

E-mobile pilot for community-based dementia caregivers identifies desire for security

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B.H. Davis, M. Shehab, D. Shenk, M. Nies. E-mobile pilot for community-based dementia caregivers identifies desire for security. Gerontechnology 2015;13(3):332-336; doi:10.4017/gt.2015.13.3.003.00 **Purpose** Dementia and the isolation it produces imposes a heavy burden on caregivers of persons with dementia as well as caregiver recipients. Mobile technology allows providers to reach people who may be isolated and desire increased social support. Telephone support groups and multimedia interventions are increasingly used for chronic disease management, such as hypertension and diabetes. **Method** 'Story-Call' is our newly-developed mobile phone application (APP) that records, archives, and presents 30- to 60-second videos by caregivers (CGs) who share success stories about how they handle common dementia home-care situations such as "She wants to go home!". Phase 1, a proof-of-concept pilot, tested how well five consented female working CGs recruited from adult day care centers could use the APP prototype with minimal instructions to successfully record stories. The impact of the intervention on perceived burden and willingness to seek social support was examined at pre- and post-intervention testing with the Zarit Burden Scale and Kaye's Gain Through Group Involvement scale. **Results & Discussion** The minimal directions enabled four of the five participants to easily access the mobile APP, to record CG success stories, and to view others' stories. However, a desire for greater anonymity and security was voiced by all five, and one participant withdrew, citing nervousness about being photographed as potentially leading to availability of personal identification. However, post-tests identified high satisfaction with the APP and ease of use, and suggest that measuring outcomes for caregiver burden across a larger group will be feasible. Barriers to recruiting and diversity were identified. Finally, in Phase 2 we will need to work to recruit diverse men and women CGs from a larger geographic region and seek both isolated rural and minority CGs, particularly working CGs.

Keywords: e-mobile, smart phone, caregiver support, dementia care, security

The Alzheimer's Association reports that 5.2 million people currently have Alzheimer's disease, a total growing each year, and estimates that in 2012, roughly 15.4 million caregivers gave 17.5 billion hours of unpaid caregiving¹. Alzheimer's disease (AD), the most commonly recognized form of dementia, and the isolation it and other dementias produce, imposes a heavy burden on informal caregivers (CGs) of persons with dementia (PWD). Such CG often carry a greater burden than for other chronic diseases². Using external and community resources and respite care can reduce CG stress and delay institutionalization of PWD³. A recent literature review⁴ notes that we do not yet understand why many CGs delay seeking external support services or respite^{5,6} and suggests four factors affecting the delay, each beginning with A. These factors are:

Availability (not all communities offer such services); Affordability (most are not covered by insurance); Attitudes (many CGs fear stigma or may have specific cultural values assigned to retaining a caretaking role); and Accessibility (transportation, convenient time and location). The problem of obtaining external support may be especially acute for working CGs, and underserved rural and minority CG. While continuing to work may stave off depression for some CGs⁷, many stop work; others show absenteeism with additional costs to American businesses, as much as \$25 billion⁸. In one survey, 69% of working CGs said they went in late, left early or took time off for eldercare issues⁹. That leaves little time for participating in needed in-person support groups or educational sessions with fixed times or at distant locations.

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E-MOBILE APPLICATIONS

E-mobile technology allows caregivers of persons with dementia to access both informational and social/emotional support at times and places convenient to them. E-mobile messaging interventions have had success in some areas of health¹⁰. A telephone intervention is working well: the national ADEAR/NLM trial on a Psychosocial Telephone Intervention for Dementia Caregivers offers CGs 16 phone calls over six months from a researcher who offers support¹¹. A review of eight technology-driven CG interventions¹² praised individualized, customized interventions and called for randomized control trials as follow-up to feasibility studies. A systematic review of 31 studies of consumer health information technology found that seven of these interventions addressed dementia¹³, citing positive response to peer-to-peer communication and increased self-efficacy. In addition, combining new technologies with culturally-sensitive social support is a potentially powerful way to reach isolated minority CGs, since smart phone ownership is higher among African-Americans and Latinos than among Whites¹⁴.

In this short note, we present an e-mobile application intended to present CGs with dementia care tips and information offered by people like themselves, as a way to learn about dementia, identify community resources, and decrease perceived caregiver burden. After describing the pilot and its evaluation, we emphasize the lesson we learned about what people want in e-mobile contexts and how application developers can meet their concerns.

CAREGIVER SUCCESS STORIES

Combining personalization with some feature of multimedia¹⁵ could attract CG interest and support their learning more about dementia care and the availability of community resources. The way information about care is given can affect how people receive it: people process information presented by stories differently from the way they process instructional content¹⁶. For example, watching video-recorded patient stories on DVD has improved blood pressure for new patients with hypertension¹⁷. Multiple websites offer digital storytelling to persons with diabetes^{18,19}. Accordingly, we developed an interactive mobile application (APP) which would include some multimedia in the form of visual storytellers sharing their successes with different aspects of dementia caregiving.

Story-Call is a newly-developed mobile phone application that records, archives, and presents 30/60-second videos by CGs who share success stories about how they handle common demen-

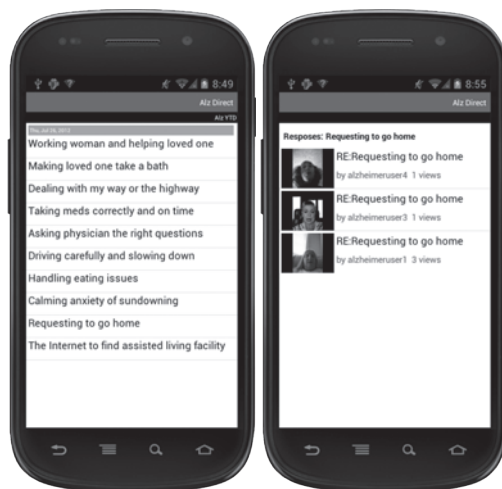


Figure 1. Dementia care situations and links

tia home-care situations such as repetitive questions or the best way to make sure a person with dementia takes his or her medications. Figure 1 displays a pair of screenshots, one showing a list of situations and the other showing links to CG responses. CGs can access, record and rate stories keyed to these situations and introduce new situations for consideration.

PHASE 1 PROOF OF CONCEPT

In this 2-week pilot assessment we tested how well CGs would be able to use minimal instructions to access the APP prototype and successfully record stories of their successes with dementia-care challenges.

Five female working participants were recruited from adult day-care centers. Although the centers were diverse in terms of race and ethnicity, all of the volunteer participants were Non-Hispanic Whites. The CGs had to have a home Internet connection to use the prototype APP, which we furnished on pre-programmed mobile phones (Android platform), and signed informed consent. CG burden²⁰ was assessed using the Zarit Burden Scale before and after using the APP²¹. Participants also completed the Gain Through Group Involvement Scale²², another short Likert-type scale used to identify willingness to seek social support, as well as a brief evaluation of their ease in accessing and using the APP after reviewing stories by the other participants. Assessments were conducted anonymously.

The minimal directions were both written as a one-page handout and demonstrated by a research assistant delivering the pre-programmed mobile phone. The directions told users how to activate the phone, access the APP, choose a topic or question to answer (such as "How do

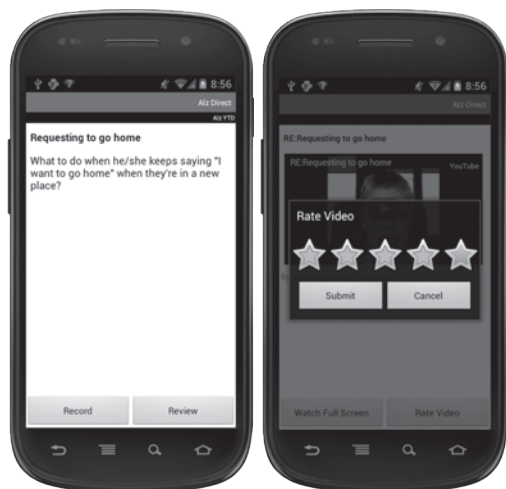


Figure 2. Choosing and rating dementia care stories

you handle giving medications?”), videorecord themselves telling a short 30- to 60-second story of success, review and save the recording, access other videorecorded stories by other persons, and assign one to five stars to rate their stories, as shown in the pair of screen shots displayed in Figure 2.

A dementia care expert (authors 1 or 3) reviewed each participant’s story and her ratings of other stories before approving them for the videorecording database whose contents were available to other participants. While stars were posted beside specific stories, the identity of raters remained anonymous.

RESULTS AND DISCUSSION

Over the two weeks that participants kept the phones, four of the five CGs accessed the APP, recorded success stories, viewed and rated others’ stories, and completed the pre- and post-scales for burden and potential group involvement. For all four participants, burden was said to be lessened by the information and pleasure obtained from the videorecorded stories. Participants also agreed that they would be more likely to reach out to community resources.

One CG signed consent, but then voiced concern about being videorecorded, and withdrew from the project. Her decision caused us to reflect on her understanding of security, and our need to increase privacy, security, and peace of mind for participants

Elsewhere we discuss more fully the topics chosen by the participants²³, and present a set of recommendations for implementing the intervention with a larger, more diverse sample. The topics included sundowning (confusion and

restlessness late in the day), repeatedly asking to go home, administering medications, and recalcitrant behaviors. Since the pre- and post-tests identified high satisfaction with the APP and its ease of use, this suggested that measuring outcomes for caregiver burden across a larger group will be feasible.

Discussions with participants made it clear that we would also need to increase their perception of security. We see this as having two major aspects: programmer and participant perspectives.

Aspect 1. Programmer perspectives

Each prospective participant asked us, during the consenting process, about how we would keep Story-Call private. From a programming viewpoint, that meant a focus on:

- (i) Security of stories being shared = Security of recordings
- (ii) Security of participant identities = Security of photo-images
- (iii) Security of rankings and ratings.

We pre-loaded the APP on the Android platform phones we checked for security and handed to participants personally. Our first step was to arrange for all videorecordings, photo-images, stories and rankings or ratings of stories to be sent directly by the APP to a password-protected, firewalled private site on Google Drive, kept on a password-protected and firewalled server. Only the first two authors had access to this data during the project, so they could review the content of the stories and make any needed adjustments or contact their authors about possible revision before putting the stories online. The database to which the data was assigned was again password-protected, and identities of participants were in an encrypted list. Pre- and post-tests were given by the research assistant; upon receiving the data, the first author assigned aliases and unique numbers to each participant and kept the spreadsheet on an encrypted flashdrive. In addition, when the research assistant delivered the phone and modeled the use of the APP, she also reminded participants not to use personal names or other identifying content in their story.

Aspect 2: Participant perspectives

The last-minute concerns affecting Participant 5, who withdrew because she was “nervous about being recorded” caused us to ask additional questions informally of the participants. We learned that we needed to go further to assure participants’ peace of mind. Their concern about security went beyond fears of being identified with a stigmatized condition in their family, it also meant additional fears of being followed online or in real life, with the chance of

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being robbed personally in real life, or digitally, through identity theft. In future expansion, participants will be given the opportunity to select an avatar, they will receive a more elaborate set of directions which will include a review of why and how their identities will be protected, and have a short training session on achieving and maintaining online security on phones, tablets and computers.

Hollenbaugh and Everett²⁴ emphasize the importance of self-disclosure in creating relationships on Internet blogs, via the online disinhibition effect. What is increasingly important, they note, is that bloggers often do not protect themselves with either discursive anonymity (the absence of 'clues' to demographic or personal features of identity through discourse) or visual anonymity

(still and moving pictures with features of identity). An interactive group of users with a shared construct (caregiving in dementia) and linked by videorecorded and participant-ranked stories shares certain features with blogs, in that participants are asked to self-disclose, thereby taking the first steps toward creating a weak-tie social network comprised of other storytellers. The recorded voices sharing successes, and visual representations of the speakers, whether real or avatar, create a personalized way to receive useful information about dementia care and may encourage participants to reach out to other resources, linked in the APP. Without some attention to security, both from personal and programming perspectives, caregivers are unlikely to participate in something beneficial to them and by extension, to the persons for whom they care.

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