

Insomnia in Caregivers of Persons with Dementia: Who is at Risk and What Can be Done About It?

Susan M. McCurry, PhD^{a,*}, Laura E. Gibbons, PhD^b,
Rebecca G. Logsdon, PhD^a, Michael V. Vitiello, PhD^c,
Linda Teri, PhD^a

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Sleep disturbances are common among caregivers of persons with dementia. Cross-sectional studies over the past 15 years indicate that approximately two thirds of dementia caregivers report they are having trouble sleeping.¹ What about the other third? How do caregivers with and without sleep complaints differ from one another? How does their sleep quality change over time? What increases or decreases a caregiver's risk for developing sleep problems? How might this information guide the development of evidence-based treatments to improve caregiver sleep?

It is known that sleep disturbances in caregivers can originate from a complex set of precipitating, predisposing, and perpetuating factors, including nonconducive sleep environments, poor sleep habits, cognitive hyperarousal and rumination, care-recipient nocturnal behaviors, age-related primary sleep disorders, and other comorbid medical or psychiatric conditions.¹ It is also known that caregiver sleep, like that of other older adults, has considerable night-to-night variability,^{2,3}

and that caregiver reports of their own or their care-recipient's sleep quality are not always congruent with what is expected based on objective measures of nighttime sleep or activity.^{4,5} Given the complexity of the phenomenon, caregiver insomnia research is challenging, but the personal and socioeconomic stakes are high: poor caregiver sleep has been linked to lowered immune function, elevated stress hormones, increased risk for cardiovascular disease, and risk for premature mortality.⁶⁻⁹ Continuing studies into the development, maintenance, and treatment of caregiver sleep disturbances are needed.

This article reviews some of the literature describing the association between caregiver sleep problems, and caregiver and care-recipient demographic, health, and psychosocial variables. Data are presented from a longitudinal study that examined factors associated with self-reported sleep problems in dementia caregivers and care-recipients over a 5-year follow-up period. Also considered is the caregiver sleep treatment outcome literature in light of results from these

^a Department of Psychosocial and Community Health, University of Washington, 9709 3rd Avenue NE, Suite 507, Seattle, WA 98115-2053, USA

^b Department of General Internal Medicine, University of Washington, Box 359780, Harborview Medical Center, 325 Ninth Avenue, Seattle, WA 98104, USA

^c Department of Psychiatry and Behavioral Sciences, University of Washington, Box 356560, Seattle, WA 98195-6560, USA

* Corresponding author.

E-mail address: smccurry@u.washington.edu (S.M. McCurry).

cross-sectional and longitudinal studies. Suggestions for future research directions are given.

CROSS-SECTIONAL CORRELATES OF CAREGIVER SLEEP DISTURBANCES

Most caregivers of persons with dementia in the United States are older women.¹⁰ Both increasing age and female gender are associated with a higher prevalence of sleep complaints in community-based samples.^{11,12} Older caregivers are also more likely to have a variety of comorbid medical problems, which combined with the medications used to treat these problems increase risk for development of insomnia.^{13–15} Finally, primary sleep disorders, such as obstructive sleep apnea and restless legs syndrome, are more common in older adults but frequently undiagnosed,^{16–18} and so may play an unrecognized role in many caregiver sleep complaints.

In addition to these predisposing and precipitating demographic and medical risk factors for insomnia, a growing body of literature suggests that the unique psychosocial circumstances faced by caregivers, and their emotional and behavioral responses to these circumstances, may perpetuate caregiver sleep complaints. Caregivers are often awakened by their care-recipients at night,¹⁹ and caregivers sleep better when they avail themselves of respite breaks away from the care-recipient.²⁰ Several studies have shown that care-recipient nocturnal behavioral disturbances are not in themselves, however, necessarily associated with poor caregiver sleep,^{2,21} and caregiver sleep problems often continue even after care-recipients are moved out of the home or die.²² There is also evidence that caregiver objective sleep quality is not significantly different from age-matched noncaregiver samples, although caregivers perceive their sleep to be worse.²³ What may be more important than the actual caregiving role in the development and maintenance of insomnia is caregivers' personal interpretation or appraisal of their situation. In recent years, a number of researchers have begun to consider how modern theories of stress and coping can inform understanding of the relationship between caregiving and caregiver health outcomes, including those important to sleep.²⁴

Using structural equation modeling, Brummett and coworkers²⁵ demonstrated that being a caregiver is related to worse sleep quality, but that this association is mediated by caregiver negative affect, which is also inversely related to perceived social support. Caregivers with good social support and low levels of negative affect may be less likely to develop sleep disturbances. In the

Brummett and colleagues²⁵ study, negative affect was measured based on self-reported depression, anxiety, and stress. Depression and anxiety are both well-known risk factors for insomnia,^{26,27} and their prevalence in caregivers is significantly increased compared with noncaregiving adults.^{28–31} In caregivers, negative affect also commonly includes nocturnal worry or rumination, grief and bereavement, caregiver vigilance or hyperalertness, and physiologic arousal, all of which have been found to relate to sleep disturbances in older adults.^{7,32–34}

The interaction between caregiver sleep disturbances and negative affect potentially flows both ways, creating a negative feedback loop that can be difficult to break. Sleep fragmentation and obstructive sleep apnea in particular cause elevations in stress hormones that further exacerbate risk for development of negative health outcomes, affect, and insomnia.³⁵ It is possible that intervention strategies that target caregiver cognitions might help interrupt this cycle. Two recent studies show that caregivers with higher self-ratings of personal mastery have lower norepinephrine reactivity and β_2 -adrenergic receptor sensitivity in response to stress than caregivers with lower mastery scores.^{36,37} Although these studies did not directly measure ratings of caregiver sleep, they do provide further evidence that positive caregiver self-appraisals may reduce the likelihood of developing stress-related physiologic responses that can worsen physical health, negatively impact mood and burden, and both directly and indirectly contribute to poor nightly sleep.

IDENTIFYING DYADS AT GREATEST RISK: LONGITUDINAL STUDIES OF CAREGIVER AND CARE-RECIPIENT SLEEP

The associations presented previously comparing demographic, physical, and other psychosocial correlates of sleep disturbance in caregivers were derived from cross-sectional studies. The factors prospectively associated with the onset of sleep disturbances in caregivers of persons with dementia, however, are largely unknown. The few longitudinal studies that have been conducted have mostly included small sample sizes, nondementia caregivers, relatively short follow-up periods, and a limited range of comparison outcome measures. Carter³⁸ measured self-reported sleep, depression, and actigraphic sleep quality in 10 caregivers of cancer patients at three sampling points over 10 weeks. She reported that caregiver depression and sleep outcomes varied widely over the 10 weeks, suggesting that accurate assessment of sleep and mood variables

requires repeated measurements in this population. Fletcher and coworkers³⁹ found that baseline levels of sleep disturbance predicted evening fatigue levels, whereas trait anxiety and family support predicted morning fatigue in 60 family caregivers of cancer patients receiving radiation treatment over a 6-month follow-up period. Their analyses, which used hierarchical linear modeling to analyze repeated measures over the study period, further illustrate the interindividual and intraindividual variability in trajectories of caregiver fatigue over time, but did not look at predictors of caregiver or patient nighttime sleep. Matsuda and coworkers⁴⁰ evaluated 103 family caregivers of persons with dementia following the care-recipient's placement in a long-term care facility. Significant decreases in the anxiety-insomnia subscale of the General Health Questionnaire were observed for caregivers whose relatives had been in residential care for at least 6 months (N = 41); however, in this study caregivers were only evaluated at two sampling points, no subjective or objective outcomes specific to sleep were included, and there were no analyses examining factors associated with improvement or decline over time.

The largest study to date examining the factors associated with new onset of sleep disturbances in dementia caregivers and care-recipients is an unpublished study by McCurry and coworkers⁴¹ that followed 164 community-dwelling individuals with Alzheimer's disease and their family caregivers over a 5-year interval. Self-report sleep data were collected as part of a longitudinal study examining quality of life in Alzheimer's disease.⁴² Subjects were 164 caregivers (mean age 69.3 years, 70% female, 82% spouses of care-recipient) and their family members (mean age 76.7 years, 59% male, average dementia duration 4.5 years) diagnosed with probable or possible Alzheimer's disease.⁴³

In the McCurry and colleagues⁴¹ study, caregiver-care-recipient dyads were evaluated at baseline and every 6 months for up to 5 years (mean = 2 years, range = 6–60 months). Assessments included caregiver reports about the care-recipient's sleep, cognitive and functional status, and level of behavioral disturbance. Caregivers also reported on their own nighttime sleep, mood, and burden. A Caregiver Sleep Questionnaire (CSQ) was used to rate the frequency of seven sleep problems occurring during the past month, including being awakened by the dementia patient, being kept awake at night by worry about the caregiving role, and daytime sleepiness or fatigue (**Table 1**). Caregivers also rated their sleep quality and whether they believed they were

getting enough, too much, or too little sleep at night. CSQ scores of 12 points or higher (out of a possible 26), which was equal to the upper twenty-fifth percentile for the sample at baseline, were considered the "sleep disturbed" range.

Care-recipient (Alzheimer's disease patient) sleep disturbance was based on caregiver reports of two or more specific nocturnal behaviors (out of a possible six behaviors, including calling out or yelling, becoming agitated, interrupted breathing spells, "jerky legs" in bed, seeing or hearing things, or snoring). Waking the caregiver in the middle of the night, three or more times a week, as reported on the Revised Memory and Behavior Problems Checklist (RMBPC)⁴⁴ was also considered indicative of care-recipient sleep disturbance.

Caregiver mood and burden was evaluated using the Center for Epidemiologic Studies–Depression scale and the Screen for Caregiver Burden (objective and subjective subscales).⁴⁵ In addition, caregivers rated their quality of life using the Quality of Life–Alzheimer's Disease scale. Care-recipient cognitive and functional status was evaluated using the Mini-Mental State Examination⁴⁶ and the Lawton-Brody Physical and Instrumental Self-Maintenance Scales.⁴⁷ Care-recipient mood and behavior were rated using the RMBPC (memory, depression, and disruption subscales).⁴⁴ Caregiver and care-recipient demographics included age; gender; and caregiver relationship to the care-recipient (marital partner vs not married).

Cross-sectional associations with baseline caregiver sleep disturbance were evaluated with logistic regression models. Survival analyses were conducted to predict the onset of sleep disturbances in patients and caregivers over the follow-up period. For each outcome, only caregivers or care-recipients reporting no sleep disturbances at baseline (as measured by CSQ, patient sleep disturbance, or RMBPC criteria) were included. Patient cognitive and functional status, depression, behavioral disturbance, and caregiver depression and burden were considered as time-dependent covariates, using the score at the time of the event, the preceding visit (6 months earlier), and the change from the preceding visit to the current one. Caregiver and patient age and gender, and patient marital status, were also evaluated.

Study results showed that baseline caregiver sleep disturbance (CSQ 12 or higher) was associated in logistic regression modeling with higher (worse) scores on the RMBPC-memory scale (odds ratio = 2.69; 95% confidence intervals [CI], 1.43–5.03); objective caregiver burden on the

Table 1
Sleep outcome questionnaires

Caregiver Sleep Questionnaire

Problem frequency (items #1–7)	Sleep quality (Item #8)	Sleep quantity (Item #9)
0 = Never	0 = Very good	0 = Enough
1 = Rarely	1 = Satisfactory	1 = Too much sleep
2 = 2–4x/month or weekly	2 = Troubled	2 = Too little sleep
3 = >once a week or daily (reverse code items #4, 6)	3 = Poor/very bad	
1. Does the care-recipient become more confused or disoriented at night?		
2. Is the care-recipient's behavior at night a problem to you or others?		
3. Does worrying about your caretaking role ever keep you awake?		
4. When you awoken at night, can you fall back to sleep within 10–15 minutes?		
5. How often do you usually nap during the day?		
6. How often do you fall asleep when you want to stay awake?		
7. How often do you use sleeping medication?		
8. Overall, how would you rate your sleep at night?		
9. Do you feel you get too much sleep, about enough sleep, or too little sleep?		
Care-recipient sleep disturbances		
At night, does the care-recipient (check if appropriate):		
Call out or yell?	Have "jerky legs" in bed?	
Become agitated?	See or hear things?	
Have interrupted breathing spells?	Snore?	
Revised memory and behavior problem checklist, item #10⁴⁴		
How often does the care-recipient wake you or other family members up at night?		
0 = Never	1 = Not in the past week	2 = 1–2x in the past week
	3 = 3–6x in the past week	4 = Daily or more often

Screen for Caregiver Burden (OR = 2.42; 95% CI, 1.37–4.27 for a five-point change); and male care-recipients (OR = 4.46; 95% CI, 1.56–12.7). Baseline patient sleep disturbance (PSQ two or higher, or waking caregiver three or more times per week) was associated with higher RMBPC-memory scores (odds ratio = 1.53; 95% CI, 1.02–2.28), and lower caregiver quality-of-life ratings (OR = 0.34; 95% CI, 0.15–0.79). Older caregiver age, increased caregiver depression, and female gender were not associated with poor caregiver sleep at baseline.

Over a mean of 24 months of follow-up (range 6–60 months), 18% of caregivers had a new onset of sleep disturbances as measured by a total CSQ score greater than or equal to 12. Current caregiver depression and previous level of objective burden were the strongest predictors of the onset of caregiver sleep problems (Table 2). Thirty-eight percent of care-recipients had a new onset of

sleep problems as measured by the PSQ (two or more problems) or RMBPC sleep item (waking caregiver three or more times per week). Current care-recipient depression on the RMBPC and higher levels of activities of daily living impairment predicted onset of care-recipient sleep disturbances (see Table 2). Caregiver and care-recipient demographics, dementia severity or duration, caregiver subjective burden, and overall level of care-recipient behavioral disturbances were not significant predictors in the survival analysis.

TREATMENT OF SLEEP DISTURBANCES IN CAREGIVERS

A number of reviews over the past decade have examined the impact and quality of evidence-based interventions designed to improve caregiver physical and mental health outcomes.^{24,48,49}

Table 2
Survival analyses

Sleep Outcome	Predictor Variables	HR (95% CI)
Caregiver sleep questionnaire: 12+	CES-D ^a (current)	1.42 (1.12–1.80)
	SCB-Objective (previous)	2.33 (1.43–3.78)
Patient sleep disturbances: PSD \geq 2 or waking caregiver \geq 3x/wk	Lawton-Brody ADL scale (current)	1.55 (1.20–2.00)
	RMBPC-Depression (current)	1.52 (1.09–2.12)

HR = hazard ratio for 5 points, CES-D, and SCB; 1 point ADL and RMBPC.

Abbreviations: ADL, activities of daily living; CES-D, Center for Epidemiologic Studies–Depression scale; HR, hazard ratio; PSD, patient sleep disturbance; RMBPC, Revised Memory and Behavior Problems Checklist; SCB, Screen for Caregiver Burden.

^a Sleep question removed.

There has been almost no research on the development of treatments to improve caregiver sleep, and almost no studies that have even included caregiver sleep outcomes, let alone targeted them for intervention.

Only two studies published to date have examined the use of cognitive-behavioral insomnia treatment techniques to improve caregiver sleep. McCurry and colleagues⁵⁰ randomly assigned 36 caregivers (age 50+ years) of persons with Alzheimer's disease into either wait list control or an active treatment that consisted of standard sleep hygiene, stimulus control, and sleep compression strategies and education about community resources, stress management, and training in the ABCs to reduce patient disruptive behaviors. In deference to caregivers' age and situation (which made it impossible to control the frequency and duration of nighttime awakenings that were caused by the care-recipient), no caregiver was asked to restrict their time in bed to less than 6.5 hours, and daytime naps less than 30 minutes in duration were permitted. Caregivers in active treatment showed significant differences in self-reported sleep on the Pittsburgh Sleep Quality Index (PSQI) total scores at posttreatment and 3-month follow-up, and improvements in weekly diary reports of nightly sleep percent. No significant differences between groups were observed for caregiver mood, burden, or patient behavior problems, suggesting that sleep improvements were not an artifact of improvements in care-recipient nocturnal behaviors or caregiver depression.⁵⁰

Carter⁵¹ subsequently used a repeated-measures experimental design to test the feasibility and effectiveness of a brief behavioral sleep intervention (Caregiver Sleep Intervention [CASI]) that included stimulus control, relaxation, cognitive therapy, and sleep hygiene elements. These

standard sleep promotion recommendations were adapted to allow caregivers to set their own sleep and relaxation goals, and to implement behavioral changes at a self-selected pace. Thirty family caregivers of advanced-stage cancer patients were randomized into either CASI or control; both self-report and wrist actigraphy data were collected at baseline, 3 and 5 weeks, and 2-, 3-, and 4-months postbaseline. Caregivers in this study were a wide range of ages (21–85 years), and no data on care-recipients' cognitive or behavioral status were reported. Improvements in both treatment groups were observed, but at 4-month follow-up, CASI subjects had significantly lower PSQI scores and greater actigraph-measured total sleep time than control subjects.

In one other relevant study, King and colleagues⁵² randomized 100 older (age 50+ years) women family caregivers of persons with dementia into either a moderate-intensity exercise (brisk walking) program or a nutrition-education attention control condition, and measured stress-induced cardiovascular reactivity; sleep quality (self-rated sleep latency, duration, and sleep quality items from the PSQI); and psychologic distress (stress and depression). Participants were introduced to an exercise training program over the first 6 weeks and then instructed to engage in a minimum of four 30- to 40-minute home-based exercise sessions per week (mostly brisk walking) for 1 year. Exercise produced improvements in systolic blood pressure reactivity and PSQI subjective sleep quality scores in caregiver participants at 1 year. Among exercisers, improvements in sleep quality were related to reductions in perceived stress and subjective caregiver burden. Although caregivers were not recruited into this study based on level of sleep complaints, and sleep was not the specific target of intervention, results add further support to the hypothesized relationship between

caregiver sleep disturbances and negative affect or appraisals, mediated by stress-induced cardiovascular reactivity.

The limited treatment literature suggests that intervention strategies that are effective for improving sleep in noncaregiving older adults (eg, sleep restriction, stimulus control, and exercise) can also help caregivers sleep better, despite the unique lifestyle and environmental demands they face. The few treatments that have been developed have largely not included all the components that may be important, however, given what is known about the correlates of sleep problems in caregivers. For example, none of the treatment studies evaluated caregiver self-efficacy; overall health (except for blood pressure in the case of the King and colleagues⁵² study); or social support. None included cognitive training to enhance overall caregiver mastery and competence. All three included measures of caregiver depression, stress, and quality of life, but in no case did these measures significantly improve as a result of treatment, perhaps because depressed or distressed caregivers were not specifically recruited for enrollment. Only one study included any measures of physiologic arousal or stress reactivity.

Furthermore, from the standpoint of the broader evidence-based sleep treatment literature, the few studies to date have other significant methodologic problems. None have recruited subjects based on research criteria for insomnia. Study sample sizes to date have been relatively small, and two of the three studies based sleep improvements solely on caregiver self-report. Caregiver samples in the three treatment studies were also quite heterogeneous, representing a wide range of ages, relationships to care-recipients, and care-recipient diagnosis (eg, dementia vs advanced cancer), further limiting the interpretation of findings. Although the existing literature supports the feasibility and potential efficacy of nonpharmacologic treatments for insomnia in caregivers, additional research is needed to understand how caregiver sleep disturbances can best be evaluated, prevented, and reduced.

SUMMARY

This article reviews the literature concerning sleep disturbances in dementia caregivers, including their prevalence, correlates, and treatments. Also provided are new data regarding factors associated with the onset of caregiver sleep disturbances over up to 5 years of caring for a family member with dementia at home. What this review has most clearly revealed, however, is that the

study of insomnia and other sleep disturbances in caregivers is still in its infancy.

Although large percentages of caregivers report that they have sleep problems, little is known about their severity, persistence, or symptom profiles. Most research to date that has looked at caregiver health and outcomes has either ignored sleep altogether, or been limited by the diagnostic and assessment strategies used to characterize sleep. Relatively little is known about how or if sleep disturbances in the context of a caregiver-recipient dyad are unique. Persons with dementia and caregivers cohabiting in community settings are often negatively impacted by one another's sleep habits and disruptions. There is growing evidence, however, that being awakened by one's demented or chronically ill spouse or parent does not necessarily lead to insomnia. The cross-sectional and longitudinal data presented in this article provide evidence that caregiver depression, burden, medical morbidity, and appraisal of their situation, and care-recipient depression and functional impairments, may be more important in the development of caregiver sleep problems than care-recipient nocturnal behavioral disturbances.

Sleep has been called the "new vital sign,"⁵³ because of the growing evidence of its important role to good health. Dementia caregivers, who are "the often forgotten patient"⁵⁴ because of their increased risk for medical and psychiatric morbidity, may be particularly at risk to suffer ill consequences from chronic sleep loss superimposed on the stress of their caregiving role. Future research is needed to identify better those caregivers who currently have or who are at risk for developing insomnia. This requires the use of standard research insomnia assessment tools that look at both nighttime sleep and the daytime consequences of sleep loss. Evidence-based interventions need to be developed that target the physical, cognitive, and emotional factors that may be precipitating or perpetuating these sleep problems in an individualized way that is capable of addressing the unique circumstances of each caregiving dyad. Finally, in conjunction with developing individualized treatments, a better understanding is needed of what is considered a clinically meaningful improvement (what truly improves the everyday quality of life) for caregivers with sleep disturbances.

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