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Involving Family Members in the Implementation and Evaluation of Technologies for Dementia:

A Dyad Case Study

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Abstract

An increasing number of individuals worldwide are affected by dementia and it is important to examine nonpharmacological care approaches. A dyadic case study of a 6-month evaluation of a technology designed to engage individuals with dementia in activities in a memory care unit is presented. Findings show one caretaker of an individual with dementia (i.e., her mother) used the computer in a manner consistent with her usual style of interaction and supportive care; she continued to maintain awareness of her mother's activity preferences and cultivated her mother's quality of life by using the provided technology. These findings demonstrate a use for technology to support activities of older adults with dementia while engaging family and provide future directions for technology design and research in this population.

In 2010, dementia was estimated to have affected approximately 15% of U.S. adults older than 70 (Hurd, Martorell, Delavande, Mullen, & Langa, 2013). In addition to cognitive impairment, individuals with dementia may experience behavioral and psychological symptoms of dementia (BPSD), such as agitation, aggression, and mood disorders (Douglas, James, & Ballard, 2004). In one study, 75% of individuals with dementia exhibited at least one BPSD in the month prior to enrollment (Lyketsos et al., 2014). The National Institute for Health and Clinical Excellence (2006) guidelines encourage caregivers to use nonpharmacological treatments as a first-line treatment for BPSD.

Recreational and leisure activities are one form of nonpharmacological treatment (Khan & Curtice, 2011) and can focus on areas such as senses (e.g., listening to music), psychosocial interaction (e.g., speaking to family members or friends), cognition (e.g., puzzles), or movement (e.g., dancing). In addition to reducing the need for pharmacological treatments, using activities to treat dementia can delay cognitive impairment progression (Cheng et al., 2014) and positively affect well-being (Schreiner, Yamamoto, & Shiotani, 2005).

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Despite the well-documented benefits of activities, many assisted-living facilities and memory care units (MCUs) do not offer sufficient activities for individuals with dementia (Hancock, Woods, Challis, & Orrell, 2006; Wood, Harris, Snider, & Patchel, 2005). One way of increasing the availability of activities is through the involvement of distant family members (also referred to as *informal caregivers*) who also benefit by being involved in care. For family caregivers whose relatives with dementia have moved to a nursing home, more visits have been associated with higher satisfaction with care (Tornatore & Grant, 2004). Kellett (2007) noted that family caregivers found meaningful ways to care for relatives in nursing homes, such as discovering new ways to accommodate deficits or new and different ways of caring. Using technology may be one way of fostering these activities during family visits.

RELATED WORK

To date, technology has been overwhelmingly used to relieve caregiving burden rather than to create opportunities for individuals with dementia to engage in meaningful activities (Smith & Mountain, 2012). Previous research has involved family members at various stages of the design process of technologies that support caregivers in caring for individuals with dementia or assisting individuals with dementia with functional limitations. In one project, researchers obtained requirements from informal caregivers to design a device to reduce repetitive questioning (Hawkey, Inkpen, Rockwood, Mcallister, & Slonim, 2005).

Previous studies have involved caregivers in the design and evaluation of the CogKnow Day Navigator, which runs on a desktop and mobile phone and was designed to assist individuals with mild dementia in functional, social, and recreational areas (e.g., through a simplified music player). The technology developers included informal caregivers by having them prioritize needs and possible solutions. In evaluating this technology, Meiland, Dröes, Sävenstedt, Bergvall-Kåreborn, & Andersson (2010) found that informal caregivers were able to discuss the types of technology they would want to use with their relatives with dementia. Another project involved distant family members of a woman living in a long-term care facility as proxies for participatory design and found that they wanted to significantly contribute to the design and research process (Cohene, Baecker, Marziali, & Mindy, 2007).

Although these studies involved informal caregivers, they lacked in-depth perspectives of family members over the course of technology deployments designed to support activities for individuals with dementia. Given family members' willingness to take part in design and research studies, and their unique perspective of the ways dementia affects their loved ones and themselves, it is important to solicit their feedback and perceptions during technology deployment. For the current study, the authors used a case study approach to explore the experience of a family member with a relative with dementia living in an MCU who participated in a study evaluating a technology intended to increase opportunities for engagement in activities for individuals with dementia.

METHOD

The current study involved a participant dyad from an evaluation of a commercially available technology designed for older adults with dementia (Figure). The touchscreen computer system contains a variety of applications to facilitate social interactions, exercise, reminiscing, and cognitive stimulation. Applications included both free and proprietary software. The technology comes with attachments, such as a joystick, camera, and hand bike.

The current study took place at a housing community within a 26-bed MCU. Residents could use the technology in three contexts: (a) weekly sessions with the researcher, (b) in the activity room with staff, and (c) in an activity group for individuals with memory issues. Three groups were enrolled in the study: (a) residents, (b) family members, and (c) staff. The technology was introduced to all staff members during information sessions. Institutional review board approval was obtained for all procedures.

The technical feasibility of the project is described elsewhere (Lazar, Demiris, & Thompson, under review). In the current article, the authors focus on one family member and resident dyad to explore perceptions of the intervention as well as its impact on their relationship. Interviews were administered to the family member at baseline (before the study began), midpoint (3 months), and exit (6 months), and were then transcribed, verified, and coded using open and axial coding. As themes emerged, they were entered into a codebook and iteratively grouped as sub-themes for larger themes that emerged.

The Case Dyad

The dyad included an 86-year-old woman (K.) and her 60-year-old daughter (F.), who both described themselves as being comfortable using computers. K.'s score on the Mini-Mental State Examination (MMSE) was 16 at baseline (i.e., a score associated with having moderate dementia) and 21 at the midpoint and end of the study, which was an improvement (Folstein, Folstein, & McHugh, 1975). On the Positive Affect Index, which measures aspects of closeness through questions (e.g., how well relatives get along), F. scored 29 on five single-item indicators at baseline, indicating a high degree of closeness (Bengtson, 1982). This score did not change substantively at 6 months.

RESULTS

Qualitative Results

Several themes emerged through data analysis. F. maintained an awareness of her mother's interests and abilities and facilitated activities for her by scheduling them and personally getting involved, as well as acknowledging and finding ways to avoid external barriers. F. also cultivated her mother's positive emotions and attempted to reduce instances of negative emotions. In addition, F. attempted to include using technology in her mother's routine to enhance her activity schedule and quality of life.

Awareness of Activity Preferences and Abilities

Awareness of Interests—When asked what K. might like to do with the study technology, F. was able to easily answer for her mother. She actively discovered her mother's interests by staying in touch with the individuals running the activity group, saying since K. had been there, "I never knew that about my mom, but since she's been here... she's quite the little crafty gal."

F. continued to discover her mother's interests through using technology. She encouraged the research team to send summaries of session activities and also attended several sessions, through which F. discovered her mother enjoyed singing, noting, "One of the first times we sat there and did the karaoke, and I saw that she really liked that...then I started noticing the singing on the [activity group] calendar so I started having her go to those...I'm learning more and more." The technology exposed K. to new activities, and F. appreciated learning more about her mother's interests so that she could incorporate these activities in her schedule.

Awareness of Limitations—F. demonstrated an awareness of what her mother found difficult due to her cognitive impairments. For example, F. scheduled activities for her mother because she realized "she's not going to be able to look at those calendars and go 'today is the seventh, they're singing at 10:30, I'd better be there.' She can't do that anymore."

F.'s understanding of her mother's limitations regarding the computer came across in her assessment: "She could never [use it on her own], really." She realized her mother was unable to remember how to use the technology, but benefited in other ways. She also understood the importance of having a single volunteer returning to use the technology with her mother and recommended that if K. were to use it on her own, it would have to be "a thousand percent easier than what it is now." F. suggested having fewer applications and fewer steps to access them.

Facilitation of Activities

Promoting Ongoing Engagement—F. managed her mother's schedule to ensure her weeks would be filled with enjoyable activities, especially those involving technology. F. made sure her mother attended the activity group as soon as it was brought to the facility. F. was able to expose her mother to a variety of beneficial activities by proactively discovering and facilitating opportunities.

Personally Participating in Activities—F. personally participated in many of the activities she scheduled for her mother (e.g., attending Nintendo® Wii™ bowling at the facility when K. was living independently and there were not enough individuals available to join her).

F. took for granted that she would attend sessions, saying, "Of course I'll go and help her do it a couple of times to get her going." In part, she saw her presence as a way of helping her mother feel comfortable using certain applications, such as Skype™, commenting, "She'd want me to do it with her, she wouldn't do it by herself." F. attended several sessions with

the researcher and once alone with her mother. Although F. said her mother enjoyed using the computer, she also noted, “[My mother’s] in this building twenty-four-seven, 365, unless I take her out. So when I come, she wants to go somewhere.” Despite being enthusiastic about the computer, F. chose to do activities with her mother outside of the MCU as she recognized K.’s desire to leave the facility.

Emotional Activation—In addition to scheduling and participating in activities with her mother, F. motivated her to partake in activities. For example, F. motivated her mother to learn to use a cell phone by telling her she could use it to call her sister, with whom she enjoyed conversing.

In the context of the current study, F. motivated her mother by speaking to her before and after technology sessions, saying:

I would always try and jog her memory...knowing that if I got an e-mail from you that said that you did that [activity], then I could say, “You must have had some fun,” and she goes, “We had so much fun.” But it takes the supporting cast to really do that. Because I can’t just say, “Did you have fun with [researcher] today?” She’ll say “yes” [and] that’s the end of that conversation.

Researchers and developers should continue to design and test new technologies with older adults and family members and not assume that these technologies will be rejected due to their novelty.

K. looked forward to sessions, in part likely due to her daughter’s enthusiasm, and was able to relive some of the positive interaction afterwards by talking to her.

Acknowledgment of Individual Barriers to Adoption—F. expressed disappointment in the ways she perceived the facility did not share her enthusiasm for activities, including technology-based activities, stating, “The workers on mom’s floor, they’re either overwhelmed, overworked with everyone, and can’t even think about something that might be fun.” In general, F. saw commitment from staff members as essential for activities, saying:

You have to have buy-in from the top, everyone has to be excited about it, you have to really get the activity director and their staff jazzed about it... And if there’s no buy-in, you might as well take your toys and go home. Because it’s just not going to work here or anywhere.

F. understood the need for staff to be enthusiastic and comfortable with technology for a technology-based activity intervention to work. She was frustrated with the lack of enthusiasm and knowledge she perceived staff had for the technology used in the current study, and took it upon herself to tell the activity group about the technology when she realized that there was no communication between the MCU and activity group about its existence, which initiated implementing it in the activity group as well.

Cultivation of Emotions

Positive Emotions—F. emphasized both with technology use and other activities the need to encourage positive emotions; she called the MCU the “gold medal floor” and told her mother that “she’s in the first class section, like on an airplane.” In addition, F. empowered her mother by giving her choices in deciding to go to activities, saying, “I tell her now... ‘you’re in charge. If you don’t want to do something today, don’t. If you want to stay in your room, you get to.’”

F. appreciated the ways technology helped her mother feel special and empowered. When asked what specific types of applications her mother would enjoy, F. answered but also said, “I think we just have to see what she likes. She’s in charge,” thereby indicating her mother was the ultimate arbiter of what she liked to do. When the study began, F. noted that using the computer helped her mother feel accomplished and good about herself “because even if [individuals with dementia are] not with everything that’s going on in the world around them, they all have in their brain that computers are it, and if they get to be on a computer, they’re gonna feel good about that.” In addition, she said that her mother benefited from sessions “because it was one-on-one with her. So she was special.”

Negative Emotions—In addition to promoting positive feelings, F. attempted to reduce negative emotions (e.g., not mentioning sad memories). Consistent with this, F. was wary of pictures of her father being shown to her mother using an application on the technology due to her fear that they would produce negative emotions. Just as F. protected her mother from negative emotions daily in their face-to-face or phone interactions, she did so when using technology.

Fitting Technology into Routine

Use and Expectations of Technology—F. had a history of encouraging her mother to use technology, such as asking her to take a computer class at age 65. F. had specific reasons for wanting her mother to learn to use different technologies, such as being able to stay in contact with her, and she saw technology as a solution to these needs. She also encouraged her mother to use technology for fun (e.g., Wii bowling). Consistent with her expectations of technology being useful, F. thought the technology would be beneficial during the baseline interview. For example, she asked if she could e-mail pictures to her mother so she would not have to print them to bring to her. F. indicated that the technology would be fun before seeing or using it, consistent with her descriptions of technology being enjoyable.

Technology to Help Individuals With Dementia—In addition to seeing technology as useful and enjoyable, F. saw it as a key to her own care plan if she were diagnosed with dementia, saying, “If it turns out to be hereditary, I’m going to be like [my mother]...so I’m trying to do everything I can to not get down the road like that, and computers I think are a huge way [to do this].” One way she saw the technology used in the current study as beneficial for individuals with dementia was in helping those who had lost verbal abilities, noting:

[A] lot of the dementia people I’ve noticed can’t speak. That doesn’t mean there’s not a light on behind their eyes, and if they could communicate, they would. And if

this [computer] program could do that, help them point to it and say “water” or...“I wanna play cards”...I think it could really help.

DISCUSSION

The current study adds to the research demonstrating that family members can benefit from being more involved with relatives in an MCU (Kellest, 2007). F. benefited from using the technology by being able to augment her mother’s usual care (e.g., through awareness of her mother’s activity preferences, and facilitating her activities and including technology in her routine).

Researchers and product designers should be motivated to accommodate and invite the involvement of family members in studies with individuals with dementia, especially as a user group who may be using technologies to treat individuals with dementia. The impetus to do so lies in the benefits experienced by family members, such as those who participated in the current study. Family members may also see uses for technology that others may not. Koch (2010) stresses the role family members may play in recognizing the capabilities of technology to serve as assistive aids for older adults. The case described by the authors is an example of this, as F. found myriad benefits and uses for the technology employed. Thus, family members, in addition to relatives with dementia, should be included as targets of both research and product development.

Studies have found that older adults are willing to use new technologies (Demiris et al., 2004; Heinz, Martin, & Margrett, 2013; Parker, Jessel, Richardson, & Reid, 2013), and the current dyad’s enthusiasm for using the technology intervention is yet another confirmation that age and ability do not preclude technology use. Researchers and developers should continue to design and test new technologies with older adults and family members and not assume that these technologies will be rejected due to their novelty.

F. believed her mother could not sufficiently and meaningfully engage in activities on her own due to the limited level of enthusiasm she perceived from staff. If F. believed the staff’s involvement was sufficient, she might take a less involved role. Designers should understand settings where technology may be introduced, as well as the needs and possible skepticism of staff and be prepared to address it proactively. In addition, staff and family members may be interested in various applications and features (e.g., one-on-one versus group games). Technologies of this kind should be designed and tested accordingly. It may be of interest to researchers to identify whether family members take a more involved role when staff members appear more involved.

It may be important to investigate in detail some of the most salient motivators that encourage family members to be interested in using technology with relatives with dementia. These motivators can then be emphasized in recruitment materials or study design. For example, the authors noticed F. was interested in adding an activity to her mother’s schedule. In the future, for similar interventions, the authors may emphasize in recruitment materials that taking part in the study could provide a weekly activity for residents.

CONCLUSION

The authors explored a dyad from a study of a technology introduced to an MCU to support engagement in activities with individuals with dementia. Because the current article is the analysis of a single case study, it is not meant to be representative. However, it contributes to the research, stating that some family members are willing and enthusiastic to be in studies that involve technology (Cohene et al., 2007) and can contribute to the research process. Future research should examine whether some of the factors that motivated F. to participate in the current study are present in other family members, and the other types of motivating factors that encourage family members to participate in the research of technological systems for relatives with dementia.

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Figure.
The iN2L Mobile FLEX Lite Package.