CHALLENGES IN CAREGIVING AND CREATIVE SOLUTIONS: USING TECHNOLOGY TO FACILITATE CARING FOR A RELATIVE WITH DEMENTIA

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Borrowing principles from total quality management and the emerging consumer-satisfaction movement in the field of ageing, we explored how technology might assist family members who are caring at home for a relative with dementia. In Phase 1, focus groups with a total of 26 current and former caregivers revealed that as caregivers and the relatives for whom they care struggle to maintain continuity of roles, relationships, and lifestyles, safety is a key concern. Despite the limited use by some caregivers of "low-tech" tools (e.g., door alarms, intercoms), caregivers lack a comprehensive system to enhance their relatives' safety. In Phase 2, we identified an Internet-based monitoring system to address caregivers' major concerns. In Phase 3, focus groups with eight caregivers evaluated the system that was identified in Phase 2. Results suggest that affordable technologies exist to assist family caregivers, and that these caregivers were amenable to the use of these technologies.

Introduction

Recognition of the role that families assume in providing long-term care to relatives with dementia is moving to the forefront of national and state policymaking (Cox, 1997; National Alliance for Caregiving/AARP, 1997). Most individuals with dementia reside in community-based housing and are cared for by family members, mostly spouses and daughters or daughters-in-law. In a 1997 survey, approximately 72% of informal caregivers to a relative or friend 50 years of age or over were women, and 52% were providing care to a parent or parent-in-law (Wagner, 1997). The typical caregiver is a married

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woman in her mid-forties who works full time, is a high school graduate, and has an annual household income of $35,000 (National Alliance for Caregiving/ AARP, 1997).

Social scientists and practitioners alike have begun to explore the use of technology to support family caregivers in their efforts to enhance relationships and well-being. For example, Arguelles and von Simson (1999) found that a family-based computer telephone integration system helped caregivers to a relative with dementia overcome some of the barriers to accessing and engaging in leisure activities. Exploring a different application of technology, a number of researchers have examined caregivers' use of the Internet for information and referral. Brennan, Moore, and Smyth (1991) found that during a one-week period, 68% of caregivers accessed the Internet to obtain information/referral and support. In a longitudinal effort, Mahoney (1998) conducted a content analysis of the messages posted on an electronic network for a 12-month period by family caregivers to a relative with dementia. Mahoney's findings support claims by Smyth and Harris (1993) that the accessibility of Internet-based information and support systems is a viable complement to existing services for caregivers. Together, findings from these investigations suggest that technology might be employed in a number of different ways to lessen some of the demands that are inherent in caring for a relative with dementia.

Despite the potential usefulness of technology for caregivers to a family member with dementia, a number of researchers have examined the reasons that older adults, among others, adopt or refuse to adopt certain technologies (e.g., Agree & Freedman, 2000; Gitlin, 1995; Mann & Tomita, 1998; Mann, Hurren, Tomita, & Charvat, 1995). Among the many reasons identified, level of technology seems particularly salient. In general, the more complex the technology, the less likely it is to be used, unless the potential user possesses a skill level to match the technology. For example, a person is much less likely to choose a computer-controlled device if they do not already possess sufficient computer skills to utilize the device.

In this paper, we present findings from a pilot project that has evolved into an on-going effort to evaluate the extent to which electronic technologies might be used to decrease the burden experienced by individuals who provide in-home care for a family member with dementia. Our efforts have been informed by the emerging consumer satisfaction movement in the field of ageing (e.g., Applebaum, Straker, & Geron, 2000). In discussing the application of total quality management or continuous quality improvement to health, housing, and long-term care services for older adults, Applebaum, Straker, and Geron identify five critical principles of total quality management: know the consumers; hear the voices of the consumers; information is essential for decision making; the group is smarter than the individual; sub-optimization is the key challenge to organizations. Our program of research has been informed by the first four of these principles. We worked with current and former caregivers to a relative with dementia to determine which aspects of caregiving should be targeted for technological intervention, we identified a potential technology, and returned to the caregivers to solicit their feedback about the technology.

The pilot work that we report here was carried out in three phases. In Phase 1, we conducted focus groups with caregivers to: (a) document the specific challenges faced by caregivers; (b) assess caregivers' familiarity with and willingness to explore electronic technology (e.g., home computers, wireless telephones, assistive technology devices); and (c) assess caregivers' knowledge about and willingness to explore the extent to which electronic technology can be used to decrease caregiving burden. In Phase 2, we used the results from focus groups to work with a technology consultant and an occupational therapist to identify technological interventions that overcome the major challenges voiced by in-home caregivers. Finally, in Phase 3, we conducted focus groups comprised of caregivers to relatives with dementia to evaluate the utility of technological interventions identified in Phase 2. In this presentation, we emphasize those findings (emerging from Phase 1 and Phase 3) that increased our understanding of how dementia impacts the nature of the relationship between caregivers and the family members for whom they care, and that elucidate caregivers' considerations about whether technology in general, and an Internet-based monitoring system in particular, might facilitate their caregiving efforts.

Phase 1 Method

Procedures

Five focus groups, comprising a total of 26 individuals, were conducted during the summer of 2001 by two members of the research team. One team member facilitated the focus group, while the second team member served as co-facilitator and took notes that were used during the group to summarize main points and guide subsequent discussion. Each group was audio-taped, and tapes were transcribed for subsequent analysis. The format for each focus group was as follows: Arriving participants were provided with printed informed consent information which they were asked to read and sign to give consent prior to the start of the group. Participants then completed a brief information sheet that recorded demographic information and characteristics of their caregiving relationship and activities. The focus group began with introduction of participants and an overview of the procedures that would be followed. Each focus group lasted approximately 90 minutes.

A series of focus group prompts were employed to explore two overarching themes: challenges in caregiving and creative solutions (with special emphasis on "gizmos, gadgets, and technology"). The prompts used to elicit discussion about each of these two themes are presented in the appendix.

Description of Focus Group Participants

To be eligible to participate in a focus group, individuals had to have experience as a primary caregiver to a relative with dementia. For the purposes of this research, a primary caregiver refers to the one individual who is most responsible for the day-to-day needs of a relative with dementia. Both current and former primary caregivers were eligible to participate in the research. In an effort to have focus groups of caregivers who demonstrated diversity in their use of technology, recruitment materials invited caregivers at all levels of technological knowledge and experience to participate in the research; use of technology was not a requirement for participation. Participants were recruited primarily through Alzheimer's Association-sponsored caregiver support groups in central Ohio. Additional participants were identified through the local Area Agency on Aging.

The average age of the 26 caregivers who participated in Phase 1 was 63.2 years (SD = 11.83); the majority of caregivers were female (76.9%). One caregiver was African American, the rest (96.2%) were Caucasian. Almost one-third of caregivers (30.77%) were high school graduates, and more than three-fifths had some college (38.46%) or were college graduates (19.23%). One participant (3.85%) had graduate-level training; three participants did not graduate from high school. On a scale ranging from 1 ("very poor") to 10 ("excellent"), the average self-rated health was 8.0 (SD = 1.47).

On average, caregivers had spent 5.5 years (SD = 4.68) in the role, and reported spending an average of 12.86 hours (SD = 9.04) per day providing care. Focus group participants included both current (65.39%) and former (34.61%) caregivers, and represented a range of kinship relationships with the individual for whom they provided care. Specifically, one-half of caregivers cared for a parent, step-parent, or parent-in-law; two-fifths (42.31%) cared for a spouse; and 3.90% each cared for a grandparent and an adult child. At the time of the focus groups, 52.94% of the caregivers and care recipients resided together; 17.65% of the caregivers resided in the community but separately from the individual for whom they were providing care. Among the remaining caregivers, 17.65% of family members with dementia resided in assisted living or a nursing home and the remainder were either deceased or the caregiver provided no information about their status.

As part of the information sheet the caregivers completed, current caregivers indicated the extent to which the relative for whom they care exhibited each of eight symptoms of cognitive decline. Caregiver reports indicated that 92.86% of the individuals with dementia had at least some difficulty remembering his/her home address; 85.70% had at least some difficulty remembering recent events, knowing what day of the week it is, remembering words, and understanding simple instructions; 57.14% had a fair amount of difficulty recognizing people that he/she knows; 35.71% had difficulty finding his/her way around the house; and 28.57% had difficulty speaking in sentences.

Current caregivers also indicated the number of days during the past week that the relative for whom they care exhibited each of 14 challenging behaviors. Caregiver ratings revealed that, in the past week, the individuals with dementia asked repetitive questions, were restless/agitated, and hid items on an average of between three and four days. They were irritable/angry, dressed inappropriately, had a bowel/bladder accident, and were suspicious an average of between two and three days. They clung to/followed their caregiver, were depressed, swore/used inappropriate language, threatened others, and kept the caregiver awake at night on an average of between one and two days. Behaviors that occurred an average of less than one day in the past week were crying easily and inappropriate displays of sexual behavior. Taken together, the caregiver ratings suggest that the individuals with dementia for whom they are providing care had advanced beyond the early stages of the disease.

Phase 1 Results

Transcripts from the Phase 1 focus groups were analyzed using a coding process developed by Strauss and Corbin (1998) that involves the identification of repeating ideas and concepts, known as concept indicators. These concept indicators serve as an organizational guide in the synthesis of the emergent themes in the transcripts. The themes reported in this manuscript include the major challenges in caregiving, caregivers' use of technology in their current day-to-day lives, and their willingness to explore technological solutions to the challenges that they identified.

Relationship Impacts of Dementia

Analysis of the Phase 1 focus group transcripts revealed that caregivers' overriding concern is the safety of their family member with dementia. Although the specific behavior that most threatened the safety of the individuals with dementia varied, caregivers were uniformly challenged to find ways to lessen or eliminate the potential threat. This manifests in marked changes in the relationship between caregivers and the relatives for whom they cared. Table 1 summarizes these findings, presenting caregivers' overarching concerns, specific domains within each overarching concern where they emerged, and quotes that illustrate the nature of the concern (pseudonyms are used for focus group participants).

Caregivers and the family members for whom they provide care attempt to maintain their roles, relationships, and lifestyles in the homes that symbolize this continuity. However, because of the dementia, these very homes present a number of affronts to the continuity of their pre-dementia lives. Discontinuities create moments of frustration, tension, stress, and conflict, and frequently emerge around issues of safety both beyond the home, as in the case of wandering, and within the home. For example, although Amanda described her

Table 1

Examples of How Dementia Impacts the Nature of the Relationship Between Caregivers and the Family Members for Whom They Care

Overarching Concern	Domain of Concern	Key Examples
safety	care-recipient hiding	Amanda, describing her mother's hiding from her in a small barn at their family farm as "a game that she played...that was hard...but it was funny...she thought it was cute."
	care-recipient not behaving responsibly	Fran, referring to her mother-in-law: "...she has a tendency to fall asleep, leave her front door open..my nephew went by a few weeks ago and there were two men on her front porch drinking. And she's sleeping in the chair, by herself, with that front door wide open.."
		Bob had begun to worry about his mother's efforts to prepare meals: "She is still quite confident as far as using the coffee maker to make coffee and using the microwave oven to heat things up, but as far as cooking on the burners of the stove, I'm just getting to the point where I'm not particularly comfortable with that."
		More dangerous was the situation that Mary's husband created: "He got up in the middle of the night, he would pace the kitchen...and he was a smoker, and we have a gas stove and when I got up in the morning after a little nap, the stove was on."
shifts in relationship between caregiver and care-recipient		Bob revealed: "Supper time...we regularly have some stress between us because she feels that her playing the role of mother...is her duty and there's no reason why her son, her boy, should have to cook for his mother. So we constantly do a little dance in the kitchen trying to work around each other and who's doing the cooking and who's helping and that sort of thing."

mother's hiding as a "game," the "game" ceased to be amusing when her mother actually began to wander farther away from home. Amanda said that on one such occasion, her mother wandered seven miles from the family home before she was found.

As can be seen in Table 1, Fran and other caregivers' concerns about safety were closer to home, and for a number of the caregivers, their family members' use of the kitchen was increasingly problematic. Mary said, "Safety in the home is a big thing. In order for somebody else or the caregiver to get some rest, you have to come up with something." Her statement was met with nods of agreement from other focus group participants.

As part of the process of providing care at home, wives become guards, husbands become prisoners, and mothers who have fed their families for decades are no longer permitted to be in the kitchen without supervision. As illustrated by Bob's second quote in Table 1, for these caregivers, ageing in place almost becomes secondary to caregivers' and their relatives' desires to seek continuity. If attempts at continuity are compromised by restrictive management of behaviors, another place, even a nursing home, might provide more continuity. Mary praised the situation at the long-term care facility where her mother had been placed. "She's doing really well. She has that whole long hallway to wander in. She wanders in that whole large dining area. There's this wonderful game room with toys and dolls and books. But mostly she pushes the sweeper and she dusts because that's what her life was: gardening, being a mother, a wife, a homemaker...And so she's content to do that now."

However, for many of the caregivers, keeping their relative with dementia at home where they could age in place represents consistency, order, familiarity, sentiment, and comfort, all of which are viewed as important to a high quality of life. As summarized by Jane, "Keeping her out of a nursing home is what we're trying to do." Fran had a similar goal for her mother: "I was determined I was going to keep her home. I was not going to put her in a nursing home until we had to," which occurred after three and a half years of in-home caregiving.

Caregivers' Use of and Willingness to Explore Technology

Analysis of the focus group transcripts indicated that as a group, these caregivers do not think of themselves as being particularly savvy about technology. However, none of the homes in which Phase 1 focus group participants resided were without any technology whatsoever. They reported using a range of technologies in their day-to-day lives, including computers for Internet access and email, and some families directly applied existing "low-tech" solutions (e.g., intercoms, alarms) to monitor, communicate with, and maintain the safety of their relative with dementia. Caregivers' current and proposed uses of technology to help them with challenges in caregiving are presented in Table 2.

As illustrated by Cindy's quote, a number of caregivers put locks and/or alarms on the exterior doors of their homes. Further, Tim, who described himself as a "technically oriented person," installed a wireless doorbell so that his wife, who frequently is confined to bed, can communicate with him when he is in other areas of their home. Tim and his wife also communicate via intercom when they are in different areas of their home. Tim has tried to think of a way to adapt an intercom or a baby monitor so his wife can communicate from her bed with visitors who come to the front door, but he has not yet

Table 2

Caregivers' Current and Proposed Uses of Technology

Problem in Caregiving	Current Uses of Technology	Key Examples
Care-recipient wandering outside the home	locks and/or alarms on the exterior doors	Cindy cared for her mother, who did not sleep through the night: "I was lucky enough to find a person who would design a mechanism for each of the doors so that when the door was opened the alarm would go off where I slept."
Communicating with care-recipient inside the home	wireless doorbell; intercom	As Tim explained, "So, when she has a problem...I'll hear the doorbell...'Ding,' and I come running. If it's a case of 'I want you to come here but it's not urgent,' she'll ring it twice."

Problem in Caregiving	Proposed Uses of Technology	Key Examples
safety while performing self-care in the home	nursing care robot	Kathleen claimed: "We want a mechanical robot to help them walk and we want a mechanical device to get them on and off the toilet easier." Tim suggested that, when assisting in the bathroom, "...with it being a robot, it could just stay in the bathroom. You know, maybe turn its back..."
safety and continuity of care in the home environment	monitoring necklace/visual monitoring system	Kathleen commented: "If we could come up with something where they could stay in their familiar surroundings, either in their own home or in the home of a family member, it would be really wonderful. Things that would monitor their wandering. Things that would monitor when they are in a dangerous situation like if they are trying to cook or something." Clyde reported: "Now, my mother-in-law would like a monitor. She could see what he [her husband] is doing in the room."

Table 2 (cont.)

Problem in Caregiving	Proposed Uses of Technology	Key Examples
safety and continuity of care in the home environment	monitoring necklace/visual monitoring system	Tim reported that, with his current intercom system, "I never know if she's asleep or awake and if she's asleep, I don't want to wake her up. If I could peek in and see, then I wouldn't bother her."
keeping geographically dispersed family members aware of what it happening	visual monitoring system	As Delores noted, "I think with family a lot of times the family doesn't understand it. And they are afraid of it so they stay away. And therefore you don't get any help from them."
		Ruthea talked about the difficulty she had explaining changes in their mother's condition to her sisters who lived several states away, before they came for a visit. "I tried to prepare my sisters before they came... And my sisters admitted afterward that I had tried to prepare them but it was really a shock to actually be there and to see it."

solved that particular challenge. For those times when Tim must be away from home, Tim's wife wears a pendant health care monitor, and he considers the cellular phones that he purchased a two-way "umbilical cord" that connects them.

With some encouragement, caregivers were able to visualize creative technological solutions to some of the demands of caregiving. Some of the proposed technological solutions to increase safety were quite ambitious (even futuristic). Participants in two groups proposed, and were quite excited about, the prospect of a "nursing care robot" that would follow behind the individual with dementia, providing physical support to decrease the probability of falls and assist with transfers from bed to chair and with toileting.

Participants in two of the groups expressed excitement about a "little necklace-type thing that had a little camera in it" that the individual with dementia would wear at all times, permitting the caregiver to view what is happening from their relative's perspective. Should the individual wander away from home, the camera would transmit an image (ostensibly, to be viewed remotely at a computer monitor) to the caregiver, who would then be able to see where the individual with dementia was wandering.

Even when considering these most creative technological solutions, caregivers were cognizant of the inherent trade-off between safety on the one hand and dignity, respect, privacy, and desires for independence and autonomy on the other hand, as indicated by the exchange between Kathleen and Tim that is presented in Table 2. Caregivers' concerns for their relatives' safety were paramount and reflected in their discussions of strategies to combat unsafe wandering, "safety-proof" their homes, and monitor their relatives' activity.

In addition, caregivers discussed technological solutions that might provide some relief from the all-consuming nature that can characterize caregiving. In Mary's words: "Everything you do is around the sick one, the one who's ill. That's where your life is." Tim quickly agreed, "You can't just decide, 'I'll go to the store now.'" In the absence of some type of monitoring system, caregivers find themselves limiting or forfeiting their own leisure time, quickly running errands while their relative naps, and sleeping fitfully if at all at night, when their relative is up and about. As indicated in Table 2, caregivers extended the application of some type of visual monitoring system to help bridge geographic distance between the individual with dementia and concerned family.

Perceived Limitations of Technology

Throughout the discussion of technologies (e.g., cameras and interactive web-based communication software), caregivers were quick to point out that some challenges in caregiving simply could not be addressed with technological solutions. Pointing to a series of scratches on her arm that resulted when Becky had bathed her relative, she asked, "How is technology going to stop this?" Although this is an extreme example, there was consensus that technology could not be expected to entirely replace or substitute for the efforts of family caregivers. Table 3 summarizes caregivers' perceived limitations of various technological "solutions" to some of their challenges.

Caregivers identified a number of trade-offs that most likely would accompany the introduction of these technologies to meet the demands of caregiving. For example, caregivers recognized that cameras that would permit them, or another person at a remote location, to monitor their relative could at the same time compromise their own privacy if, for example, personal hygiene and bathroom behaviors were monitored. Another consideration for caregivers was whether access to the images could be controlled and/or limited if web-based technology were employed.

Despite this concern, caregivers were amenable to the idea of respite care at a distance, whereby someone at a remote site could monitor the activities of the individual with dementia while the caregiver performed other responsibilities. Kathleen said, "In the earlier stages it would be better than leaving them totally on their own."

Table 3

Caregivers' Perceived Limitations of Technology

Technological "Solution"	Limitation	Key Examples
camera for monitoring	compromised privacy	As Bob put it, "It could present some awkward situations if [the individual with dementia] would accept being monitored."
		As explained by Kathleen: "My feeling is you wouldn't want a camera looking at them taking a bath or going to the toilet, but if..you knew they were in the bathroom that wouldn't really take away from the privacy necessarily. You would know where they were but, as far as having a camera in there watching them I don't think you would want that because that would really be bad.. for their dignity."
	contolling access to the monitoring system	As pointed out by Kathleen, "It might be a safety factor if it was just open and anybody could watch it because if somebody was aware that these people are not all together...it would be a good chance for a bad person to focus in on going there and bothering this person."

Sally agreed, admitting:

> "There's been lots of times before she [her grandmother] got really bad that I would be nervous going to the store because there would be no one there. This is before she got really bad and you would be so nervous you couldn't shop or do anything. So that would be nice. That way you would feel comfortable when you left her."

When prompted, Kathleen and Sally suggested that, were such a monitoring process in place, at the first sign of trouble a message or alert could be sent either to the caregiver or to a neighbor who was on call who could quickly respond to the emerging problem. Kathleen and Sally's comments underscore that such monitoring is not a panacea; it is not universally appropriate for all individuals with dementia at any stage in the disease process. An additional concern not addressed by caregivers is the extent to which individuals with dementia might attempt to tinker with and/or remove sensors and cameras. As such, careful placement of these devices would be required.

In addition to these issues, caregivers advised that to maximize utility, technological solutions to challenges in caregiving should take into account the likelihood of multiple users (i.e., both the caregiver and the individual with dementia, as well as other family members) and be sensitive to the variable and changing levels of functioning in an individual with dementia. In general, caregivers felt strongly that technological solutions were neither appropriate nor useful across all situations, and that monitoring their relatives with dementia via technology clearly was not a substitute for their presence. Ultimately, caregivers made it quite clear that they do not aspire to become "technology whizzes"; rather, they are interested in easily obtained, affordable, easy-to-use solutions to some of the challenges they face.

Phase 2

Method and Results

The purpose of Phase 2 of the project was to use the results of Phase 1 that dealt with caregivers' attitudes toward and use of technology, along with findings from the existing literature, to select a currently available Internet-based technology that could be evaluated for its potential to lessen some of caregivers' major challenges. Based on the findings from Phase 1, two members of the research team, a computer industry consultant and an occupational therapist, used five major criteria to select that technology.

First, the technology had to be readily available and serviceable for the average, "non-computer-type" consumer. Second, the technology had to be easily adapted to a particular caregiver's environmental demands and caregiving challenges. Third, the solution had to be technologically stable, such that it did not require frequent updating and would not become obsolete too quickly. Fourth, the learning curve for using the solution had to be modestly sloped and time limited. Finally, the solution had to be relatively low cost.

After careful consideration, the team members selected the Xanboo Smart Home Management System (hereafter referred to as the system). The system allows for monitoring of a residence through placement and control of video cameras and sensors. These sensors and cameras may be set to provide a caregiver or other interested party with immediate notification by email, pager, text messaging cell phone or personal digital assistant (PDA). The backbone of the system is the Internet website operated and maintained by Xanboo (www.xanboo.com). Computer access to the Internet site is by subscription and logon requires a registered user ID and password by which the system can be accessed from anywhere Internet service is available. The website also allows for saving and downloading video images and video clips to a personal computer.

To demonstrate the system to caregivers, a household in a Cincinnati, Ohio suburb was outfitted with the system. A video camera was placed in the kitchen and family rooms. A sound sensor was placed near the phone. Door-opening/closing sensors were placed on the front and bathroom doors. A sensor on a window monitored breaking glass, and a water sensor was placed in the bathroom to monitor tub/toilet overflow. A detailed description of this phase of the project is available from the authors upon request.

Phase 3

Method and Procedures

In Phase 3, two focus groups comprised of eight individuals were conducted in the fall of 2001 to solicit caregivers' assessments of the specific system identified in Phase 2. All 26 participants from Phase 1 were invited to participate in a Phase 3 focus group. Unfortunately, logistic barriers, caregiving demands, and time/travel restrictions experienced by researchers limited the number of Phase 3 focus groups that could be conducted. The original two focus group facilitators from Phase 1 also conducted the Phase 3 focus groups. The format for each focus group mirrored the format of the Phase 1 focus groups, with the exception that participants in Phase 3 were not asked to complete the demographic sheet and the focus groups were not audio-taped. Rather, the co-facilitator took extensive notes during the two groups, and quotes were excerpted from the co-facilitator's verbatim notes. Each focus group began with each participant introducing him/herself, and providing a brief update of how his/her caregiving situation compared to six months before, when they participated in Phase 1. Facilitators introduced the demonstration of the system with a summary of the earlier two phases of the project, followed by demonstration of the system, and concluded with open ended questions to elicit feedback. Each focus group lasted approximately 90 minutes.

Description of Focus Group Participants

All Phase 1 participants were contacted by a member of the research team and invited to participate in a Phase 3 focus group to observe a demonstration and critique the technological solution that was developed in Phase 2. T-tests revealed that the eight caregivers who participated in both Phase 1 and Phase 3 of the project did not differ significantly from caregivers who only participated in Phase 1 with respect to age, education, or their subjective ratings of health. However, t-tests revealed that on average, Phase 1 caregivers reported being in the caregiver role for a longer period of years than the Phase 3 caregivers (6.6 v. 3.4 years, $p < .05$). The percentage of caregivers who were female was virtually identical for the two phases.

Phase 3 Results

Field notes from the Phase 3 focus groups were also analyzed using the coding process of Strauss and Corbin (1998). Again, repeating ideas and concepts were identified, and these concepts aided in the interpretation of the participants' views. Compared to the Phase 1 analysis which highlighted caregiving challenges and innovative caregiving solutions, analysis of the

Phase 3 focus groups centered on participants' views of the system and the extent to which they believed it might facilitate their caregiving efforts.

Caregivers' Evaluation of The System

Phase 3 focus group participants had many comments and questions about the system, although attitudes were generally quite positive. As Julie said, "That's an excellent idea—I wish I had that several years ago." Delores concurred, "This is wonderful." Tim added, "There could be a security camera outside the [front] door; you could access it [the camera] from anywhere—in the house or outside the house."

Because initial evaluations were so positive, participants were prompted to identify potential problems with the system. Potential problems included need for a computer with Internet access, cost of the system (although caregivers acknowledged that it was relatively inexpensive), and concerns about whether customizing the system to meet particular needs is possible (e.g., "I wouldn't want the pager going off every time the phone rang. I'd only want emergency things making the pager go off").

Subsequent discussion ranged over related issues involving the use of technology in the home. Phase 3 focus group participants were reminded that in the Phase 1 focus groups, some concerns were expressed about having cameras in the home. When asked whether this was still a consideration after having seen the system, Julie commented, "It would be okay if it was in my mother-in-law's house; it wouldn't be in my house." Others indicated that it would be acceptable if they could control the cameras. As one participant noted, "Put a towel over them if you need some down time."

Throughout this conversation, participants' comments remained positive. Betty said,

> "Yes—it is wonderful! I have a daughter in Monroe, Michigan, and she really doesn't understand what it is like.... She comes down once a month, but that's really not enough; if you don't live with it...."

The implication was that, with the system as it was demonstrated, her daughter could access the website and use the cameras to see what was going on. Some discussion ensued about the adaptability of this technology to other settings, including assisted living and/or long-term care facilities. Madeline said:

> "My husband is healthy except for this disease ... he could be wandering for years. Wandering is my number one problem. In a nursing home, couldn't this technology help?"

Participants were probed on a number of important issues. For example, with respect to the costs of the system, Kevin said, "Compared to nursing home costs, this is really cheap! Do you think there could be a tax incentive for home caregiving or something?" The idea was introduced that an agency, perhaps an Area Agency on Aging, could offer a respite monitoring service using this technology. Ruthea agreed:

> "Someone could make a lot of money with this. I could have a home business and give up my day job. I could work out of my home, watching people for others so that they could get out."

Finally, focus group participants were asked if there were "places where you and/or your relative with dementia wouldn't want cameras." Kevin said, "My mother would probably be offended, but it depends on the person..." Ruthea suggested that context could mean everything: "If you don't live with it, you just don't know. Families could use this to check in."

Discussion

It is well documented that older adults prefer to age in place, and this preference is not lessened by the onset of dementia. However, ageing in place does not assure a high quality of life. Continuity of place is not always accompanied by continuity in roles, relationships, and lifestyles, especially in the face of dementia.

Caregivers told us that they and the relatives for whom they provide care are in an evolving, increasingly challenging struggle. At the heart of this struggle is the caregiver's overriding desire to assure his or her relative's safety. When home becomes a restrictive environment because of concerns related to the safety of the person with dementia, it can become the very source of discontinuity—it changes roles and relationships.

For caregivers, the best of all possible worlds would be to have their relatives with dementia age in place in the least restrictive environment possible. One strategy for accomplishing this is to use technology to enhance continuity and minimize discontinuity so that home can contribute to, rather than threaten and limit, a high quality of life for both caregivers and their relatives.

There is mounting empirical evidence that environmental modifications/interventions, including the use of computers, web cams, and wireless devices, have the potential to reduce caregiver burden and distress, and promote more adaptive behavior among individuals with dementia (e.g., Gitlin, Corcoran, Winter, Boyce, & Hauck, 2001; Marshall, 1999; Schulz, Maddox, & Lawton, 1999).

The results of this pilot project demonstrate that affordable technologies exist that might well be suited to this task. Further, caregivers in our research identified a range of applications for this technology. For one caregiver, it was the potential respite such technology could provide from the constancy of near-24-hour vigilance. For another, it was the prospect that an adult child living in Michigan could "look in" and perhaps better understand the consequences of dementia for his/her parents. However, all of the caregivers were in agreement that the use of technology in general, or the system in particular, was not a panacea to all of their challenges in caregiving.

Limitations

There are a number of limitations associated with this research. First, the small number of participants (especially in Phase 3), combined with the use of focus group methodology, limit the ability to generalize our findings. Second, because we relied on participants' reports to characterize the abilities and behaviors of the family members for whom they cared, we could not make definitive statements about the level of impairment of the individuals with dementia.

Finally, because our intent was to determine whether family caregivers would be receptive to this type of technological intervention, several issues associated with implementation of the intervention were not systematically explored in great detail with participants. Nonetheless, these issues did emerge during the conversations, and warrant additional investigation. One such issue is the tradeoff between caregivers' efforts to maintain the safety of their relatives with dementia while maximizing the autonomy of those relatives. Elaboration of this classic dilemma is beyond the scope of this manuscript; Parmelee and Lawton (1999) provide a review of this issue. A second and related issue concerns privacy. Even careful placement of cameras and sensors may result in private behaviors becoming observable to others. This may be the case for individuals with dementia as well as for both individuals with dementia and their caregivers, whose private behaviors could become visible to other family members who log onto the website from hundreds of miles away. It is our view that in addition to the two issues identified above, successful implementation of the technology will require the development of clearly articulated protocols and procedures to guide responsible use of the technology described in this manuscript.

Summary

Despite the emergence of the consumer satisfaction movement in a range of services for older adults, it does not appear that research on technology and ageing has involved the voice of the consumer in the development and evaluation of technological interventions. A comprehensive review of the literature on caregiving and technology (Kart, Kinney, Murdoch, & Ziemba, 2002) failed to reveal research in which the ultimate "end users" or consumers (in this case, family caregivers) were involved in the research process such that they aided in the identification of the problem area to be targeted; provided information about the optimal characteristics that a technological intervention should possess; and then provided feedback on an actual technological intervention. Such involvement of consumers appears to be critical, especially in light of the literature on consumers' hesitation to adopt various technologies (e.g., Agree & Freedman, 2000; Gitlin, 1995; Mann & Tomita, 1998; Mann, Hurren, Tomita, & Charvat, 1995), and is a strength of this research.

Nonetheless, in the present research, caregivers' evaluation of the technology was limited to a one-time demonstration of the technology in a focus group format. Currently, we have installed the technology in the homes of 19 caregivers who are evaluating it over a six-month period. Although even more time- and labor- intensive than the research reported in this manuscript, the results of this evaluation will yield ecologically valid information that should prove informative to technology engineers and designers and social science researchers alike.

In conclusion, electronic technologies likely will be critical components of caregiving in the 21st century. These technologies have enormous potential for helping caregivers meet their numerous responsibilities. More important, these technologies have the capacity to provide and support an integrated infrastructure for caregiving in the homes of persons with dementia. However, success of these technologies will be enhanced to the extent that caregivers' voices are used to inform those who design, develop, and implement these technological interventions.

Appendix 1

Prompts Used in Phase 1 Focus Groups

Prompts to Elicit Challenges in Caregiving

- Tell us who you are caring for, and how long you have been providing care.
- Tell us the about the last time you and/or your relative had a particularly good day at home.
- For every good day as a caregiver, you have probably had a not-so-good day. Tell us about a day at home that was particularly challenging for you and/or your relative.
- If you think about caregiving, is there one recent day that stands out? It can either stand out because it was a particularly good day, or a particularly not so-good day. Either way, please tell us about a recent day in caregiving that really stands out to you.

Prompts to Elicit Creative Technological Solutions

- Think about all of the aspects of caregiving that we have been talking about. Are you using any gizmos/gadgets/technology to help you care for your relative?
- Are there any gizmos/ gadgets/technologies that would make your life as a caregiver easier?
- If you could invent one gizmo/gadget or type of technology to make it easier to care for your relative, what would it be/do?

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1. Each focus group concluded by asking participants whether there were any issues that the facilitator and co-facilitator had overlooked or any other issues that were important to discuss before the group ended the discussion.

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