

Dementia caregivers' technology preferences: Design insights from qualitative interviews

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Background Emerging information technology may ease the burden of family caregivers, particularly those caring for adults with Alzheimer's disease or other dementias. User-driven information technology design methods can determine which information technology design characteristics and functionality family caregivers of adults with dementia would find most helpful. **Purpose** To determine which information technology design characteristics and functionality family caregivers of adults with dementia would find most helpful. **Basic procedures** Between February and April 2014, we conducted structured interviews with 12 English-speaking adults aged 18 years of age or older who self-identified as a family caregiver. We then identified sub-themes and central themes based on participants' responses, and generated technology recommendations based on the central themes. **Main findings** We identified 15 sub-themes, leading to description of seven central themes and eight technology design recommendations. Family caregivers were overwhelmingly receptive to the idea of website or smartphone technology interventions and detailed specific needs that technology could address, including alleviating the psychological burden and social isolation inherent in caregiving, providing access to information and resources, and helping them to ensure care recipients' safety and track the progression of disease. **Principle conclusions** Our findings highlight potential technology solutions to address the overwhelming social isolation and stresses prevalent among family caregivers of adults with Alzheimer's disease and other dementias. Given the unmet needs of this growing group of consumers, researchers and developers of information technology should incorporate caregiver perspectives, both during the design process and in the resulting products themselves.

Keywords: Alzheimer's disease, family caregivers, dementia, information technology

Literature points to wide consensus on the immense psychosocial burden of family caregiving for adults with Alzheimer's disease or other dementias¹. Family caregivers often experience social isolation and lack support, and they report significantly higher measures of loneliness and depression compared to non-caregiving spouses². Family caregivers also suffer from higher rates of anxiety than matched controls³.

Less well understood is how emerging information technology may ease family caregivers' burden, although a 2008 needs assessment suggests that technology may address safety, security, and social needs⁴. Psychosocial needs are particularly acute and relevant to caregivers when defining their needs apart from care recipients: In a purposive sample of 14 spouses of adults with dementia, the balance between 'my', 'your' and

'our needs' was fluid, but the needs of the caregiver are often subordinated⁵. Schölzel-Dorenbos et al.⁶ found that caregivers need information on dementia, behavior and mental state, emotional support, emotional distress (depression and anxiety), social interactions and company.

Previous research highlights opportunities for products that encourage social engagement⁷ and enable family caregivers to complete practical tasks, such as documenting clinical information⁸. Most existing products focus on assistive technology that augments the functional ability of people with dementia, ranging from highly-specialized interventions such as 'smart homes'⁹ to telehealth-oriented interventions that use technology to provide peace of mind to caregivers through remote monitoring and fail-safe sensors¹⁰ or to facilitate support groups¹¹. The use of

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the Internet as a vehicle for virtual, psychosocial support for caregivers has shown feasibility and promise¹². However, much of the prior research both predates information technology such as smartphones, which are now highly accessible to consumers and may be helpful in disseminating useful products to alleviate caregiver burden, and is not designed around the portability and economy of newer devices.

We built upon previous research by conducting structured interviews to inform consumer information technology product design. Our aim was to determine which information technology design characteristics and functionality family caregivers of adults with dementia would find most helpful. We believe that user-driven information technology design methods can result in interventions that improve family caregivers' experiences and address their specific, daily needs.

METHODS

Participants

We contacted adult day centers, memory care clinics, and geriatrics clinics in the Providence, Rhode Island metropolitan area and asked staff to disseminate an informational flyer. We also posted information on two virtual community message boards (a listserv and a website). The flyers and messages solicited family caregivers of adults with dementia to participate in "a short, anonymous survey with the goal of developing future technology that will specifically benefit caregivers of adults with dementia and Alzheimer's disease".

Potential participants emailed or phoned to volunteer, be screened, and schedule a phone inter-

view. Individuals were eligible if they were English-speaking adults aged 18 years of age or older and self-identified as a family caregiver who in an average week, provided 'care or assistance to someone with dementia [a care recipient] outside of primary employment'. We interviewed all eligible volunteers (i.e., did not sample) and did not provide any incentives.

Technical information

We developed an interview guide based on an environmental scan of currently available consumer information technology products and a comprehensive literature review. To establish a framework for product design that was not confined to categories delineated during previous research, we included open-ended prompts intended to allow participants to freely share ideas and to define caregiving experiences on their own terms. The interview guide included questions asking participants about their experiences as caregivers, their needs for caregiving solutions to common challenges, and their interest in smartphone and website applications. Probes were included to allow for additional description or clarification of responses, if needed (*Table 1*).

The interviewer (J. Shreve) conducted structured interviews via phone between February and April 2014. As described above, potential participants contacted the interviewer in response to flyers or messages; he did not know any of the participants prior to this contact. At the beginning of the scheduled interview, he screened participants for eligibility and asked them to provide verbal consent if they met inclusion criteria. He then used the structured interview guide to

Table 1. Guide used by the interviewer

#	Item
1	I would like to discuss your duties as a caregiver. In a normal week, what tasks or activities related to an older adult with dementia do you participate in?
2	Thinking about the care and assistance you provide, what are your biggest needs? By 'biggest need', I mean a task with which you may struggle to find time or energy to complete.
3	Are there any areas where you've had successes in providing care for a loved one with memory impairment? (PROBE: Successes might include finding a way to document medications, a system for dividing tasks with other family members or anything which you and the person you provide care for might find rewarding.)
4	Do you think that a website, smart phone application or other technology would help you with planning or completing your caregiving tasks? (PROBE: Is there a need you have in providing care and assistance to a loved one with dementia for which you wish there was a solution?)
5	Which areas of caregiving are most of interest to you? For instance, this could include coordination of medical care (doctor visits or medication), learning more about a medical condition or respite care. (CLARIFICATION: Respite care is short term, temporary relief for caregivers.)
6	Do you think a website or smart phone application might be helpful with any other caregiving experiences? These could include tracking the condition of a loved one, preventing wandering or another area of concern.
7	Is there anything else you'd like to add about your caregiving experience?

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elicit participants' thoughts about caregiving and health information technology. To protect confidentiality and encourage candor, we did not collect any demographic data about either participants or their care recipients. We recorded each interview using phone voice recording technology, per the protocol approved by the Brown University Institutional Review Board (IRB).

Statistics

We transcribed the interviews and coded themes using nVivo research software (Melbourne, Australia). As with prior research⁶, we categorizing references in the text of transcriptions with thematic coding labels, in order to identify sub-themes and central themes based on participants' responses; we then sought to align technology recommendations with the identified common themes. We also categorized responses about openness to technology using a binary variable (Y/N) and counted the number of activities of daily living (ADLs) with which care recipients needed assistance. One of the co-authors (J. Shreve) identified and defined the initial thematic framework, which was further refined in discussion with the other co-authors.

This study received exempt status from the Brown University IRB, as we did not capture any identifiable information from or about participants.

RESULTS

We conducted structured interviews with a convenience sample of 12 family caregivers. As noted above, we did not collect any demographic data about either participants or their care recipients. We inferred gender based on name; most participants were female (n=11, 92%). Ten participants (83%) reported providing their care recipient with assistance with at least one ADL: bathing, dressing, eating, toileting, or walking. Although we did not ask specifically about the relationship between the family caregiver and care recipient, most of the participants referred to their relationship with the care recipient in the interview, identifying spouses, siblings, and other relatives.

Consumer information technology

After asking participants about their caregiving experiences, the interviewer asked whether participants felt that a website, smart phone application, or other consumer information technology would help "with planning or completing caregiving tasks" (one question) or "with any other caregiving experiences" (another question). Nearly all participants (n=11, 91%) were receptive to using information technology to ease the caregiving burden; several spoke of being "open to anything" or "willing to try anything promising". They supported their affirmative responses

by providing specific examples where technology might be helpful; for example, by providing caregivers with access to clinical information or to professional care services, without requiring them to leave their homes.

"I'm online because I don't get out." [Participant #2]

As nearly all participants felt consumer information technology would be helpful, we analyzed their responses about technology and the experience of caregiving to identify the sub-themes, themes, and recommendations (Table 2). Below, we describe the central themes.

Psychological burden

The theme mentioned most frequently was the psychological burden of caregiving, which manifested in the near constant mental and emotional stress of caregiving:

"It's so hard. It's mentally draining. The physical part is hard, the mental part is even worse. The mental part is the hardest part of all – and you don't have any help out here." [Participant #2]

Ten participants (83%) cited psychological stressors, and nine (75%) connected this stress to a specific need for psychological support. One participant said, "There's no emotional support - that's the biggest thing". The type of support desired differed from one participant to another, but often included both psychological and social support: desire for access to a support group, counseling, or simply a person to be a 'sounding board' for frustrations. Participants expressed optimism that consumer information technology strategies could be developed to address these needs.

Self-efficacy in caregiving

Although participants emphasized the difficulties inherent in caregiving, they also described coping mechanisms and successes. The act of caregiving emerged as a dynamic learning process involving trial and error. Perhaps as a result of the unpredictability inherent in the progression of Alzheimer's disease and other dementias, which many participants specifically mentioned, there was a great deal of heterogeneity in terms of how participants dealt with caregiving and what they defined as success. They spoke of developing and relying on support networks, working toward effective caregiving systems and the importance of accepting care recipients' conditions: *"I've gotten more comfortable with how the disease has developed. But it took a long time and it's not 100% comfortable. The [success] is just experiencing [a] moment where she is happy. I've learned to capture the moments." [Participant #9]*

Several participants also spoke of savoring meaningful moments. They emphasized enjoying mo-

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Table 2. Themes and consumer information technology design recommendations based on structured interviews with caregivers of adults with Alzheimer's disease and other dementias (n=12)

Central theme	Sub-theme	Caregiver Mentions,		Design recommendation
		n (%)	Counts	
Psychological burden and lack of support	Dealing with constant stress of caregiving	10 (84)	27	Develop tools that connect caregivers to support groups (both locally and online), web-based message boards, counselors and psychologists with experience in caregiving stress, and helplines
Successes and self-efficacy in caregiving	Able to obtain needed support from family and friends	11 (92)	25	Target meaningful caregiver outcomes using validated survey measures of depression or emotional wellbeing when evaluating new technology products
	Able to create successful caregiving systems	3 (25)	3	
Social isolation	Feeling disconnected from friends and family	5 (42)	9	Develop a personally tailored guide for activities or entertainment that is sensitive to care recipient personality and preferences
	Desire for social engagement	8 (67)	19	
Concern for physical safety	Seeking to balance care recipients' mobility and physical safety	8 (67)	14	Improve available tracking applications by adding customizability and social and communication features
	Desire for a tracking application	9 (75)	14	Pursue features beyond mobility monitoring (for instance, mental status, communication, self-identified successes) for location tracking
Challenges related to disease progression and behaviors	(S/he) was difficult on certain issues and did not want help	6 (50)	6	Provide highly specific information and guidance on how to manage new and distressing behaviors
Individual and dynamic needs for information	Desire to chart progression / key events	5 (42)	10	Develop tools that incorporate disease status, caregiver preferences, and sensitivity to information overload – including outlook on disease progression
	Desire for information	5 (42)	7	
	Desire for information on disease progression	3 (25)	8	
	Fear of information overload; desire to have just in time information, but not necessarily to know what the future will bring	3 (25)	6	Ensure that any application is dynamic over the course of disease progression and can be customized
Need for professional care services	Desire for care respite or someone to spend time with care recipients	7 (58)	14	Develop tool that vets respite for home health workers and that connects caregivers to workers with specific disease stage expertise and schedule availability
	Feeling unable to manage	5 (42)	4	
	Desire to keep care recipients at home	4 (33)	4	

ments of dignity, where care recipients' agency and confidence was emphasized, or laughter. Many participants described refining their approaches based on care recipients' changing needs and their shared personal histories. The five participants (42%) who, unprompted, mentioned their overall 'caregiving goal' spoke about encouraging care recipients' happiness and ex-

pressions of selfhood.

"[It's about] finding a way for her to have any decision-making power – let's go for a walk down to the lobby, let's go for a walk to the elevator. Let's come back. Generally, I would say [I defined success] when she felt she would have some say in determining what the activity was, some agency."
[Participant #5]

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As family caregivers developed greater understanding of the illness course and of how to manage day-to-day situations, gaining this 'self-efficacy' was a success.

Social isolation

Eight participants (67%) referred to their desire for human contact or social engagement, and many linked the feeling of being disconnected to psychological burden. One participant said that caregiving is "very isolating work". Another said that people want to help, but "do not know the situation well enough". It was, at times, difficult to parse the isolation experienced by the participant from isolation experienced mutually with a care recipient or empathy felt by the participant on behalf of the care recipient. Regardless, participants clearly articulated a desire for social engagement and for activities both within the caregiving dyad and with a broader social network. One said that "What helped me the most was just talking to people". Participants seemed to search for social activities that helped them to recognize, or perhaps preserve, their care recipients' selfhood. Several emphatically defined success as any activity that conferred a sense of agency, dignity, or confidence, no matter the source. This sentiment might best be summed up by a one participant, who said that her care recipient wants to remain "in the conversation", even if her comprehension diminishes.

Concern for physical safety

Participants spoke of a desire to monitor a care recipient in real time, primarily to ensure physical safety. For example, they spoke of both preventing wandering behaviors and being aware of general movement, to prevent falls and avoid other potentially dangerous situations. Several participants suggested possible technology solutions to monitor safety, including communication methods (such as a two-way intercom system) or global positioning system tracking devices. However, they also mentioned weighing the value of monitoring physical safety against the risk of interfering with care recipients' mobility or privacy; as one participant said, "There's a fine line between making sure someone's OK and being creepy".

Disease progression and behaviors

In addition to monitoring safety, participants also spoke of using real-time monitoring to track disease progression and to document specific events, either for personal reasons or to communicate with healthcare providers. They discussed using medical records, journals, and other mementos for this purpose: one participant traced the progression of disease through her care recipient's changing art.

"Her artwork turned out to be some of the most interesting stuff that I've kept... at the beginning, [it] was color-correct, in the lines and well-done, neat. Through the two years, we went to out of the lines, to coloring so hard it went through the pages, to monochromatic [...] to psychedelic – it was like someone took Quaaludes and drew." [Participant #3]

Monitoring trends allowed participants to prepare for behavior changes, for example by seeking counseling to handle behavior changes or the challenge of coping with a care recipient's deterioration. We identified the sub-theme of interacting with a loved one who did not want help and whose behavior otherwise made providing care more difficult, which was a distinguishing feature of dementia care.

Needs for information

When discussing how consumer information technology might be helpful, participants spoke of their desire to customize information and support to their individual needs, and how doing so could improve their caregiving experiences and care recipients' quality of life. For example, participants mentioned using technology to access to real-time information tailored to the progression of the care recipient's condition. "You have to give [caregivers] the information when they need it", said one participant. Another said that a lot of information is not available "until you have both feet in". At the same time, they were wary of information overload – having too much information from various sources – and knowing too much about the progression of illness in the future:

"Keep it simple, keep it straightforward... A doctor might be the smartest [doctor], but if he can't communicate what good is it? The bottom line is you have to communicate on a level everyone can understand." [Participant #4]

The heterogeneity of participants' responses speaks to the need for highly personalized information and support: participants dealt with caregiving in a variety of ways and did not coalesce around a uniform strategy.

Professional care services

As mentioned above, participants spoke of their desire to use technology to access professional care services without requiring them to leave their homes. Participants spoke about using the Internet frequently for this reason: it was accessible despite the fact that they were not able to leave the house as easily as before they began caregiving. Their desire to access professional care services arose from two sub-themes: (i) concerns regarding their ability to manage and (ii) the emphatic goal of keeping care recipients at

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home. "I refused to put my parents in a nursing home", said one participant. Yet at times, participants felt that care recipients needed someone else to spend time with them, either because the participants needed respite or because they felt unable to manage without assistance. One participant commented on the need for professional care services by saying, "I feel like I depend too much on family members". Another talked about the difficulty of accessing services, saying "I was making a lot of calls to social service and home care agencies".

In summary, we identified 15 sub-themes, leading to description of seven central themes and eight technology design recommendations (Table 2).

DISCUSSION

We interviewed 12 family caregivers of adults with Alzheimer's disease or another form of dementia, in order to learn what they would find helpful for the design and content of consumer information technology products. This included identifying common unmet needs and linking them to technology recommendations. Technology design recommendations included an activities guide, a caregiver assessment, a communication or location live log, an individualized guide to responses to behavior problems, an integrated clinical status and 'scrapbook' online service, and a referral service. There are contemporary systems poised to become a platform for technology solutions such as these; these systems include the Alzheimer's Association's 'Patient Navigator' program¹³, 'Open Notes' electronic health record systems, and wrap-around clinical care by providers, such as SeniorLink Caregiver Homes¹⁴. However, neither the authors nor the family caregivers participating in this research were aware of any such services widely available now.

Participants were overwhelmingly receptive to the idea of website or smartphone technology interventions and detailed specific needs that technology could address, including alleviating the psychological burden and social isolation inherent in caregiving, providing access to information and resources, and helping them to ensure care recipients' safety and track the progression of disease. These findings add to previous research on caregivers' preferences, which highlights opportunities for products that encourage social engagement⁷ and enable family caregivers to complete practical tasks⁸. Much of the prior research predates technology, such as smartphones, which are now highly accessible to consumers and may be helpful in disseminating useful products to alleviate caregiver burden. More recent studies still grapple with variability in both content and meth-

odology in a field that is still taking shape¹⁵.

Although we believe strongly in including the voice of the patient, we focused narrowly on family caregiver needs; interviewing patients was outside the scope of our research. We interviewed family caregivers because they are essential to any intervention involving people with dementia: interventions involving both care recipient and caregiver, preferably in a home setting, have proven more successful than interventions that focus solely on the needs of people with dementia¹⁶. Recent randomized, controlled trials have also shown the effectiveness of the 'collaborative dementia care model', an approach that includes family caregivers¹⁷. Future research may consider evaluating patients' Health Information Technology (HIT) needs, either alone or as part of the patient-caregiver dyad. In addition, as technologies such as remote monitoring and smart homes advance, research will be needed to determine patients' and caregivers' ethical considerations weighing autonomy, safety and privacy.

This study affirms previous findings that psychosocial support is a major need for caregivers and should be included in technology-based interventions. Many participants identified psychological needs related to the daily tasks of caregiving, as well as the uncertainty in disease progression, especially since caregiving can result in isolation from family, friends, and community, making it difficult to access the social support, activities, information, or respite necessary to ease the caregiving burden. Participants voiced beliefs that their psychosocial needs could be addressed through consumer information technology interventions. Technology that fails to ease psychological burden or enrich the caregiving experience will neglect what we believe to be this population's most urgent need.

To successfully match caregivers' needs with technology, we need to use a translational process that puts interventions into the everyday language of caregivers. Schulz et al.¹ developed a taxonomy of technology for a general population of older adults across all life domains¹⁸. The matrix of life domains and technology functions considered by the authors is easily understood and instructive; where caregivers are concerned, the relative weighting of these needs often occurs twice over. The process of parsing out the distinct needs of caregivers, while recognizing the interrelatedness of the caregiving dyad, is often muddy. However, our effort considered the caregiver voice, without divorcing the caregiver from the context of the dyad, allowing them to use language to describe how technology might fill unmet needs.

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We found that participants derive therapeutic power not simply from services rendered, but in wherever they can improve care recipients' dignity and agency. Often, this occurs in a narrative form: the ability to recount and laugh at stories of stressful events, a personalized note about a loved one from a healthcare worker, or a story told to a person with dementia that aspires to reach them, even if not fully understood. Taken with the psychosocial needs identified, this finding elaborates previous research that suggests increased self-efficacy and decreased symptoms of depression should be the most important targets for intervention¹⁹.

We note several limitations. First, we used a convenience sample and subject to a number of potential biases, including volunteer bias and limited representativeness of the sample. To preserve anonymity and encourage candor, we did not collect any demographic data about either participants or their care recipients so we are unable to assess these biases. Second, although in-person interviews conducted over multiple sessions may be preferable, we conducted our interviews via a single phone session. We elected this approach for ease of scheduling and as a result of limited resources. Third, our findings are based on research conducted in a single metropolitan area, Providence, Rhode Island, and may not be generalizable to caregivers' experiences and needs elsewhere. Fourth, our results reflect participants' perceptions and may be limited by the type and content of questions we asked. For example, our use of open-ended approach relies on the information participants choose to reveal. There may be consumer information technology solutions that caregivers find helpful, but were neither identified in our analysis of themes nor

suggested by participants. Finally, although participation was voluntary, no identifiable data were collected, and we kept participants' comments confidential, so there may be a response bias where participants have a conscious or unconscious desire to please the interviewer.

CONCLUSION

Understanding the shared needs and the complex adaptive relationship of the caregiving dyad is vital to efforts to create consumer information technology products. Our findings highlight the social isolation and stresses that are prevalent among family caregivers of adults with Alzheimer's disease and other dementias, but also hint at the technology solutions that may help to address these burdens. We find that caregivers need access to the right information, in the right place, at the right time. To know what is 'right', however, means using a consumer-driven process that empowers caregivers to tell us what they want and need, and when. Further research is needed to develop and test interventions, and we believe that researchers and developers should continue asking questions of consumers – both during the design process and in the resulting products themselves.

Authors' roles

As his Master's thesis, J. Shreve conceptualized and designed the study, conducted the interviews, performed the qualitative analysis, and wrote the first draft of the paper. R. Baier, G. Epstein-Lubow, and R. Gardner provided subject matter expertise and oversight related to the interview methods, subject, and analysis. Subsequently, all four authors collaborated to revise the draft to its final form.

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