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Improving Caregivers' Well-Being by Using Technology to Assist in Managing Nighttime Activity in Persons with Dementia

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Abstract

This paper reports the qualitative arm of a mixed-methods study designed to test an in-home nighttime monitoring system (NMS) that tracks the nighttime activity of persons with dementia (PWD). Fourteen caregiver interviews were analyzed using grounded theory/full conceptual description methodologies to determine the issues associated with providing care at night, and to explore the benefits of using the NMS.

Caregivers not using the NMS experienced sleep disruption, overwhelming worry and loss of personal space leading to decreased energy, and changes in mood. When the NMS was used, caregivers reported improved "peace of mind." The fear and uncertainty associated with worry was alleviated by reliable alerts regarding the whereabouts of the PWD. Some caregivers were able to better balance needs for personal space with needs to remain in contact with the PWD. Generally caregivers reported an improved quality of sleep although some caregivers reported more awakenings resulting from the system alerts.

Keywords

nighttime activity; caregiver burden; sleep; quality of life; dementia

Introduction

Nighttime wandering behaviors of persons with cognitive disabilities present unique challenges for family caregivers concerned for their safety. Altered sleep-wake patterns are commonly experienced by individuals with cognitive disabilities such as elders with dementia or children with autism (Ancoli-Israel, Klauber, Gillin, Campbell, & Hofstetter, 1994; Hering, Epstein, Elroy, Iancu, & Zelnik, 1999; McCurry et al., 1999). Because of these altered sleep patterns, people with cognitive disabilities awaken more frequently at night and often leave their beds, their cognitive disabilities predisposing them to errors in judgment that may result in serious consequences. For example, an individual may leave the home and be unable to find his or her way back, resulting in exposure or even death (Rowe, Feinglass, & Wiss, 2004). Older individuals with dementia are also at significant risk for falls and other serious injuries

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that may result in nursing home placement (Alden, Rabbitts, & Yurt, 2005; Rowe & Fehrenbach, 2004; Walter, Lui, Eng, & Covinsky, 2003).

Once an individual with cognitive disabilities begins to get up (sometimes multiple times) during the night, a caregiver may become worried about that person's safety and lose sleep in an effort to provide supervision. Because of the unpredictability of nighttime waking, caregivers often force themselves to awaken periodically to check on the person at risk, or they may sleep through events in which they are actually needed (Rowe, 1999). Caregivers, in general, report poor sleep quality (Teel & Press, 1999; Wilcox & King, 1999) especially when depressed (Kochar, Fredman, Stone, & Cauley, 2007). However, it has been difficult to consistently identify abnormalities in objective (e.g. actigraphy) or subjective (e.g. sleep diary) patterns that would explain the reports of poor sleep quality. In a recent review, McCurry and colleagues (2007) noted that changes in caregiver sleep are caused by a multitude of factors including irregular sleep/wake routines, depression and burden, and caregiver medical morbidity. Nocturnal awakenings by the PWD, caregiver depression and burden were also found to be predictive of disrupted caregiver sleep in some studies (Creese, Bedard, Brazil, & Chambers, 2008), but not in others (Willette-Murphy, Todero, & Yeaworth, 2006). Despite some incongruities in caregiver sleep research, it seems clear that compromised caregiver sleep and (at least occasional) lapses in nighttime supervision of a care recipient are hazards of caring for a PWD who arises unpredictably during the night. An innovative technology was recently developed to provide family caregivers with a reliable alert when a person with cognitive disability leaves the bed at night (Rowe, Lane, & Phipps, 2007). The purpose of this paper is to report on the qualitative arm of a mixed-methods study designed to evaluate the benefits of this in-home nighttime monitoring system (NMS) that tracks the wandering behaviors of persons with Alzheimer's type dementia.

The prototype of the NMS used in this study consisted of an information center placed at the bedside of the caregiver and sensors placed at the bed of the PWD and in other strategic areas of the house, including exit doors. Initial installation of the wireless system required about 1.5 hours. Caregivers determined safe and unsafe zones in the home, and then the NMS was set to alarm at the caregiver's bedside using varying tones of urgency according to these predetermined zones of danger. In this way, caregivers were alerted when a PWD got in or out of bed and could track, from the bedside, the location of the PWD as he or she moved about, or towards an exit door. Varying tones of urgency from the pre-set alarm allowed caregivers to determine from their bed whether or not they needed to get up and attend to the PWD. For example, one caregiver might set a low tone to sound if the PWD merely left the bed, went to the bathroom, and returned to the bed. That same caregiver might set a high tone to notify them if the PWD entered the kitchen or attempted to exit the front door. Another caregiver, concerned about falls, might set a high tone to sound if the PWD even attempted to leave the bed. Thus, the NMS could be programmed to reflect not only a range of PWD locations but also a range of concern levels on the part of the caregiver. Daily activation and deactivation of the NMS was similar to operating a normal home security system, requiring less than a minute.

Investigators in this study postulated that the new technology would prevent falls and unintended home exits. Although little research has been done in this area, they also reasoned that caregivers' sleep and psychological state would be: a) adversely affected by the need to continually awaken through the night to ensure the safety of the care recipient and b) enhanced by a system that reliably alerted them to actual bed exits. In order to investigate these questions, both quantitative and qualitative data were collected. This report focuses on the qualitative arm of the study, which was designed to address the following research questions: 1) What psychological, sleep, or other problems are associated with providing nighttime supervision to persons with dementia? 2) What are the benefits (consequences) to caregivers of using the NMS? and 3) How are those benefits conveyed?

Design and Methods

Design

The quantitative part of the study was a controlled clinical trial with 26 caregiver/care recipient dyads assigned to the experimental group (received the NMS) and 27 assigned to the control group. Six subjects who completed the control condition opted to enroll in a crossover study in which they received the NMS. Quantitative data was collected at nine points in time (months 1 through 6, 8, 10 and 12) from experimental and control subjects, and 3 additional time points (months 2, 4, 6 after completion of main study) for crossover subjects. An independent researcher, not involved with the development of the NMS, was brought in for the qualitative arm of this research, which consisted of interviews with 14 primary caregivers who were caring for a PWD who wandered during the night.

Subjects

The qualitative arm of the study began approximately 18 months after initiating the quantitative arm. After IRB approval was obtained, researchers contacted primary caregivers who were still enrolled under quantitative study protocols and obtained consent from 14 of them to participate in semi-structured interviews. Participants included seven of the 26 experimental subjects, four of the six crossover subjects, and three of the 27 control subjects. They included seven wives caring for husbands, one husband caring for his wife, five daughters caring for their mothers, and one granddaughter caring for her grandmother (see Table). The average caregiver age was 64.00 ± 11.27, with a range of 38 to 86 years. Eleven caregivers were White, not Hispanic; two were African-American and one was Hispanic. Five caregivers slept in the same bed as the person with dementia, and seven slept in a separate room. At the time of the interviews, caregivers in experimental and crossover groups had used the NMS for a minimum of six months. All care recipients had dementia of the Alzheimer's type except one with vascular dementia. The average Mini Mental State Examination (MMSE) was 13.36 (±5.95) with a range of 2 to 21. The mean age was 80.42 (± 9.11) with a range of 62 to 97.

Data and Analysis

Although some of the analytic tools of grounded theory were used in this analysis, we were not seeking to formulate a substantive theory or to identify a core variable to explain the process of how caregivers deal with nighttime activity of a PWD. Rather, we sought to: a) explore the psychological, sleep or other *problems* associated with caring for a PWD who arises during the night; b) discover the full range of *consequences*, or benefits, that caregivers using the NMS had begun to mention to study investigators during the quantitative portion of the study; and c) explore the *process* by which a structural solution (the NMS) might convey the benefits that caregivers were beginning to experience. In this sense, the analysis process more closely resembled what Glaser (1992) described as full conceptual description in his *Basics of Grounded Theory Analysis.*

Data consisted of 14 transcribed interviews and written summaries given by four caregivers who were asked to respond to the veracity of initial findings. The interviews were conducted in caregivers' homes and, in an effort to reduce caregiver burden, were kept between 20 and 60 minutes each. In order to differentiate NMS benefits from other benefits of participating in the study, all 14 caregivers (control, experimental, and crossover) were initially asked general questions about whether participating in the study had affected their lives and their experience of caregiving, and how it was for them to have researchers coming into the home. Additionally, experimental and crossover subjects were asked to describe any changes they might have observed in their caregiving experiences since introduction of the NMS. Interviews were tape-recorded, transcribed, checked for accuracy, and printed out on pages with wide right margins. They were then hand coded line-by-line to identify codes, using subjects' own words whenever possible. Codes were grouped into conceptual categories and their properties. As new codes emerged in the data, they were assigned to one or more existing categories or grouped into new ones. Categories were then examined in relation to one another. Throughout this process the researcher made memos, reflections that served to preserve her thoughts/insights regarding the emerging categories and properties and their possible relationships. Interviews were conducted simultaneously with analysis over the course of approximately nine months. In that way categories and properties that emerged in early analysis could be more fully explored in interviews with subsequent (new) participants. Twice during the interviewing and analysis process questions were added to the interview schedule that served to clarify and expand upon emerging concepts.

Line-by-line hand coding of data continued until all relevant conceptual categories were identified. When data became repetitious and no longer added to the analysis, interviewing ceased. Transcripts were then reexamined in electronic form. The cut and paste function of MS Word was used to organize the relevant concepts and their properties in relationship with one another and to connect these concepts with illustrative caregiver quotes. Relationships between concepts were then examined through a process of several iterations of combining memos and writing up findings.

Credibility of Findings

Preliminary findings were shared with other members of the research team, who had been in caregivers' homes throughout the study, to verify that conclusions fit with their assessment of caregiver experiences. They were also returned in written form to five participants from the original study. Each was asked to respond, to verify or amend findings with comments throughout the manuscript and in a written summary. Four caregivers provided feedback: three who had used the system and participated in the qualitative arm of the study and one who had used the NMS but had not been interviewed. Summary comments from the four included:

1. "This report does an excellent job of summarizing your findings. I can see myself in it in many places – not just where my quotes or comments are noted."
2. "Most of the report was very true for me although I didn't have more sleep because previously I was not as concerned. Mom was in better shape." (Comment reflects findings.)
3. "Personally I found the report to be very comprehensive. I wouldn't omit one line, and I can't think of anything that was left out."
4. "I am so thankful for the NMS and the research team. They have improved the quality of rest I get as a caregiver so I can provide better care for the patient, my mom.… What great peace of mind the NMS has brought me!" (Comment from this non-interviewed participant reflects findings).

In response to findings, caregivers mentioned two concepts that had not surfaced in the original data. One respondent noted that the NMS enabled her to keep her mother at home without the added expense of an overnight caregiver, indicating possible financial impacts of the system that were not explored in the original report. Another noted how other family members are positively impacted when the caregiver gets more sleep and is less irritable.

Results

Beyond the daily challenges of monitoring a PWD, caregivers in this study carried the additional burden of supervising potentially troublesome or dangerous nighttime activity as well. As they stepped into this nighttime supervisory role, caregivers began to experience an increase in worry, a loss of personal space, and disruptions in their sleep. These, in turn, contributed to loss of energy, changes in mood, decreased desire to connect with others, and decreased motivation to carry out routine tasks of life or engage in self care. There was some indication that these difficulties negatively impacted quality of care as well. Following, we discuss caregiver difficulties associated with moving into a nighttime supervisory role. We then describe benefits to caregivers of using the NMS and suggest how these benefits may be conveyed.

Consequences of the Nighttime Supervisory Role

Increase in caregiver worry—Caregivers in this study had a lot to worry about: the deteriorating condition of the PWD, managing care needs like medications or doctor appointments, the unknown future, and added household responsibilities. Once a PWD began to get up during the night, however, caregiver concerns escalated. They now worried about the individuals' safety during the night and their own abilities to awaken to ensure that safety. Some, most notably daughters caring for mothers, also worried about the emotional states of care recipients who were unable to verbally communicate needs during nighttime activities.

Dimensions of caregiver worry most affected were uncertainty and fear. Intolerance of uncertainty has been associated with, and may play a central role in the development and continuation of worry (Dugas, Freeston, & Ladouceur, 1997; Lachance, Ladouceur, & Dugas, 1999). Referencing a cognitive model of adult worry developed by Dugas, Gagnon, Ladouceur, and Freeston in 1998, Laugesen, Dugas, and Bukowski (2003) stated that people are intolerant of uncertainty when they "find uncertain situations stressful and upsetting," "believe that unexpected events are negative and should be avoided," and when they "think that being uncertain about the future is unfair" (2003 p. 56). When caregivers were not using the NMS, they found the uncertainty associated with nighttime activity both stressful and upsetting. A wife, for example, whose husband had slipped out one night and attempted to cut down a tree, lamented,

> God I'd hate to see him out there in the middle of the night just wandering around and *I wouldn't know* [italics added] how to even find him…. Jesus, you know, I'm thinking he's out here with - there's, there's snakes around. *I don't know* [italics added] what they do at night but I worry about it.

Uncertainty was also a fact of life. As one daughter stated, "Sometimes [Mom] gets up… and some nights she sleeps through the night, um, and it's very erratic. There's no way of predicting that." Caregivers often noted how the uncertainty of "not knowing" contributed to their worry, as expressed by a daughter who "worried about [Mother] getting up and maybe falling and not *being able to know* [italics added] that she's fallen until I get up to go check on her," or by a granddaughter who spent time "just worrying or wondering if [her grandmother would] fall" during the night. Caregivers expressed uncertainty regarding whether the PWD was in or out of bed, where they might be wandering, what they might be doing during the night, and their own ability to awaken in time to prevent unwanted events.

Fear was another dimension of worry for these caregivers. As one wife stated, "I used to be scared to go to bed at night 'cause I never knew what he would do." Caregivers' biggest fears were that the PWD would fall: "Fallin' is my biggest concern, 'cause he has fallen and hit his head before," or that the PWD would leave the house at night or would otherwise suffer harm: "[I was] scared to death that he was gonna get out or get away." Fear was sometimes grounded in harm that had actually occurred during a nighttime wandering episode: the husband who had fallen and hit his head or a mother who fell in the bathroom, broke a hip, and was not found until the following morning. Caregivers also feared what *could* happen, like the wife who feared snakes or other "wild animals" might harm her husband when he went outside at night.

A few caregivers described cognitive components of worry, specifically negative anticipation and rumination. Negative anticipation consisted of thinking about unpleasant and undesired possibilities, as expressed in the statement, “Before [the NMS] every time he moved in the bed I would wake up thinking he was going to fall out of bed or get out of bed or do something like that.” When caregivers ruminated, they dwelt on their thoughts, running them over and over in their minds. “I go to bed, I lay there and I think of all these things that are going on in my head” described one caregiver’s experience of rumination. Negative anticipation and rumination may account for nearly 30% of the thoughts that make up the cognitive component of worry (Szabo & Lovibond, 2002).

Disruptions in sleep—Caregivers found that nighttime supervision disrupted both the quantity and quality of their sleep. The amount of sleep caregivers lost in the nighttime supervisory role depended upon: a) the number of times the PWD got up during the night and how long it took to get them settled back in bed, b) how often the caregiver actually heard them get up (how soundly they naturally slept or how close they slept to the PWD), and c) how compelled a caregiver felt to stay awake to listen for, or get up and check on, possible nighttime activity. Loss of sleep was also closely related to worry, as fear and uncertainty motivated caregivers to stay awake to listen for nighttime activity. Additionally, time spent in negative anticipation and rumination was time spent not sleeping. As one daughter stated, “I couldn’t sleep ‘cause I was worried about, you know, she’d do something… it’s just a worry.” Another daughter gave an extreme example of how thoughts generally could affect sleep, “The train just keeps going with the thought, just keeps going on, and then I’m laying there for like another hour, another hour and a half and then I go to sleep.”

The quality of sleep was also affected by nighttime supervision duties as fear and uncertainty motivated caregivers to stay awake to listen for nighttime activity or to attempt to maintain a level of awareness even as they slept. As one daughter stated, “When I didn’t have [the NMS] I, you know, I couldn’t sleep soundly because I would always be worrying she [was] up in the bathroom,” and another said, “Even though I don’t necessarily wake up a hundred percent I’m still aware and so I’m not getting the, the deep sleep that I need.”

Loss of personal space—Nighttime supervisory roles also resulted in loss of privacy, or personal space, for some caregivers. A few lost physical space, like a wife and a daughter who temporarily slept on couches to be closer to the PWD. The need to be constantly aware of a PWD meant loss of mental/emotional space, or time to one’s self, as well. As one wife described, “I had to be pretty much alert 24 hours a day.… I was at my wits end.… They’re your responsibility twenty four seven.” In addition to maintaining a sense of vigilance throughout the day, when a PWD wandered, the caregiver had to remain on duty at night as well. As this granddaughter expressed, “I would have to just, you know, get up on my own and check on her throughout the night just to make sure she’s okay.” The perceived need to be constantly vigilant could be stressful and exhausting, as indicated by a daughter who stated,

> I need to get some respite care because of, it’s just really weighing down on me … getting, you know, harder and harder because I’m my mother’s sanctuary. She doesn’t see me, she gets very upset and she wants to know where I am. And, uh, if I’m not right where she can see me, she keeps yelling and calling.

Secondary consequences—Worry, sleep disruptions, and loss of personal space eventually took their toll on many caregivers in this study. As noted above, worry and the perceived need to be constantly available to the PWD contributed to sleep disruptions. Poor sleep had its own consequences, which included: a) *decreased energy* “If you’re not [feeling well from a good night’s sleep] you’re really dragging during the day,” b) *changes in mood*, like feeling “irritable,” “cranky,” “depressed,” or “hopeless. “The worst scenario is bad ‘cause

I have gone through NO sleep at all, and then I'm just real irritable the next day," c) *decreased desire to connect to others* "[Without sleep] I'm cranky, cranky and uh, when that happens I usually just go outside try to be away from people," and d) *less motivation to carry out routine tasks of life or engage in self care* "I was just so worn out that I just didn't want to eat." These changes in caregiver energy, mood, connectivity to others, and motivation not only adversely affected caregiver quality of life, they also had the potential to affect the person with dementia. As one caregiver stated, "If this year had passed without me having the system, I would probably… not be as good a care giver because when I don't have enough sleep it really, it really has an impact." This daughter perhaps summed it up best by saying,

> I'm exhausted all the time and I don't feel like doing things, its really hard to make myself take care of things and its hard for me to even take care of her to the best of my ability when I'm tired.... its more depressing, you know, more tendency to feel depressed when I'm tired…and sorta helpless and hopeless and all that.

Comments such as "I was at my wit's end," "It's just really weighing down on me," "You're really dragging during the day," and "I always feel as if oh, my god, it's another day" conveyed the stress and weariness experienced by some of these beleaguered caregivers as they described life without a NMS.

Benefits to Caregivers of Using the NMS

Peace of mind—When asked how using the NMS had changed their life or their experience of caregiving, subjects in the experimental and crossover groups overwhelmingly reported that the system had given them "peace of mind." For them, peace of mind was conveyed as the NMS: a) alleviated the worry associated with nighttime wandering activities and b) enabled them to better balance their needs for personal space with their desires to remain connected to the PWD during the night. Most caregivers noticed a change within a month. They described their newfound peace of mind by saying: "Peace of mind is just relaxing in your life, not being totally stressed." "I just had peace of mind knowing that I didn't have to worry." "…less worry, everything revolves around the worry part." "It's a wonderful peace of mind. I mean, it relaxes you to a certain degree… Oh Lord, it's the only peace of mind I have."

Worry gave way to peace of mind as knowledge replaced uncertainty and as trust in the system replaced fear. Once the NMS was installed caregivers knew whether or not the PWD had exited the bed, what part of the house they were in, or whether they were attempting to leave. Knowledge replaced uncertainty, which helped alleviate worry. As one wife stated, "To know where he is and what he's doing, uh, has really lightened up the worry a lot." Caregivers also no longer had to wonder whether they would awaken in time to care for the PWD, as expressed by a daughter who said, "I think I'm less worried because I know that I'll get up when she gets up," and a wife who stated, "I knew that if he left the bed it was going to wake me and that would be good."

Fear diminished as caregivers came to trust that the system would indeed reliably awake them the moment the PWD attempted to leave the bed. As one wife stated, "I don't have to worry about him getting' up and cuttin' down trees in the middle of the night 'cause the equipment works." She added a comment about her initial weeks in the study, "[The researcher] kept saying, 'don't rely on it [yet]. Don't rely on it. You gotta wait.' But I could see it was working, so I was relying." [A reliability period of approximately 2 weeks occurred just after installation to ensure reliable system operation; caregivers were instructed not to rely on the system during this time.] A daughter elaborated,

> Having the system has enabled me to go to bed calmly, not worried sick about whether or not my mother is gonna get up and when she would get up and where she would be and whether or not I'd know it. It has really helped me not have to be so concerned

> about that because I have peace of mind that the, the system is going to, um, wake me up in enough time and I'm going to be able to get to her in time.

Another consequence of using the NMS was that it allowed caregivers to balance needs for privacy and personal space with the need to remain in contact with the PWD. Because the sensors were placed in the bed of the PWD and the alert box at the caregiver's bedside, caregivers did not have to sleep in close proximity to the PWD in order to hear them during the night. Because they trusted the system to awaken them when needed, they could actually relax and not have to maintain that constant vigilance. As one husband stated, "I didn't have to be quite as close on her as I did before, see. This [system] told me when she got up… and then I'd be alert and ready to go." The NMS allowed caregivers just a little bit of personal space during the time their charges actually slept at night, and did so without sacrificing connectedness to the PWD. By the time of this study, the PWDs were largely unable to communicate nighttime needs to caregivers, adding to caregiver distress. Another component of peace of mind was, therefore, the ability to know that the PWD still had a means of communicating during the night, albeit indirectly. As one wife stated, peace of mind meant "being able to know that the person you're caring for, uh, still has contact with you even though you're resting." A daughter expressed it this way,

> I had peace of mind that when I turned [the NMS] on it would work and it would wake me up. Peace of mind is also, just knowing that there's a system that, um, is enabling us to, it's enabling my mother to communicate with me without having to communicate with me.

Better sleep—The NMS had a variable effect on the *amount* of sleep caregivers got. A couple of caregivers, who were heavy sleepers, reported they got less sleep once they started using the NMS. As one said,

> I'm more tired because I am getting up at night with her; but I need to, so the system, I guess it brings peace of mind, but its, I'm not getting more sleep because I have to get up. All the time my sleep is disturbed.

Others reported getting more sleep as they relaxed their vigilance. "It allowed me to get more sleep, and I wasn't having to just constantly listen for him to make a noise" related one wife. It is possible that sleeping in one's own bed, not engaging in negative anticipation or rumination, and being able to choose whether or not to get up to check on a PWD also contributed to increased sleep, but the extent to which these factors affected sleep could not be determined from the data.

Users of the NMS noted almost universally that the *quality* of their sleep improved once they came to trust that the system would reliably alert them to nighttime activities. They described their sleep as "better," "more comfortable," "more settled," "more intense," or "deeper." For many, the changes in sleep quality were dramatic. For example, one woman who had cared both for her mother and husband before getting the system stated emphatically, "Man I didn't even know I could sleep that hard.… I hadn't slept soundly in years, honest to God, years." Before system installation, fear and uncertainty motivated caregivers to stay awake to listen for nighttime activity or to attempt to maintain a level of awareness even as they slept. As caregivers came to trust the system to actually awaken them as needed, they allowed themselves to relax and sleep a little deeper, as evidenced by the following comments. "I could sleep more comfortably and deep, more deeply because I knew that the…machine was working and it would wake me up if he got up." "I had more settled sleep whenever I, I knew I could depend on this machine." "My sleeping was a little more intense and better for me because I had the [NMS] to remind me when she got up."

Energy for self-care and care of PWD—As worry subsided and sleep improved, many caregivers reported that they had more energy and were beginning to engage in more activities of self-care. As one daughter stated, “When you don’t have to worry or wake-up during the night you can sleep more and then you have more energy.” This increase in energy enabled caregivers to devote a little more time and attention to things like personal appearance, healthy eating, or care of the home. One caregiver, for example, stated that now “I do have energy… I’ve gone on a diet. I’ve colored my hair.… I actually did something about it and I think that this equipment is letting me do these things.” Another wrote in her feedback on findings report, “I am able to walk with a friend two times a week because I am sleeping better at night. Without the NMS I doubt I would have the energy or interest in doing that.”

A few study participants indicated that having the NMS also allowed them to function better as caregivers, as comments on two written feedback sheets suggest: “I am so thankful for the NMS and the research team. They have improved the quality of rest I get as a caregiver so I can in turn provide better care for the patient, my mom,” and,

> I believe that my ability to have my mother continue to live with us would be dramatically reduced if we didn’t have NMS. So, that means quality of care for the person with Alzheimer’s can be maintained so much longer with the NMS, because living at home with it is <u>so</u> much better than having to be moved to a nursing home.

Discussion

The psychological and sleep disturbances associated with providing care for a PWD who is up at night have been understudied. In this qualitative study, findings indicated that caregivers were broadly impacted by caring for a PWD who was up during the night. Caregivers experienced increased worry, loss of personal space, and disruptions in sleep when they stepped into a nighttime supervisory role. Loss of energy, mood changes, decreased desire to connect with others, and decreased desire to carry out routine tasks of life or engage in self-care ensued. Those participants who had the NMS introduced into their caregiving experience reported a significant decrease in worry and an increase in “peace of mind.” They were better able to balance their need for personal space with their need to be available to the PWD during the night. They noted that the quality of their sleep improved as they no longer had to get up numerous times during the night to check on the PWD or to attempt a state of hyper-vigilance. As a result, some users of the NMS noted that they now had more energy and were engaging in more self-care activities. A couple of participants even indicated that they were better able to care for the PWD after they began to use the system.

The findings that caregiver sleep was disrupted, not only from the nighttime activity of the PWD, but also by psychological factors of caregiving, were similar to those in two recent articles. In a conceptual review article, McCurry and colleagues (2007) noted that changes in caregiver sleep are caused by a multitude of factors including irregular sleep/wake routines, depression, burden, and nighttime rumination or intrusive thoughts. Nocturnal awakenings by the PWD, caregiver depression and burden were also found to be predictive of disrupted caregiver sleep by Creese et al. (2008). In this study we were able to explicate how two dimensions of worry, uncertainty and fear, prompted caregivers to either arise periodically to check on the PWD or attempt to maintain a state of hyper-vigilance in hopes of fully awakening should the PWD arise during the night. We were also able to note how negative anticipation as well as nighttime rumination added to cognitive components of caregiver sleep disruption. Moreover, we found that the tension between the need for personal space and the need to remain connected to the care recipient during the night was a source of worry and stress for some participants that could also negatively impact caregiver sleep.

Areas for Future Research

It is important to note that not all participants actually got more sleep once they began using the NMS. For heavy sleepers, the alerts of the NMS actually awoke and alerted them to nighttime activity that they might otherwise have slept through. In further studies it will be important to determine the extent to which this sleep loss is balanced by other benefits of the NMS for this subset of heavier sleepers, or whether there are other means available to compensate for the increased sleep disruptions. The fact that all the experimental and crossover group caregivers chose to keep the NMS after the study was completed lent some credence to caregiver perceptions that the benefits of the NMS outweighed any burdens. It is also useful to note that, although users of the NMS overwhelmingly reported improved sleep quality, there was no way in this study to determine the degree of restorative sleep the caregivers actually experienced. Future studies are needed to more specifically describe and measure sleep variables of both users and nonusers of the system, and determine the degree to which restorative sleep may be enhanced as factors such as hyper-vigilance, nighttime rumination, and privacy/connection issues are ameliorated.

Findings from this study also suggest the need for future research comparing the efficacy of the NMS with pharmaceutical, cognitive and behavioral, counseling, support group, and other problem solving interventions aimed at improving the sleep of caregivers of persons with dementia. Several studies have focused on interventions to improve the sleep of the PWD, thus decreasing the need for nighttime supervision. Although a variety of interventions have been tried, including bright light (Sloane et al., 2007) and behavioral interventions (McCurry, Logsdon, Vitiello, & Teri, 2004), there has been at best moderate improvements of sleep in only some of the participants. Since nighttime awakenings still occur, caregivers must remain on alert through the night to ensure a safe environment. None of these intervention studies examined the effect on caregiver sleep, as most of them have been conducted in formal care settings. Interventions to improve caregiver sleep, such as an anxiety reduction program (Akkerman & Ostwald, 2004) and a multi-component program of sleep interventions plus caregiver education (McCurry, Logsdon, Vitiello, & Teri, 1998), have also had some success; however, it is unclear whether the sample included caregivers who needed to provide supervision at night and whether this subset of caregivers improved.

While a multifaceted approach to the problem is likely needed, options for monitoring the nighttime activities of the PWD could prove a useful addition. Currently options for monitoring during the night are quite limited and consist of intercom systems (i.e. baby monitors), individual door alarms, and creative homespun solutions. Intercom systems are problematic because there is no guarantee that the noises the PWD makes when up will be loud enough to awaken the caregiver. Individual door alarms sound as the door opens and, when made loud enough to hear throughout the rest of the home, can be quite startling to the PWD. Creative homespun solutions, such as changing the caregiver sleeping location, bells on door knobs, or using double-keyed deadbolts, all place an added burden and may still not reliably awaken the caregiver. To our knowledge no studies exist that examine the efficacy of these other monitoring options for improving caregiver sleep.

Finally, further qualitative research is needed to explore in greater depth how loss of personal space (privacy, mental/emotional space) impacts caregivers of persons with dementia and how caregivers attempt to balance their own needs in this area with their desires to remain available to and connected with the PWD, particularly during nighttime activity, when the PWD may be especially vulnerable. In our study it was daughters caring for mothers who most poignantly expressed this conflict, particularly as they felt concern for the emotional state of mothers who could no longer adequately verbalize their needs. To what extent might this concern be shared by sons caring for a parent or spouses caring for a partner? How might the felt need to be emotionally available to a parent or spouse affect a caregiver's ability to be present and attentive to their own activities, and how might this lack of presence affect caregiver well-being?

Study Limitations

There are several limitations to this study. The qualitative arm of the study began after some participants had completed quantitative study protocols, limiting the number of subjects available for interview. Additionally, not all of the available subjects consented to participate in this part of the study. Because of these two factors none of the five sons caring for parents were available to interview. Moreover, in an effort to reduce caregiver burden, we limited the interviews to between 20 and 60 minutes each. Therefore, although important concepts emerged in the data, we do not consider them to be exhaustive. For example, caregivers who reviewed preliminary findings mentioned that use of the system might convey financial benefits and positively impact other family members: two concepts that did not appear in the original interview data. Further in-depth interviews with a wider variety of caregivers could enlarge upon and further elaborate our findings. Also noteworthy is the fact that caregiver recollection of caregiving before receiving the NMS may be subject to both emotional and memory overlays and, until quantitative data is further analyzed, it is difficult to determine whether caregiver assessment of worry and sleep changes are reflected in that data as well. In a review of literature regarding sleep disturbance among caregivers of persons with dementia, McCurry et al (2007) noted that factors predisposing sleep disturbance are complicated and may extend beyond concerns with nighttime risings of care recipients. They also noted that self-reported sleep disturbances of caregivers and care recipients is not always well-correlated with polysomnography results. These findings notwithstanding, participants in our study believed that the NMS had positively impacted their experiences of caregiving.

Conclusion

This study reinforces prior research indicating caregivers may either periodically awaken during the night to check on persons with dementia (McCurry, et al., 2007; Rowe, 1999) resulting in fragmented, non-restful sleep for the caregiver (Teel & Press, 1999; Wilcox & King, 1999) or they may sleep through nighttime awakenings (Rowe, 1999) leaving the PWD unsupervised and vulnerable to falls and other untoward events. Interventions addressing these concerns have important consequences for both caregivers and care recipients. Alone or in combination with other interventions, the NMS has potential to be an important addition to efforts directed at improving both the safety of persons with dementia, and the sleep and psychological well-being of their caregivers.

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Demographic Characteristics of Subjects

	Qualitative Arm	**Full Study**
	n (%)	**n (%)**
Caregiver/Care Recipient Relationship		
Wife/husband	7 (50)	21 (40)
Husband/wife	1 (7)	6 (11)
Daughter/mother	5 (36)	20 (38)
Son/mother	0	3 (5)
Son/father	0	2 (4)
Granddaughter/grandmother	1 (7)	1 (2)
Race		
White, non-Hispanic	11 (78)	42 (79)
African-American	2 (14)	9 (17)
Hispanic	1 (7)	2 (4)
Type of dementia		
Alzheimer’s disease	13 (93)	41 (78)
Vascular	1 (7)	4 (8)
Other	0	7 (14)
Caregiver sleeping location		
Same room	5 (36)	20 (38)
Different room	9 (64)	33 (62)`
Age	M±SD	
Wives	67 ± 4.82	68 ± 7.70
Husband	86[*]	78 ± 6.83
Daughter	59 ± 6.30	49 ± 7.81
Granddaughter	38[*]	38[*]

[*] Note. n=1.