Published in final edited form as:

Clin Nurs Res. 2013 May ; 22(2): 139–150. doi:10.1177/1054773812460545.

In-Home Monitoring Support for Dementia Caregivers: A Feasibility Study

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Abstract

Technology provides new opportunities for interventions to improve quality and access to health care. This study evaluated a telehealth application to support family dementia caregivers providing homecare. We explored feasibility of in-home video monitoring and feedback to help caregivers and reduce caregiving burden. A caregiver-patient dyad was recruited from The University of Kansas Alzheimer's Disease Center. The caregiver triggered video-recordings on a laptop computer using a remote control that also recorded 5 minutes prior to pressing "record." Recordings were automatically uploaded via the Internet for interdisciplinary team review and feedback. Issues related to Internet transfer and storage of health information and computer security were addressed. Professionals reported the value of video-recordings for identifying antecedents and evaluating caregiver responses. The caregiver reported improved communication and behavior management and ease of use. This study developed protocols, processes, and contractual arrangements and established the feasibility and benefits of home monitoring as a basis for ongoing research.

Keywords

Telehealth; Dementia; Caregiver

Video-Based Support for Dementia Caregivers: Feasibility Case Study

Family caregivers, typically a spouse or child, save the U.S. health care system \$375 billion annually by caring for persons with dementia (PWD) at home (National Alliance for Caregiving, 2011). Caregivers must cope with their loved one's progressive memory loss, self-care impairment, communication breakdown, and disruptive behaviors, thus

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experiencing significant stress, strain, and burden that contribute to negative physical and mental health outcomes and increased mortality for caregivers (Monin & Schulz, 2009). A variety of interventions designed to support caregivers have had only minimal effects on reducing stress, burden, and the negative health effects of caregiving (National Family Caregiver Association, 2011; Olazaran et al., 2010; Parker et al., 2008), now recognized as a growing public health problem (Talley & Crews, 2007).

Loss of the ability to communicate is a major concern for caregivers of PWD (National Family Caregiver Association, 2011). Most caregivers report decreasing attempts to communicate with PWD and identify communication breakdown as an added stressor (National Family Caregiver Association, 2011). Communication breakdown has also been linked to disruptive behaviors of PWD that further increase stress and burden for family caregivers (Williams, Herman, Gajewski, & Wilson, 2009).

Disruptive behaviors including vocalizations, wandering, and physical aggression burden family caregivers, increase use of physical and chemical restraints, and cause caregiver injuries (Kunik et al., 2010). An estimated 90% of PWD develop these progressive behaviors that are linked to caregiver burden and negative health outcomes and frequently precipitate nursing home (NH) placement, at an average annual cost of \$83,585 for a private room (Buhr et al., 2006). Avoiding premature NH care is critical if society is to meet the care needs of the rapidly expanding aging population experiencing prevalent Alzheimer's disease and other dementias.

Evidence from decades of research evaluating interventions to support family caregivers of persons with dementia has identified key features for effectiveness. Interventions can support caregivers by arranging services to provide care, teach caregivers new skills, and support adjustment to the caregiver role (Montgomery et al., 2011). Best practices include incorporating psychological as well as educational interventions, with interventions addressing a variety of caregiver stressors provided in adequate dosages (Zarit and Femia, 2008; Schulz et al., 2003). Multicomponent, interventions that address a wide variety of caregiver stressors, tailored to meet the individualized caregiver needs and goals are most effective. Actively involving caregivers and providing ongoing coaching are other key factors of successful interventions (Seignourel et al., 2008).

Evidence-based communication and behavior management strategies for caregivers of PWD rely on identifying antecedents, consequences, and actual behaviors as a basis for modification (Moniz-Cook et al., 2008). Typically, caregivers report communication breakdown and disruptive behaviors to health care providers during phone or office visits. Overwhelmed caregivers may be unaware of or may forget specific details about situations in which behaviors occur, leaving professionals with limited data for identification of appropriate interventions. In contrast, when professionals observe actual behaviors and communication encounters, they can identify precipitating factors and caregiver responses and can tailor interventions to meet individual needs (Moniz-Cook et al., 2008). Home video monitoring provides an opportunity for caregivers to record actual interactions in the home, providing professionals with rich video data for analysis.

Home monitoring is one telehealth technology with potential to extend access and timeliness of health care, and is endorsed by family caregivers as a means to reduce time and stress, increase ease and efficacy of providing care, and improve safety (National Alliance, 2011). Telehealth interventions for dementia care include internet-based information and support groups, robotic companions, and the use of smart phones to report symptoms (Czaja & Rupert, 2002; Powell, Chiu & Eysenbach, 2008; Steis et al., 2012). Effective utilization of telehealth capacities depends on identifying standards and best practices for telecare,

preparing providers with new skills and attitudes, and assuring that telehealth interventions are ethical and meet caregiver needs without adding to stress and burden (American Telemedicine Association, 2008; Mahoney et al., 2007; Pecina et al., 2011; Richardson et al., 2009).

The new monitoring technology tested in this study was successful in improving parent and teacher management for behavior problems of autistic children in home and school settings (Oberleitner et al., 2007). This paper describes our research adapting this technology with professional feedback to support family caregivers of persons with dementia. This report describes feasibility testing with our first caregiver-patient dyad as a basis for ongoing research.

Methods

Behavior Imaging technology, including Behavior Capture and Behavior Connect products, developed with the NIH grant “Novel Data Capture and Assessment Technology for Behavior Disorders” (2-R44-HD052340-02) for remote behavioral monitoring of children with autism, was adapted for use with family caregivers of PWD. Behavior Capture uses a “go-back-in time” digital system, which saves up to 30 minutes of video recording for review prior to the trigger activation with the intent of capturing events leading up to a behavior. Including antecedents enables effective assessment of behaviors as well as communication, and home-collected data supports accurate behavior management care plans. Behavior Connect provides automatic HIPAA-secure transfer of video recordings to Internet storage for timely review.

Following approval from the university institutional review board for protection of human subjects, potential participants were identified by Alzheimer’s Disease Center clinicians who were members of our interdisciplinary team. We contacted each potential participant and arranged a home visit to provide additional information about the study and to obtain signed consent. Consent was obtained from the family caregiver (also legal surrogate decision maker) with assent from the person with dementia

Surveys were completed by the caregiver at baseline and after 2 months of participation in the study. Caregiver burden was assessed using the 12-item modified Zarit Burden Inventory (Bédard et al., 2001; Burgio et al., 2009). Caregivers rated their emotional and physical strain using a 5-point Likert scale with scores total scores ranging from 0 (never) to 44 (nearly always). Cronbach’s alpha was established at 0.85 in the Resources for Enhancing Alzheimer’s Caregiver health (REACH) study (Burgio, et al., 2009). The 31-item Revised Memory and Problem Behavior Checklist (Roth et al., 2003; Teri et al., 1992) was used to elicit caregiver reported frequency of behavior occurrences and caregiver perceptions of bother related to 24 memory, depression, and disruptive behaviors of a PWD, occurring in the past week with Cronbach’s alpha of .785 (Roth et al., 2003). Caregiver efficacy for providing care for their loved one at home was assessed with the *Short Sense of Competence Questionnaire*, (Vernooij-Dassen M.J., Felling A.J., & Brummelkamp, 1999) a 7-item rating scale of caregiver perceived competence in caring for a PWD using a 5-point Likert scale. Validity and reliability are reported in the range of .76 to .88. Our goal was to choose a battery of surveys that would take less than an hour to complete to avoid adding to caregiver stress and burden.

A laptop computer was purchased for dedicated use for the project and a high definition web cam and remote control transmitter was installed in USB ports. Our Institutional Review Board (IRB) required us to use an encrypted computer due to data security concerns. We installed the Behavior Capture program using Site Kiosk (Provisio Software Engineering,

Inc), a program that limits the use of the laptop to study purposes. With these protections, the computer was set to remain on at all times to avoid increasing requirements for caregivers to log on and adjust settings. Hibernation and sleep settings were turned off and we selected automatic uploading of recorded videos to a Behavior Connect account. We installed a wireless modem to communicate with the laptop computer and to permit moving it to different areas of the home.

In collaboration with our IRB and Computer Security offices, we identified a protocol for security of protected health information. This included special business agreements and data contract that were negotiated with the Behavior Imaging company who were responsible for storing the video recordings. This required legal counsel and delayed implementation of the planned project.

An expert home and telehealth nurse made home visits to set up the computer and train the caregiver to use the system. Although the caregiver did not attend the interdisciplinary team meetings, the nurse participated on the interdisciplinary team and communicated feedback to the family caregiver on a weekly basis through phone and home visits. Unanticipated technical problems that interfered with continuing operation of the computer program occurred and resulted in the nurse making additional visits for troubleshooting. The goal was to have the home monitoring unit run continuously and ready to record when triggered by the caregiver without requiring the caregiver to enter login and password information or to adjust computer settings. The computer settings required fine tuning to avoid interruptions in the program.

Findings

Our first participant dyad included a 70-year-old man diagnosed with Alzheimer's disease approximately two years ago with a current MMSE of 11/30 and his wife who sought feedback for convincing her husband to attend adult day care and to improve responses when he repeatedly asked about his wife, their home, and adjusting to a visit from grandchildren. The nurse made weekly home visits for the first month, selecting a priority issue to focus on each week and providing feedback from the professional review team. After the first month, contacts were primarily via phone. The team reviewed one to three of the videos (0 to 8 were submitted weekly) over the three-month period that the home monitoring unit was placed in the home. After 3 months, there was mutual agreement between the caregiver and the team that the caregiver no longer required intensive feedback to manage care. During the 3-month intervention, the team reviewed videos weekly and developed interventions based on years of expertise. Our nurse practitioner provided years of experience counseling caregivers and the team social worker had published a protocol manual for managing disruptive behaviors. Topics of the weekly "care plan" feedback forms are listed in Table 1. A sample "care plan" listing suggested interventions is provided in Table 2.

The interdisciplinary team overwhelmingly found that the videos provided essential information for understanding the context of this caregiver's concerns and for advising her on how to intervene. For example, we were able to advise her to employ positive communication around attending adult day, emphasizing how her husband was needed to help with the program. Suggested interventions for anxiety and agitation included using physical touch to reinforce positive verbal support and avoiding overstimulation from activity and cell phone use. Videos also helped the team see that the wife's focus on keeping the home tidy conflicted with the husband's need for activity. The team advised having a special drawer in the house and an area in the garage so that the husband was able to manipulate things without upsetting his wife.

Survey responses collected before and 2 months after implementing the home monitoring were compared and they reflected increased confidence in providing care and reduced caregiver burden. Caregiver surveys reported reductions in the total Zarit burden score from 3.08 to 2.66, an increase in efficacy for providing care from 10.85 to 13.15, and reduced caregiver perceptions of bother related to dementia symptoms and behaviors decreasing from 19.5 to 17.7 on the Revised Memory and Problem Behavior Checklist after 2 months of using the home monitoring and professional feedback intervention.

The caregiver was also interviewed, and she reported that the professional feedback was helpful to improving her caregiving skills and added new and more effective strategies. She denied added stress from using home monitoring but reported she may have modified her behavior due to awareness of being recorded.

Discussion

This pilot study established feasibility to support our ongoing research to evaluate the potential benefits of home video monitoring for family caregivers of PWD. We believe that home monitoring with professional feedback provides a new intervention that may support family caregivers, reducing stress, burden, and negative outcomes while supporting their ability to continue to care for their loved one at home. This study was limited to one case, designed to test feasibility for home monitoring and feedback and further research is needed to establish caregiver benefits. This intervention may be especially useful in rural areas, effectively linking caregivers with professional guidance. Characteristics of the intervention that increase the potential for success include active engagement of caregivers in selecting recordings according to their priorities for feedback and ongoing coaching.

We did not anticipate the number and complexity of technological and data security requirement challenges that were encountered in operationalizing the project. Investigators should be aware that other researchers have reported similar barriers to implementing promising new technology supports (Mahoney et al., 2007). We plan to use additional technological advances in ongoing testing of home monitoring and feedback, including use of teleconferencing for interdisciplinary team and nurse-caregiver communications. In addition, future research must identify skills and attitudes nurses will need to be effective telehealth providers, and those skills must be integrated into nursing education (American Telemedicine Association, 2008; Richardson et al., 2009). Costs for home monitoring and feedback in relation to caregiver and patient outcomes will also be important to evaluate potential dissemination of this technology (Pecina, Takahashi, & Hanson, 2011).

An informational session with a group of older adults in a continuing care retirement community generated comments to address in our ongoing research. Caregivers may hesitate to video record their family members due to privacy issues and many caregivers who are older adults may shy away from bringing complex computer technology into the home. It will be important to emphasize that the caregiver controls the capture and submission of recordings and that automatic computer settings avoid the need for caregivers to manipulate the computer. Ongoing testing and support to assure automated computer operation will be critical to ensuring participation.

Increasing the immediacy of feedback to caregivers is another planned advance for this project. We plan to test using HIPAA-secure Polycom teleconferencing for team meetings and to communicate feedback to caregivers on their home computer or a tablet. Future research should also incorporate a control group to test whether phone contact alone would yield similar results. We are currently testing this technology with caution to avoid caregiver use of home monitoring to replace care by their primary provider or for emergency

situations. Future plans include testing home monitoring for rural populations and integrating recordings into the electronic medical record.

Application

Advancing technology has potential application to improve health care. However, potential issues related to protection of human subjects and privacy of protected health information may require extended start-up planning. Technological support may also be needed.

Home monitoring with professional feedback may expand interventions to support caregivers of persons with dementia at home, reducing some of the stress of caregiving and negative caregiver outcomes. Home monitoring may also reduce premature nursing home placements, reducing health care costs while supporting families to continue home care with privacy, dignity, and quality of life.

Acknowledgments

This work was supported by a the University of Kansas NIH Alzheimer's Disease Center (grant P30AG035982) and a CTSA grant from NCRR and NCATS awarded to the University of Kansas Medical Center for Frontiers: The Heartland Institute for Clinical and Translational Research #UL1RR033179 (formerly #UL1RR033179). The contents are solely the responsibility of the authors and do not necessarily represent the official views of the NIH, NCRR, or NCATS. The Authors appreciate the support of Carol Smith RN, PhD, FAAN during this project.

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Table 1

Sample Care Plan Feedback Topics

Going to work/day care
Searching behaviors
Grandchildren visiting
Anxiety about leaving home
Repeatedly asking about/not recognizing spouse
Smoking safety
Confusion/Anxiety

Table 2
Selected Care Plan Feedback

Going to Adult Day Care (ADC):
● The team thought you did an excellent job with this situation and that this video was a good example of effective communication.
● The team identified that XXX has anxiety for (1) being separated from you and (2) going to the ADC.
● The team suggests a few strategies to help alleviate XXX's anxiety about ADC
○ A framed photo with signed affirmations from staff and or attendees may reinforce his contributions (how much they love him as a volunteer, how well he relates to these people).
● Sample wording for reinforcing statements:
○ "Just your presence with the vets makes such a difference."
○ "They love you there."
○ "Just your being there is a big help."
○ "It just comes naturally to you. You and I are the kind of people who follow what we say ... they are counting on you. "