to try reason what is going on, amnesics may call for police assistance or even wander around the city looking for a familiar landmark that might give a clue to where they are and what it is they are supposed to be doing. In either case, their loved ones often helplessly wait and worry.

A participatory design team involving six amnesics was created with the goal of designing a computer tool to address this problem of disorientation. In this paper, we present the design process used and the system envisioned by our participatory design team. The resulting application is called the OrientingTool and it presents situational information (for example, time of day, location, user intentions and goals) to help an amnesic who is disoriented get back on mental track. We have trained several amnesics how to use our tool and have conducted two complementary user studies to evaluate its effectiveness in ecologically valid contexts. Finally, we discuss the implications of amnesia on the design cycle as well as its influence on the tool we built.

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

RELATED WORK
Research into orientation devices has typically been limited to wayfinding and obstacle avoidance [2, 4, 14]. Such

systems provide location and position awareness. In developing several wearable orientation and wayfinding interfaces, Ross and Blasch [18] noted that orientation information should include: current location and heading, distance and direction, overall layout of the surroundings, and things of interest to the user in the environment. The first three items aid spatial orientation and mobility; the last item suggests that additional information relevant to the current situation is needed. We believe that situational information such as intent of a user's actions and context should also be included in orientation. Some of this information can be provided by memory aids.

Researchers have argued for the use of electronic devices as external memory aids in the rehabilitation of memory-impaired individuals [11, 15]. Many such devices use built-in alarms to remind patients to carry out tasks at particular times while messages are displayed to provide details of the task. For example, NeuroPage [10, 22] is a pager system for assisting memory-impaired individuals in remembering tasks. A caregiver uses a desktop computer to input prompting times and messages. At the appropriate times, the pager transmits those messages to the wearer through a small display on the pager. MAPS-LifeLine [5] is a guided prompting system that supports diminished executive and memory functions by allowing caregivers to track and support clients in remote locations. A caregiver uses a web browser on a desktop computer to create support scripts that that can then be used on a client PDA while clients perform day-to-day activities such as shopping. Both NeuroPage and MAPS-LifeLine are distributed support systems in which caregivers must be able to create plans in addition to ensuring successful task completion. In contrast, the goal of our work is to focus on improving self-sufficiency and thus independence in memory-impaired individuals. We hope to support them as they manage their own plans, thereby interactively participating in their own rehabilitation.

Perhaps the most promising orientation aids are mainstream PDA applications. Reminding software such as Note Pad (in the PalmOS), BugMe! (http://www.bugme.net/bugme/), and DiddleBug (http://diddlebug.sourceforge.net/) allow someone to store short notes on their PDA, which can later be displayed through an alarm. These notes can take the form of prospective tasks such as a mental note to remind oneself that a task needs to be completed at a later time. As a result, these applications can be used for storing notes that convey orientation information. However, none of these general-purpose applications have been designed for memory rehabilitation nor do they allow management of a situation in a structured way.

BACKGROUND

Our current project has been preceded by over a decade of work by researchers from the Baycrest Centre for Geriatric Care, a major research and clinical setting working with senior citizens and patients with deficits such as amnesia. One of their major research agendas focused on developing non-technological compensatory strategies for people who have memory impairments. Richards et al [17] developed a paper memory book to assist memory-impaired individuals in carrying out prospective memory tasks. These tasks include scheduling appointments, storing contact information and recording messages for others. The memory book consists of a specialized alarm mechanism and a binder with paper-based day planner enclosed (see Figure 2).

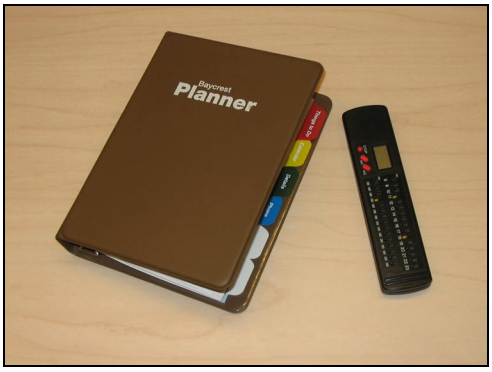

Figure 2. Memory book (alarm detached for illustration).

More recently, Richards et al. have extended their work by successfully training individuals with amnesia to move from their paper-based memory book to electronic PDAs (Palm Pilots). They used mainstream scheduling software, and evolved training techniques for electronic media based on the techniques they developed for the paper artifacts. This is the context of our current research.

FIELD STUDY

To better understand the domain, we conducted a set of semi-structured interviews. A total of 18 people participated in these interviews: 8 amnesics, 8 caregivers (of the amnesics), 1 health care worker, and 1 occupational therapist. It was important *not* to solely rely on the responses from the amnesics because their memory deficits could interfere with data collection. Yet they are our primary informants, and their mental faculties other than memory are strong, so we needed to hear their voices. We recruited our interviewees from a group of amnesics and their families who were involved with the Memory-Link program [1] at Baycrest. The Memory-Link program is an outpatient service that aims to train and support amnesic individuals and their families. The program includes participation in a psychoeducational support group, skills training for memory aid use, and resources and links to other relevant services in the community. Consequently, there was a bias in our sample population. The amnesics we interviewed had been utilizing memory aids that have been developed at Baycrest (in particular, the paper-based memory books). Though members of this group were not representative of "typical" amnesics who are likely to have had less formal memory training and support, we learned a great deal from this relatively small population. We arranged the interviews as site visits, in which a researcher would visit the homes of the amnesics and their families to learn more about memory

issues and how they impact their lives. See [26] for details on the insights gathered from these interviews.

The motivation for our work arose from discussions with our amnesic participants during our interviews. One amnesic individual described a situation during which he experienced disorientation and high levels of anxiety as a result. He was on vacation in an unfamiliar city. On this particular day, he was in a casino. As he exited the restroom facilities of the casino, he suddenly realized he had no idea where he was, what he was previously doing, or even who he was with. Looking about, he knew that he was in a casino, but did not recognize any landmarks. He tried to think back and trace through what happened that day, but could not recall anything. Becoming very anxious and feeling lost, he literally shut down and decided to stay where he was, figuring someone would eventually come and find him. Fortunately, his wife, who was concerned about his long absence, went to look for him and did indeed find him.

This issue of sudden disorientation was more prevalent than we at first believed. We found strong evidence of wandering due to disorientation in all our amnesic interviewees and families. The majority of the family members considered that losing their loved one in a crowd was one of their primary fears. Six of the eight amnesics that were interviewed have experienced situations in which they have become totally disoriented while out on their own. The remaining two have had milder disorientating experiences lasting minutes, mainly because their family members tend to keep a tight watch over them and are usually around to cue and reorient them. While all the amnesics indicated that they had experienced these milder episodes of disorientation, there were individual differences in the frequency with which they occurred..

The amnesics we interviewed had various techniques for handling the situation when lost. Responses following an episode of disorientation were unpredictable; Different families dealt with the same situation in different ways. One amnesic acknowledged that he tried to wander around to see if he could recognize any landmarks. In contrast, two other amnesics reported that they adhere to a basic rule of staying within the same building when lost. Another amnesic typically resorts to calling a taxi to return her to familiar territory. In 3 incidents, police assistance was required.

PARTICIPATORY DESIGN APPROACH

We decided to take a participatory design approach [9] for several reasons. Special needs populations have often been marginalized and thereby disadvantaged, but the principles of participatory design advocate respect for all collaborators and thus encourage all participants to contribute. Also, personal expertise is extremely important when special needs are considered. It can be extremely difficult for designers to imagine the experience of coping with a cognitive impairment, resulting in a gulf in understanding between the impaired and non-impaired individuals' experiences of the world. This gulf can be bridged through mutual learning [3], a key tenet of participatory design.

We gathered a multidisciplinary design team that consisted of six amnesics, one neuropsychologist (third author), and one computer scientist (primary author). Our design team was diverse in age (ranging from 25-55) and past occupations (including a judge and power tools designer). Our amnesic participants were selected from a larger group of amnesics involved with Memory-Link. We selected participants whose level of memory function enabled them to retain some memory for workable periods of time, rather than involving the most severely impaired amnesics who were unable to retain information for more than a few minutes. The amnesics have been living with amnesia for some time and are aware of their cognitive strengths and weaknesses. They provided many first-hand experiences and insights into their memory difficulties.

Doing participatory design in the face of such cognitive impairments was challenging, so we architected the design process to accommodate working with amnesics. We used four techniques to directly support memory during and in between design sessions. In the next subsections we provide a brief description of these techniques to highlight our approach. For a more thorough elaboration on our participatory design process including the activities, artifacts, rationale, and how they fit into the broader notion of participatory design with vulnerable individuals please see [25, 26].

Incorporating Structure in Review and Activity

The most obvious solution to the problem of forgetfulness is to review items throughout a meeting, using redundancy to advantage. We have found through our interviews that presenting details at a later stage can help trigger recall of the larger memory encompassing those details. At the beginning of each session, we verbally reviewed the key components from the previous session to put the current meeting into context. At key points during a meeting, such as before a consensus decision was to be made, we would review key details, including arguments from different perspectives. Finally, at the end of each session we discussed choices that were made throughout the meeting.

From our interviews, we learned that amnesics often deal with problems in a structured manner to increase the chances of successfully completing a task. We thus tried to use activity structuring as much as possible. For example, in one of our meetings, content was divided into sections, and each section had one or more goals that were to be addressed. Since each section was independent of the others, there was no need to recall earlier details of the meeting at later points of the session.

Emphasizing Physical Artifacts

As with past case studies [23], our field study had shown that amnesics rely heavily on external memory aids, such as a calendar or an action item list. This is somewhat equivalent to memory triggers, for example strings on fingers, which people use when they want to remind themselves to do

something. With an amnesic, however, using a strategy such as a string on their finger will likely fail because remembering the original message attached to the trigger is difficult. Thus, though physical artifacts can aid memory, they must be used in a specific way.

We used two different kinds of artifacts in our participatory design sessions. Paper documents such as meeting agendas and use case scenarios were used extensively for guiding discussions. We also created physical artifacts such as storyboards and referred to them when relevant to our discussion (see Figure 3).

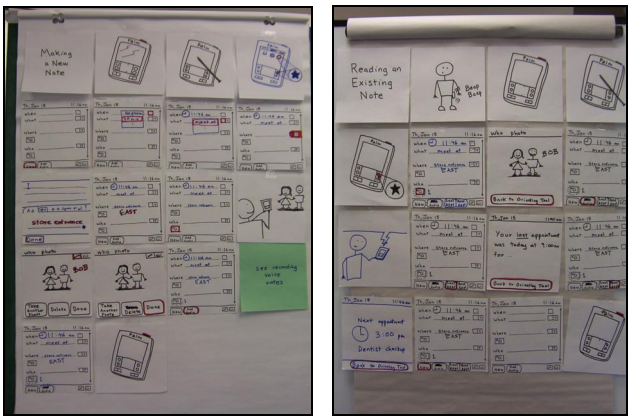

Figure 3. Two example storyboards illustrating device usage.

Creating Environmental Support

Some research has specifically used a person's environment to reduce the demands on memory [6, 20]. A simple illustration is the use of name tags that allow people to refer to one another by name. The tags remain with their wearers and constitute a part of the environment. Names need not be committed to memory because of this external support.

One example of how we made use of environmental support is in the location we decided upon for our design meetings. We arranged to use a board room at Baycrest. All of our design partners agreed that the room conveyed a feeling of importance. We utilized much whiteboard space along with poster stands and physical artifacts within the room to help provide various distinctive contextual cues to aid memory.

Documenting Design History

Supporting memory between design sessions is one goal in the field of design rationale, which seeks to capture and maintain documentation detailing how designers reason and arrive at their decisions [16]. Though creating documentation can be tedious and time consuming, it becomes vital when working with amnesic individuals.

One way of supporting memory between weeks is to allow all participants to take the contents of the meeting with them when they leave, so as to allow review in between sessions. We knew that each member of our design group used a Palm device on a daily basis. We wanted to make use of the Palm to store meeting notes that would be typed up on a laptop during a meeting, so we beamed these notes to each Palm. In this way, members could take home the minutes and would have access to them throughout the week. Since the memo application was frequently used, the likelihood of reviewing the material from our meetings was reasonably good.

ORIENTINGTOOL APPLICATION

We wanted to develop a system that could be used to help an amnesic get back on track after disorientation. The basic premise is that amnesics would carry around PDA software that would provide contextual information to cue them to the current situation.

Our approach is to have the user enter contextual information into their portable system before they begin an activity that may lead to disorientation and then have the system return that information later when needed. This requires that an amnesic must make a conscious effort to input the data beforehand, but how can someone know in advance that they will get lost? Through our interviews we learned that amnesics know their limitations and are good at recognizing situations in which they may be vulnerable. Amnesics have comfort zones, or routines and places with which they are familiar. Oftentimes, it is the deviation from these zones that leaves an amnesic susceptible to being lost or confused. The ultimate vision of our system is that it will allow someone to push beyond their comfort zone and independently explore new spaces and new situations. Reliability of the device would instill more confidence in one's ability to expand their experiences and situations, rather than solely sticking to what is currently comfortable or known.

As members of Memory-Link, our amnesics each owned and operated Palm devices, so our design team chose to design for the Palm platform. We developed the OrientingTool, a software application for Palm Pilots that can assist an amnesic who becomes disoriented. We used the Palm Zire 71 (http://www.palmone.com/) as the PDA hardware for prototyping the OrientingTool (see Figure 1). The software application was developed using C++ and runs on the PalmOS 5 platform. Our application was also programmed to be backwards compatible with PalmOS 3.5 and will thereby run on the majority of existing Palm devices on the market.

Basic Functionality

Once the OrientingTool is launched, its main form is displayed (see Figure 4). This form is used to record the current situation. It is also the same screen that is shown for cueing an amnesic. The main form always shows the current day and time at the top of the screen. The body of the form is organized into four sections, labeled by: When, What, Where, and Who. The What, Where and Who sections each contain a labeled pop-up trigger, a text field, and a button. The text fields are filled in with appropriate information pertaining to the situation. A set of buttons are listed at the bottom of the screen. The New button clears the form completely. The Today button retrieves and displays all appointments on the current day from Palm's Date Book application (Date Book is an application provided by the

Palm). The Done button signals that a complete note has been entered into the application.

Having all the details on one screen allows an amnesic to see the pertinent information all at once, decreasing the chance that the user misses some information because of inaction or lack of adequate exploration.

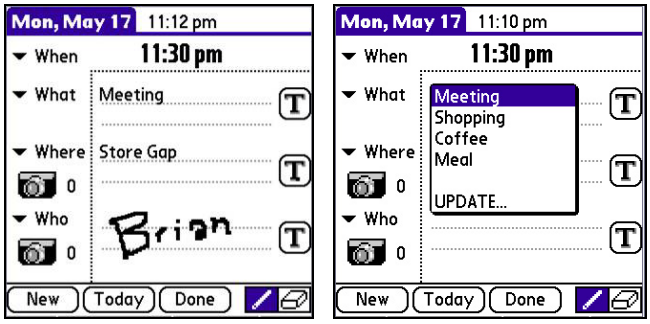

Figure 4 (left) The OrientingTool main form. (right) A shortcut menu is displayed when the What trigger is tapped.

Tapping on one of the four triggers will activate a menu of options. For example, the What shortcuts are displayed on the right in Figure 4. For the What, Where and Who triggers, the menu lists a set of shortcut options. Tapping on a shortcut will insert text into the text field. Similarly, the Who trigger pops up a list of names and a subsequent tap on a listed name dismisses the menu and appends the selected name to the text field. We incorporated these shortcuts for commonly used phrases to help reduce the total interaction time because entering words through a digital keyboard can be slow.

Tapping on one of the buttons (labeled T) beside a text field will bring up the system keyboard so that customized text can be appended into the associated text field.

The When pop-up trigger is used to set an optional alarm for external prompting to request user attention. This feature is intended for spontaneous meeting arrangements, rather than scheduled appointments (like meetings with a doctor) that are kept in the Date Book. When the trigger is tapped, a list of durations is presented (1 min, 5 min, 10 min, etc). As opposed to how an alarm is set with the Date Book, where a time (precise to the minute) is explicitly set using at least 7 taps, the alarm in the OrientingTool is set using only 2 taps (one to trigger the menu, one to select the interval). After the user selects one of the options, the system calculates the time that the alarm will ring and displays this time to the right of the trigger. When the alarm is triggered, a series of reminder screens that is consistent with how Date Book behaves is presented to get the attention of the user.

EVALUATION

One of the fundamental difficulties [15] in evaluating the effectiveness of cognitive aids is demonstrating ecological validity. This is largely because many experiments require that variables be controlled, a feat easier to achieve in the laboratory. While demonstrating use of a system in a laboratory environment is useful, this may shed little light on effective deployment and use of a device in real situations. We wanted instead to observe OrientingTool usage in ecologically valid contexts.

We conducted a pair of user studies: one short-term focused evaluation, and the other a medium-term freeform study. We were interested in how the application would be used in real settings, but we faced an unusual dilemma. The goal of the OrientingTool is to help amnesics when they are feeling lost or disoriented, but we wanted to avoid placing them under any source of anxiety during our evaluations. Therefore, in our first study we orchestrated some reasonable situations and made direct observations. In our second study, we installed the OrientingTool on the amnesics' Palm devices so that it could be used with their families in real situations. However, it was made clear to each participant that the tool was only to be used in situations with which all parties felt comfortable.

We first trained the amnesics for skill acquisition using scenarios as examples, then we let them enact scenarios at a mall in a designed situation, and finally we allowed them to use the tool both at home and away from home in arbitrary situations.

Training

Over the past decade, researchers have discovered that procedural memory systems are preserved in amnesics, who are capable of learning new associations and interaction sequences under specific conditions [19, 21]. Amnesics are able to learn how to do something through repetition. For instance, they can learn how to type through practicing on a keyboard, but will not be aware of how or when they learned. We have made use of much of this past research as we trained our amnesic participants to use the OrientingTool.

In total, 7 amnesics and 7 trainers participated in hour-long training sessions. One amnesic and one trainer would progress through 20-30 trials each day. An individual trial consisted of all the interactions involved with the entry of one note into the OrientingTool. Trainers verbally provided scenarios and reinforced details as required, simulating a situation akin to an amnesic receiving cues from a caregiver. We were successful in training all our amnesics and noticed that the skills were fully retained even after several days. Further details may be found in [26].

Evaluation Phase 1: Short-Term Focused Study

We planned a two-hour evaluation of the OrientingTool in a local shopping mall so as to test a scenario in which there were many possible realistic distractions. A total of 15 people were involved in this evaluation: 6 amnesics, 7 confederates, and 2 observers. We were curious to know if there might be a difference in reactions to the OrientingTool between amnesic designers in our group and amnesics who were not involved with design. As such, of the 6 amnesics, 3 were from our design team and 3 were not. One of the participants (F) acted as a control in our evaluation. He had not been previously

trained to use PDA's, but made use of a paper memory book [13, 17].

Each amnesic had the OrientingTool loaded onto their Palm, and was paired with a confederate partner. The paired teams were to meet at designated times and locations throughout the mall, but before these meetings, the teams were to engage in shopping activities that included: product price matching, finding a gift or item, and collecting specific product details. We chose these activities as they are common shopping tasks. The activities were presented to the teams as a scavenger hunt, to be completed as the partners worked together. Each team received a different selection of activities. We ran 3 trials in total, with each trial lasting for 30-40 minutes. All the pairs had to meet together at the same time. We chose this format instead of meetings between two pairs because we did not want any groups waiting around should one of the groups miss their meeting. No amnesic worked with the same confederate more than once. This allowed us to examine each amnesics' tool usage from at least three perspectives.

The confederates were to stay with the amnesics to ensure that they did not get lost, and they also helped as direct observers, distracters, and prompters. At the end of each trial, the confederates recorded notes about usage of the OrientingTool. During trials, in order to prevent the amnesics from consciously concentrating on remembering that a meeting was scheduled, the confederate partner acted as a distracter by engaging the amnesics in shopping activities. If after 10-15 minutes the amnesic did not inquire about what should be done next, then the confederate casually asked if they remembered what should be done next. By doing so, we observed if the prompting led to access of the OrientingTool. We also wanted to know whether or not the notes could trigger a correct recall of the situation, how much prompting and intervention was needed to use the device, and if there were any spontaneous unguided accesses to the OrientingTool by the amnesic.

During the trial, some confederates asked the amnesics if they knew what was to happen next, and watched if the amnesics responded by checking the OrientingTool. Confederates also watched for any checking of the tool without external prompting. We paid attention to the alarms, errors in tool use, and whether or not additional reinforcement from the confederate was needed when the amnesic made an orienting note.

Evaluation Phase 1 Results

Ambient Noise Obscuring the Alarm Cue

We did not anticipate that the ambient noise in the shopping mall would interfere with the Palm alarm, but the alarm was heard in only 7 of the 15 trials despite being set to maximum volume. In one of these trials, only the amnesic heard the alarm while the confederate did not. In the six other cases when the alarm was noticed, the pairs were either away from the traffic of people or walking inside less busy stores. In the cases when the alarm was not heard, the confederate prompted the amnesic five minutes after the meeting time asking them if they knew what was to happen next. In every case that this was asked, the amnesic took out their Palm and checked. Upon activating their Palm, a reminder screen was already displayed (as in the default behaviour of the Date Book) that was used to see the last input OrientingTool note. In 12 of the 15 trials, the amnesic then mentioned relevant information to the confederate.

Spontaneous Use of the Tool

We observed two instances in which an amnesic spontaneously checked their device without an alarm or confederate providing the cue. In the first case, subject Y wanted to check the meeting time before proceeding onto the next shopping activity. He checked his Palm and realized that the alarm had already gone off. In the second case, the confederate partner of subject M wanted to sit down briefly to jot down a few quick notes. As the confederate sat down, subject M asked aloud what time the next meeting was scheduled for while pulling out his Palm. He saw that the meeting was to happen soon and voiced the location to the confederate. Shortly thereafter, another pair (Y and confederate) walked by and subject M pointed out to them that they were heading in the wrong direction for the next meeting. Subject Y then pulled out his Palm and confirmed this. This sharing of information by the amnesics occurred in 3 of 15 trials (2 of these were as a result of spontaneous access to the tool).

Dependence

In the first trial, only half of the pairs made it back to the meeting location in under 30 minutes. The confederates did not know the meeting times or locations until they were announced to all the pairs. In one instance, the confederate was actually relying on the amnesic's Palm to ring at the proper meeting time (she forgot the group meeting time).

There was a notable difference between the pairs using the OrientingTool and the subject that did not. Subject F relied almost entirely on the confederate to remind him of the meeting. The confederate used his watch for timing. In all trials, subject F did not want to use his paper memory book, saying that it was used for other things (scheduling, phone numbers, etc). He did write the meeting details on the mall map that he carried. However, this was not reliable because he forgot to check the map. Not surprisingly, the reliance on the confederate added greater responsibility and a larger mental load on that individual.

Errors

In 6 of the 15 trials, the amnesic initially started to use the Date Book to schedule the meeting. In five of those cases, the confederate pointed out that there was something else that could be used, and upon hearing this, each of the amnesics made use of the OrientingTool. In the lone case where the confederate did not realize this, the amnesic (subject J) used the Date Book to schedule the meeting. However, the alarm

in the Date Book was not set, and so when it came time to meet there was no cue. Upon closer examination of how the Date Book was used, no contextual information was added other than the meeting location. He neglected to specify that there would be a meeting, nor did he mention who would be present.

Evaluation Phase 2: Medium-Term Freeform Study

A second evaluation (running 3 weeks) was planned to explore real situations in which the OrientingTool might be spontaneously used. We wanted to better understand how the tool is utilized, in what situations, and how often the caregivers provided cues or prompts. We realized that any solution that would be integrated into the amnesics' lives must involve the caregivers or family, who must be constantly present for prompting until the behaviour is learned. We handed out observation sheets to each of the family members for recording every instance of tool use.

We installed the OrientingTool onto the Palms of 5 amnesics and asked them to make use of the device in situations with which they felt comfortable. 4 amnesics who participated in this study were from our design team (D, M, J, L). Amnesic Y was not a designer, and lived independently; as we noticed that he had used the tool spontaneously in the first evaluation phase, we included him in Phase 2.

We held two general group meetings, one after the first week and the other at the end of the 3 weeks. All the family members and the amnesics were invited to discuss their experiences with the OrientingTool and suggestions for interface or functionality improvements. For those members who missed any one of the meetings, phone interviews were arranged. In addition to these direct discussions, some computer logging was also done and this data showed that there was consistency between what the amnesics and caregivers reported. The third author of this paper is the clinician responsible for care of these individuals. He was able to confirm the credibility of the data in terms of his long experience with the amnesics and their caregivers.

Evaluation Phase 2 Results

In our first user study, we knew that some of the amnesics might be cued to use their tool by other amnesics who immediately used it within their proximity when the meeting times and locations were announced. In contrast, this second study paid closer attention to whether or not the tool would be spontaneously accessed for input as well as checking without external cues.

There were at least 11 uses of the OrientingTool during the 3 week period. The situations included setting up a lunch meeting, getting back to finish the laundry, returning from a biking trip, shopping, walking the dog, and waiting for an appointment. Amnesic M's caregiver observed that once they become more accustomed to using the tool, they would be able to use it much more often. Amnesic L mentioned, "I use it… oh… about two times a day", becoming "…very comfortable using it." He had used the OrientingTool very much independently from his family member, who did not supervise use of the tool at all, but noticed through casual observance and discussion that it was being utilized daily.

Initial Reservations

There were some initial reservations from three of our amnesics (D, Y, L) because they felt that the OrientingTool was a duplication of the Date Book functionality, but when they started to use the OrientingTool, they began to understand the differences and found the tool useful. A caregiver observed, "When he finds it helps, then he'll use it. First he thought it was the stupidest thing... He thought it was duplication, and now he sees the use for it." At the same time, one amnesic was reluctant to use his OrientingTool when he was prompted because he felt he would remember the detail. His family member commented, "He'll get mad at me because he thinks he can remember that one little thing. Like if he wants to do the laundry or something around the house, he thinks he'll remember and I can't sort of remind him because he'll get mad at me… Even with this new tool, he got mad at me the first couple of times we tried it… But he goes 'You know what? This works.' And then he did it on his own because he went to take the laundry out and there wasn't anyone to go with him, and he used it – on his own."

Spontaneous Use of the Tool

Spontaneous use of the OrientingTool is a vital step for autonomous functioning. At least 5 cases were spontaneous in that the amnesic chose to use the device without prompting from another person. Of these uses, 2 were for laundry, 2 were for waiting for an appointment, and 1 was for setting up a lunch meeting. Amnesic L mentioned that he used the tool by himself at least twice a day. This was confirmed by the family member who did not prompt him at any point during the 3 week period.

Sample Personal Accounts and Interface Implications

On the first day after the tool was installed, amnesic L was waiting by himself at Baycrest for a doctor's appointment at 3pm. He arrived early at 2:20 pm and decided to stay in the main lobby as there was a piano performance in the public space. Once that ended, L read a book on one of the benches. At 2:50 pm, he began to wonder why he was there. He knew where he was, but did not know for what purpose. Reasoning that he was not there for a board meeting as he was wearing shorts, he figured that he was probably there for a doctor's appointment but still did not know with whom or when. Without external cueing, he took out his Palm device and started the OrientingTool – this reoriented him in to what was going on.

Amnesic L took his father to a dentist appointment, which lasted 40 minutes. While waiting for his father, he decided to get a cup of coffee from the coffee shop across the street from the dentist. Before leaving the dentist's office, he utilized the OrientingTool and simply used the What field to say that he was waiting for his father who was in a dentist appointment. He did not use an alarm. While sipping his

coffee, he placed his Palm on the table where he could see it. After finishing his coffee, he checked his device and saw that he was to pick up his father from the dentist. This allowed him to return to the dentist's office.

Amnesic J and his family member used the OrientingTool in a few shopping scenarios. In one case, they used it for a grocery shopping task. The family member prompted J to input the note into his Palm before leaving the house. When they arrived at the grocery store, the family member asked if J knew what they were doing there. He replied that he knew they were to go to the grocery store, but he forgot why. He automatically took out his Palm without further cueing and launched the OrientingTool, where he saw what he needed to do. He then proceeded to enter the store and pick up a food item while the family member observed him through the large store windows from the outside.

Amnesic D went bicycling with his daughter a couple of times. In both cases, D's wife wanted him and their daughter to return in half an hour, and suggested that he use the OrientingTool. In the past, D's wife had to go out to find them because they would not return from their excursion. "He argued it for a second," said D's wife, "but then I know he'll be back." On both these occasions that the tool was used, D returned with his daughter on time.

We were surprised to see that amnesic Y used the OrientingTool, particularly because he did not have a family member prompt his usage of the tool. He used the OrientingTool while doing his laundry. After putting his clothes into the washing machine, he marked a 15 minute alarm into his device and wrote in "laundry". When asked about his first impressions of the tool, he claimed, "In many ways, I thought it was useless – but you know what? It actually helps. It does make a difference – *for me*."

Support for Short-Duration Tasks

We found that some of our amnesics were making use of the OrientingTool in a way that was slightly different from how we expected they would use it. We started our designs by focusing on helping amnesics with orientation when they were lost. However, it seems that through actually using it, the use of the device has shifted away from assistance with disorientation to assistance with keeping on track for shorter-duration tasks (lasting around 10-30 minutes), such as doing the laundry or mailing a letter while walking the dog. These particular tasks were not mentioned during training sessions or design meetings. This is a more functionally-driven use of the OrientingTool rather than a preventative focus. On this realization, one caregiver mentioned, "Yeah, we can use this everyday – like a couple of times everyday… Practically, it's got more uses than you [originally] thought." This may be an important step toward eventual integration of the tool in real life. As this usage pattern is frequent and habitual, it improves the tool's readiness and availability when needed for situations that could potentially lead to disorientation.

Confidence and Assurance

One of the goals of our work is to improve the confidence and autonomy of our amnesic participants. On this matter and on the OrientingTool, amnesic M commented, "Pretty unique. Certainly gives you a feeling a confidence… that helps develop independence again… independence is really my ultimate goal."

At the same time, the OrientingTool provided much comfort and assurance for the family members of the amnesics. One caregiver recalls, "…we've gone to a trade show or one of those big places where you could get lost. You'd [normally] say 'I'll meet you at [location]', but I could never do that with him. We relied on the cell phone – we always had a cell phone. But now I know for sure [that] if the cell phone doesn't work in the building or something, I don't have to worry – he'll know where to meet me." This reassurance was echoed by all the other caregivers in our group. "I can't think how many times we were at [a store] that [he] wanted to go wandering and he'll say I'll meet you in 15 minutes, and I'm walking – *looking at him* because I have to keep an eye on him… And now I have confidence that he'll know where to meet me… At the book aisle or the cash... It's huge for that."

ISSUES AND DISCUSSION

Some issues and barriers that we faced include device acceptance, specific versus general-purpose tools, and implications of training on the design process. We also reflect on our participatory design experience.

Acceptance

Though assistive devices can be invaluable, people with cognitive deficits may be reluctant to use them in public if this may label them as impaired or disabled [8, 13]. As a result, there is often a stigma associated with assistive technologies [12], leading to lower acceptance rates of such devices. We did not observe this response from our design partners who were in fact very excited about the prospects of the OrientingTool. This might have been due in part to the nature of their involvement in this project, as some researchers have suggested that consumer involvement improves acceptance of the device [24]. We also posit that the decision to use Palm hardware positively contributed to their perceptions of the orientation application. PDA's are used by a broad range of people for a variety of different reasons such as games or appointment scheduling, and so being associated with something like a Palm Pilot in no way labels the user as impaired. Thus, the use of a mainstream hardware platform for our software seems to have reduced the barrier to its acceptance as a memory aid.

Special-Purpose versus General-Purpose Tools

Given that our users must train before they are able to effectively use an application, we could have conceivably trained them to use a general-purpose application instead of the OrientingTool. The problem with this is that general-purpose applications were not built with the needs of someone with severe memory impairments in mind, and so

conventional systems often follow other guidelines that are based on a different value system. For example, if we had trained amnesics to use Palm's Memo Pad application in a manner similar to the OrientingTool, an amnesic might write paragraphs of text to describe their situation, but because the application is freeform with no logical structure, we conjecture that there is an increased potential for error through leaving out important details.

Implications of Training on the Design Cycle

Training our amnesic participants was a necessary step toward effective use of our tool. One result of this was that all our users became experts with the interface before the tool was deployed for evaluation. This has serious implications on the duration of design cycles. Design is inherently iterative, involving cycles of system design, development, and testing. In our project, training can take a large amount of time and thus there exists a lag between prototype development and testing. It is important to identify if there may be ways to shorten this lag and thus the duration of the design cycle. One thought is to break the prototype into chunks that can be trained in a staggered manner so that the entire system need not be built before portions of it are evaluated.

As design is iterative, recommendations to change the interface between cycles necessitates that new skills must be acquired and old skills corrected. While training is essential, researchers have also argued for minimal training of memory-impaired people, since past skill sets may interfere with new ones [22]. Since we spent a non-trivial amount of time on training, we cannot test a prototype, make an interface change, and test it again in a reasonable time frame. We have tried to address this problem by considering possible interface conflicts in the early stages of design. However, iterations must build upon each other carefully, and this issue reduces a team's ability to explore vastly different design ideas once a prototype is developed.

Reflection on Participatory Design Experience

We have had major contributions from all members of our team. Active participation in the design sessions led to at least one amnesic from our group feeling more confident in his ability to handle disorientation incidents. In one instance when participant L made use of the OrientingTool, he remembered having discussed the OrientingTool extensively during design meetings and felt confident in the tool's ability to keep him on track. His confidence appeared to encourage him to use the tool more often.

One way of examining whether our participatory design approach was appropriate in our project is to examine the end results and product. The fact that the design team worked together as a cohesive unit, despite differences in opinion at times, was encouraging. As well, the success of the OrientingTool as a product of our design suggests that we succeeded in achieving our design goals. In terms of mutual learning, the two non-amnesic design members (ie. the author and neuropsychologist) learned a great deal about amnesia from those living with memory impairments. Likewise, though the amnesic individuals had difficulty remembering the specific details of their design group experience, they developed an appreciation for the design work in which they were direct contributors. In another incident, amnesic S was shocked to see the initial electronic prototype of the OrientingTool being demonstrated on a Palm. When asked why she was surprised since the team had been designing the tool for a couple of months, she commented that she had previously been in many meetings that resulted in a lot of talk, but with little action or results.

The majority of our design team had amnesia (6 of 8 individuals), but in actuality everyone in the team experienced memory lapses during our design sessions. The amnesics were relieved to see that the non-amnesic individuals (ie. the author and neuropsychologist) could make mistakes based on poor memory, and derived enjoyment from lighthearted joking about the situation. We sometimes used these episodes of memory failure as common ground with the amnesic participants, and as a way to remind them that our design work may have implications for those with normal memories as well.

CONCLUSION

We have demonstrated that participatory design is a viable option for special needs populations with cognitive impairments. For the most part, participatory design teams with cognitively impaired populations have in the past involved single-subject cases in which the design partners offered suggestions to an external designer, but did not act the role of the designer. Our team consists of a majority of amnesics who made design decisions by consensus. We developed four techniques that support memory during and in between sessions. These techniques may have a greater applicability beyond amnesia as no one is immune to normal memory lapses.

Through our participatory design sessions, we have designed and developed the OrientingTool for Palm devices, specifically created to accommodate the needs of people having amnesia. This tool assists amnesics when they feel lost or disoriented by providing information as to their whereabouts and their intent for being where they are. We have successfully trained a group of amnesics for interaction with the OrientingTool and have evaluated this tool under both a designed situation and more realistic settings. Our results suggest that it allows amnesics to effectively manage situations in which disorientation would otherwise provoke high levels of anxiety. Long term follow up studies of the tool's everyday application are planned.

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REFERENCES

1. Baycrest Directory of Programs and Services: Memory-Link. Last accessed on September 10th, 2004. http://www.baycrest.org/directory/directory_memory_link_se12.asp.
2. Blasch, B., Wiener, W., Welsh, R. (1997). *Foundations of Orientation and Mobility*. 2nd edition. American Foundation of the Blind.
3. Bødker, S., Ehn, P., Kammersgaard, J., Kyng, M., & Sund-blad, Y. (1987). A UTOPIAN experience, *Computers and Democracy - a Scandinavian Challenge*, P. Ehn, G. Bjerknes, and M. Kyng, (Eds). 251-278.
4. Busboom, M., & May, M. (1999). Mobile navigation for the blind, *Proceedings of ICWC 1999*.
5. Carmien, S., & Gorman, A. (2003). Creating Distributed Support Systems to Enhance the Quality of Life for People with Cognitive Disabilities, *Proceedings of UbiHealth 2003*.
6. Craik, F., Anderson, N., Kerr, S., & Li, K. (1995). Memory Changes in Normal Ageing, *Handbook of Memory Disorders*, B. Wilson A. Baddeley, & F. Watts, (Eds). John Wiley & Sons. 211-241.
7. Curran, T., & Schacter, D. (2000). Cognitive Neuropsychological Issues, *Patient-Based Approaches to Cognitive Neuroscience*, M. Farah & T. Feinberg, (Eds). The MIT Press. 291-299.
8. Fluharty, G.P., D. (1993). Methods of increasing client acceptance of a memory book. *Brain Injury*, 7(1): 85-88.
9. Greenbaum, J., & Kyng, M. (1991). *Design at work: cooperative design of computer systems*. Mahwah, NJ.: Lawrence Erlbaum Associates, Inc.
10. Hersh, N., & Treadgold, L. (1994). NeuroPage: The rehabilitation of memory dysfunction by prosthetic memory and cueing. *Neurorehabilitation*, 4: 187-197.
11. Kapur, N., Glisky, E., Wilson, B. (2004). Technological memory aids for people with memory deficits. *Neuropsychological Rehabilitation*, 14(1/2): 41-60.
12. Keates, S., Clarkson, P.J., Harrison, L., & Robinson, P. (2000). Towards a practical inclusive design approach, *Proceedings of CUU 2000*. 45-52.
13. Kime, S.K., Lamb, D.G., Wilson, B.A. (1996). Use of a comprehensive programme of external cueing to enhance procedural memory in a patient with dense amnesia. *Brain Injury*, 10(1): 17-25.
14. Kray, C., Elting, C., Laakso, K., & Coors, V. (2003). Presenting route instructions on mobile devices, *Proceedings of IUI 2003*. 117-124.
15. LoPresti, E.F., Mihailidis, A., & Kirsch, N. (2004). Assistive technology for cognitive rehabilitation: State of the art. *Neuropsychological Rehabilitation*, 14(1/2): 5-39.
16. Moran, T.P., & Carroll, J. (1996). *Design Rationale: Concepts, Techniques, and Use*: Lawrence Erlbaum Associates.
17. Richards, B., Leach, L., & Proulx, G. (1990). Memory rehabilitation in a patient with bilateral dorsomedial thalamic infarcts. *Journal of Clinical and Experimental Neuropsychology*, 12: 395.
18. Ross, D.A., & Blasch, B.B. (2002). Development of a Wearable Computer Orientation System. *Personal and Ubiquitous Computing*, 6(1): 49-63.
19. Schacter, L. (1996). Implicit memory: A new frontier for cognitive neuroscience, *The cognitive neurosciences*, M.S. Gazzaniga, (Eds). MIT Press. 815-824.
20. Sohlberg, M.M., & Mateer, C.A. (2001). *Cognitive Rehabilitation: An integrative neuropsychological approach*: The Guilford Press.
21. Squire, L.R., & Frambach, M. (1990). Cognitive skill learning in amnesia. *Psychobiology*, 18: 109-117.
22. Wilson, B.A., & Evans, J.J. (1996). Error-free learning in the rehabilitation of people with memory impairments. *Journal of Head Trauma Rehabilitation*, 11: 54-64.
23. Wilson, B.A.(1999).*Case Studies in Neuropsychological Rehabilitation*: Oxford University Press.
24. Wilson, B.A., Emslie, H.C., Quirk, K., & Evans, J.J. (2001). Reducing everyday memory and planning problems by means of a paging system. *Journal of Neurology, Neurosurgery, & Psychiatry*, 70(4): 477-482.
25. Wu, M., Richards, B., & Baecker, R. (2004). Participatory Design with Individuals who have Amnesia, *Proceedings of PDC 2004*. 214-223.
26. Wu, M. (2004). The Participatory Design of an Orientation Aid for People with Amnesia. MSc thesis, Dept of Computer Science, University of Toronto. http://www.dgp.toronto.edu/~mchi/download/AmnesiaThesisFinal.pdf