Interdisciplinary Design of an Electronic Organizer for Persons with Alzheimer's Disease

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Abstract. Because of cognitive problems, it is very difficult for individuals with Alzheimer's disease (AD) to manage their time. Consequently, they are dependent on their caregivers or use pen-and-paper organizers, both of which have limitations. A more interesting alternative could be an electronic organizer that optimizes the functional autonomy of persons with AD. This article describes the development of an electronic organizer called AP@LZ by an interdisciplinary team of computer specialists and clinicians. The results show how knowledge of technology and knowledge of the cognitive capacities of persons with AD can be combined. A pre-experimental phase confirmed that AP@LZ was easy to use by elderly participants.

Keywords: Alzheimer's disease, memory deficits, electronic organizer, compensatory memory device, interdisciplinary approach.

1 Introduction

Memory deficits are central to Alzheimer's disease (AD). One of the first signs of AD is the difficulty remembering recent events [1]. For example, individuals with AD may forget what they did the day before. They may also have difficulty remembering tasks to be done at a specific time in the future, which involves prospective memory [2]. For example, they will forget to buy milk after their doctor's appointment even though they pass a grocery store. Consequently, they have difficulties in scheduling activities and appointments.

The integration of any type of device in daily life to compensate for cognitive problems in AD depends on the person's ability to learn how to use it. Some studies, employing conventional aids such as calendars, to-do lists and pen-and-paper organizers [3, 4], used errorless learning methods that promote preserved learning mechanisms in AD, such as procedural memory. They all found that persons with AD can learn to use these aids independently. Although some studies have shown some benefits of using pen-and-paper organizers in AD [5, 6], these organizers can have limitations: persons with AD may feel stigmatized, they may have difficulties in updating information or they may write notes that are incomplete or illegible. Also, pen-and-paper organizers are not interactive: they do not have automatic reminders and the

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person must remember to check them at the right time. The disadvantages of pen-and-paper organizers could easily be addressed by using existing electronic organizers that have many integrated features, such as a phone and a reminder. In addition, electronic organizers are being used increasingly and successfully with individuals with cognitive disorders, such as people with traumatic brain injury [7], multiple sclerosis [8], mild cognitive disorders [9] or schizophrenia [10].

Very few studies have looked at the use of electronic aids by persons with AD. One of these aids, the pager NeuroPage [11] reminds people of appointments or things they must do. NeuroPage vibrates (or beeps) and the name of the activity or scheduled appointment appears on the screen. According to Wilson, Emslie, Quirk, and Evans [12], NeuroPage can be used by people with degenerative diseases such as multiple sclerosis or AD. Although interesting, the NeuroPage system can only handle short messages. In addition, users with vision problems (common in older adults) may have difficulty reading the messages because of the small display. Finally, the service that sends the reminders of appointments and activities must be informed of them at least two days in advance. Users are thus dependent on this remote service, which can be a limitation.

Oriani and collaborators [13] studied the use of an electronic memory aid (voice recorder) by five persons with AD. The participants were asked to do seven activities, described in a recorded message, when an alarm went off. The results suggest that this type of aid is effective but for very simple preprogrammed activities in an experimental context (e.g. leave the room). Szymkowiak et al. [14] explored the usefulness of a simple interface specially designed for personal digital assistants (PDA). The interface comprised mainly two functions: consultation and registration of diary information and appointments. The PDA was used in their daily lives by five individuals between the ages of 34 and 93 with different degenerative diseases. Unfortunately, no information is given regarding the types of degenerative diseases or if the participants used their PDA efficiently in their daily lives.

In conclusion, electronic memory aids have significant potential in fostering the autonomy of persons with AD. However, most of the electronic assistants need a remote center or caregivers to register appointments and activities. Also, commercial memory aids that include electronic organizers appear too complex to be used by persons with AD. Their interfaces display a lot of information and it takes several steps to enter appointments. The first objective of this study was thus to create an electronic organizer interface tailored to the capacities of persons with AD (conceptual phase). The interface had to be very simple and allow the users to register their activities and appointments by themselves, without the help of a remote center or caregiver. The second objective was to pretest the interface with elderly participants to explore if it was easy to use (pre-experimental phase).

2 Conceptual Phase

2.1 Method

To ensure that the organizer met the users' needs, it was developed using a user-centered design (UCD) [15]. In this case the users are persons with AD. The conception phase was done with the help of secondary users, namely two neuropsychologists and an occupational therapist (clinicians) with expertise in the cognitive assessment and rehabilitation of persons with AD. Two main reasons justify this approach. First,

elders with AD lack introspection and are therefore unable to express their needs and difficulties encountered in their daily lives and with assistive devices, either pen-and-paper or electronic organizers. Second, people with AD experience stress when facing adverse situations that place too much demand on their cognitive functions. Thus it was more feasible to design the organizer with clinicians who are able to express their needs and then to validate the interfaces with the end users.

In three preliminary working sessions, the computer specialists and clinicians determined the specifications based on the needs of clients observed in clinical settings. The computer specialists proposed various assistive devices to help people with AD to organize their daily lives, such as MOBUS. This previous electronic organizer was developed for adults with schizophrenia or head injury by the DOMUS laboratory [16]. It was designed to help users to remember appointments and activities, and to notify their caregivers when these activities are done. The planned activities are registered by the caregivers.

The researchers decided to pinpoint the MOBUS functionalities and the simplified interfaces that could be used by persons with AD. New sections were added, such as personal and medical information and a photograph album to help with reminiscence. A priority was to limit the functionalities to make the device easy to use but also to allow extensions in the future. Thus the use of contextual information was deliberately eliminated. The main change for the new organizer was to enable persons with AD to use the organizer without the assistance of their caregiver. The MOBUS client server architecture needed to set up the link between user and caregiver was eliminated. Finally, smart phone models were chosen on the basis of specific characteristics such as a touch screen and a large display.

Subsequently the clinicians and computer specialists met 18 times (over a five-month period) to develop the new prototype of the organizer called AP@LZ. The UCD method was applied by iteratively presenting preliminary versions of the organizer interfaces until agreeing on a solution that satisfied the clinicians. One of the main challenges was the choice of functions to schedule appointments and activities (e.g., how to register activities, alert users of an upcoming activity, manage occurrences, change appointments already registered). Another major challenge was the depth of information processing. The depth, which means the steps to go through in various screens to schedule an appointment or find information in the organizer, had to be minimized so that individuals with AD would not lose track of the purpose of what they were doing when using AP@LZ. Compromises had to be made between information that had to be available and information that could be displayed on the screen, the choice of words and icons, the buttons' place, and the size of the screen.

2.2 Results

At the end of the design phase, it was decided that persons with AD should have six basic functionalities available on a smart phone, according to their cognitive difficulties and their needs in daily living. The main functionality of AP@LZ, i.e., reminder of appointments and activities, comes up automatically on the home page when the smart phone is turned on. It shows the time, date and day of the week (Figure 1.a). Users can view what they did yesterday or what they have to do tomorrow by selecting the arrows at the top of the screen. The other five functionalities are accessible from the AP@LZ

home page: 1) *Appointments* contains a list of pre-entered personalized activities and their location. Users select the activity, date and time, and indicate if they wish to be reminded 1 hour and/or 24 hours in advance (Figure 1.b). At the time of the appointment or activity, the organizer beeps and a message appears on the screen until the person reacts and pushes a specific button; 2) *Personal* contains the person's name, address and phone number; it also includes a "photos" option where recent or older photos are displayed like a slideshow (Figure 1.c); 3) *Medical* contains the person's medical history and list of medications; 4) *Contacts* brings up a list of people to call (Figure 1.d); to call a contact, the user simply selects the name; and 5) *Notepad* can be used to enter different types of information such as a grocery list. A functional version of AP@LZ was installed under J2ME for a smart phone with integrated Global Positioning System. The AP@LZ application operates in standalone mode so that users are completely independent and do not have to be connected to a remote service.

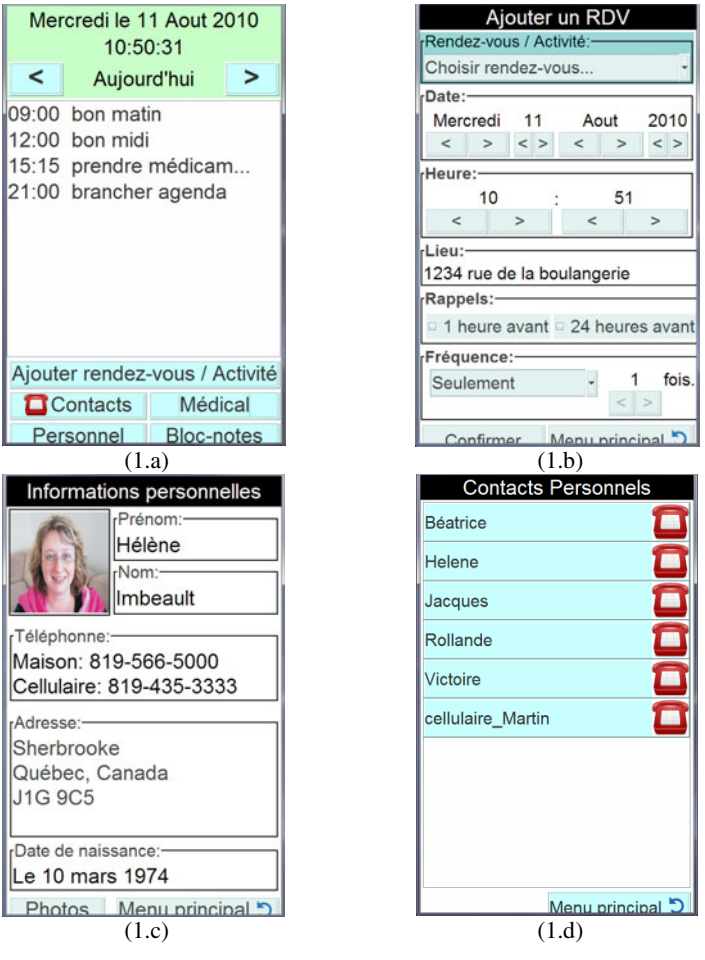

Fig. 1. AP@LZ screens: 1.a Home page, 1.b Appointments, 1.c Personal, 1.d Contacts

3 Pre-experimental Phase: AP@LZ Used by Elderly Participants

3.1 Method

Participants. To test AP@LZ, two users over 70 years of age participated in a pre-experimental phase. This first phase ensured that the interfaces demonstrate usability characteristics for elders. It helped to get feedback during this initial stage, where the elders could express their feelings about the drawbacks and advantages of the organizer. It is expected that if the elders without AD need a long time to learn AP@LZ, people with AD will not be able to use it.

The two elderly participants reported forgetting a few minor things that had no significant impact on functional independence and did not met AD criteria, as shown by their scores on the Mini-Mental State Examination (cutoff = 25 based on age and education) [17, 18] and the Mattis Dementia Rating Scale (cutoff = 123) [19] (see Table 1).

Table 1. Participants' demographic characteristics and general cognitive functioning

	Participant 1 (P1)	Participant 2 (P2)
Age (years)	74	72
Gender	Male	Male
Education (years)	9	15
MMSE	27/30	28/30
DRS	133/144	134/144

MMSE: Mini-Mental State Examination [18]; DRS: Mattis Dementia Rating Scale [19]

Procedure. Participants used AP@LZ in their daily lives for 12 to 18 days and were asked to report any problems they had with the organizer (for example, if it stopped working). Their use was also tested objectively in individual meetings. In the first two sessions, the participants had to answer fifteen specific questions, such as "What do you have to do to enter an appointment in your organizer?" In sessions 3 and 4, the participants had to do five role-playing exercises in each session, such as simulate an appointment with the doctor. The participants' performance was scored on a 4-point scale (see Table 2) for a maximum of 20 points per session.

Table 2. Scoring scale for performance when using the organizer

0	Nothing done or error in the functionality choice AND incorrect information registered
1	Needs a cue for the functionality choice AND the information content
2	Needs a cue for the functionality choice OR the information content
3	Selects the appropriate functionality but needs a light cue to register the information content OR needs a light cue for the functionality choice but registers the appropriate content.
4	Correct information registered in the appropriate functionality

The fifth and final session involved five "real-life" activities. For example, the experimenter called the participants on the smart phone to make an appointment. The

same scoring scale was used for the real-life activities (see Table 2). The specific questions, role-playing and real-life activities were used to objectively rate how older adults interacted with the AP@LZ organizer, what difficulties they encountered and how these difficulties could be avoided.

3.2 Results

Participant P1 used AP@LZ first, so that adjustments resulting from his experimentation could be tested by the second participant (P2). During these five sessions, the participants' success rate varied between 73% and 100% (Figure 2). According to Nielsen's criteria [20], it was confirmed that the application was easy to learn because, from the very first session, both participants learned the main functions of AP@LZ. They were able to extract information from the organizer, such as previous activities, the day's appointments, list of medications and medical history. The second session showed that the application usage was easy to remember (another Nielsen criterion) since once again both participants had a high success rate using AP@LZ. In subsequent sessions, the level of difficulty was different since the participants were asked to role-play in the experimenter's office. In sessions 3 and 4, participant P1 had more difficulties than participant P2. One of these difficulties was navigating between the screens to add new activities to the personalized list ("Add appointment/Activity" functionality). After making a change, navigation was easier, which was confirmed by the higher success rate of participant P2 using AP@LZ with the modification.

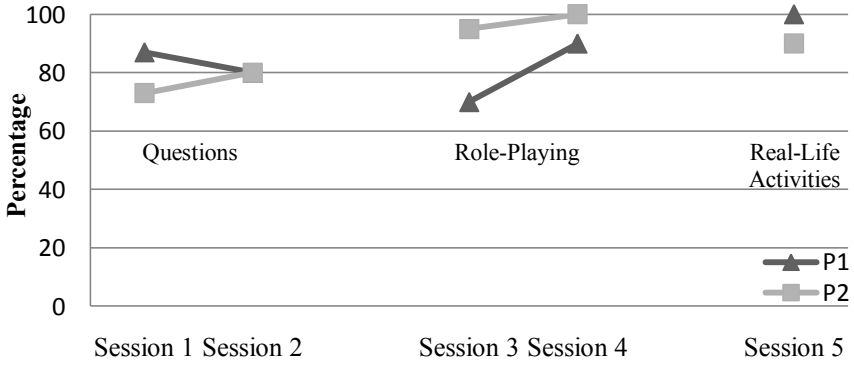

Fig. 2. Results obtained on each session by the two participants

During the real-life activities, the participants were able to phone the experimenter at the scheduled time, enter an appointment spontaneously and receive calls.

By the end of the test period in their daily lives, the participants found the AP@LZ application easy to use and intuitive. For example, one of the participants added a medication to his list (Medical section) without a previous learning session. Both participants liked using the arrows shown on many of the screens. During the design phase, an effort was made to keep the arrows consistent throughout the interface. The

participants also found the Contacts section easier to use than on their own mobile phone since the phone contacts were previously registered.

4 Conclusion

The AP@LZ organizer was designed to be easy and pleasant to use by people who are not familiar with the latest technology and have significant cognitive problems, such as in AD. To ensure the prototype was adapted to the target population, we used a UCD method and interdisciplinary approach combining the knowledge of researchers and specialists in computer science, occupational therapy and neuropsychology.

AP@LZ was developed at the DOMUS laboratory from an existing model called MOBUS. Various functionalities were added for AP@LZ. The main challenge was to create an interface that would enable persons with AD to register their appointments and activities by themselves, without any help. We therefore decided to include a list of preprogrammed personalized activities. Thus, the completion of the information needed for specifying an appointment (date, time and place) requires only one AP@LZ screen, allowing the person with AD to register the appointment in one step. We also stressed the importance of reducing the depth necessary to interact with the electronic organizer and limit the amount of information displayed on the screen. Homogeneity in the language and symbols used also facilitates the learning process. We chose a smart phone with a large screen so that the messages could be more detailed yet still legible for older adults. Unlike the device used by Szymkowiak and colleagues [14], AP@LZ provides a variety of functions including a slideshow of recent and older personal photos. The Contacts functionality is also a safety feature since older adults can use it to call for help if necessary.

By the end of the pre-experimental phase with the help of two elderly participants, we were able to stabilize AP@LZ and demonstrate its usability for elders. The next step is to test AP@LZ with persons suffering from AD, which is currently being done. Many challenges, such as the importance of memory problems and apathy in AD, will have to be addressed in these future studies to ensure that AP@LZ will be correctly learned and used by this population. However, AP@LZ is promising and opens up new rehabilitation possibilities in dementia.

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