Field Evaluation of a Collaborative Memory Aid for Persons with Amnesia and their Family Members

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ABSTRACT
The loss of memory can have a profound and disabling effect on individuals. People who acquire memory impairments are often unable to live independent lives because they cannot remember what they need to do. In many cases, they rely on family members who live with them to accomplish everyday activities, such as coordinating a doctor's appointment. To design technology for persons with amnesia and their families, we involved end users in the participatory design of a collaborative memory aid called Family-Link. We evaluated Family-Link by comparing it to a commercially available calendar application. We found that participants shared significantly more events when using Family-Link. Qualitative evidence also suggests that Family-Link increased participants' awareness of family members' schedules, enabled caregivers to track the person with amnesia leading to a greater a sense of security and reduced stress, and reduced the amount of caregiver coordination effort. The paper concludes with design implications.

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

General Terms: Design, Experimentation, Human Factors.

Keywords
Amnesia, family, collaboration, design, memory aid, user study.

1. INTRODUCTION
Among the various cognitive disabilities that exist, impairment of memory can have a profound and disabling effect on individuals [21]. A large proportion of memory-impaired individuals are unable to live independent lives. Prior research suggests that in addition to families bearing much of the responsibility for caregiving, the adoption, use, and maintenance of assistive technologies become a family responsibility [8]. In a previous study, we learned that families coping with amnesia collaborated together to accomplish everyday activities such as planning and coordinating doctors' appointments, relatives' visits, and family outings [23]. Yet, these activities can be undermined when one of the members has severe memory impairment.

Technology has been used to combat a range of memory-related conditions [10, 11]. While digital voice recorders, mobile phones, and PDAs with patient-friendly software have helped individuals with mild to moderate memory impairments, there is some evidence that suggests that individuals with more severe memory impairments have difficulty benefiting from such electronic aids [19]. As well, such memory aids have not explicitly supported the collaboration between family members and persons with memory deficits.

In this paper, we present the evaluation of a collaborative memory aid called Family-Link (see Figure 1.1). This system was designed with PwAs[1], their family members, and clinicians. We evaluated Family-Link in a real-world deployment with four families with a PwA over six months. The study compared Family-Link and the Palm Calendar, the latter being the system with which participants were most familiar. Results suggest that participants shared more events when using Family-Link as compared to Palm Calendar. We learned that Family-Link also increased awareness of other family members' schedules. For caregivers, this meant a greater sense of security, increased time savings, and a reduction in the amount of effort needed to coordinate. Persons with amnesia and caregivers found different aspects of Family-Link useful. Design implications arising from our results are discussed.

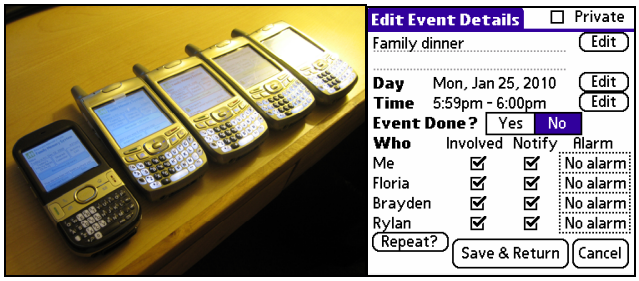

Figure 1.1 (left) Palm devices running Family-Link software. (right) A screenshot of the event editing view in Family-Link.

[1] For readability in this paper, *PwA* refers to a person with amnesia, and *PwAs* to refers to the plural. Also, *family with a PwA* refers to a family that includes a person with amnesia.

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2. RELATED WORK

2.1 Anterograde Amnesia

Amnesia results from neuronal 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, and traumatic head injury. *Anterograde amnesia* [7] refers to difficulty in consciously recalling activities and events that occur following damage to the declarative episodic memory system. The extent and severity of these impairments to conscious recollection differs between individuals, depending on the location and extent of the 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. However, anterograde amnesia undermines one's ability to perform everyday tasks due to the difficulty in remembering the relevant information necessary for task completion.

While currently there is no restorative intervention capable of repairing underlying neuronal damage, functional recovery (improvement in day-to-day functioning) can be achieved through compensatory strategies that capitalize on preserved cognitive abilities such as procedural memory. *Procedural memory* [17] refers to the ability to learn new skills and associations based on prior experiences without the conscious recollection of the experiences. Performance improves through the successive activation of the processing networks involved in accomplishing a task. Procedural memory forms the basis of our ability to acquire skills and habits that require repeated practice (e.g., swimming, touch typing).

2.2 Memory-Link

Our research has been preceded by over two decades of work by researchers from the Memory-Link program at Baycrest, a major research and clinical setting working with the elderly. 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). In order to teach PwAs how to use memory aids, Memory-Link researchers developed a training technique that teaches clients how to use paper-based planners and electronic alarm devices [16]. More recently, the researchers began training the use of Palm devices that had integrated software calendars and alarm capabilities [20]. The devices offered additional benefits in terms of storage capacity and user acceptance that paper-based systems lacked.

2.3 Memory Aids

Over the past decade, a number of researchers and clinicians have had success designing technology to assist memory [2, 10, 11]. The majority of these systems are individual tools for a cognitively-impaired person. The role of the family in these systems is often limited to training and support of these aids. However, four exceptions – NeuroPage, MAPS, MEMOS, and Memojog are described next.

NeuroPage [9] is a pager system for assisting memory-impaired individuals in remembering appointments and tasks, such as taking medication. MAPS [3] 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 handheld device. MEMOS [18] is a prompting system that supports task execution for memory-impaired patients with head injury. Patients can use a handheld device to call a service centre and record a message, which is reviewed by a therapist or caregiver who enters the task into the system. Memojog [11] 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. Any of the user, caregiver, or care professional can make changes to the users' schedule.

While these systems have been designed to explicitly include family members in memory rehabilitation, each system offers a slightly different model of how collaboration should occur. Both NeuroPage and MAPS gives control of scheduling to caregivers and leaves execution of the tasks up to the cognitively-impaired individuals. This limits a memory-impaired person's autonomy and does not facilitate rescheduling of their activities in the face of changing circumstances that may be encountered during the day. MEMOS allows people with memory impairments to request creation and postponement of their appointments, but all requests must be fulfilled by a caregiver who may decide to cancel the request or expand upon it by adding other related appointments. Finally, while Memojog enables users to make modifications to the memory-impaired user's schedule, appointments made by different people do not appear differently in the system. This can be a source of confusion for PwAs.

2.4 Shared Calendars

There exists a number of commercial or freely available online electronic calendars (e.g., Yahoo Calendar, MS Outlook with Exchange Server). Some enable users to view and sometimes edit personal schedules of other users. One example is ClearSync (http://www.clearsync.com), a web-based shared calendar system that operates on Palm devices and also work or home PCs. This system allows families to view and edit shared family calendars and contact lists that are synchronized by the system. The family calendars can be viewed overlaid with work calendars to easily see schedule conflicts, yet the work and personal data does not mix. As well, users cannot edit personal calendars of other users.

There are a few notable research calendar prototypes. The InterLiving Family Calendar [15] is a shared calendar system for multi-generational family members. LINC [14] is a shared calendar that helps families coordinate everyday activities. CareNet [5] is an ambient interactive photo frame to help members of the care network coordinate care for elders.

Although none of the systems target the specific needs of PwAs, lessons learned from the above systems influenced our design work. Our prototype is an instantiation of existing solutions that facilitated our evaluation.

3. DESIGN AND IMPLEMENTATION

3.1 Participatory Design

We assembled a participatory design team [22, 24] consisting of six PwAs, two neuropsychologists (one was the third author), one graphic artist, and the primary author. Five family members also participated in two design sessions.

Our design team met at Baycrest for approximately an hour and a half every week. We completed 20 design sessions. These sessions covered concept design, requirements analysis, high-level and low-level design, and low-fidelity prototyping. Feedback at each stage was incorporated into the system design.

3.2 Family-Link

We designed a shared calendar system called Family-Link (see Figure 1.1) to support families in scheduling their everyday activities together. The system comprises of multiple Palm handheld devices, each one operated by a different family member. These devices wirelessly connect to a server application operating on a PC and that data is automatically synchronized between devices. Palm devices were chosen because our design partners with amnesia had extensive experience with previous Palm devices in their memory training at Baycrest [20].

Family-Link provides a personal calendar for users to manage their events. We define an *event* as a calendar entry with a textual title, date, start time and end time. Each event can have one alarm for every member of the family, an optional textual note, and an optional chat thread. Users can check off events as completed, and are able to set alarms for their own events or the events of others. Finally, Family-Link allows users to view calendars of other family members, and allows any member of the family to create, modify, and delete events for themselves or others. Any appointments added to someone else's personal calendar is preceded by a tag indicating who created the event.

Family-Link enables PwAs to create and edit shared resources independent of caregivers or an administrator. It synchronizes shared information and provides notifications of changes. These features when considered together are uncommon in assistive technologies that support prospective tasks.

Family-Link was implemented in BASIC and C++ and works on any PalmOS 3.5+ device that supports network data connectivity. The server component was written in Java and operates on a PC.

4. EVALUATION

4.1 Study Design

We wanted to evaluate the effectiveness of Family-Link and compare it to the Palm Calendar in everyday settings because PwAs have been shown to successfully utilize the Palm Calendar on a daily basis [20]. A Palm Treo smartphone was given to every participant for the duration of the study. The hardware platform was new to all study participants. For their participation and time, participants were allowed to keep the smartphone devices, regardless of if they withdrew in the middle of the study. Families with a PwA used either the Palm Calendar or Family-Link calendar application in alternating phases throughout the study.

An ABAB design was used [1], involving baseline and intervention phases. There are four key phases in this design: first baseline, first intervention, second baseline and second intervention. During Baseline phases, measures are taken and used as a basis for comparison with data from other phases. In our case, participants exclusively used the Palm Calendar which they were trained to use in Memory-Link [20]. During Intervention phases, participants exclusively used Family-Link. The ABAB design enabled us to examine and compare the effects of the presence and absence of Family-Link. Two training phases were introduced to the design. The order of the study phases were as follows: a training phase (T1), a baseline phase (B1), another training phase (T2), followed the intervention phase in which the collaborative aid is introduced (I1), a return to baseline in which the collaborative aid is withdrawn (B2), and finally an intervention phase where the aid is reintroduced (I2). Each phase lasted approximately 3 weeks.

Before A1, participants went through a training phase (T1) to learn how to use the Palm Treo devices. This was particularly important for PwAs as the new hardware carried slight nuances (e.g. location of the power button, location of the stylus, button to disable screen guard) that made it difficult for someone with memory problems to pick up and easily use on first attempt. We adapted training procedures used by researchers in Memory-Link to train PwAs [20].

After B1, PwAs went through a second training phase (T2) to learn how to use Family-Link. PwAs were trained using the same techniques applied during T1. They learned how to add an event, add a note, add a chat message, and check off an event as completed. Both T1 and T2 phases lasted approximately 3 weeks with 3 training sessions (lasting one hour each) per week.

We piloted our study procedures with two families with a PwA recruited from Memory-Link, and refined our procedures before the main study began. Data from the two pilot families are not included in this paper but can be found in [25].

4.2 Participants

We recruited four families with a PwA from Memory-Link (see Table 4.1 and Table 4.2). All families live within the Greater Toronto Area. Individual participants fell under one of three categories: PwAs, primary caregivers (typically a spouse), or secondary caregivers (other family members, typically children). Family 1 consisted of a PwA (A1), his wife (C1), and two daughters (D1 and E1). Family 2 consisted of a PwA (A2), his wife (C2), their daughter (D2) and her husband (E2). Families 3 and 4 were couples (A3 and C3; A4 and C4).

Table 4.1 Each code represents a study participant. Ages (in years) are indicated in brackets.

Family	PwA	Primary Caregiver	Secondary Caregiver	Secondary Caregiver
1	A1 (53)	C1 (49)	D1 (24)	E1 (19)
2	A2 (45)	C2 (43)	D2 (26)	E2 (35)
3	A3 (47)	C3 (49)	-	-
4	A4 (55)	C4 (58)	-	-

Table 4.2 Memory-Link clients participating in our study.

PwA	Diagnosis	Years in Memory-Link
A1	Limbic encephalitis	3
A2	Aneurysm	4
A3	Ruptured aneurysm	1
A4	Surgical removal of right temporal neocortex and hippocampus	6

4.3 Data Collection

Data collection consisted of electronic logs, face-to-face interviews, phone calls and questionnaires.

We instrumented the Palm Calendar and Family-Link to log user interactions and automatically transmit data to the server PC.

At the end of each baseline and intervention phase, we conducted an interview with each participant. This enabled them to speak freely without needing to consider if their comments would judged by other family members. The interviews lasted approximately 45 minutes. A questionnaire assessing the usefulness of Family-Link features was administered after B2. Interviews were audio recorded and transcribed for analysis.

We also called the primary caregiver once a week to monitor for technical glitches and assess study progression.

Finally, we conducted follow-up interviews with primary caregivers approximately one month after the end of the study.

5. ANALYSIS AND RESULTS

This paper focuses on results germane to collaboration, but a larger set of results appears in [25].

5.1 Shared Events

We hypothesized that participants would share more events in their calendar during Intervention as compared to Baseline. To count the number of shared events in the participant families, we define the concept of a *shared event*. A shared event is an event that appears in more than one calendar. This represents a real-life event that involves one or more members of the PwAs' family. In a sense, shared events are akin to shared landmarks [13], objects around which people can coordinate in digital social spaces.

We saw that shared events included events that needed to occur at specified times (e.g., meetings, social outings), events that represented general tasks (e.g., shopping activities), and events that provided awareness of occasions (e.g., holidays) or locations of other family members (e.g., travel plans).

We first examined the quantitative data to measure how many events were shared between participants, and then explored the qualitative data to learn more about how events were added.

5.1.1 Counting Shared Events

Identifying shared events can be challenging in practice. One issue is that two people might refer to the same real-life event in different ways. For example, Jill might have the event "Dinner with Bob" while Bob might have the event "Dinner with Jill", even though they are both referring to the same real-life event. Another issue is that the shared event might show up on Bob's calendar at 5pm while it shows up on Jill's calendar at 6pm. To account for these variances, we created a set of heuristics (see [25]) to determine whether two events, appearing on different calendars, are shared. Two events are shared if both events occur on the same calendar day, and the titles of each are similar. Note that events can be shared three-ways such that the calendar entry appears on three calendars while satisfying the above conditions.

To minimize the effect of confounding factors, there are a number of events that we excluded. We counted calendar events for each Baseline and Intervention phase, but not events falling on the boundaries of phases (i.e., days during which the primary author met with participants at the end of each phase). This is because on those days, participants could have used both calendars, which may be a confounding factor. We also only counted events occurring a week after each phase started. This had the benefit of mitigating learning effects. For example, when using Family-Link for the first time, we found that family members tended to create shared events for the sole reason to try out the procedures and new software. We did not include these events into the counts. As a result of the above procedures, two weeks of data was counted for each phase.

We applied our shared event heuristics to manually compare all events occurring on each participant's calendar with events of their family members. We noted a couple of issues with events in Baseline phases:

- In Baseline phases, shared events on multiple calendars almost always had mismatching start and end times. This can lead to serious coordination issues in the family.
- There were obvious errors in some calendars during Baseline phases. For example, in E1's calendar, "Dad to Baycrest" was listed every two weeks. However, E1 put the repeating event on the wrong alternating weeks. This was a failed attempt to replicate an event of A1's in her calendar.

The mean counts of shared events are graphed in Figure 5.1.

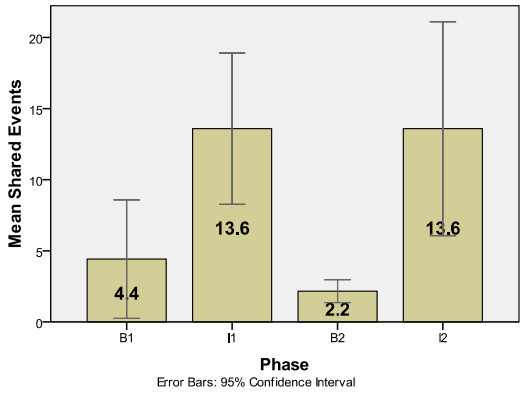

Figure 5.1 : Mean shared events counts across phases.

A repeated measures analysis of variance (RM-ANOVA) was carried out to determine if there was an effect between shared event counts and phase. The dependent variable was the number of shared events observed and the within-subjects variable was the phase. The assumption of sphericity for RM-ANOVA was not met. Mauchly's Test of Sphericity was significant ($\chi^2(5)=18.76$, $p<0.05$); therefore, the degrees of freedom was corrected using the Greenhouse-Geisser estimates of sphericity ($\varepsilon=0.478$). The results showed that there was a significant effect between the number of shared events and the phase, $F(1.43, 15.77)=9.78$, $p=0.003$.

To explore our hypothesis about shared events, two paired t-tests were applied (comparing I1 with B1, and I2 with B2). A Bonferroni correction was used to address issues resulting in making multiple comparisons. A statistical level of 0.025 (i.e. 0.05/2) was used to determine significance. Both tests were significant: The mean of I1 (13.58) was significantly different from the mean of B1 (4.42), paired $t(11)=3.074$, $p=0.011$. The mean of I2 (13.58) was significantly different from the mean of B2 (2.17), paired $t(11)=3.631$, $p=0.004$.

Qualitative data reinforced the finding that more was shared during Intervention phases than Baseline phases.

"I find that with the Family-Link thing I use it more… Somehow it seems easier to put it in and send it over to him… With just the regular calendar, I just put in, you know, I put in for myself. There's less sharing of everything with the (Palm) calendar… if

I'm just using the regular calendar, I wouldn't put his (appointment) in there. I probably wouldn't put anything that he was doing." (C3)

When asked whether items were shared more with Family-Link or Palm Calendar, C4 replied:

"It was mainly with Family-Link. I did not know (his schedule) unless he would tell me. I have no way of knowing." (C4)

5.1.2 How Events Were Shared

5.1.2.1 Events in PwAs Calendar

Family-Link enabled caregivers to create events in the PwAs' calendar. C3 made use of this feature, as the following quotes illustrate.

"I liked it. I liked that we could communicate. That I think that was probably the best thing… like if I wanted to tell [A3] to remember something, rather than have to depend on him to put it in. I could just put it in and send it to him, which I liked that... I find even that I miss it now" (C3)

However, members of Family 1, 4, and 5 rarely did this. Whenever C1 wanted to create a shared event that was the primary responsibility of the PwA, she left a paper note for him and had him enter the event himself.

"I would leave a note for him… It's quicker for me to do a lot of things but I can't live that way. I can't do that. Because eventually, what is he doing? Then he has no independence. I think it would take five steps backwards if I started doing that because he may not remember putting it in. But while he's doing it he knows he's doing it. So he has a sense of independence. Sense of self-respect." (C1)

Family-Link enabled users to modify existing events in another family member's calendar. C1 mentioned that A1 did not realize that there were changes in his calendar. To address this, C1 encouraged A1 to take charge of modifying events in which he was involved.

"If I were to ever change anything, which I have once in a while, I tend to make him in charge of it." (C1)

C2 also spoke about the issue of editing events in A2's calendar.

"I've always had a problem with touching [A2]'s Palm because it's their calendar. For me to alter his calendar, I found it was difficult… Now I'm messing with his stuff… Let him edit the info himself. To do it to him is a confusing situation… He didn't remember putting the information in there, whereas if he hears it once he puts it in, he goes back and can see it. Validation gets stronger each time as opposed to someone else doing it." (C2)

To overcome this issue, Family 2 developed a coordination routine where one person would take care of adding the shared event into Family-Link after discussion.

"The good thing about us as a family is that we will discuss the situation and then one of us would say I'll add it, or I'll do it. And then we were all informed and we took care of things. We did Father's day and Mother's day through our Palm Family-Link program which really worked out well. The boys doing their planning and then us doing our planning, which was nice. It was nice for [E2] and [A2] to plan, leaving us out for it. And then it was nice for us to plan, leaving them out of it." (C2)

It should be noted that all PwAs in our study reported having no issues with their family members seeing their schedules or adding appointments into their calendars.

"I don't think it would bother me. It must be important if they're going to put it in there. I think it's okay." (A1)

5.1.2.2 Events in Other Caregivers' Calendar

Although caregivers wanted PwAs to input and edit events themselves, caregivers liked the flexibility in being able to add appointments to other caregivers' calendars. This was mostly utilized in Family 2. C2 explains that the caregivers support one another's memory this way:

"She (D2) will add things to my calendar. Not so much changing things but add stuff. If there's something I have to do, or forgotten to put in to my scheduler, she'll add it in. And that's where it's nice for her and I to be in touch with the Family-Link program. I will forget that I'm supposed to do something, so she'll put it into my calendar for me." (C2)

5.1.2.3 Titles of Shared Events

Members of Family 2 noted in the interviews that more thought was needed in coming up with appropriate titles in shared events during Intervention. For example, A2's "Doctor's appointment" might be shared with D2 because she was providing transportation for A2. However, D2 might see it on her device and wonder if the appointment listed is hers.

5.2 Awareness

In our analysis of sharing, participants mentioned having greater awareness of other family members' schedules during Intervention as compared to Baseline. We examined our qualitative data, specifically focusing on three aspects of awareness when using Family-Link: (1) whether PwAs were aware of events in caregivers' schedules, (2) whether primary caregivers were aware of PwAs' schedules, and (3) whether caregivers were aware of other caregivers' schedules.

5.2.1 PwAs' Awareness of Caregivers' Schedules

All participants spoke about experiencing increased awareness of other family members' schedules during Intervention phases.

A1 explained how increased awareness during Intervention provides a way for him to reach his family members if needed.

"(Family-Link) let's me know what other people are doing: if someone goes to work, or where they are. So if I need them I can get a hold of them." (A1)

However, this was limited to whether caregivers added information into the program.

"It depends on if they (D1 and E1) put something in it I can see it. But if they don't, I can't see… When [D1] goes to work, or she's going out, or [E1]'s going to a friend's house, she puts it in, I can see. If they don't, then I don't know." (A1)

A2's knowledge of C2's schedule reduced panic situations for himself.

"(For) [E2] and [D2], it's nice to know what they're doing but not as much as [C2]. I like to know what [C2] is doing, especially when the routine is interrupted. Like she doesn't come home at work, like if she's got an appointment of some sort. If I'm sitting at home at 4:30, 5:00 rolls around, 5:30 rolls around

and she's not home I start to go into a panic mode. What's wrong? Where is she? Is she been into an accident?" (A2)

C3 spoke about how A3 was aware of her change in transportation plans from the usual bus ride and how Family-Link provided an alternative method for informing A3.

"Last Thursday, instead of having a bus home from [the appointment], I came to pick him up there… He knew about [the bus] beforehand, but then you know I tried to call him on the way to tell him I was coming to get him and of course his phone was off so I sent [it using Family-Link]" (C3)

When asked to reflect upon how aware A4 was about C4's schedule before Family-Link, A4 explained that C4 had different paper calendars for her work at home.

"Different projects had different calendars. That's why I didn't keep track of it. It wasn't in one place. When I look at the hardcopy of the calendar I wouldn't know what she (was) doing…" (A4)

5.2.2 Caregivers' Awareness of PwAs' Schedules

For caregivers, awareness of PwAs calendars during Intervention enabled them to know what PwAs were doing, know what events were completed, avoid scheduling conflicts and reduce the necessity of making constant phone calls to monitor PwAs.

C1 explained that browsed A1's calendar to find conflicts.

"I liked to be able to have access to his calendar to see if there was any conflicts. Not to see if he did things because we had those verbal discussions usually…" (C1)

C2 reported a number of benefits of increased awareness provided by the Family-Link program.

"The Family-Link program was extremely beneficial for us 'cause we found it let us know where each of us were, or kept in contact and full communication, where sometimes we don't have the option with the actual [Palm Calendar]." (C2)

C2 mentioned how being more aware led to a reduction in the number of phone calls she made to A2 to monitor him.

"I really enjoyed being able to be more aware of what was going on on a daily basis without having to pick up a telephone every 20 minutes" (C2)

C2 provided some examples of how Family-Link was used to increase her awareness of A2's whereabouts and schedule, and how it was as if A2 was in the presence of a secondary caregiver.

"Cause I'm at work all day so I couldn't constantly be looking at it. Weekends a lot more, to see where [D2] was or see where [A2] was. Whereas if I were at home and he (A2) had to do something, I found that came in very handy as well. Cause I didn't have to get up and write a piece of paper and say, by the way I'm heading out. And leave him asleep… And I was also able to get him to do things (tasks)… That was really quite beneficial. And then if he would disappeared and went out somewhere… it was almost like having [D2] or mom being their on full time basis without [D2] or mom being there." (C2)

C4 spoke about how greater awareness led to an increased sense of security.

"I'm always worried. He could cross the street and be hit by a car and I wouldn't know, so… Yeah, (it gives) me a sense of security to know." (C4)

Primary caregivers were not as aware of PwAs' events during Baseline phases. This was a result of calendar information not being accessible unless caregivers physically accessed the PwAs' Palm devices. This was seldom done because caregivers viewed the Palm device as a personal and private tool for the PwA. C4 spoke about how she would not be aware of changes during Baseline unless by chance she heard the alarm on his device and was reminded that way.

"Well I don't know unless I'm here and I hear it. But If I'm not here, I mean if he forgets to tell me, then I don't know about it." (C4)

An aspect of awareness to consider is whether or not PwAs would mind caregivers seeing their events. Qualitative evidence suggests that PwAs recognized the benefits to keeping their caregivers apprised of their events and were keen to allow family members access to their schedules. They were also aware that their primary caregivers were keeping an eye on them. For example, A2 recognized that C2 used Family-Link to check on him.

"I know she checks on me. Because I can mark an event as done that's what she looks for. She just has to look at my calendar and she can see where I am in my day. Where she looks at me and it's 3 o'clock at the afternoon and the only thing I've done all morning is showered at 10 o'clock, I'm not checking things off or I've gone back to bed, right? She keeps an eye on me that way." (A2)

5.2.3 Caregivers' Awareness of Other Caregivers' Schedules

C2 mentioned how awareness was helpful for finding other family members and providing flexible prospective planning.

"Keeping in contact with all of us. Finding where each of us was at any given time. Or if I wanted [D2] to do anything with [E2] then we double checked her schedule first and booked her in without picking up the phone and having to contact with her... It wasn't just a question of ok well we can't do that because she's busy that day. She's busy up to 3 so she at 5 can technically do this... So it did have its benefits…" (C2)

D2 spoke about how awareness of her parents' location made her feel safe,

"From my perspective, it definitely helps to keep track of where the parents were which at some point, if the phone's not answered, really makes me feel safe." (D2)

She later added that awareness also led to better coordination.

"I knew where they were at all times. There was a couple times where my parents had their little night out or whatnot and it leaves me, not in a horrible panic, but 'Oh I need to talk to [A2] or mom (C2)'… No one would answer the phone, so I would get onto their Palm and I would jump into [A2]'s calendar. Right, they're out at the puppy park or they were out for dinner. So at least I would know okay, they're scheduled to be back at 9 so I can call at 9:30... It was very useful." (D2)

5.3 Usefulness of Family-Link

At the end of the study, we administered a questionnaire to all participants assessing usefulness of Family-Link features. The questions had a 4-point Likert scale that ranged from 1 (Not Useful) to 4 (Very Useful). We were interested to know whether there were differences between PwAs and caregivers in how they responded to

the usefulness questions. By grouping the results by subject type, it seemed that PwAs and caregivers held differing opinions about which features they found useful.

Table 5.1 Mean usefulness ratings. An asterisk denotes a rating that approaches significance while double asterisks denotes a significant difference between the rating and 2.5.

	PwAs	Caregivers
Viewing other family members' calendars	2.3	3.7**
Adding events to family member's calendar	2.8	3.4**
Seeing who created events on your calendar	2.7	2.9
Setting alarms for yourself	3.5*	2.9
Getting reminded until the alarm is cleared/snoozed	3.3	2.8
Setting alarms for other people	2.0	2.6
Having the changes in calendars automatically sync with other calendars	3.0	3.3**
Being notified of changes in events	3.0	3.1
Attaching notes to an event	3.3*	2.8
Attaching chat messages to an event	1.7	2.2
Searching for events in your calendar	3.5*	3.2
Marking an event as completed	3.0	3.0
Seeing if an event is completed or not	3.0	3.0
Filtering to see only uncompleted events	3.0	2.8
Overall Mean	**2.9**	**3.0**

In considering only PwAs' responses, Wilcoxon Signed-Rank tests were carried out for each question. The tests found no significant differences between the mean ratings for each feature and the average rating of 2.5, but the following features approached significance: Setting alarms for yourself ($z=-1.857$, $p=0.063$) with mean rank 3.5, Searching for events in your calendar ($z=-1.857$, $p=0.063$) with mean rank 3.5, and Attaching notes to an event ($z=-1.890$, $p=0.059$) with mean rank 3.3.

In considering only caregivers' responses (primary and secondary caregivers combined), Wilcoxon Signed-Rank tests found that the following features were rated significantly higher than the average rating of 2.5: Viewing other family members' calendars ($z=-2.598$, $p=0.009$) with mean rank 3.7, Adding events to another family member's calendar ($z=-2.021$, $p=0.043$) with mean rank 3.4, and Having the changes in calendars automatically sync with other calendars ($z=-2.460$, $p=0.014$) with mean rank 3.3.

These statistics suggested a trend: it appeared that PwAs were most concerned about features that would support their memory, while primary caregivers indicated that the awareness and sharing features were most important to them.

6. Design Implications

Our evaluation has resulted in a number of implications for the design of collaborative memory aids.

Implication 1: Allow PwAs opportunity to interact with critical information

Our results suggest that PwAs can play an integral role in their own cognitive rehabilitation. They should be allowed to actively manage, change, and interact with information relevant to their care, rather than only being a recipient of such information. Repetition and repeated exposure to critical information can also help PwAs become more familiar with such information.

Implication 2: Allow for personalization of shared resources

Events shared in Family-Link have the same textual title across multiple devices. However, titles that may be meaningful to one person may not be meaningful to another. For example, consider that "Doctor's appointment" is a shared event that appears on two family members' calendars because one member is attending the appointment while another is providing transportation. This title may lead to confusion as it does not indicate who has the actual appointment. Family-Link attempts to address this issue by adding the event creator's name in brackets in the title of shared appointments that are created by others. This enables family members to distinguish such ambiguous events, but sometimes these events still caused confusion. Ideally, the system should allow shared events to be renamed in personal views to be more meaningful to the user while retaining the original title for others. Adding this feature for personal views of shared resources can help prevent confusion.

Personalization could also potentially help PwAs become more familiar with shared resources, as suggested by the levels-of-processing model of memory [6]. This model suggests that the deeper the level of processing of information (e.g, form a relationship, make an association, attach a meaning to the information), the greater the retention of memory.

Implication 3: Support resource sharing without limiting PwAs' independence

Most collaborative assistive technologies rely on caregivers to create all shared resources for persons with cognitive disabilities. Rather than taking such an approach, Family-Link explored a more symmetric interaction where PwAs and caregivers were able to create and edit shared resources. We observed an interesting dilemma; while caregivers found that adding events to PwAs' calendars was useful, they did not want to take away the sense of independence and responsibility from PwAs. Thus, collaborative memory aids should support methods of resource sharing in a way that does not limit independence of persons the aids are designed to support. One way to do this is provide PwAs with the ability to explicitly approve new events that are added to their calendars.

Implication 4: Provide different user interfaces and functionality for different stakeholders

PwAs ranked features supporting their memory highly, while caregivers valued sharing and awareness features. One could imagine designing two user interfaces (UI), each providing access to separate functionality. Carmien and Kintsch [4] propose the idea of using one interface for persons with cognitive impairments and one interface for caregivers to simplify the complexity of systems. Simplification of the UI would result in decreased training time and ease of use for PwAs. Deciding on the right amount of functionality exposed to the user can be based on individual user preference and skill.

7. LIMITATIONS

This study was comprised of a convenience sample and so the results may not be representative of all families with a PwA. All PwAs are adult males, and all primary caregivers are adult females. The results may differ for families not of this configuration (e.g., different gender, age). In our shared events analysis, we ignored

spelling errors, which allows for some flexibility but potentially increases the number of false positives. We chose Palm device for our study because it was the most familiar platform for our participants. However, other PwAs may benefit from different platforms.

8. CONCLUSIONS

To design a collaborative memory aid to support families with a PwA, we assembled a participatory design team that included PwAs and also family members on occasion. The outcome was a technology called Family-Link, which we implemented for Palm Treo devices. We evaluated Family-Link with six families over a six-month period. Two families participated in the pilot study and another four in the actual study. Our participants shared significantly more events in their calendar when using Family-Link. Family-Link also increased awareness of family members' schedules, which benefited all participants. Caregivers found that awareness enabled them to track their PwA, giving them a sense of security. As well, some caregivers reported that the increased awareness afforded by Family-Link reduced stress, saved them time and reduced the amount of effort needed to coordinate.

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