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Wearable Technology to Garner the Perspective of Dementia Family Caregivers

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Abstract

Family caregivers of persons with dementia typically have limited opportunity during brief clinical encounters to describe the dementia-related behaviors and interactions that they find difficult to handle. Lack of objective data depicting the nature, intensity, and impact of these manifestations of the underlying disease further constrains the extent to which strategies recommended by nurses or other health care providers can be tailored to the situation. We describe a prototype wearable camera system used to gather image and voice data from the caregiver's perspective in a pilot feasibility intervention study conducted with 18 caregiving dyads. Several scenarios are presented that incorporate salient events (i.e., behaviors or interactions deemed difficult by the caregiver or identified as concerning by our team during screening) identified in the resulting video. We anticipate that future wearable camera systems and software will automate screening for salient events, providing new tools for assessment and intervention by nurses.

Keywords

family caregiving; dementia; technology

Caring for a family member with dementia requires mastery of new knowledge and skills for handling a wide array of behaviors manifested by the underlying disease. Behaviors such as repetitive questioning, agitation and resistance, impulsive or disinhibited actions, and wandering or way finding difficulty, among others, may compound cognitive and motor deficits to undermine an individual's self-care ability and capacity to manage a household or interact with the outside world. Dementia-related behaviors typically evolve over time,

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placing ever-changing demands on the caregiver to observe, interpret, and take action in anticipation or response. To prevent or mitigate the distress that such behaviors may cause in one or both members of the caregiving dyad, caregivers often engage in a process of trial-and-error before seeking advice from health care providers.

During brief clinical encounters involving community-residing persons with dementia, health care providers rely heavily on family caregivers to report behavioral issues. However, discussion of these concerns, if it occurs at all (Hunsaker et al., 2010), may be tempered by imperfect recall on the part of the caregiver. Caregivers may also be reluctant to describe the nature and intensity of particular behaviors as well as possible strategies for dealing with them in the presence of the person with dementia.

The absence of objective data by which health care providers can assess how dementia-related behaviors, especially those deemed difficult by the caregiver, are being handled at home led our team to test a novel wearable camera system within the context of family caregiving. Our objective was to use this technology to garner information about the specific challenges faced by each caregiving dyad and learn how they were being handled, as a basis for tailored intervention. In this report we present several caregiving scenarios which illustrate how data recorded while our system was worn not only validated caregivers' concerns but also raised new issues that informed our intervention.

Method

We conducted a pilot intervention feasibility study that was approved by the institutional review boards at the University of Pittsburgh and Carnegie Mellon University. Participants were recruited through the Alzheimer Disease Research Center and the Clinical and Translational Science Institute at the University of Pittsburgh, community bulletin boards, and other dementia caregiving studies whose participants had previously agreed to be contacted for future studies.

Sample

Family caregivers eligible for participation were age 21 or older; provided care at least 15 hours per week, on average, for at least 6 months to a community-residing person with dementia; reported caregiving distress or difficulty with dementia-related behaviors; and could read and speak English. Their care recipients were age 50 or older; had Alzheimer's disease, frontotemporal dementia, Lewy body dementia, or vascular dementia; and were able to speak and understand English prior to the onset of their dementia. Dyads were excluded if caregiving primarily occurred in a household with individuals under age 21.

The 18 caregiving dyads in our sample were predominately Caucasian ($n = 12$; 67%) and included 8 male and 10 female family caregivers ranging in age from 35 to 89 (63.7 ± 14.0) years. They were spouses (6 husbands, 3 wives) and adult children (2 sons, 7 daughters) of a person with dementia. Eighty three per cent of the caregivers had more than a high school education; all but 6 were retired or unemployed. At least half of caregivers had a household income of \$50,000 or more. In 15 households the caregiving dyad lived together, including 3 caregivers who had stopped working and moved in since the onset of dementia. The 18

persons with dementia included 6 males (3 husbands, 3 fathers) and 12 females (6 wives, 6 mothers) age 59 to 99 (78.6 ± 9.1) years, 72% of whom had more than a high school education; none was employed. Caregivers not caring for a spouse were married ($n = 3$), never married ($n = 3$), or divorced ($n = 3$), whereas persons with dementia who were not spouses of the caregiver were married ($n = 1$), widowed ($n = 4$), separated ($n = 1$), or divorced ($n = 3$) (see Table 1).

Technology

Our prototype wearable camera system consists of a fisheye lens camera secured to a custom printed circuit board and enclosed within a small plastic housing, all of which weighs less than 2 ounces. The camera housing is worn at eye level, clipped onto either earpiece of lensless overglasses frames that are large enough to fit over eyeglasses, if necessary. A cable connects the camera to a Universal Serial Bus (USB) hub which, in turn, links a small computer (approximately the size of a compact disk case) and microphone to the electronics and lithium battery. These latter components are secured within a custom-made, multi-layered, unisex “video vest” designed to be washable and easily donned and removed by persons of varying weight, height, and girth. Image and audio data are continuously recorded on a 32GB microSD card at an average rate of 24 frames/second in 20-minute segments labeled by date and time. The microSD card resides in a flash drive holder inserted into a cable connected to the embedded computer. To minimize power and processing requirements, data captured to the on-board computer are downloaded remotely to a computer at our research center, and special software is used to assemble the captured images and audio data into a video format. Because it is essential for the user to control when recording occurs, a red on/off button on the upper region of the vest front is attached to the embedded computer and lights up during recording. Pressing the lit button causes recording to cease for up to 10 minutes, after which time it resumes recording, but only after the button is pressed again. The system (i.e., camera, overglasses, electronics, battery, and vest) weighs a total of 3.4 pounds. Further detail regarding this prototype technology and its usability are described elsewhere (Matthews et al., 2015).

Procedures

Written informed consent for participation was obtained from the family caregiver during a home visit, and consent or proxy consent, with care recipient assent, was obtained from the person with dementia. Consent was also obtained whenever possible from non-participating household members age 21 years or older, such as adult children, siblings, or hired caregivers, whose voice or images could be captured while the caregiver wore our system. Information regarding the dyad’s sociodemographic and health status, caregiving situation, and use of technology was collected separately by two members of our team, with one interviewing the caregiver while the other administered a brief battery to the care-recipient (if able to respond) and provided companionship so that the caregiver could speak candidly during data collection.

During a second home visit the caregiver was shown how to don and remove the overglasses and video vest, change the microSD card, replace and recharge the battery, and turn the system on and off. After practicing these procedures, the caregiver was supplied with 7

microSD cards in separate flash drive holders, two interchangeable batteries, a laptop, and illustrated instructions. The caregiver was asked to wear the system for two 7-day periods (before and after intervention for the first 10 caregivers) or a for a single 3 to 5-day period (before intervention for the remaining 8 caregivers) during as many waking hours per day as desired, but especially at times when difficult behaviors or interactions most commonly occurred or were anticipated. To optimize privacy, the caregiver was advised to stop recording in the presence of unconsented individuals (e.g., unexpected visitors or callers) and, if desired, during personal care activities. To signal when the person with dementia was receiving medication or engaging in behaviors considered difficult, the family caregiver was asked to flash a neon card in front of the camera. The caregiver was also asked to maintain a brief log noting when medication taking and difficult behaviors or interactions occurred. Daily calls were made to remind the caregiver to perform requested study activities. Additional home visits were made as necessary to address technical difficulties.

Data from the microSD card in the laptop were transmitted via air card and LogMeIn.com to a secure server at the University of Pittsburgh, converted to video, and screened to identify salient events and delete or anonymize (by distorting or blurring) the voices or images of non-consented individuals. To preserve dignity and protect privacy, we also deleted or blurred all video in which study participants appeared undressed, regardless of whether the data were intentionally recorded. Due to the volume of video for this pilot work, the two team members who screened the video did not screen the same segments.

We defined salient events to be episodes of dementia-related behavior or caregiving interactions that were: (1) reported by the caregiver during eligibility screening or baseline data collection; (2) signaled as difficult when the caregiver flashed the neon card during data capture; and/or (3) identified by our team during screening, despite not having been deemed problematic by the caregiver. These salient events were reviewed by the principal investigator (JTM) and representative video clips were used to formulate an intervention plan to address the dyad's unique situation. Each intervention entailed sharing briefer versions of the video clips with the caregiver during a discussion of new strategies to try. One of two interventionists, a nurse or a social worker, delivered the intervention, either face-to-face during a home visit (first 10 caregivers) or remotely via iPad and FaceTime (remaining 8 caregivers), with the video clips uploaded back to the laptop based at the caregiver's home. All caregivers received follow-up phone calls and printed materials developed by the REACH Project (Burns, Nichols, Martindale-Adams, Graney, & Lummus, 2003) to reinforce the strategies discussed, and a home visit 3 months later to assess caregiving burden and dementia-related behaviors.

Measures

In addition to data on gender, age, race, marital status, education, employment, income, and self-reported health, the following measures analyzed for this report were administered by interview. The family caregiver responded to items pertaining to caregiving and provided all other responses on behalf of him or herself and the person with dementia, unless otherwise specified.

Cognitive function—We administered the 30-item Mini Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975) to both members of the caregiving dyad, to screen for cognitive impairment (score ≥ 24).

Caregiving situation—Three measures were used: an investigator-developed questionnaire that determined duration of caregiving; the 24-item Revised Memory and Behavior Problems Checklist, to measure the occurrence (yes/no) and extent of bother or upset (0 = not at all; 4 = extremely) by memory and behavioral problems related to dementia in the past week, with higher scores indicative of greater frequency and reaction to such problems (Teri et al., 1992); and the 12-item Zarit Caregiving Burden Interview, with response options ranging from 0 (never) to 4 (nearly always). Higher scores indicate greater caregiver distress; a total score ≥ 17 is considered high burden (Bédard et al., 2001).

Technology use—A questionnaire developed by the Center for Research and Education on Aging and Technology Enhancement (Czaja et al., 2006) at the University of Miami was adapted to ascertain the total number of 24 commonly available technologies (e.g., smartphone, tablet, video camera, video game console, DVD, home security system, ATM) currently used by the caregiver.

Analysis

Univariate descriptive statistics were computed for all discrete and continuous variables using SPSS® Statistics (version 22, IBM Corp., Armonk, NY). Screening of the video involved listening to and viewing each video segment, then annotating on an Excel spreadsheet the daily activities, behaviors, and interactions observed, including a detailed description and the start and end time of each observation. Salient events were signified by color coding on the spreadsheet.

Findings

The 18 family caregivers in this study had been providing care for their family members with dementia for 5.5 ± 3.7 years, excluding one caregiver who reported 25 years in the role. Most ($n = 14$; 78%) received help from family and friends or hired caregivers; all but one was the primary caregiver. Mean scores were 16.1 ± 8.2 on the Zarit Burden Interview and 43.3 ± 12.4 on the total frequency scale of the Revised Memory and Behavior Problems Checklist. Repetitive questioning, forgetting what day it is, difficulty concentrating on a task, starting but not finishing activities, losing or misplacing things, and trouble remembering recent or significant past events were the most frequent dementia-related behaviors reported by more than 50% of caregivers. Less frequent but more bothersome were destroying property, behaving in ways that embarrassed the caregiver, talking about death or feeling worthless, waking the caregiver or others at night, and being argumentative, irritable, aggressive, or complaining. The majority of caregivers ($n = 11$; 61%) rated their health as good or fair, rather than very good ($n = 5$; 28%) or excellent ($n = 2$; 11%) and, on average, they used 11.72 ± 3.04 everyday technologies. MMSE scores were 29.0 ± 1.4 for caregivers and 15.2 ± 11.2 for persons with dementia.

A total of 341 hours of usable video resulted from caregivers wearing our camera system over a combined 123 days, for an average of 2.8 hours per day. Screening of the video yielded 248 salient events that we broadly categorized in four ways that often overlap: validating the caregiver's observations and approach, identifying new caregiving concerns, managing expectations, and reinforcing the need for respite. Here we present scenarios to illustrate each category and selected strategies that we suggested as part of the tailored interventions.

Validating the caregiver's observations and approach—Caregivers typically welcomed the opportunity to demonstrate the manner in which they dealt with the physical, social, and psychological impact of dementia on their care recipient and themselves. Receiving feedback commending their caring and competence often prompted unsolicited remarks about how few people really understood the many responsibilities they assumed, nor the way it has altered their everyday life.

One middle-aged woman cared for her father who lived on his own in a nearby community. He was intact physically but cognitively impaired with significant short-term memory loss and diminished executive function. He tended to be anxious and verbally aggressive, especially when offered assistance with personal care through VA in-home services. The family caregiver visited daily and demonstrated a remarkable aptitude for maintaining calm when telling her father it was time to bathe, change his clothes, take his medicine, or eat (which he would forget to do), rather than asking or engaging him in contentious debate regarding the merits of doing so. Her success in defusing her father's resistance was noted in our interventionist's praise of her patience and communication skills that allayed his anxiety and reduced his agitation. This paved the way for discussion about the current living arrangement and whether it still sufficed. Acknowledging that this topic was uppermost in her mind, the caregiver affirmed her desire to seek alternate living arrangements and subsequently did so.

Identifying new caregiving concerns—Seeing how family caregivers perform personal care and transfer activities offered us the opportunity to suggest safer ways of accomplishing a task, often to the benefit of both the caregiver and the person with dementia. For example:

A middle-aged caregiver who spent all of her time caring for her mother with advanced Alzheimer's disease relinquished her responsibilities only once a week to run errands while a hired caregiver provided brief respite. Her mother was nonverbal, had severe flexion contractures of the shoulders, hands, hips, and knees, and was unable to perform any self-care. Although the daughter cited as her major concerns her mother's frequent crying and tearfulness, apparent anxiety and sadness, and need for assistance with all activities of daily living, her video revealed that she handled these in a competent, albeit intense, manner. Of particular concern to our team were images of her mother's painful grimaces during bathing, especially evident when the daughter lifted her arms or extended her fingers for vigorous scrubbing. With personal hygiene high on her list of actions to reduce the

likelihood of life-threatening infections, the daughter could not be convinced to temper her bathing technique. However, she agreed to pre-medicate her mother with a short-acting analgesic prior to activities that involved significant joint manipulation. Beyond implementing our suggestion that she use a soothing tone of voice and touch to calm her mother, the caregiver added massage in order to further allay anxiety and induce relaxation before she attempted personal care activities.

During follow-up phone calls she reported that all of these strategies were helpful.

Specific safety concerns were not typically reported by caregivers, but they were often detected by our team during screening of their video. For example, we could see flash burns on a toaster that suggested a fire had occurred in the home of a person with dementia who lived alone. An exchange of remarks between a husband and wife indicated that the spouse with dementia had left the refrigerator door ajar on a number of occasions, with the result that food was spoiled. We also observed unsafe transfer techniques that placed both members of an elderly dyad at risk of injury. In each case we suggested eliminating hazards or improving technique. When indicated, we explored additional safety issues such as the inadvisability of continuing to drive by a person who had limited ability to remain on task.

A particularly harrowing observation involved a caregiving daughter who stood at the base of a long stairway, coaching her mother as she walked down the steps. The daughter derived great pleasure, and deservedly so, from having built up her mother's strength and stamina after bringing her to live with her family. It was a source of pride that her mother was flourishing physically in a way that she had not while living elsewhere with the daughter's siblings. Despite this accomplishment, it was our view that the mother was too unsteady and impulsive, as we had observed elsewhere in her video recordings, to navigate the steps alone. Thus, we recommended that the daughter or other family member always accompany the mother on the stairs, walking beside her and steadying her with a hand on her belt or waistband as she moved, which the daughter agreed to do.

Managing expectations—We encountered many instances of caregivers with the best of intentions underestimating how much their family member's dementia had progressed, rendering ineffective compensatory strategies that may have worked well during an earlier stage in the disease trajectory. In these cases our interventions focused on providing the caregiver with an opportunity to reexamine the benefit of such strategies, followed by ways to simplify or replace the approach that could no longer produce its desired effect. Specifically, our interventionist would describe the level of disability typically associated with dementia at the current stage and contrast it with examples from the caregiver's own video clips that showed how the strategy as implemented required greater capability (e.g., memory and attention, information processing, problem solving skills, ability to perform multi-step tasks, emotional regulation) than was evident in their care recipient. We provide this example:

A devoted husband caring for his wife with early onset Alzheimer's disease diligently engaged her in many of the household chores and social activities that had filled their busy life prior to her diagnosis. He posted a detailed daily schedule on a wipe board in the kitchen and apprised her of upcoming commitments

throughout the day, continuing this narrative even at times when she was agitated. Though physically strong, the wife was severely impaired in terms of memory, concentration, communication, and mood. Especially distressing to her husband were her often tearful expressions of her own worthlessness, loneliness, and death, as well as her episodic aggressiveness, threats of self-harm, hallucinations, and perceptions of abandonment by others. Sometimes her husband could soothe her by praying together, as was their habit, or reminiscing using a photo album he had compiled to chronicle her life. At other times she was inconsolable. The caregiver hoped that newly prescribed medications would help, and the team provided ongoing assessment and follow-up of the care-recipient's threats of self-harm. He was alternately saddened by his wife's loss of personhood and overwhelmed as her sole source of support, having married late in life and being without children or other relatives who could lend a hand. In addition to commending the caregiver for his extraordinary patience and creativity, our interventionist pointed out the mismatch between the caregiver's persistence in keeping his wife informed about the details of their daily life and her limited ability to process the stimuli he provided. Indeed, the dry erase board schedule and ongoing narrative about the day's events likely resulted in cognitive overload and frustration, potentially exacerbating her emotional fragility. Eliminating the former and simplifying the latter were suggested. The caregiver reported that lessening his daily narrative was emotionally difficult, as it affirmed the severity of his wife's illness. He had viewed his narration as an expression of hope in her ability to retain some pockets of comprehension. However, he also acknowledged that adopting these suggestions reduced his own care burden and offered a break to his wife.

Reinforcing the need for respite—Although every family caregiver recognized the value of receiving periodic respite from the demands of their role, their available options varied considerably from one dyad to the next. Each dyad differed in its proximity to relatives who could and would pitch in, its financial wherewithal to pay for hired caregivers or adult day programs, and its eligibility for philanthropic or government-sponsored services that could be of help. Yet several caregivers initiated or increased their respite arrangements with our encouragement. One situation illustrates this point:

A wife caring for her husband had several adult children who lived out of town and supported her with frequent phone contact but infrequent visits. Constant vigilance was required due to the husband's compulsive walking, both at home and outside. He could feed, shower, and dress himself with minimal assistance, and he helped with small household tasks. He was typically gracious and pleasant unless prevented from walking. His compulsion motivated him to pace inside the house and walk around the block up to 10 times a day, regardless of the time or temperature. The wife dealt effectively with the situation by notifying neighbors and the police of his route, slipping a GPS tracker in his pocket whenever he went out without her, and remaining vigilant about his whereabouts. A brief but painful illness of her own combined with our encouragement prompted the caregiver to begin taking her husband to an adult day care program, gradually increasing his time there from a few hours to a few days per week. This approach enabled the

husband to become familiar with the new setting and the wife to gain confidence that he would be permitted to walk safely as desired, making the respite arrangement beneficial to both.

Discussion and Implications for Nursing

Many of the family caregivers in our study had several years of experience caring for a family member with dementia. Not only were they (and their care recipients) willing for us to see and hear from their perspective what they regularly contended with at home, they were also receptive to considering our recommendations for new ways of approaching the challenges they faced. Several speculated that sharing their video clips with other family members and their care recipient's health care providers could be very helpful, as a way of conveying in a contextual and irrefutable manner how dementia currently affected their care recipient. Nearly palpable was caregivers' desire to have others understand their circumstances, their need for vigilance and respite, and the extraordinary effort that was required to fulfill their role.

Wearable camera systems like the one we developed to record for hours rather than minutes at a time are not commercially available. Neither is there software that would fully automate and replace the labor-intensive screening process we used to identify salient events. Novel machine learning and computer vision techniques (Del Giorno, Bagnell, & Hebert, 2015) are likely to spur these needed advances, providing valuable new tools to facilitate objective nursing assessment and evidence-based intervention to influence dementia care in home and other non-clinical settings. Nurses in home care, primary care, and other community-based environments are especially well positioned to elicit family caregivers' perceptions and intervene as indicated by their assessment. We envision a time when recording what transpires in the usual rhythm of life at home will inform clinical nursing care, providing a more objective means of assessing symptoms and response to treatment than self-report alone.

Conclusion

This study demonstrated that dementia family caregivers can and will use a wearable camera system to reveal dementia-related behaviors as well as their interpersonal dynamics, with data garnered from their perspective providing a valuable springboard for tailored intervention. Further, our findings suggest that caregivers are receptive to feedback and suggestions informed by objective observation of their caregiving practices.

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Table 1Sample description (N=36)[†]

Characteristic	Family Caregivers (n=18)	Persons with Dementia (n=18)
Gender, n (%)		
Male	8 (44)	6 (33)
Female	10 (56)	12 (67)
Mean age (SD)	63.7 (14.0)	78.6 (9.1)
Ethnicity, n (%)		
Caucasian	12 (67)	14 (78)
African American	3 (17)	3 (17)
Other	3 (17)	1 (6)
Marital status, n (%)		
Never married	3 (17)	--
Married	12 (67)	10 (56)
Separated or divorced	3 (17)	4 (22)
Widowed	--	4 (22)
Education, n (%)		
High school	3 (17)	5 (26)
Vocational/some college	6 (33)	6 (33)
College degree or higher	9 (50)	7 (39)
Household income, n (%)		
\$20,000 – \$49,000	7 (39)	--
\$50,000	9 (50)	--
Did not know/declined	2 (11)	--

[†] Percentages may not add up to 100% due to rounding