

Requirements Gathering with Alzheimer's Patients and Caregivers

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ABSTRACT

Technology may be able to play a role in improving the quality of life for Alzheimer's patients and their caregivers. We are evaluating the feasibility of an information appliance with the goal of alleviating repetitive questioning behaviour, a contributing factor to caregiver stress. Interviews were conducted with persons with Alzheimer's disease and their caregivers to determine the nature of the repetitive questioning behaviour, the information needs of patients, and the interaction abilities of both the patients and the caregivers. We report results of these interviews and discuss the challenges of requirements gathering with persons with Alzheimer's disease and the feasibility of introducing an information appliance to this population.

Categories and Subject Descriptors

K.4.2 [Computers Milieux]: Social Issues - *Assistive technologies for persons with disabilities*, H.5.2. [Information Interfaces and presentation]: User Interfaces - *User-centered design*

General Terms

Design, Human Factors, Experimentation

Keywords

Alzheimer's disease, assistive technology, user-centered design, information appliance, cognitive aging.

1. INTRODUCTION

This study is part of ongoing multidisciplinary research between the Faculties of Computer Science and Medicine at Dalhousie University investigating the role technology can play in the lives of Alzheimer's patients. This particular project examines whether an information appliance designed for those with Alzheimer's disease (AD) may help reduce their reliance on caregivers for information and thus reduce repetitive questioning behaviour.

Alzheimer's disease, the most common cause of dementia [26], is characterized by the loss of intellectual functions to the extent that the loss interferes with daily activities [1]. One of the symptoms of dementia is repetitive questioning whereby a person asks the same question over and over again of their caregiver [14].

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Repetitive questioning is a troubling behaviour for caregivers. Amnesic behaviours have been reported to be the most common spontaneous complaint by the family members of those with Alzheimer's disease [24]. During the Atlantic Canada Alzheimer's Disease Investigation of Expectations (ACADIE) [25], individual goals set by persons with Alzheimer's disease (PwADs), caregivers (CGs), and physicians often included a desire for a reduction in repetitious behaviour and an improvement in the ability to remember daily events and activities.

Current guidelines for coping with repetitive questioning behaviour are provided for caregivers at various Alzheimer's information web sites. These guidelines include: writing the answer down and later directing the PwAD to the written answer [3]; having them find the answer for themselves (i.e. in response to "Is it lunch time?", suggesting they look at the clock) [4]; providing reorientation with written reminders, signs, clocks, calendars, and whiteboards as well as through familiar objects and memories (photos, discussion, music) [2, 26]; and misleading or distracting them if the true answer could cause distress [5].

The reasons for repetitive questioning behaviour can include short-term memory loss and lack of recall [4, 24], boredom, feelings of insecurity or anxiety about their ability to cope, and anxiety about future events [4]. With short-term memory loss, the PwAD may either not remember previously asking the question or not remember receiving the answer. While the reasons behind repetitive questioning are varied, this research will focus on the problem of the PwAD not remembering information due to problems with recall, and will not attempt, at this time, to satisfy some of the underlying psychological needs. The hypothesis is that an information appliance that provides information in an accessible manner to PwADs can help decrease caregiver stress caused by repetitive questioning by allowing the AD patient to access the desired information on their own.

The term information appliance, although varied in its definition, implies a computerized device that is communication-oriented and specialized to serve a well-defined purpose in a manner that is easy to use [18]. We have selected an information appliance as the target of our design, instead of an application for use on a traditional desktop computer, as the reduced functionality of an information appliance will generally result in reduction in complexity [19]. In our case, the specialized purpose of the device will be to provide information in an accessible manner to Alzheimer's patients with cognitive limitations on their interaction capabilities. The precise requirements of the information appliance under design, including its functionality, degree of mobility, interaction techniques, and technologies used, was explored during the information gathering phases of this study. As the onus will be on the caregiver to ensure that the information

desired by the PwAD is available on the device, any solution must also provide caregivers with a quick and easy method to update the information on the device.

This first phase of this project explored the dimensions of repetitive questioning in an effort to provide a user and needs analysis for a proposed technological intervention for the problem. Underlying issues such as the role that technology may play in improving the quality of life for Alzheimer's patients and their caregivers were examined. We were also interested in whether or not those with AD would be willing to use technology, the barriers to use of the technology for this population, and the effectiveness of technology at relieving some of the caregiver stress associated with the repetitive questioning behaviour.

We first provide background about the nature of Alzheimer's disease and current assistive technology research for this population. We then present the methodology and results of our exploratory study. We discuss the challenges of gathering requirements from AD patients and their caregivers and the feasibility of introducing an information appliance to those with mild or moderate Alzheimer's. We conclude with future work.

2. BACKGROUND

2.1 Characteristics of Alzheimer's Patients

As Alzheimer's disease progresses, individuals move through several stages: from the decline in cognitive abilities characteristic of normal aging to mild cognitive impairment (MCI) without dementia, through to the mild, moderate, and severe stages of AD [26]. As we age, it is normal to experience some decline in cognitive functioning, although the precise extent of that decline has not yet been determined [20]. Age related memory impairment is subjective in nature; individuals may forget words or names but can generally remember them at a later point in time. Individuals with MCI have an objective memory impairment accompanied by normal general cognitive functioning and no decline in functional abilities that would impact activities of daily living. Individuals with MCI have a high risk of progressing to dementia or AD with rates found to be between 6 and 25% per year [20].

Repetitive questioning is common in individuals with early and moderate dementia but disappears for those with severe dementia as their awareness declines. Severe stage patients are completely dependent upon others and mostly unaware of their surroundings and both recent and lifetime events [26]. Repetitive questioning is relatively uncommon for those with MCI and can be used as a marker for the progression of cognitive impairment [24].

Mild and moderate stage Alzheimer's patients, the focus of this research, have several characteristics that impair their ability to use standard user interface techniques. These include cognitive impairment, declining language abilities and normal effects of aging.

2.1.1 Cognitive Impairment

Mild stage AD patients have difficulty handling complex tasks that require sequencing of actions and problems with recent memory, but can be prompted [26]. Those with moderate AD need help with basic activities of daily living (ADLs) [26].

2.1.2 Language Abilities

Alzheimer's patients also exhibit declining language abilities [26]. Reading comprehension is typically impaired before auditory

comprehension. Mild stage patients may occasionally stammer, substitute words that are similar in meaning, and describe functions of items when they can't recall the name of the item. Moderate phase patients exhibit incomplete sentence structure, have increased difficulty in naming objects, and substitute syllables within words.

2.1.3 Aging

Additionally, most Alzheimer's patients are elderly and thus have the normal limitations on their vision and hearing associated with aging. Hand tremors may limit their input abilities with keyboards, mice, and styli, while speech input can be limited by voice tremors and short-term memory limitations. Touchscreens have been found to be a viable option for those with dementia [12].

2.2 Related Work

There are several research initiatives investigating ways of providing technological support for aging populations, from ubiquitous systems such as smart homes to assistive robotics [13]. While some of the systems primarily monitor the elderly for safety and assurance purposes, cognitive orthotic systems provide aids for those with reduced cognitive abilities. For example, the Assisted Cognition Project [15] is developing aids for persons with Alzheimer's such as the Activity Compass to reduce spatial disorientation and the ADL Prompter that assists with the completion of activities of daily living (ADLs). Artificial intelligence techniques are being used to provide sophisticated reminder systems. Autominder [21] models the daily living plans of memory impaired individuals and then reasons about when to issue a reminder and whether or not it is appropriate to do so. Other systems enlist the aid of caregivers and other providers. One system, a memory aid, allows remote entry of reminders [27]. The prompting system MAPS [8] provides a dual user interface that allows caregivers to create a script (images and verbal prompts) for ADLs.

Other systems in development [9, 12] are working to provide reminiscence therapy and support to help those with dementia to participate in conversations thereby enhancing social interaction. These systems can be generic in nature [12] or personalized to the individual's life story [9]. Another social memory aid [17] will allow those in the earlier stages of cognitive impairment to perform name and face recognition drills.

Systems for Alzheimer's patients are often designed to assist the patient without requiring them to initiate the interactions. For example, the ADL Prompter monitors the patient as they complete ADLs and only prompts them when they become stalled [15]. However, those with AD do interact with their caregivers throughout the day and may be capable of initiating some interactions with technology. Dementia participants in the CIRCA project [12] often interacted with a conversation aid initially designed for use by caregivers.

3. REPETITIVE QUESTIONING STUDY

3.1 Methodology

In order to map the problem of repetitive questioning to a technological intervention through an information appliance, certain questions need to be answered such as: What are the information needs of Alzheimer's patients? What are their best modes of interaction? How can we provide information in a

manner that is timely, informative, and relevant? How can the caregiver input the information with less stress and effort than answering the PwAD's questions?

A "multi-method" qualitative approach [22] of interviews and diaries was undertaken to explore the dimensions of repetitive questioning. Semi-structured interviews [7] were conducted with persons with Alzheimer's disease and their caregivers. Semi-structured interviews have been found to be useful for elderly participants and can elicit many additional useful insights over static questionnaires [10]. Interview questions explored not only the existing repetitive questioning behaviour and strategies employed, but also the role that technology could play through learning about the information needs and interaction abilities of participants. Caregivers were also asked to record in a diary the actual instances of repetitive questioning behaviour and their responses over the course of one week.

Patients and caregivers were interviewed separately and asked to speak freely about their experiences. Caregiver interviews were approximately 45-60 minutes and PwAD interviews were approximately 20-30 minutes in length. We gathered most of the information about the repetitive questioning behaviour from the CGs, and limited asking the PwADs about what kind of information they would like to have available to them and how they would like to access it. Sensitivity was needed regarding discussion of the "problem" of repetitive questioning in front of the PwAD. We phrased it as "many people with Alzheimer's have difficulty remembering information about their plans for the day and things in their lives. What kinds of things do you want to know about and would like to be able to find out?"

In six of the seven cases, interviews occurred within the pair's home, while the other occurred at the Memory Disability Clinic following an appointment. Conducting interviews at home allowed the patient and caregiver the convenience of not making an extra trip for the interview and may have made them more comfortable, thus leading to better content arising from the interview [7]. It also allowed the interviewees to demonstrate their current methods of dealing with memory needs (similar to the technology demonstrations observed in [10]) and allowed the interviewer to form impressions of the normal environment and the circumstances under which the repetitive questioning occurred. Interviews were recorded to tape and later transcribed.

3.2 Participants

To be eligible, participants had to have been diagnosed with mild to moderate probable Alzheimer's disease and live with a responsible daily caregiver who knows them well. They needed to be experiencing overall memory deterioration and be having periods when they repeatedly ask the same question of their caregiver. Participants were recruited through the Nova Scotia Alzheimer's Society and the Memory Disability Clinic at the QEII Health Sciences Centre in Halifax, Nova Scotia.

Seven pairs of AD patients and caregivers were interviewed (see Table 1). Five (2F/3M) of the AD participants were married to their caregivers, while two (2F) were now living with a daughter. Four of the AD participants were diagnosed with mild Alzheimer's disease, three with moderate AD.

4. RESULTS

Qualitative analysis of the transcripts revealed several categories of information needs and experiences. As there is little existing

Table 1. Sex, age, relationship, and diagnosis of the interviewed Alzheimer's patients and their caregivers.

Pair ID	Person w/ AD	Caregiver	Relationship	AD Diagnosis
P1	F, ~70	F, ~50	Mother/daughter	Mild
P2	M, ~70	F, ~65	Husband/wife	Mild
P3	F, ~85	M, ~80	Wife/husband	Mild
P4	M, ~80	F, ~70	Husband/wife	Mild
P5	M, ~80	F, ~80	Husband/wife	Moderate
P6	F, ~60	M, ~65	Wife/Husband	Moderate
P7	F, ~75	F, ~45	Mother/daughter	Moderate

research cataloguing the specific dimensions of the repetitive questioning behaviour, a primarily inductive analysis approach was taken, whereby categories are obtained gradually from the data [23]. It is important to note that, due to the nature of semi-structured interviews, not all topics were discussed at the same level of detail with all participants.

Generally results are reported as being attributed to a pair (CG and PwAD) instead of an individual participant. In cases of factual disagreement, credence was given to the caregiver's version of events and key differences were noted.

4.1 Repetitive Questioning Behaviour

4.1.1 Experience of Caregivers and Patients

While two of the PwADs maintained that they had no problem remembering information (P7) or that the problem had stopped (P1), the remaining five had some awareness of their memory issues. One (P4) was aware that he was having some memory problems, but thought it was a normal part of aging. He had been diagnosed with Alzheimer's for only one month, so may have still been coming to terms with his memory problems. When later speaking with the caregiver, it became clear that this PwAD was unaware of the full extent of his memory problems and information needs (e.g. he said he had no grandchildren, so did not require information about them – the caregiver clarified that he does have grandchildren and has been having difficulty recognizing their relationship to him). One PwAD (P5) was aware that there was information he needed help to find out, but was accustomed to relying on others to provide it, as he was a professional who had always relied on his wife and his secretary to manage all personal and business information. The remaining three (P2, P3, P6) were very aware of their limitations and were willing and able to discuss the information they desired in detail.

All the caregivers reported that repetitive questioning was a daily problem, although the amount was variable depending on the day's activities and the anxiety of the PwAD; three pairs (P1, P3, P6) reported that the amount of questioning increased with anxiety levels. Overall there were no regular patterns of questioning according to time of day, although there did appear to be some association with the level of tiredness of the AD patient. One caregiver (P7) did report regular patterns of questioning associated with approaching mealtimes. Questions occurred both while at home and away from home, but there appeared to be less questioning while away (P2, P3, P7 reported questioning was primarily at home). Within the home, questioning occurs

anywhere; however, the PwADs often tended to remain in the main living areas for long periods of time as the day unfolded.

4.1.2 Current Strategies

Although all of the caregivers stated that they normally just answer the questions as asked or sometimes refer the PwAD to a source of the information, sometimes the stress of the situation led to other responses. Five mentioned times when they had ignored the PwAD when it got to be too much (P1), left the room (P2), yelled (P4), got noticeably impatient (P5), or sometimes challenged the PwAD to answer herself, not believing that she didn't know (P7).

Only three of the pairs (P3, P4, P6) were actively maintaining calendars or other information sources for the AD patient and found them to be effective. Calendars were used by all three, with P6 additionally using notes, notepads, and pictures. One pair (P5) was using lists put on the mirror for reminders, but was finding it ineffective. The remaining three pairs (P1, P2, P7) were currently making no attempt at providing information support for the PwAD.

Four of the pairs do maintain a journal or diary. While two were maintained only for the caregiver (P2, P4), one (P6) is maintained jointly by the CG and PwAD as a memory aid for recent events. This pair records each day's activities with the CG dictating. This caregiver finds it such a good resource that he has committed to maintaining it as his wife's writing abilities decline. One PwAD (P5) said he kept a pocket diary, but its actual usage was unclear.

Message boards had been tried by one pair (P7), but were found to be ineffective. Newspapers had been found helpful as a resource for date information by P4, but ineffective by P7. Index cards had not been tried by any pairs.

4.2 Information Needs

Information needs fell into several categories. Each will be presented beginning with typical questions related to this type of information that were given as examples of repetitive questioning throughout the interviews. However, as only one diary (containing just 3 entries) of actual questioning behaviour was returned by the CGs, these questions should not be considered complete. Where possible, questions are followed by a more detailed presentation of the associated information needs.

4.2.1 Time

What time is it? What day is it?

Questions of this type were described by five pairs (P1, P4, P6, P7). Four caregivers (P1, P5, P6, P7) discussed how the concept of time seems to be changing for the Alzheimer's patient. They felt that it was sometimes unclear if a specific time (e.g. 3:00 pm) had meaning in relation to the current time.

Time is less of an issue to the PwAD throughout the day as their schedule is often flexible and they are generally not the one responsible for being ready. However, four pairs (P2, P3, P6, P7) did say that they refer to the time or are aware of the time throughout the day. Two pairs (P4, P5) said that being retired, time is not as important to them.

4.2.2 Schedule

What's happening today? What day is ___? How long until ___? When is ___? When do I have to go? What time do I have to be ready? When are you coming home?

Questions of this type were described by five pairs (P1, P3, P4, P5, P6). The typical daily schedule was dominated by household events such as shopping and errands. The PwADs world is typically very small and they are often content to sit and let the day pass as the caregiver works around the home or to accompany the caregiver on errands. Television schedules were not considered to be important information. Although most watched some television, this was mainly when the caregiver already happened to have it turned on. Only two pairs (P4, P6) could think of specific shows (both news programs) that the PwAD regularly tried to watch.

The caregiver was responsible for getting AD patients to appointments, giving medication, and otherwise guiding their activities throughout the day. Only in one pair (P6) was the caregiver often away for extended periods throughout the day so that other forms of reminders were necessary. However, it was still seen as desirable for an information appliance to have both reminders and the ability for the PwAD to find out information about scheduled appointments and activities (five pairs (P2, P3, P4, P6, P7) felt a combination would be appropriate). Reminders were viewed as limiting independence, but were also thought to be helpful as often the PwAD may forget what to ask.

If being given the time for an appointment or event, five of the PwADs (P1, P2, P3, P5, P7) say they would always prefer to be told the exact time (e.g. 3:00 pm). Currently, only four of the CGs (P1, P3, P4, P5) say that they give the exact time when reminding of an upcoming event. P2 uses terms like "later this afternoon" in an effort to limit questioning. P6 gives both the exact time and a relative time ("she's coming at 3:30, that's 3 hours from now") in an effort to increase understanding.

Caregivers may currently limit advance notification of an event in an effort to reduce questioning (P2, P4, P5, P6). There was no agreement between CGs and PwADs about the optimal notification time, with the exception of P6 who agreed that family gatherings should be known far in advance. In four pairs, the Alzheimer's patient felt the optimal time was earlier than the caregiver is currently divulging it (P1: prefers 1 week's notice, told 1-2 days ahead; P2: prefers 1-2 weeks' notice, told 5-30 minutes ahead; P4: wants to be told when event found out, told day or shortly before; P5: wants to be told when found out; only told then if the event is good news). For two pairs, the caregiver was currently telling the information sooner than the PwAD felt they would like to know (P3: CG told when found out, PwAD prefers to know day before or morning of; P6: CG told 24 hours before, PwAD prefers to know 30-60 minutes ahead of time).

4.2.3 Current Event Details

Are we going to ___? Where are we going? Who are we going to see? What are we doing? What are we going to the doctor for?

This type of question was described by four pairs (P1, P2, P4, P6). Although related to schedule questions, questions of this type appear primarily to be related to the event currently underway rather than an event yet to happen.

4.2.4 Information

Where is ___ item? Did I take my pill yet? Have I had breakfast? Can you tell me how to ___? What was it the doctor said?

This type of question was reported by five pairs (P2, P3, P4, P5, P7). Problems with misplaced items (keys, glasses, etc.) were mentioned explicitly by six pairs. This was not felt to be a huge concern as the items were generally fairly easily found and were not crucial given the limited daily activities of the PwAD. Only two pairs (P1, P4) mentioned that the weather was an important piece of information.

Information needs tended to be about recent history. All of the PwADs could remember past events fairly well. When asked about the need for information about family and friends, all pairs thought that it might be a useful type of information to have available. In three pairs (P4, P6, P7), the caregiver noted that the PwAD was sometimes mistaking the relationships between family members and that some of their identities were starting to fade. Brief biographies with photos may be useful, particularly for those with more advanced Alzheimer's. However, this information was considered more important from the caregiver's perspective than it was to the AD patient who appeared to be unaware that they were not remembering things correctly.

4.2.5 Opinions/Feedback

Do I need a jacket/cap? What should I wear? Am I doing this right? Is the cat allowed in? Is the cat allowed out?

Three pairs (P4, P6, P7) reported questions of this type. One caregiver (P6) said that reinforcement questions were recent and due to the declining self-confidence of his wife.

4.3 Interaction Abilities

4.3.1 Person with AD

Computer use. Three (P1, P5, P6) have never used a computer; two (P2, P4) have used a computer before, but are now unable; and one (P3) reported doing some email with the help of her husband (she only contributes to the message portion). Two caregivers (P1, P7), both daughters, have been unsuccessfully trying to convince their mothers to use the computer for entertainment or communication purposes. None of the PwADs are currently able use a computer by themselves.

Mechanical interactions. While five listened to the radio on a regular basis, none appear to actually manipulate the channels. Only two (P3, P5) are still able to use the remote for the television, but P5 is having increasing difficulty. The others have found the remote to be too complex and stopped using them. As one caregiver (P4) reported, he stopped because "he fools it all up and then he panics". Only two (P3, P5) have used tape recorders. Two have begun to have difficulty with the telephone, either with dialing (P5) or with remembering to hang up the receiver (P6). There were limited reports of using kitchen appliances: three still make tea or coffee (P1, P2, P7), two still use the microwave sometimes (P1, P6) and two still use the stove sometimes (P5, P6).

Ability to initiate and follow through activities. Five of the PwADs (P1, P2, P4, P6, P7) were characterized by their caregivers as having problems initiating activities. Five (P2, P3, P4, P5, P7) were characterized as having problems completing tasks and following steps, in many cases even for simple chores that they were previously able to do.

Linguistic abilities. Difficulties with reading absorption and comprehension were noted by six caregivers (P1, P2, P3, P4, P6, P7). PwADs have either stopped reading magazines and books or

are having difficulty absorbing what they are reading or following the plot. Writing abilities are also questionable: only two (P3, P6) appear to write regularly, while three (P1, P4, P7) were noted to have stopped writing or were writing unintelligibly. However, all were able to carry on a pleasant and often humorous conversation during the interview and were generally found to have intelligible speech. Some difficulties were observed during the interview or noted by caregivers: four (P3, P4, P6, P7) had difficulty coming up with the right word, three (P1, P6, P7) had difficulty with complex questions (e.g. "would you like X or would you like Y"); two (P1, P4) relied heavily on stories; two (P1, P7) sometimes resorted to periods of agreeing and seemed to be having difficulty understanding; one (P5) had very slow speech; and one (P6) was beginning to have some problems with pronunciation.

Physical abilities. All PwADs had good vision and hearing, in some cases with correction. Only one (P5) is having difficulty with hearing because he often will not wear his hearing aid. While fine motor skills were noted to be declining in six pairs due to arthritis (P1, P3), tremors (P7), cramping or carpal tunnel syndrome (P1, P4), or slowing movements (P5, P6), in all cases the caregiver felt that some form of manual input (touch, stylus, mouse) would be possible.

4.3.2 Caregiver

Computer experience. Four of the caregivers (P1, P3, P6, P7) are computer literate to some extent; however, P1 just uses it to play games. The remaining three have no experience. Although P4 has a computer and has an interest in using it, she has not been able to find the time to do so given her current responsibilities.

Physical abilities. Five of the caregivers are elderly. However, with the exception of poor speech and motor skills due to Parkinson's disease (P3) and hearing difficulties during the interview even with hearing aids in place (P2), the health concerns noted will likely only have a mild impact on interaction capabilities of caregivers.

5. DISCUSSION

5.1 Requirements Gathering Challenges

5.1.1 Recruitment

There was some difficulty with recruitment for this study. The first interview was conducted nearly three months after recruitment began. Some caregivers and clinic staff were concerned that the interview process may be traumatic or overwhelming for the Alzheimer's patient. Reluctance to participate was primarily noted for those persons with AD who were recently diagnosed and who may be in denial about the extent of their cognitive problems. In one case, an interview was scheduled by the caregiver, but was cancelled when the researcher arrived for the interview as her husband did not agree with his recent diagnosis so felt he was ineligible to take part in the study.

5.1.2 Data Collection

We had asked caregivers to keep a diary of the actual repetitive questioning behaviours observed and their responses for one week. This proved to be an unreasonable request. Only one managed to fill in a diary and return it (with only three entries). The others had various reasons why they were unable to complete this task including illness and concerns about the PwAD feeling monitored. Caregivers said it was difficult for them to both record

the information as the questioning occurred or to later recall the details.

5.1.3 Fluid Reality of Alzheimer's Participants

It can be difficult to determine how much denial of memory problems is face-saving and how much is an actual unawareness of the problem. Interviewing the person with AD first was crucial in order to validate the accuracy of the information given with the caregiver. One participant (P7) was very convincing about her lack of problems and gave a great deal of information about how she was finding out information. During the subsequent interview with her caregiver, several items (i.e. her daily activities, information finding skills, housing arrangements) were found to be inaccurate. According to her caregiver, "those are her realities.. it's a very fluid reality..." "she's tricking the doctors too when she says that.. she has some standard answers and she has things that she says when she doesn't know the answers... she's really... she's lying..." However, the caregiver was also not able to give full insight into the needs and desires of the PwADs as was evidenced by some very different opinions about optimal times for learning about events. It was very important that we interviewed both the caregiver and the Alzheimer's patient and integrated both perspectives.

There are tradeoffs when determining whether to interview both the caregiver and the person with a cognitive impairment or only the caregiver. It is often easier to gain access to caregivers and there may be fewer ethical hurdles, however relying solely on the caregiver's perspective can skew the understanding of the situation. Persons with mild to moderate cognitive impairment have been found to be fairly reliable and consistent when responding to questions about preferences, choices, demographics, and their involvement in decisions about daily living [11]. However, without explicit confirmation from the caregiver, it is difficult to identify the inconsistencies and know which answers are not accurate. Where possible, we recommend gaining both perspectives.

5.1.4 Competing Interests

The interests of the Alzheimer's patient and caregiver may at times compete. Some of the differences noted about optimal times for advance notice of events were due to this problem. The CG limited or delayed information that the PwAD wanted in order to reduce chances for questioning.

For example, in P2 the PwAD would prefer to know things a week or two ahead of time while the caregiver limits the information to a half hour or less ahead of the event because her husband asks questions from when prompted "until we leave... I'll often tell him the same information 5-6-8 times". Her husband was aware that knowing information in advance caused him to ask more questions, but felt that a week or two in advance (rather than a month or more) would be an appropriate balance. This caregiver also limits the number of details she gives about events "because it's just one more piece of information that he might ask questions of". From her husband's perspective, a lot of detail is necessary: "Like if they say you've got an appointment to see Joe Blow today, that's meaningless to me, because now I've got to find out who's Joe Blow and where I've got to meet him and when and how I'm going to get there. There's all those things. But if I've got the information that says you've got to meet Tom Smith at 1:00 downtown by the post office, you know that kind of stuff... that's the information I'd like to know".

Competing interests have similarly been observed when designing a domestic alarm system: the elderly users of the system only wanted nine types of activities monitored and displayed to caregivers and other stakeholders; the caregivers wanted twenty-six activities detected [16].

When designing an information appliance to help reduce repetitive questioning, it will be important to take both interests into account and allow the users the flexibility to adjust the timing and amount of information displayed. Without the ability to easily experiment to determine the configuration that is satisfactory for both parties, it is doubtful that the device will gain acceptance.

5.1.5 Difficulties Isolating Information Need

Although this research focused on the problem of the Alzheimer's patient not remembering information due to problems with recall, it is unrealistic to expect assistive technology to succeed if some of the underlying psychological needs are not also met. A lack of self-confidence in knowing what the information is and how to respond to it was a common theme during interviews.

Even if the PwAD has the information available, they may still confirm the information with the caregiver. For example, one caregiver (P3) discussed that his wife checks the calendar, either of her own accord or when he refers her to it, but will then come back to him and ask about the information. He reported that she often went back and forth between him and the calendar, seeming not to trust that she understood the information.

Any information appliance must of course convey the information appropriately and accurately. However, unless the person with Alzheimer's not only trusts the device to give the wanted information, but also her ability to understand the information, she is likely to continue the repetitive questioning behaviour.

5.2 Changing Information Needs

5.2.1 Level of Detail

A need for a richer level of detail about an appointment was mentioned by two participants (P2, P3) and can be seen in the typical event-based questions as well. The previous quote from P2 illustrates this well. While somebody without a memory impairment may be able to jot down "Dr. Smith, 2pm" in their calendar, this PwAD said that he would need to have information about the role of Dr. Smith, where to find Dr. Smith, how to get to the appointment and possibly other information such as when to leave and what to wear.

5.2.2 Purpose of Information

The typical daily schedules showed that the responsibilities of a mild/moderate PwAD living with a caregiver are minimal. While information is desired about the day's activities, this need appears to be more for peace of mind rather than for information necessary to function. For this population, reminders (such as those provided by Autominder [21]) were not of primary importance. The exception was the one PwAD (P6) who still was left on her own for periods throughout the day. She occasionally had to remember to take her pills or be ready for a friend's visit when her husband was out. Her husband leaves breakfast out for her if he gets up early and will leave a note reminding her to take her pills, etc. This was not always effective. "She may or may no [take the pills]t... the note is there and the question is whether the note is read at the right time... she might read it, have her breakfast and then... [forget the message]."

A patient with mild Alzheimer's that is not yet reliant on a caregiver would have a need for more kinds of detailed information and be supported with reminders for those things that are crucial they remember.

5.3 Feasibility of an Information Appliance

An information appliance for Alzheimer's patients has many requirements including the need to satisfy various information needs in a variety of settings. It must meet the changing needs of its users as their cognitive abilities decline and their information needs evolve. However, the interaction abilities of this population tightly constrain the device. We next discuss some of the requirements for the device resulting from the diverse information types it should support and the challenges of introducing technology to this population.

5.3.1 Requirements

In order to be viewed as an authoritative information source, an information appliance should be able to answer most of the person with Alzheimer's questions. However, as seen in the results, the questioning behaviour covers many information types.

Presenting information about time and schedule is straightforward. A subset of the more general information questions would also be straightforward, but some additional information would be required for others. For example, item location questions would require sensor technology.

While the information in an event-based question is similar to that in a schedule question, it requires context about the event underway and should perhaps be location-aware. The various settings for repetitive questioning behaviour suggest that the device should be at least moveable within the home, if not fully mobile outside of the home. A smaller mobile component or a card with details of the activity outside the home may help alleviate questions regarding the event underway.

Questions relating to opinions and feedback are more difficult. While some common rules (e.g. the cat is allowed outside) may help, others require reasoning that is more complex. For example, the current temperature may help answer questions about appropriate clothing. A list of the steps required to complete common actions could help an PwAD confirm the appropriateness of their actions. While this is similar to the functionality of the ADL prompter [15], the repetitive questioning arises from the insecurity of the PwAD; telling them only when they are doing something wrong may not fulfill their need for reassurance.

5.3.2 Challenges of Introducing Technology

Mechanical skills/fears. While we did not expect that the AD patients would be able to use computers, we were surprised at how few device interactions they have in general. We had hoped to leverage their experiences with radios and remote controls when developing interaction techniques, however, usage of these types of devices was minimal. It is clear that the information appliance will have to virtually eliminate the chance for errors and have only the most basic of interactions. Direct input appears to be feasible, probably in the form of touch. Speech may also be a possibility, but may be challenging due to their declining language abilities, particularly their difficulty in remembering words.

During discussions with the caregivers, it appeared that much of the reluctance to use devices such as remotes and kitchen

appliances has arisen from bad experiences. It is not so much that the PwAD cannot use the device, as that they are afraid to use it because of past experiences. In contrast, young adults with cognitive disabilities who were already familiar with gameboys and other devices were willing and able to use a handheld device for prompting [8]. Psychological barriers related to complexity and anxiety about technology is common with the elderly [10] and appears to be exacerbated for those with dementia.

We believe there may be a better chance of success if a device is introduced during earlier stages of memory decline when the PwAD is more confident of their abilities to interact with devices in general. In any case, it is important that the device not resemble a computer or other complex piece of equipment.

Maintaining a presence. Some of the recommended strategies (memory boards, calendars, newspapers, notes) were found ineffectual by caregivers. Just because an information source is available, does not mean that the person with AD will remember to check it or remember to act on the information at an appropriate time. Caregivers do seem willing to refer the PwAD to an information source, but often find it easier and less stressful for the PwAD to just answer the questions. An information appliance would need to always be on and ready to use and have some method of gaining the attention of the PwAD. Available information must be visible; hiding functionality in menus would be overly complex. Interface design will be challenging.

Willingness of caregiver to maintain. The limited number of pairs with a caregiver actively maintaining an information source for the AD patient is a concern for adoption of an information appliance that puts the onus on CGs to provide the information. As some of the common recommendations to alleviate questioning were unknown to caregivers in the study; it is possible that, with knowledge, more may choose to maintain a system. Indeed, research has shown that caregivers have been found to be successful at decreasing repetitive questioning when trained to use written cues [6]. However, caregiver stress comes from both the behaviour and the burden of caring for the PwAD and the household. It is of primary importance that any device be effective enough at lessening the questioning behaviour to justify the burden of maintaining the information.

6. CONCLUSIONS AND FUTURE WORK

We have learned a great deal about the repetitive questioning behaviour and the information needs and interaction abilities of mild to moderate stage Alzheimer's patients and their caregivers. With this knowledge has come the understanding that unless the design carefully addresses the many constraints associated with this user population (both persons with AD and caregivers), an information appliance to reduce repetitive questioning behaviour is likely to fail. Before moving to the design phase, we need to further investigate some areas that are likely to affect the adoption of this technology: introducing the device at an appropriate phase and ensuring that the level of detail of information is appropriate for that phase.

Our future research will include elderly adults with normal cognitive functioning and those with mild cognitive impairment to learn more about the types of information these individuals forget or need to keep track of, their current methods of finding and recording this information, and their willingness to use assistive technology. We wish to determine how the information needs and

interactions of individuals with AD differ from those in earlier phases of memory decline. We will then evaluate whether there is a need for a specialized solution targeted to Alzheimer's patients or whether a more general solution could adapt to the changing requirements of an elderly individual as their abilities deteriorate. Further research is also needed to explore how technology might assist with the repetitive questioning behaviours that arise not from a need for information due to memory impairment but from a need for reassurance due to insecurity about the ability to understand the information and to cope with upcoming events.

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