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Dementia Behavioral and Psychiatric Symptoms: Effect on Caregiver's Sleep

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Abstract

Aims and objectives—To examine caregiver sleep quality, especially in relation to the daytime and nighttime behaviors and psychological symptoms exhibited by persons with dementia (PWDs).

Background—Caregivers of PWDs experience poorer sleep in comparison with noncaregivers, and poor sleep is related to negative health outcomes. The reasons for caregivers' poor sleep are complex, and it is known that the nighttime behaviors of the PWD contribute to caregiver sleep disruption. However, the frequency of behavioral and psychological symptoms of dementia has hitherto not been sufficiently explored as a contributing factor to poor caregiver sleep.

Design—A nonexperimental cross-sectional design.

Methods—Eighty caregivers completed questionnaires on the frequency of behavioral and psychological symptoms of the PWD, the Dementia Severity Rating Scale, the Pittsburgh Sleep Quality Index, and the Center for Epidemiologic Studies–Depression Scale.

Results—Poor sleep was reported with awakenings by the PWD occurring for more than half of the caregivers. The frequency of behaviors and symptoms did not make a unique contribution to the variance of caregivers' global sleep. The frequency of behaviors, and specifically of agitation and apathy, contributed to the variance in subjective sleep quality, as defined by the caregivers' appraisal of their sleep.

Conclusions—The findings demonstrate the relationship between (a) daytime and nighttime behaviors of PWDs and (b) their caregivers' sleep quality, and emphasize the complexity of the factors that contribute to caregiver sleep quality.

Relevance to clinical practice—These findings suggest that nurses should be cognizant of the relationship between daytime behaviors of the PWD and the caregivers' appraisal of their sleep, realizing that appraising one's sleep as poor can be a contributing factor to perpetuating sleep problems. Interventions aimed at helping the caregiver manage the PWD's agitation or the caregiver's emotional response to PWD apathy may improve caregivers' perception of their sleep.

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Contributions:
Study Design (CS, PC)
Data Collection and Analysis (CS, PC)
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Keywords

Sleep quality; caregiving; dementia; behavioral and psychological symptoms

INTRODUCTION

In the United States, over 15 million informal caregivers—family members and friends—provide care for persons with Alzheimer's and other dementias (PWDs) with 50% living in the same household (i.e., residential caregivers) but up to 15% living as far away as 2 hours from the person they provide care for (non-residential caregivers) (Alzheimer's Association 2012). One consequence of caregiving is poor sleep quality. Caregivers experience poor sleep for complex reasons including both caregiver behaviors and disturbances by the PWD. Sleep disturbances contribute to adverse health outcomes for caregivers such as depression, and thus they often lead to institutionalization of the PWD (Wilcox & King 1999, Colten & Altevogt 2006, Mausbach *et al.* 2006). Providing interventions to promote good sleep can improve health outcomes for caregivers and, therefore, potentially delay the institutionalization of PWDs. But the relationship between caregiver sleep quality and sleep disruption by the PWD has not yet been sufficiently explored. The purpose of this study was to explore how problematic behaviors of the PWD effect caregiver sleep.

BACKGROUND

Correlates to poor sleep in caregivers of PWDs include caregiver behaviors such as getting up to go to the bathroom during the night, caregiver depression, and nighttime behaviors by the PWD (Wilcox & King 1999, Kochar *et al.* 2007, Creese *et al.* 2008). Previous research on the nighttime behavior of the PWD and how the PWD's disrupted sleep impacts the sleep quality of the caregiver has been inconclusive. Early studies found that the more frequently the caregiver was disturbed at night by the PWD, the higher the caregiver's reported level of poor sleep (McCurry *et al.* 1999, Wilcox & King 1999). Two more recent studies objectively measured the impact of nighttime behaviors of the PWD on caregivers' sleep. Beaudreau *et al.* (2008) found that caregivers' appraisal of distress caused by the PWD wakening the caregiver or family members did not significantly contribute to the variance in caregiver sleep parameters such as sleep efficiency (the amount of time in bed spent sleeping). McCurry *et al.* (2008), who used sleep efficiency of 85% over seven nights as a measure of good sleep, reported that some caregivers experienced good sleep despite the fact that the PWD was experiencing poor sleep quality during the same time period. Neither of these studies measured the impact of daytime behaviors of the PWD on caregivers' sleep.

Daytime activities of the caregiver can affect sleep. The "three-factor" cognitive model of predisposing factors, precipitating factors, and perpetuating factors that lead to persistent insomnia (Perlis *et al.* 2005) has been applied to caregivers and how they develop poor sleep. McCurry *et al.* (2007) describe a scenario where caregivers predisposed to sleep disturbances (e.g., increased age or being female) experience a precipitating event such as the PWD's awakening them; when this happens repeatedly, the caregiver can develop routines such as napping during the day or drinking caffeine to stay awake that perpetuate their sleep problems. Another example has been found in our own work: decreased total sleep time. Residential caregivers sacrifice hours of sleep so that they may have personal time while the PWD sleeps or take care of daily tasks that cannot be accomplished during caregiving. Non-residential caregivers lose sleep because of excessive worry and not being able to "shut off their thoughts" about caregiving at night. Caregiving can both create and increase sleep problems in caregivers.

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Yet, one aspect of caregiving not fully explored is the daytime behaviors of the PWD and their effect on caregivers' sleep. Evidence does suggest that increased behavioral and psychological symptoms in the PWD results in poorer sleep quality when measured subjectively and objectively (Mills *et al.* 2009, Son *et al.* 2007) but the effects of separate behaviors have not been studied. Identifying whether specific behaviors are related to poor caregiver sleep would help to identify caregivers at risk and would allow tailoring of interventions. This study examines caregiver sleep quality, particularly in relation to the daytime and nighttime behavioral and psychological symptoms of dementia (BPSD) exhibited by the PWD. We hypothesized that caregivers of PWDs with frequent BPSD (both daytime and nighttime symptoms) would experience poor levels of sleep quality.

METHODS

Design

This study used a nonexperimental, single-group cross-sectional design.

Sample

A nonprobability sample of caregivers of community-dwelling PWDs was recruited from a central Texas metropolitan area. The use of such a convenience sample introduces the possibility that these subjects were atypical and not representative of all caregivers, and this will be considered in the interpretation of the results (Polit & Beck 2004). Participants were at least 21 years old, self-identified as the primary caregiver, and able to communicate in English, and they freely consented to participate. *Primary caregiver* was defined as the person assuming the majority of responsibility in either direct care (e.g. providing basic activities of daily living assistance) or supportive care (e.g. managing finances, arranging and transporting to doctor's appointments) for the PWD, not defined by living arrangements. Non-residential caregivers were included to examine the influence of living arrangements and BPSD of the PWD on caregiver sleep quality. Seventy-four percent of the caregivers lived with the PWD, and 26% identified themselves as the caregiver for a PWD living in an assisted living facility, in the PWD's own home, or with another family member unable to provide the majority of care. Phone interviews were conducted to identify exclusion criteria. Caregivers were excluded from participation if previously diagnosed with a sleep disorder (e.g., sleep apnea) that was not well controlled (e.g., by not using CPAP or simply because they experienced symptoms); such medical conditions can contribute to sleep disruption. Caregivers with active symptoms of major depressive disorder prior to caregiving were excluded, because insomnia is a symptom of depression (American Psychiatric Association 2000).

Procedure

After approval by the Institutional Review Board, 82 caregivers were recruited utilizing flyers and direct solicitation in a variety of settings (e.g., a geriatric psychiatric practice, a clinical research practice specializing in drug studies for Alzheimer's patients, and community outreach and educational programs). Two participants were disqualified because of untreated obstructive sleep apnea revealed after consent. The final sample included 80 caregivers. After providing written consent, caregivers completed all questionnaires in an interview format in a place of their choosing. Interview sites included the caregiver's home, respite programs where the person with dementia participated, and coffee shops. All data were collected by the same researcher.

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Measures

Caregiver demographics—Data collected included standard demographics (e.g., age, gender, race/ethnic background, education level, current employment status). Perceived health status was measured with the item "How would you rate your overall health?" on a Likert scale of 0 = *excellent* to 4 = *poor*. Socioeconomic status was assessed by asking caregivers whether the family unit had *more than enough*, *just enough*, or *not enough* money to meet monthly household expenses, including medical and recreational expenses. Caregiving data included the relationship to the PWD; amount of hours spent caregiving per week; and number of years caregiving, with *caregiving* defined as providing physical, mental, financial, emotional, and spiritual support to PWD. The beginning of the caregiving role was defined as the time identified by the caregivers as when they assumed roles and responsibilities that the PWD could no longer manage independently. Information was also gathered from the caregiver regarding the PWD (e.g., age, gender diagnosis, time since diagnosis, education level).

Caregiver sleep quality—Subjective sleep quality is defined by the individuals perception of his or her overall sleep experience. The Pittsburgh Sleep Quality Index (PSQI, Buysse *et al*. 1989) is the most widely used measure of self-report *global* sleep quality because it assesses critical elements of the sleep experience on seven subscales: subjective sleep quality, sleep onset latency, duration, sleep medication use, efficiency, sleep disturbances, and daytime dysfunction. The subscales are summed to provide the global sleep score (range of 0 to 21). Scores greater than 5, indicating poor sleepers, have been reported to have a diagnostic sensitivity of 89.6% and specificity of 86.5% (Buysse *et al*. 1989). Cronbach alphas have ranged from 0.61 to 0.73 in previous studies (Castro *et al*. 2009, Roepke *et al*. 2009). Cronbach's alpha in this study was 0.61.

To evaluate the impact of behavioral and psychological symptoms of dementia on caregivers' sleep experience we used both the global sleep score and the individual subscale for duration, sleep onset latency, sleep efficiency and subjective sleep quality (the appraisal of the caregivers' sleep experience, referenced as such in the Results Section). In the original PSQI, there was an "other" as a possible sleep disturbance. The "other" question was replaced with "Had to get up because the person with dementia was awake or needed help." Answers were scored on a Likert scale from 0 = *not at all* to 3 = *three or more times a week*, in response to listed reasons for the disturbance. This item was used to assess the nighttime behaviors of the PWD.

Behavioral and psychological symptoms—Behavioral and psychological symptoms of dementia are defined as problematic behaviors exhibited by PWD and include: agitation/aggression; psychosis such as hallucinations or paranoia; apathy; dysphoria or depression; anxiety; wandering; daytime napping; or inappropriate behaviors. These items, taken from the Neuropsychiatric Inventory (Cummings *et al*. 1994) represent the most common negative PWD behaviors. To examine daytime behaviors and the relationship with caregiver sleep quality, caregivers were asked how frequently they had observed the PWD exhibit these behaviors and symptoms over the past 30 days. Participants were offered definitions or examples of these behaviors if they were unfamiliar with the terms. The four item response scale ranged from *no occurrence* = 0, *rarely* = 1, *frequently* = 2, to *daily* = 3. The scores on the occurrences of the individual behaviors were summed to provide a daytime *behavior index* (the range of scores possible was 0 to 27). Higher scores indicated more frequent occurrence of the combined behavioral and psychological symptoms of dementia. Cronbach's alpha for this questionnaire was 0.63. The nighttime behaviors of the PWD were assessed by the single item of the PSQI described above and one item from the Neuropsychiatric Inventory regarding PWD sleeplessness. Caregivers were asked "How

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often does your loved one have a sleepless night?" The four item response scale ranged from *no occurrence* = 0, *rarely* = 1, *frequently* = 2, to *nightly* = 3. Non-residential caregivers were asked these same questions to collect events such as nighttime phone calls from the PWD or regarding the PWD.

Dementia severity—The cognitive and functional ability of the PWD, which is a potential stressor for the caregiver defines dementia severity. Dementia severity was measured using the Dementia Severity Rating Scale (DSRS; Clark & Ewbank 1996), which provides the caregiver's assessment of the PWD's function on 11 domains (memory, orientation, judgment, social interactions, home activities, personal care, speech/language, recognition, feeding, incontinence, and mobility). Each item is scored on a Likert scale with 0 = *normal function* and a high score of 3–7, depending on the domain. Total scores ranged from 0 to 51, with higher scores indicating lower functional ability. Test–retest reliability at 2 weeks = 0.90, interrater reliability = 0.87, and internal consistency = 0.92 have been reported (Clark & Ewbank, 1996). Concurrent validity test showed correlates with the Mini-Mental State Exam ($r = -0.77$) and the Consortium to Establish a Registry for Alzheimer's Disease Neuropsychological Assessment Battery ($r = -0.73$) (Clark & Ewbank 1996). Cronbach's alpha for the DSRS in this study was 0.93.

Caregiver depressive symptoms—Caregiver depressive symptoms were measured because depression is a potential outcome of caregiver stress (Pinquart & Sörensen 2004) correlated with sleep quality (Carter & Acton 2006). Depressive symptoms were measured with the Center for Epidemiologic Studies Depression Scale (CES-D; Radloff 1977). Scores of 16 or higher (range of possible scores, 0 to 60) indicate increased risk for clinical depression. Criterion validity has been studied in a population of community-dwelling adults of ages 55 to 85 years; the CES-D was found to have a sensitivity of 100% when the cut-off was 16, a specificity of 88%, and a positive predictive value of 13.2% (Beekman *et al.* 1997). Cronbach's alpha for the CES-D was 0.87 in the present study.

Analysis

Descriptive statistical analyses were performed on variables of caregiver demographics, and t tests were used to explore similarities and differences in subsamples (i.e., good sleepers' PSQI score ≤ 5 and poor sleepers' PSQI score > 5, high sleep aide use and no use, residential and non-residential caregiver). To better understand the relationship between PWD behaviors and caregivers' sleep quality, bivariate correlations were used. Bonferroni adjustments were made to decrease the risk of Type I error. For the comparison of means and correlational analysis, 11 separate tests were performed with the Bonferroni adjustment technique, resulting in an operation alpha level of 0.005 (0.05/10). Multiple regression analysis was used to examine the variance in caregivers' sleep quality based on daytime behaviors of the PWD. Factors considered to be possible confounding variables (age, gender, health status, hours per week caregiving, residential status) were entered first. Depression was entered second because of its known correlation to sleep. Finally, the behavior index and specific behaviors correlated to sleep quality were entered to determine the contributions of shared or unique variance. Post hoc diagnostics were conducted, including analysis of the descriptive statistics and residuals, testing for normality, and plotting to ensure that data met the assumptions of multiple regression. The analyses were performed using SPSS version 19.

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RESULTS

The caregivers

This sample of informal caregivers, 71 females and 9 males were primarily white, non-Hispanic, well educated, and reported having enough money to meet their family needs. Forty-four percent were retired, but 42% were working full- or part-time. Of the caregivers still working, 41% reported having had to cut back work hours because of caregiving. The results for all demographics are presented in Table 1.

Caregivers were asked questions about their caregiving experience. The length of time caregiving ranged from 2 months to 12 years, with the majority (56%, $n = 46$) having provided care for less than 5 years. On the average, caregivers spent over 80 hours per week caregiving. Residential caregivers ($n = 59$) spent more hours per week providing care (M 118 hours, SD 60) in comparison to non-residential caregivers (n = 21, M = 43.7 hours, SD 46.3), but the range was very broad for both groups (6–168 hours).

The PWDs were older and more evenly divided between male and female (see Table 1). The reported level of severity for this sample was moderate (M 25.4, SD 11.2). The most frequent BPSD reported by the caregivers was daytime napping followed by anxiety. The least reported BPSD for this sample was wandering. Table 2 shows the frequency of occurrence of the behavioral and psychological symptoms. The mean for the daytime behavior index was 8.77 (SD 4.20).

Caregiver sleep quality

The caregivers' mean score for global sleep quality was 7.51(SD 3.65), indicating poor sleep. The mean score on the appraisal of the caregivers sleep experience (subjective sleep quality subscale) was 1.20 (SD .72), representing reports between good and fair sleep. The sleep latency (amount of time it took to fall asleep) varied over a wide range from 1 minute to 2 hours, with an average latency of 22.27 minutes (SD 24.9). The total hours of sleep averaged 6.37 (SD 1.4), with a range from 3 to 9.5. The average sleep efficiency was 80% (SD 13.7%), with a range from 50% to 100%. Twenty-five of the caregivers took sleep medication to help initiate or maintain sleep, and 19 used sleep medications three or more times a week. There was no statistical difference for age, health status, hours per week caregiving, daytime behavior index, or dementia severity rating between caregivers taking medication three or more times a week and caregivers not taking medicine to sleep. Depression scores did differ ($t = -2.20$, $p = 0.04$).

Not all caregivers were poor sleepers. Nineteen were good sleepers (scoring less than five on the PSQI); these were spousal caregivers ($n = 11$), adult children ($n = 7$), and one daughter-in-law. Good sleepers reported 1 more hour of sleep (M 7.2, SD 1.10) than did poor sleepers (M 6.1, SD 1.33; $t = 4.67$, $p < 0.001$). Good sleepers' sleep efficiency averaged 91%; poor sleepers' sleep efficiency averaged 77% ($t = -6.20$, $p < 0.001$); and sleep latency was shorter for good sleepers (M 9 minutes, SD 6.90) than for poor sleepers (M 27 minutes, SD 26.9; $t = 4.67$, $p = 0.001$). Age, health status, hours per week caregiving, living arrangements, and DSRS scores showed no significant difference between good sleepers and poor sleepers after Bonferroni adjustment. but there was a statistically significant difference in the daytime behavior index ($t = 3.62$ $p = 0.001$) and in the level of depression reported ($t = 5.70$, $p < 0.001$).

Living arrangements did not distinguish caregivers that were good sleepers from poor sleepers. As expected, non-residential caregivers were disrupted at night less often (M 0.33, SD 0.80 vs. M 1.56 SD 1.33; $t = -5.00$, $p < 0.001$). However, there were no statistical

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differences in the frequency of daytime behavioral index, sleep quality or depressive symptoms reported by non-residential caregivers compared to residential caregivers.

Impact of BPSD on caregivers' sleep quality

The correlation between (a) the behavior index for the PWD and (b) the caregivers' global sleep scores was weak and not statistically significant. However, the correlation between the behavior index and the caregivers' appraisals of their sleep quality was statistically significant. The relationship between individual behaviors and psychological symptoms and caregivers' global sleep quality and appraisal of their sleep quality did not reveal a statistically significant relationship except in four tests. Caregivers' reports of apathy, agitation, depression and inappropriate behaviors as more frequent in the PWD were related to reports of poorer appraisal of the caregivers' sleep quality with apathy and total *daytime* behaviors significant after Boneferroni adjustment. (See Table 3.)

As expected, the PWDs' nighttime behaviors were disruptive to caregivers' sleep. Fifty-two percent of the caregivers reported being disturbed by the PWD, and 22.9% reported that disruptions occurred three or more times per week. The most common reason reported for disturbance was that the PWD went to the bathroom and that the caregiver was alert to this, often having to assist. The second most common reason for being disturbed was that the PWD awoke and was confused or disoriented. The correlation between disruptions at night by the PWD and the global sleep score was significant ($r = 0.22$, $p = 0.05$) as was the relationship between disturbances by PWD and poorer appraisal of the caregivers' sleep experience ($r = 0.25$, $p = 0.02$). There was not a significant correlation between the caregivers' report of how often the PWD had a sleepless night and caregiver sleep quality.

A series of multiple regression models was constructed to analyze the variance in both global sleep quality and the caregivers' appraisal of their sleep that could be accounted for by the daytime behaviors of the PWD. Global sleep quality was regressed on the behavior index as well as on the two most strongly correlated BPSD, apathy and agitation. Confounding variables controlled in the model were caregivers' age and gender (because of the changes in sleep with age and gender differences in sleep quality), hours per week caregiving, living arrangements, reported health, and depressive symptoms as shown by CES-D scores (because of the relationship of depression to sleep quality). The same series of models was used to regress subjective sleep quality. For global sleep quality, the final model explained 45% of the variance [$F(3,70) = 6.38$, $p < 0.001$], with neither the individual behaviors nor the behavior index making a unique contribution to the total variance. For the caregivers' appraisal of their sleep quality, the final model explained 34% of the variance and the model demonstrated a good fit [$F(3,70) = 4.06$, $p < 0.001$]. The individual BPSD made unique contributions to the variance of the caregivers' appraisal of their sleep (agitation $\beta = 0.41$, $t = 2.71$, $p = 0.008$), as did the caregivers' reports of greater frequency in PWD apathy ($\beta = 0.41$, $t = 3.24$, $p = 0.002$). (See Table 4.) Studentized residuals met the assumption of normal distribution.

DISCUSSION

The present study provides additional support for our knowledge that caregivers of PWD experience poor sleep and that the reasons for poor sleep are complex. In this study, we have described the impact that PWDs' nighttime behaviors and (for the first time) daytime behaviors have on caregiver reports of sleep quality.

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Caregivers' sleep

Consistent with previous studies describing caregiver sleep quality (Gallant & Connell 1997, Wilcox & King 1999, Castro *et al.* 2009), the caregivers in the present study reported poor sleep, with less total sleep time, lower sleep efficiency, and longer sleep latency than are considered to constitute good sleep. This was reflected in the global sleep score for the sample above the cut of 5, indicating poor sleep on the PSQI. A surprising finding was that, unlike in other caregiver studies, 24% of our participants reported using sleep medications three or more times a week. This is in direct conflict with findings reported by cancer caregivers who expressed reluctance to take sleep medications because of excessive somnolence and inability to monitor patient needs (Carter & Chang 2000). The use of sleep medications in this sample was more consistent with levels/frequency of use reported by patients diagnosed with major depressive disorder and chronic pain (Liu *et al.* 2010), yet only 8 of the 22 frequent sleep medication users scored ≥ 16 on the CES-D. The higher use of sleep medication in this sample reflects the difficulty that caregivers of PWDs have in trying to obtain good sleep.

In an attempt to capture the complexity of caregiver sleep quality and the factors that contribute to it, we explored the potential impact of several confounding variables: caregiver age, gender, living arrangements of the dyad, number of hours caregiving per week, and depression. Age has been recognized as a predisposing factor for sleep disturbances (Bliwise *et al.* 2005, McCurry *et al.* 2007) in the general population. However, age did not contribute to the variance in sleep quality in this sample. It must be noted that this sample was younger than most caregiver samples, with some of the caregivers as young as 28 and an overall mean age of less than 65 years. Gender, on the other hand, a known correlate to poor sleep (Pearson *et al.* 2006), did contribute to the variance in global sleep. It was anticipated that caregivers sharing a home and nighttime experiences with the PWD would be at greater risk for nighttime disturbances and thus for poor sleep quality. Non-residential caregivers reported less frequency of nighttime disturbances but comparable levels of daytime behavioral and psychological symptoms of the PWD, sleep quality, and depressive symptoms as residential caregivers. This is new information about a sub-group of caregivers that will likely grow and warrant further study to explore and understand the unique stressors of non-residential caregiving.

Depressive symptoms made the most significant contribution to the explanation of variance in caregiver sleep quality in comparison with all other variables. This was expected, given the known association between poor sleep quality and depression found in epidemiologic studies (Ford & Cooper-Patrick 2001) and in caregiver populations (Carter & Acton 2006). Overall, this sample scored below the cut score for depressive symptoms, and depression scores were lower than in some previous studies (Creese *et al.* 2008, McCurry *et al.* 2008); however, 30% scored well above the cut score of 16.

Impact of BPSD on caregiver sleep quality

Inconsistent with our hypothesis, the relationship between caregiver sleep quality and the combined frequencies for all types of BPSD was not strong or statistically significant when measured *globally*. The nighttime behaviors of the PWD, such as getting up to go to the bathroom, did impact more than half of the caregivers and decreased the quality of their sleep, as has been found in other studies (McCurry *et al.* 1999,Wilcox & King 1999). On the other hand, PWD daytime behaviors did not correlate with global sleep quality or make a unique contribution to the variance in global sleep. Thus, our hypothesis that daytime behaviors and psychological symptoms would decrease sleep quality was not supported for global sleep quality.

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However, the true *subjective* sleep quality, or how the caregivers appraised their own sleep, demonstrated a stronger relationship to the total frequency of behaviors as well as to the individual behaviors of apathy, agitation, depression, and inappropriate behavior by the PWD. Thirty-five percent of caregivers reported PWD apathy occurring frequently or daily, and apathy was significantly correlated with sleep quality appraisal and did contribute to the variance in the caregivers' appraisal of their sleep. This finding is in contradiction to Meiland et al. (2005), who found in their sample of 85 caregivers that apathy occurred in 76% of the PWDs but had little emotional impact on the caregiver.

How a caregiver appraises his or her own sleep can be a perpetuating factor in sleep problems and can lead to the development of chronic insomnia (Espie 2007). Identifying how caregivers appraise (i.e., assess the frequency of) the behaviors and psychological symptoms of the PWD provides an opportunity for intervening with the caregiver. For example, one might speculate that a caregiver's appraisal of PWD daytime behaviors may create distress, worry, and rumination because the caregiver finds the change in behavior inconsistent with his or her image of how the loved one behaved before the diagnosis of dementia. These negative feelings and thoughts may be a part of nighttime worry or rumination, causing the caregiver to feel that he or she has not gotten a good night's sleep even when other measures such as reported sleep efficiency are calculated as good. In this way the daytime behavior of the PWD can become a precipitating factor in eroding the caregiver's sleep quality. Chronically poor sleep can develop if the caregiver begins to perpetuate the poor sleep through other distorted thoughts about sleep (worrying that he or she may not get a good night's sleep). Future research in this area should include objective measures of sleep such as actigraphy or ambulatory polysomnography to confirm or refute the caregivers' perceived sleep quality and help educate the caregiver about his or her sleep.

Limitations

Certain limitations to this study must be acknowledged. Given the small sample size, the present findings cannot be generalized to the population of all caregivers. A question of sample bias exists because the caregivers who chose to participate were themselves seeking help in their role as caregivers (via caregiver support groups, educational programming, or psychiatric offices), and so the present caregiver sample may have been more informed than caregivers without such support. Future research should replicate this study but with enhanced recruitment efforts from the community-at-large to decrease the potential bias noted here and to include more male caregivers and a more ethnically and racially diverse sample.

Regarding instruments used, the reliability of the PSQI scale was low, though consistent with previous findings. The present approach captured the caregiver's perception of his or her sleep experience by using a self-report measure. This may have created a caregiver response bias and a risk for external validity. As mentioned previously, the inclusion of objective measures of sleep such as actigraphy can enrich the collected data and reduce the response bias. Likewise, the behavioral index was modeled after the frequency component of the Neuropsychiatric Inventory (Cummings *et al*. 1994) but future research would be enhanced by using the full scale. The full scale would capture not only the frequency, but also the severity of the BPSD as well as the amount of emotional distress that the behaviors cause the caregiver and how that distress is related to sleep quality.

CONCLUSION

Despite these limitations, this study adds to our body of knowledge regarding the complexity of problems that contribute to poor caregiver sleep. The present findings support previous findings that the PWD's nighttime behavior is a primary source of sleep disruption

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for many caregivers, but even non-residential caregivers experience poor sleep. In addition, the present study provides new information about the relationship between the types and frequency of daytime BPSD and caregivers' appraisal of their sleep quality. Caregivers reported poor sleep quality when they reported more frequent occurrences of nighttime disruptions by the PWD, more apathy, episodes of agitation, depression, or inappropriate behavior in the PWD.

RELEVANCE TO CLINICAL PRACTICE

The clinical implications of the present study suggest that nurses should be cognizant of the relationship between daytime behaviors of the PWD and caregivers' appraisal of their sleep; the appraisal of one's sleep as poor can be a contributing factor to the perpetuation of sleep problems. Assessment of a caregiver's sleep should include discussion about the PWD's behaviors, with reference to their number, type, frequency, and emotional impact, as well as to current management techniques used by the caregiver and the effectiveness of those techniques. Cognitive behavioral therapies are known strategies to improve caregiver sleep and improve health outcomes such as depression (Carter 2006). Current research in health promotion activities and specific interventions to improve caregiver sleep have demonstrated the benefit of multicomponent interventions as well as interventions that expand on or diverge from traditional cognitive behavioral therapy techniques (Rose *et al*. 2008, Elliott *et al*. 2010, Rowe *et al*. 2010). Instructions to caregivers about sleep (sleep hygiene strategies) must also include guidance and instruction about managing or minimizing dementia behaviors as well as the impact of those behaviors on the caregivers' emotional and psychological well-being, in order to reduce the risk of worry and rumination. Psychoeducational interventions that include components of active participation (e.g. role playing) have demonstrated the best outcomes in caregivers' feelings of burden, depression, and well-being (Pinquart & Sörensen 2006). These approaches could benefit caregivers' sleep. Improving caregivers' sleep can benefit health outcomes for the caregiver and potentially reduce the cost to the family by preventing early institutionalization of the PWD.

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Table 1

Characteristics of Caregivers (N = 80) and Persons with Dementia (N = 80) Including Scores of Caregiver Depressive Symptoms and Dementia Severity

	CAREGIVERS					PERSONS WITH DEMENTIA				
	N	**%**	***M***	***SD***	**Range**	***N***	**%**	***M***	***SD***	**Range**
Age			63.3	12.8	27 – 88			79.3	9.1	53 – 95
Gender										
Female	71	88.8				47	58.8			
Male	9	11.3				33	41.3			
Relation										
Married	39	48.8								
Partner	1	1.3								
Adult Child	33	41.3								
Sibling	2	2.5								
Other	5	6.3								
Race										
White	72	90.0				73	90.0			
Black	8	10.0				8	10.0			
Ethnicity										
Not Hispanic	69	86.3				70	87.5			
Hispanic	11	13.8				10	12.5			
Education (years)			15.5	2.9	8 – 24			14.3	4.2	0 – 24
Income Level										
More than enough	45	56.3								
Just enough	32	40.0								
Not enough	3	3.8								
Other Roles										
Caring for children	18	22.5								
Volunteering	37	46.3								
Health Status			1.41	1.0	0 – 4					
Dementia Severity Rating								25.39	11.22	
CESD			12.9	9.3	0 – 38					

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Table 2

Behavioral and Psychological Characteristics of Persons with Dementia (N = 80)

Item	N	%
Behavioral and Psychological Symptoms		
Agitation		
No	23	28.7
Rarely	22	27.5
Frequently	22	27.5
Every day	13	16.3
Anxiety		
No	20	25.0
Rarely	18	22.5
Frequently	28	35.0
Every day	14	17.5
Apathy		
No	40	50.0
Rarely	15	18.8
Frequently	16	20.0
Every day	9	11.3
Day Time Napping		
No	8	10.0
Rarely	16	20.0
Frequently	15	18.8
Every day	41	51.2
Dysphoria/Depression		
No	31	38.8
Rarely	17	21.3
Frequently	22	27.5
Every day	10	12.5
Sleeplessness		
No	39	48.8
Rarely	11	13.8
Frequently	18	22.5
Every Day	12	15.0
Wandering		
No	58	72.5
Rarely	11	13.8
Frequently	5	6.3
Every Day	6	7.5
Inappropriate Behavior		
No	54	67.5
Rarely	15	18.8

Item	N	%
Frequently	8	10.0
Every Day	3	3.8
Psychosis		
No	41	51.2
Rarely	19	23.8
Frequently	11	13.8
Every Day	9	11.3

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Table 3

Correlations of Frequency of Daytime Behavioral and Psychological Symptoms of Dementia with Sleep Quality in Caregivers (N = 80)

	Daytime Behavioral and Psychological Symptoms of the Person with Dementia								
	Agitation	**Anxiety**	**Apathy**	**Depression**	**Day Time Napping**	**Psychosis**	**Inappropriate Behaviors**	**Wandering**	**Daytime Behavior Index**
Global Sleep Quality	.12	.07	.23	.18	−.02	.12	.19	.05	.23[*]
Subjective Sleep Quality	.27[**]	.01	.33[***]	.26[*]	−.10	.09	.23[*]	.10	.29[***]

[*] *p* < .05 (1-tailed);

[**] *p* < .01 (1-tailed);

[***] *p* <0 .005 for Bonferonni adjustment

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Table 4

Standardized regression coefficients for sleep quality (N = 80)

	Model 1	Model 2	Model 3
Global Sleep Quality			
Caregiver age	−.17	−.12	−.12
Caregiver gender	.21	.23*	.24*
Caregiver health status	.25*	.11	.10
Hours per week caregiving	.30*	.15	.21
Lives with the PWD	−.17	−.15	−.20
CESD score-depression		.47***	.51***
Agitation			.14
Apathy			.20
Daytime Behavior Index			−.26
R^2	.24	.42	.45
Adjusted R^2	.19	.37	.39
R^2 Change	.24	.18	.03
Δ F	4.71***	22.73***	1.23
Subjective Sleep Quality			
Caregiver age	−.20	−.16	−.09
Caregiver gender	.03	.06	.04
Caregiver health status	.04	.07	.04
Hours per week caregiving	.11	−.01	.02
Lives with the PWD	.04	.06	.08
CESD score-depression		.39***	.35**
Agitation			.41**
Apathy			.41**
Daytime Behavior Index			−.25
R^2	.09	.21	.34
Adjusted R^2	.03	.15	.25
R^2 Change	.09	.12	.13
Δ F	1.44	11.20***	4.72***

$^{*}p$ <.05

$^{**}p$ <.01

$^{***}p$ < .001