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A Mobile Multimedia Technology to Aid Those with Alzheimer's Disease

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A first-generation, mobile, video-based reminder system offers memory support to those afflicted with mild-stage Alzheimer's disease.

Demographic changes are creating new demands on society. Of particular relevance is the challenge of dealing with the major health conditions associated with aging and long-term chronic conditions such as dementia. On a global scale, an estimated 18 million people are affected by dementia, a figure that is greater than that associated with cardiovascular related death. Published estimates suggest that persons with dementia are approximately four times more likely to require permanent, institutionalized care than those without dementia. Presently, it is estimated the global costs attributed to the provision of such care amounts to approximately $315.3 billion per year. Directly associated with the rising numbers of persons with dementia is the increased strain placed upon caregivers, many of whom don't have the support required to provide the necessary levels of care.

Dementia is an umbrella term used to describe symptoms arising from the progression of several distinct diseases. Such diseases include Alzheimer's disease (AD), multiple occurrences of stroke, and severe brain injury. Those suffering from dementia display a range of symptoms, including impairments in memory, orientation, speech, and perception. Recent trends in the area of information and communication technology solutions for home support have the potential to assist in the management of some of these symptoms through the integration of technology within a person's home.[1,2]

Indeed, there are positive economic as well as personal reasons for encouraging dementia sufferers wishing to remain in their own home to do so for as long as possible. Given that up to one-third of sufferers live alone, home support provided at an early stage is likely to be one of the most cost-effective solutions. When surveyed, people express preference to remain in their own home for as long as possible.[3] For some, doing so has shown a sustained quality of life for a longer period.[4] The system presented here is designed around an everyday technology—the mobile phone—to offer reminder support for persons with dementia. The desired effect of using this assistive technology is to offer greater independence for the person with dementia and to ease the caregiver's burden.

Although a large number of devices and systems have been developed to address these issues (see the "Related Work" sidebar), there have been relatively few studies specifically focusing on technology for persons with early stage dementia. In the project described here, we are aiming to develop and evaluate an entirely novel system for providing frequent memory prompts to those persons with mild stage AD. The initial concept and vision of this cell phone video streaming (CPVS) system have been presented previously.[5] This article provides an update to the previously presented work and reports on the results and user experiences following a pretrial evaluation of the first iteration of the CPVS system.

Method

The primary aim of the current project is to offer persons with mild AD an assistive presence

Related Work

The system presented in this article is designed to assist those who have mild dementia in remembering their daily activities. Our interest in this work was inspired by a study highlighting that approximately 10 percent of persons with Alzheimer's disease were currently living alone.[1] These individuals were viewed as being at particular risk of requiring permanent institutionalization due to the progressive nature of the disease. In an attempt to help such individuals manage more effectively at home, a cohort of patients with mild stable dementia took part in a project to evaluate various cognitive rehabilitation methods. Results highlighted that patient functional abilities improved following the use of simple methods of memory aids such as notepads and written lists.

In a complementary study, a group of researchers undertook an assessment of the needs of a cohort of elderly people with respect to assistive technologies.[2] Two of the technologies that were viewed as potentially useful were medication management devices and interactive memory aids. To date, a wide range of home-based technologies have been introduced with the aim of improving levels of independence while reducing the demand placed on caregivers.[3,4] Such technologies include devices that can support self-management and assessment of vital signs (for example, blood pressure or temperature), devices that can automate the home (for example, door or window openers), and devices that are based on visionary concepts (for example, robotic companions or pets to assist with stimulating social interactions).

From a clinical perspective, a person suffering from dementia stands to benefit from the simplest of memory-enhancement techniques, such as written checklists. The evolution of this concept into its technical representation gives rise to the term *cognitive prosthetic*, which is a device that provides timely cues and memory support via electronic means. Several research efforts have previously been directed toward the development of cognitive prosthetics. The forget-me-not device offered reminders to those suffering from cognitive impairments through an electronic calendar.[5] The NeuroPage system is designed to facilitate reminding though a message pager system.[6]

Another example is the Clockweisser system (see http://www.clockweisser.com/), which offers the ability to deliver reminders at different times of the day as a series of static audio messages such as "take lunch" or "visit the doctor." The CogKnow system is designed to offer support through control of the environment and delivery of reminders through a touch-screen device embedded in the home.[7] Additionally, devices such as VoiceCue and Mem-X (see http://www.mem-x.co.uk/) record spoken reminders for delivery at preset times. Specifically, with these solutions, caregiver's record a limited number of reminders directly onto the device and set the date and time that the reminder should be delivered. Users are typically required to press a single button on the device to receive the messages.

More recently, mobile phones have become a means to facilitate independent living.[8-10] Through the modification of fascia design, for example, single-button mobile phones have been developed to facilitate direct calls between users and their relatives.[11] Such devices also exist to promote social contact, another key cognitive deficit associated with dementia.

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Table 1. Recognized scales for assessing dementia characteristics.

Dementia level	Test scale
Cognition	Mini-Mental State Examination
Neuropsychiatric status	Neuropyschiatric Inventory
Functional ability	Disability Assessment for Dementia

in the home environment through the provision of frequent memory cues in the form of video reminders delivered via a mobile phone. Using a distributed Internet-based care model, caregivers are provided with secure access to a custom interface through which video reminders can be recorded using an integrated webcam. Recorded reminders are scheduled by the caregiver and uploaded automatically via a secure server connection to a backend database for future retrieval. At regular intervals, a collection of video reminders are transmitted via the server to the user's mobile phone where they are scheduled for playback, providing a virtual caregiver to assist with reminding users of daily activities.

Our belief is that using video reminders, instead of text or voice alone, will increase levels of task compliance and improve user satisfaction because the videos will contain caregivers' recognizable voices and faces. The system has the capability to monitor user interaction with the phone following delivery of the reminders. The receipt and acknowledgement of reminders can be monitored by the caregiver via an Internet-enabled interface.

The project is currently at the end of its second year of a proposed three-year work plan. Following the initial phases of user-need analysis and system development, the system was put through pretrial tests with several participants. This pretrial evaluation was conducted to inform and dictate the refinement and technical developments for future iterations of the prototype. The first actual trial will be conducted with up to 10 patients suffering from mild dementia in the third year of the project, which will then be followed by a second trial that will test the system with up to 30 participants and will involve each participant using the system for up to three weeks.

We have planned to adopt an ABA experimental design. Initially, in the A-phase, a baseline is recorded by assessing participants on their ability to remember daily activities using their normal memory aids. These memory aids typically include items such as personal diaries, notepads, and Post-It notes, as well as reliance on a caregiver. Subsequently, patients are assessed in the B-phase with using the CPVS system as a method for replacing their traditional memory aids. Finally, in the second A-phase, the system is removed to observe the effects on the patient's ability to remember without the assistive technology.

Establishing user needs

An investigation addressing the analysis of user needs was conducted during the first 12 months of the project. In the initial phase, user needs were collected through structured interviews with a group of dementia sufferers and their caregivers. Employing interactive questionnaires, patient functionality was assessed to quantitatively estimate their quality of life. Complementary information was gathered from local Alzheimer's support groups. Incorporated into this initial investigation was an assessment of the patient's technical ability in terms of being able to interact with mobile phones. In total, the aim was to identify six to 12 potential target-reminding activities. Among the main target-reminding activities that were identified as a result of this phase were medication, appointment, and meal time reminders, as well as lighting and electrical appliance management.

Screening and recruitment

We identified potential subjects following their attendance at the Belfast City Hospital Memory Clinic. We screened subjects for suitability for the research study by considering several inclusion and exclusion criteria. Only those patients with a diagnosis of mild stage AD were invited to participate, provided they had a willing caregiver able to participate in identifying user needs and engage with researchers in the necessary programming of reminders using a remote computer and webcam. These patients had a Mini-Mental State Examination score that was greater than 18. The lower the score, out of 30, the more severe the disease is. Upon enrolment in the study, a patient's baseline characteristics were assessed using a set of internationally recognized scales as highlighted in Table 1.

Prototype development

The CPVS system incorporates several technical components as shown in Figure 1. We

implemented a collection of services using an Apache-based server to control and monitor the secure uploading of videos and schedule related information from the caregiver's stationary device (CSD). The server manages the delivery of new video reminders to the patient's mobile device (PMD). We designed a back-end, MySQL database to store relevant schedule information in addition to personal data such as caregiver passwords, unique patient IDs, and details of patient's respective caregiver assignments.

The PMD, the core of the CPVS system, automatically requests new video and schedule information from the server. This request process is conducted periodically and can be personalized depending on the volume of reminders delivered. This client–server request also serves as a heart beat to confirm that the network connectivity between the PMD and the server is operating correctly. Essentially, the PMD is a portable device supporting General Packet Radio Service (GPRS) data transmission and multimedia playback in the form of Third Generation Partnership Project (3GPP) and MP4 video. In the current project, we used a mobile phone as a relatively inexpensive everyday platform that is widely available and familiar to the general population.

During the period between the delivery of new video reminders, information regarding the current time and date are provided on the phone's display to assist users with their awareness and orientation of date and time. An alarm (both audio and visual) is generated by the device whenever a new reminder is ready to be presented to the user. To start the playback of the video reminder, the user is prompted to press the only button visible on the PMD. This button press also serves as an acknowledgement of reminder notification, which is subsequently relayed back to the database and can be accessed by caregivers through their CSD interface. Figure 2 presents photographs of a phone running the PMD prototype and highlights the three stages of PMD operation.

One of the perceived problems with incorporating a phone into the system for use by persons with dementia was the large number of small buttons that are commonly present on such devices. We decided to use a single-button device because then the user would only be required to initiate playback of a video reminder and acknowledge such reminders
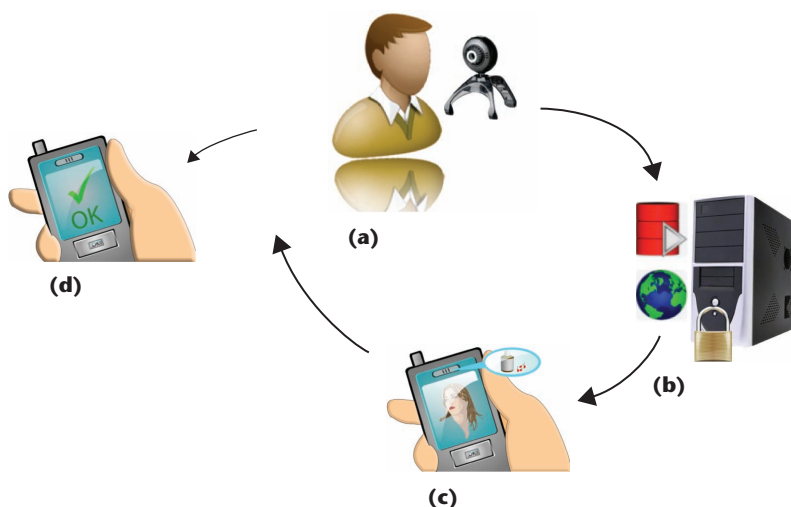

Figure 1. Proposed solution highlighting the links between the various technical components. (a) caregiver's stationary device, (b) secure server and database, (c) patient's mobile device, and (d) caregiver's mobile device.
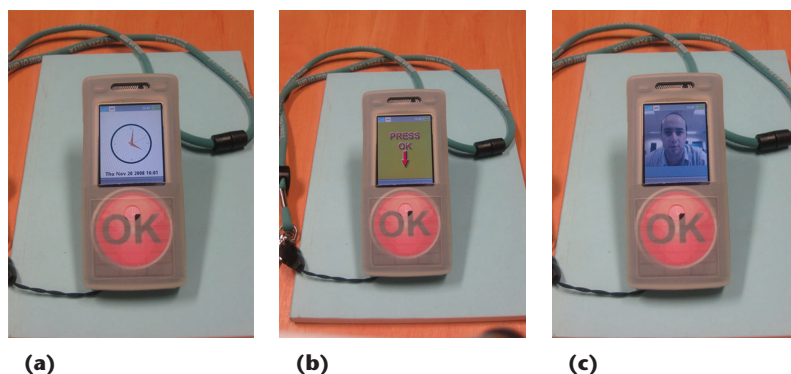

Figure 2. Photographs presenting the first prototype of the patient's mobile device: (a) interim clock display, (b) reminder alert (accompanied by alert sound), and (c) video reminder delivery. Also shown is a lanyard, which is attached to each device.

through a single button press. But our goal was to use everyday technology, so we designed a simple plastic cover that could be mounted over existing phones. Figure 2 presents the fascia currently in use; it is made of silicon with a cardboard button.

The CSD provides a platform for caregivers to record and schedule video reminders. The CSD consists of an Internet-enabled PC and a webcam. Given the likelihood that caregivers of the target group will themselves be elderly, we designed the CSD application to guide the user through the process of recording and scheduling a reminder by presenting the user with a set of simplified, clear, and concise options. Incorporating this wizard approach

Figure 3. Screenshots highlighting the caregiver's stationary device interface. (a) The user signs into a secure application, (b) positions his or her face inside the phone outline via webcam before starting the recording process, (c) selects the date on which the reminder should be scheduled, and (d) confirms the date and time of the reminder.

(a)

(b)

(c)

(d)
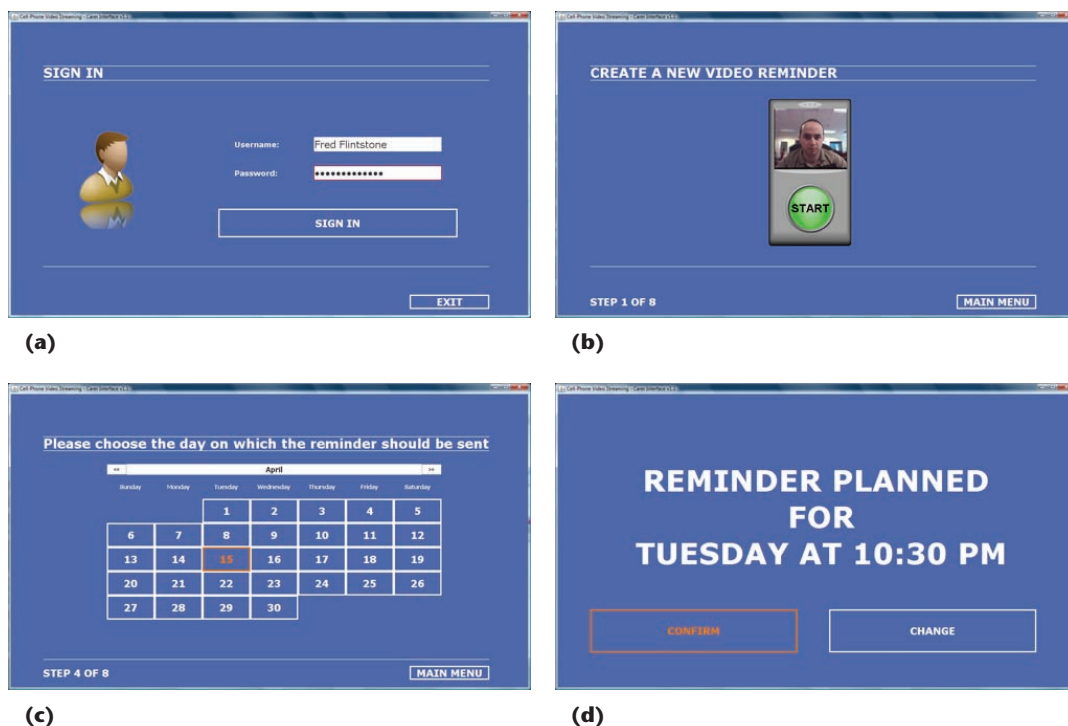
minimizes user confusion while increasing user confidence. The user is guided through eight main steps. Figure 3 presents a subset of the CSD steps.

Results

The main purpose of the pretrial evaluation was to gather feedback regarding the stability and the usability of the system prior to a full trial. For the initial trial group, we recruited three young controls, two elderly controls, and four people with mild dementia. All trials lasted approximately three days each during which six personalized prerecorded video reminders were delivered to each participant via the PMD. On the first day of system use, we provided training for each of the users and their caregivers.

Following this training, the user took home a PMD; the first reminder was scheduled for delivery on the second day of evaluation. The caregiver prerecorded the series of video reminders under the guidance of a technical researcher and a research nurse. Prior to recording the videos, the caregiver was provided with basic system training through a demonstration of recording a video and its subsequent delivery through the PMD.

Key personalized reminders were assessed using a mixture of simulated and real scenarios. Simulated scenarios involved, for example, placing a phone call to the research nurse, while real scenarios were guided by the participants' needs and included, for example, reminders to have lunch or to begin preparations for an appointment. The functionality of the PMD was measured by considering successful interaction with the device, video transmission rate, video and audio quality, and reliability of reminder delivery through patient acknowledgement via button interaction with the device.

User case reports

Following the evaluation, we conducted post-trial interviews with both the caregivers and users. In the case of the young controls, participants served as their own caregiver and recorded a series of reminders and later acknowledged receipt of these on the PMD. Table 2 presents the information regarding each participant, outlining details of group assignment, age, and gender in addition to living arrangements and an indication of previous mobile and computing experience.

The young controls who participated were all information and communication technology professionals working with assistive technologies. However, none had any previous experience with the CPVS system. Given their level of expertise with this specific type of assistive technology, this group was able to provide

Table 2. Pretrial evaluation participant details.

Case Study	Group	Age (years)	Gender	Mini-Mental State Examination score	Relationship to patient	Living situation	Mobile experience	Computer experience
1 Patient	Young	23	Male	—	—	—	Expert	Expert
2 Patient	Young	24	Male	—	—	—	Expert	Expert
3 Patient	Young	29	Male	—	—	—	Expert	Expert
4 Patient	Elderly	64	Male	—	Daughter	With spouse	Novice	Novice
Carer		35	Female	—			Expert	Moderate
5 Patient	Elderly	75	Male	—	Spouse	With spouse	None	None
Carer		70	Female	—			None	None
6 Patient	Mild dementia 2–3 yrs	80	Female	26	Daughter	Alone	None	None
Carer		56	Female	—			Expert	Moderate
7 Patient	Mild Alzheimer's 2–3 yrs	77	Male	22	Spouse	With spouse	Novice	Novice
Carer		73	Female	—			Novice	Novice
8 Patient	Mild Alzheimer's 2.5 yrs	76	Female	28	Spouse	With spouse	Novice	Novice
Carer		82	Male	—			Moderate	Moderate
9 Patient	Mild Alzheimer's 5 yrs	79	Female	24	Spouse	With spouse	None	None
Carer		76	Male	—			Moderate	Moderate

constructive feedback in terms of the technical design of the prototype. In addition to using three young controls, we used two elderly controls in the initial trial, with the rationale being to gain general feedback regarding usability issues with the system. These two elderly participants had limited or no mobile and computer experience. In the third and final grouping, we recruited four patients with AD.

The participant mean age was 78 ± 2 years and the mean MMSE score was 25 ± 3. Due to the nature of the AD, it was considered necessary to include feedback from users in the presence of their caregivers. We discovered that during the initial training and interview process, three out of the four AD participants required reminders about the function of the PMD and their role in using the device during the evaluation period. What follows is a qualitative summary of the nine users' experiences during the evaluation period.

Table 3 (next page) outlines the experiences of the user participants, while Table 4 outlines the views of their caregivers. Each table presents details regarding the physical appearance of the PMD, the perceived functionality and usability of the device, the recommendations for future development, and the general outcomes of each trial. The young controls were responsible for recording their own reminders. Given the level of expertise among these participants, the CSD was easily navigated and used without any requirement for training. The other caregivers had different levels of expertise and all participated in training sessions prior to using the CSD.

Technical observations

In addition to the qualitative information captured through the pretrial and post-trial interviews, the PMD can record quantitative measures to gain further insight into assessing the usefulness of the technology. Such measures could include GSM signal strength, PMD power consumption, accelerometer data (if supported by mobile device), server communication stability, time taken for user acknowledgement of reminder, and indication of which region of the acknowledgment button was pressed. To date, only data about the communication stability between the PMD and server has been integrated into the system.

Table 3. Summary of patient's mobile device (PMD) user experiences and opinions.

Experience type	Young controls	Elderly controls	Alzheimer's disease patients
Physical appearance feedback	—Appropriately sized. —Too heavy to wear. —Screen too small. —Single button a good idea.	—Button size good. —Screen too small. —Comfortable to wear. —PMD swung on neck.	—PMD kept near through trial. —Single button a good idea. —PMD too bulky. —Unwilling to wear PMD in public. —Weight-to-size not an issue.
Functionality/usability feedback	—Easy to use. —User friendly. —Video clear and visible. —Volume too low. —Standby mode confusing.	—Satisfied with concept. —Volume too low. —Issue with recharge reminder.	—Audio/video quality good. —Reminder alert sound unpleasant.
Future recommendations	—Replay function. —Recharge reminders.	—Replay function. —Recharge reminder.	—Slimmer and lighter. —Alternative alert sounds.
General outcomes	—All reminders delivered at correct times. —Video reminders useful.	—Technical difficulties. —Straightforward to use.	—Needed PMD function reminders. —Technical difficulties.

Table 4. Summary of caregiver experiences with the caregiver's stationary device.

Experience type	Young caregivers	Elderly caregivers	Alzheimer's disease caregivers
Functionality/usability feedback	—Easy to navigate system. —Intuitive wizard structure beneficial to elderly users.	—Experiences varied. —Easy to use and navigate. —Reluctant to use mouse.	—Easy to use. —Training needed for one caregiver without experience.
Future recommendations	—Consider an advanced mode for younger caregivers.	—Include automated training session. —Port CSD onto a touch screen.	—Port CSD onto a touch screen.
General outcomes	—Feedback positive and future recommendations valuable.	—Personal experiences generally positive.	—Caregivers saw need for technology. —Caregivers found CSD to be user-friendly.

During normal operation, a remote connection between a PMD and the server periodically exists to facilitate the transfer of new video content and updated schedule information from the server to the PMD. As a result, this regular contact with the server serves as a way to indicate the correct operation of a PMD. Nevertheless, due to the reliance upon the GSM network, PMDs exhibit occasional connection failure with the server because of poor cellular coverage. In the event of a communication problem, a PMD backs off and reattempts a connection later. By recording this information, it's possible to profile the stability of the PMD connection. In addition, we have used this service to help to identify potential problems with the software architecture.

Discussion

On the basis of the pretrials, we made several useful observations to refine the prototype for the planned trials scheduled to commence in the final year of the project. In terms of physical appearance, one participant commented that reducing the size of the button on the PMD to facilitate an increased screen size would be useful for those persons with poor eyesight. Furthermore, participants felt that the PMD was potentially too heavy to wear on a lanyard around the neck for long periods.

In terms of functionality, young controls reported that the video playback on the PMD was clearly visible and of acceptable quality. Two out of the three participants expressed concern regarding the clarity of the audio

accompanying the video playback due to the low volume level. A replay function was viewed as being potentially helpful to permit recently delivered reminders to be replayed within a pre-determined period. Another suggestion was to automate charge battery reminders so that the caregiver could routinely recharge the PMD.

Young controls were responsible for recording their own reminders. Given the level of expertise among these participants, the CSD was easily navigated and used without any requirement for training. In this respect, the CSD was viewed as being intuitive to use, with the wizard structure being reported as a good approach for the target group of elderly persons. Nevertheless, the young controls commented that for younger caregivers, a more advanced CSD interface could be introduced to permit a more streamlined approach to recording video reminders and scheduling their delivery.

Reporting on the physical appearance, elderly participants found the button size to be sufficient. However, one commented that perhaps a larger screen could be considered. Elderly controls reported the PMD was comfortable to wear, but noted that the lanyard permitted the PMD to swing about. In terms of the functionality of the PMD, participants found the audio volume to be too low and suggested that a replay function be introduced so that the previously delivered reminder could be watched a second time, if required. In one of the user trials, the caregiver recorded a reminder to charge the device, but the PMD required charging prior to the delivery of the reminder.

In terms of recording the video reminders, the caregivers' levels of experience differed across trials. In the first trial, the caregiver was 35 years old and was experienced in using both mobile and computer technology; she commented that the CSD was easy to use and navigate. With regard to future development, the caregiver suggested that the user could be led through an automated training phase at initial login to test the volume of their voice and to make them aware of the importance of speaking clearly.

The caregiver in the second trial was elderly (70 years old) and had previously never used a computer. The researcher was required to guide the caregiver through the CSD due to her reluctance to operate the computer's mouse. The caregiver commented that she possessed previous experience with touch-screen

Figure 4. Slimmer and lighter handset used to provide more comfort to users.

technology through working as a cash register operator. When informed that the CSD could be presented via a touch-screen interface, the caregiver stated that this might lead to making the technology more appealing to elderly caregivers. Following these comments, a prototype of the CSD was ported to a 9-inch touch-screen device. The interface design of the current CSD lends itself well to a touch-screen interface due to the large buttons on each screen and the stepwise wizard.

We conducted four AD patient trials. The caregivers reported that all patients willingly kept the PMD in their possession throughout the duration of the trials. One of the patients did comment on the bulkiness of the device and suggested that a lighter and slimmer device would be more appealing. Furthermore, 50 percent of the participants reported that they would not feel comfortable wearing the device outside of their home environment. Following the trials, we reviewed available phones and chose a slimmer and lighter handset to replace the handset used in the evaluations. Figure 4 presents photographs of a thinner version of the PMD device. The screen quality remains the same.

The caregivers found the concept of the project interesting and said they could see clear benefits for the introduction of such a device. The idea of simplifying a mobile device through the introduction of a single button was viewed as being particularly beneficial. All of the caregivers participating in the trials of the AD patients found the CSD easy to use, but one participant required more training than the other participants who were regular computer users. Considering that the mean age among the caregivers was over 71 years, this observation is a testament to the user-friendliness of the CSD.

Technical challenges

Several technical challenges arose during the evaluation. These challenges related to both the PMD and the CSD components. In terms of the PMD, several participants commented on the inadequate sound volume. This issue is primarily related to the default volume at which phone manufactures set the safe volume of each device following a device being powered on. Once the device is powered on, it's possible to increase the volume to suit user needs by manually adjusting the volume during playback. We have modified the PMD so that an initial reminder instructs the caregiver to increase the volume of the reminder playback. This initial reminder fires on a PMD 15 seconds after being powered on, following automatic launch of the PMD application.

Related to the volume of the media content delivered through the PMD was the choice of alert sound used for indicating a new incoming reminder. One AD participant commented that alternative alert sounds to indicate incoming reminders should be made available. As a result, several additional alert sounds are now available to participants. These can be personalized through the use of an advanced configuration program present on each PMD.

In terms of the physical appearance of the device, several participants noted that it was difficult to determine whether the device was powered on when it went into standby mode. Indeed, this has been a challenge for the project team to solve, because keeping the backlight of the PMD turned on quickly drains the phone's battery. As a compromise, the revised version of the PMD activates the PMD backlight prior to the notification of a new reminder in order to attract user attention to the device. Additionally, the default screensaver provided by the phone manufacturers is activated, displaying a simple animation to indicate that the device remains powered on.

Another feature that we added to the PMD is repeat reminders for those reminders that were not acknowledged. Using the configuration tool, caregivers can personalize this feature for each user by specifying the number of repeats that should be issued before the reminder is categorized as ''missed,'' the duration that the alert sound lasts, and the amount of time that should be allocated between repeats.

Perhaps the most noted issue with the pretrial technical iteration of the PMD was the stability of the network connectivity between the PMD and the server. Upon analysis of the log files obtained from each PMD, we found that on some occasions multiple simultaneous requests where being made by a single PMD. The limited number of GPRS uplink slots supported on the PMDs caused network conflicts resulting in poor network management and service delivery. In an attempt to address these serious issues, the revised PMD solution uses a queuing system whereby server requests from several multithreaded processes are placed on a single queue and served by a dedicated process at a fixed interval. In testing the revised network protocol, we found that these changes resolved the stability issues.

Other than porting the CSD to a touchscreen device, the only other suggestion was to provide an advanced mode for more technically experienced primary caregivers. This mode would be used to facilitate the scheduling of repeat reminders with a video library. However, we have not yet undertaken development of this functionality.

Conclusions

The aim of the evaluation we discussed in this article was to validate the user requirements of the system along with its technical stability. Each of the trial groups provided valuable feedback and helped us refine the system in terms of usability and technical stability in preparation for a larger trial of the prototype scheduled to be conducted on a group of 30 users. Following this, the next stage in our work will be to conduct a health economic assessment of the technology along with assessment of its deployment with different user groups. **MM**

Acknowledgments

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