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Sleep disturbances in caregivers of persons with dementia: Contributing factors and treatment implications

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Abstract

Estimates suggest that there are more than 10 million adult caregivers of persons with dementia, two-thirds of who experience some form of sleep disturbance during the course of their caregiving career. Health care professionals are in the best position to detect and address this significant public health problem. Three major contributors to caregiver sleep disturbance are discussed in this paper: 1) the presence of caregiver disrupted sleep routines; 2) caregiver burden and depression; and, 3) the caregiver's physical health status. Successful treatment of a caregiver's sleep disturbance requires careful consideration of each of these contributors. We review and analyze the scientific literature concerning the multiple complex factors associated with the development and maintenance of sleep disturbances in caregivers. We provide a clinical vignette that illustrates the interplay of these contributing factors, and close by providing recommendations for clinicians and researchers treating and investigating the development and maintenance of sleep problems in family caregivers.

Keywords

sleep; insomnia; caregivers; Alzheimer's disease; dementia; depression

The National Alliance for Caregivers estimates that there are 44.4 million caregivers age 18 and older in the United States, representing 21% of all U.S. households. (1) The vast majority of these caregivers are women, who are either living with the care-recipient or visiting them at least weekly, and who receive no paid and very little unpaid assistance with their family member's care. In a 2003 national survey, 23% of caregivers reported that they were caring for someone with Alzheimer's disease, dementia, or other mental confusion. (1)

Sleep disturbances are common among dementia caregivers. Studies over the past 15 years have reported that approximately two-thirds of older adult caregivers have some form of sleep disturbance. (2–4) Caregiver sleep problems are often presumed to be linked to nighttime behaviors in the care-recipient. Obviously, if a person with dementia is awake and roaming around the house at night, this behavior impacts the caregiver's sleep as well. In fact, research

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shows that care-recipient sleep disturbances are one of the most common reasons cited for moving a family member with dementia into an institutional setting. (5)

However, not all caregivers develop sleep problems, and when they do occur they are not necessarily simply explained or categorized. One study found that family caregivers of demented and non-demented older adults had similar 24-hour rest-activity patterns. (6) Another showed that although spousal caregivers complained more about their sleep, it was not objectively worse (as measured by polysomnography) than non-caregiver controls. (7) Similarly, caregiver proxy reports of sleep disturbances in demented care-recipients have been found to have only modest correlations with actigraphic measures of care-recipients' sleep. (8,9) These findings, combined with the observation that rates of self-reported sleep disturbances in caregivers are generally much higher than those reported for persons with dementia (Table 1), suggest that factors other than nocturnal awakenings in the dementia sufferer contribute to caregivers' sleep complaints.

In this paper, we examine several possible causes for the development and maintenance of sleep disturbances in dementia caregivers, specifically, the impact of irregular caregiver sleep/wake routines, depression and burden, and caregiver medical morbidity. We consider the implications of these contributing factors for health care providers who are treating caregivers of family members with dementia, and present a vignette that helps illustrate the interplay in a typical clinical setting. Finally, we provide a frame of reference for subsequent recommendations for clinicians and researchers investigating the development, maintenance and treatment of sleep problems in family caregivers.

Sleep and disrupted routines

According to the "3P model" developed by Spielman, the development of sleep disturbances is a multi-faceted event that arises from a combination of predisposing, precipitating, and perpetuating factors. (10) For caregivers of persons with dementia, these factors can be independent of the caregiving situation, as well as directly related to the influence of the care recipient. Predisposing, independent risk factors for changes in the sleep of the typical caregiver include increasing age and female gender, both of which are associated with a higher prevalence of sleep complaints. (11,12) Most dementia caregivers are older women (either spouses or adult children), and as such they are at risk for age-related sleep disturbances including increased sleep latency, decreased sleep maintenance, decreased slow wave and REM sleep, nocturnal temperature dysregulation, more frequent shifts between sleep stages, and circadian rhythm disturbances, particularly advanced sleep phase. (13,14) Each of these age-related changes contributes to increased nighttime wakefulness and fragmentation of sleep. (15) In addition to having more fragile sleep than young adults, sleep disturbances in older persons are also more likely to recur and become chronic than those in younger individuals. (16)

Following Spielman's 3P model, sleep disturbances will occur when a person who is predisposed to poor sleep encounters some event that precipitates nighttime wakefulness. For dementia caregivers, the precipitating events are often changes in the nighttime routines of the persons for whom they are caring. For vulnerable caregivers, it can be very difficult to fall back asleep after being awakened by a care recipient who needs assistance with toileting, redirection back into bed, orientation, or emotional reassurance, particularly when these nocturnal interactions are prolonged or emotionally charged. Caregivers who are awakened frequently by their care recipients can fall into iatrogenic sleep routines that are part of an ineffectual attempt to compensate for having their nightly rest disturbed. For example, caregivers may start cat-napping throughout the day, drinking coffee to stay awake or alcohol to help fall asleep, or spending longer hours in bed trying to "catch up" on lost sleep, with the ultimate result being a further decrement in their nightly sleep quality and quantity. Thus, although patient behaviors

may initially precipitate caregiver awakenings, inadequate sleep hygiene can subsequently become a perpetuating cause for caregiver disrupted sleep patterns even after patient nocturnal behavioral disturbances are no longer present. (17)

The caregiver's situation is analogous to that of a rotating shift worker who must be alert both at night and during the day, often on an inconsistent schedule. This overextension of responsibilities can lead to chronic fatigue and a decline in quality of care. For example, caregivers who are chronically sleepy during the day may be more irritable with their care-recipient, prone towards household or motor vehicle accidents, and more likely to have difficulty with rapid or complex problem-solving in the face of dementia-related behavioral disturbances. Scheduled napping has been shown to be beneficial as part of a regular daily sleep routine for shift workers and healthy older adults, (18,19) but its feasibility and utility for caregivers who may be interrupted from such naps by the dementia patient has not been studied. A recent uncontrolled pilot study (20) suggested that caregiving training in meditation and yoga techniques might help improve caregiver sleep and reduce daytime fatigue, but additional research examining the efficacy of such training, particularly with older caregivers, is needed.

There have been no studies examining the indirect impact to nighttime sleep and daytime fatigue that results from the changes in daytime activities and routines associated with dementia care. Social rhythms are an important “*zeitgeber*” or time cue which can help to maintain the setting of the body's circadian biological clock. (21,22) The loss of time and opportunity for recreation, social contact, or even scheduling of routine daytime chores that most caregivers experience may further contribute to the overall deterioration of their sleep/wake routines.

Practice points

1. Since many caregivers are older adults, age-related changes in sleep architecture and circadian rhythmicity are important predisposing factors for caregiver subjective sleep complaints and a breakdown in optimal sleep habits and routines.
2. Nighttime awakenings by persons with dementia are a common precipitating cause of sleep/wake disturbances in vulnerable caregivers.
3. The development of poor sleep hygiene practices, sleep-wake scheduling irregularities, and decay of daytime structured social activities can perpetuate sleep disturbances and daytime fatigue in vulnerable caregivers.

Sleep and caregiver burden

A second major contributor to the development and maintenance of sleep problems in dementia caregivers is caregiver burden. Caregiver burden has been defined as, “the physical, psychological or emotional, social, and financial problems that can be experienced by family members caring for impaired older adults.” (23) “Objective burden” (24) includes primary stressors produced by the care-recipient, such as nighttime wandering, physical agitation, and incontinence. “Subjective burden” includes secondary stressors that arise in response to patient behaviors, such as caregiver feelings of depression and loneliness, isolation from family and friends, feelings of helplessness and inability to cope, and changes in roles and relationships with the care-recipients. Caregivers' appraisals of these primary and secondary stressors affect their physiological and behavioral response to these stressors, and ultimately, their subsequent morbidity and mortality risk. (25)

The extent to which care-recipient nocturnal disturbances are a source of objective burden for caregivers depends, in part, on the type of sleep-wake disturbance being exhibited. Our research has shown that having to cope with frequent nocturnal awakenings is far more distressing for

caregivers than having a family member who gets up too early in the morning, (26) perhaps because in the latter case, caregivers can cope by adapting their sleep-wake schedule to that of the care-recipient. (6) Similarly, caregivers might react quite differently to nighttime wakefulness in a calmly confused individual who naps too much during the day, as opposed to someone with severe psychiatric symptoms such as physical aggression or hallucinations, (26,27) which are themselves risk factors for caregiver burden and institutional placement. (28)

Alternatively, subjective caregiver burden can lead to caregiver sleep disturbances even in the absence of patient awakenings. Depression and anxiety are well-known risk factors for insomnia, (29-31) and the prevalence of depression and anxiety in caregivers is significantly increased compared to non-caregiving adults. (32-34) In a longitudinal study conducted by our research group, 231 community-dwelling dementia caregivers were followed every six months for five years. Caregiver depression and subjective burden were found to be the most powerful predictors of the onset of new caregiver sleep disturbances. (35) The nature of the caregiving relationship most likely also influences caregivers' reactions to nocturnal disturbances. Family caregivers who have poor relationships with their demented family member are more likely to experience higher levels of strain and burden, and to report more conflict or criticism in their daily interactions. (36-38) Our research suggests that caregivers who are more critical and reactive to their family member's behavioral disturbances in general are also more prone to over-report patient nocturnal sleep disruptions. (9)

Since sleep disturbances are themselves a risk factor for onset of depression and anxiety, (31, 39,40) caregivers can develop a self-perpetuating spiral of sleep and mood disturbances that is difficult to break. The consequences can be quite serious. Caregiver strain, co-morbid depression and anxiety, and insomnia have all been linked to suicide in older adults. (41-43) Recognizing these risks, many physicians prescribe sedating antidepressants at bedtime or a combination of some standard antidepressant agent with a short-acting benzodiazepine to enhance sleep. The use of sedating medications and antidepressants to improve sleep in older adults and the long-term side effect risks have been well described elsewhere. (16,44,45) Unfortunately, there are limited data describing the long-term use of sedative hypnotics in older people with insomnia, and treatment effect sizes are relatively small. (46,47) Surveys have shown that trazodone remains the most commonly prescribed medication for the treatment of insomnia in the United States, (48) despite the lack of empirical evidence supporting its use and its known side effects including dizziness and psychomotor impairment, which occur with particular frequency among the elderly, putting them at increased risk for accidents and falls. (49) Although psychotropic medications are widely used to treat insomnia in older caregivers, (50,51) there have been no controlled clinical trials investigating their use in this population.

Non-pharmacological options are generally recommended as a first line of treatment for managing sleep disturbances in older adults, including caregivers of persons with dementia. (52) There is a large literature reviewing the efficacy of cognitive-behavioral strategies, including sleep hygiene, stimulus control, and sleep compression for treating sleep disturbances in older adults, (53,54,55-57) and the interested reader is referred to these sources for detail on their implementation. Cognitive-behavioral strategies have been shown to be useful for improving the sleep of elderly dementia caregivers, (58) including caregivers whose insomnia symptoms are long-standing and whose care-recipients are no longer in their homes. (59) Other non-pharmacological interventions such as relaxation and biofeedback, light therapy, and acupressure can also improve sleep in older adults (56,60) but there has been no research to date examining their efficacy in dementia caregivers.

Psychological interventions are also known to be useful for reducing the psychiatric morbidity that can precipitate or perpetuate caregiver sleep problems. A comprehensive review of the

caregiver intervention literature by Schulz, et al. (61) concluded that clinically significant improvements in caregiver depression and anxiety can be achieved using a variety of educational and psychotherapeutic methods including problem-solving, coping skills training, behavior management training, support groups, cognitive-behavioral therapy, and other forms of counseling. Interventions that focus on helping caregivers maintain or reintroduce pleasant activities in their daily life may be of particular value when alleviation of both mood and sleep disturbances is the goal. A national survey of 1,500 caregiving households found that dementia caregivers give up vacations or hobbies more often and have less time for other family relationships than other types of caregivers. (62) The inverse relationship between level of participation in pleasant activities and depression has been demonstrated in clinical trials with dementia caregivers (63) as well as non-caregiving older adults. (64) Helping caregivers establish or maintain a healthy balance of pleasurable activities may thus be important both as a means of reducing depression and sleep symptoms, as well as for augmenting social activity *zeitgebers* that help entrain regular sleep routines and circadian rhythms.

Interestingly, caregiver sleep problems often continue after the care-recipient's sleep improves, or even after the demented family member is no longer in the home, (65) further suggesting that subjective caregiver factors independent of the care recipient are critical for understanding insomnia in this population. Intrusive thoughts and cognitive arousal have been shown to play a key role in the development of sleep disturbances associated with bereavement-related depression. (66,67) A recent study suggests that grief and bereavement issues may also be an important perpetuating factor in those caregivers who continue to have significant ongoing sleep complaints after the death or institutionalization of their demented spouses. (59) A related factor that may contribute to the perpetuation of sleep disturbances is caregiver "vigilance," (68) a pattern of hyper-alertness and physiological arousal at night. Similar to parents of young children, caregivers who are worried about the nighttime activity of their family member tend to sleep with their "eyes and ears half open," and this readiness to respond can over time become a habit. Caregiver vigilance is not necessarily diminished even when professional caregivers are hired to provide assistance or institutionalization occurs. (69)

In sum, both objective nocturnal behaviors by the care-recipient, and subjective caregiver burden, particularly depression and anxiety, can precipitate and perpetuate sleep disturbances in caregivers of persons with dementia. Although sedating medications are widely used to improve sleep, there have been no empirical data supporting their efficacy for dementia caregivers, and limited data supporting the long-term use in the treatment of insomnia in older adults. However, research does support the use of psychological interventions to improve the sleep and mood of older adults and caregivers. Interventions that enhance lifestyle regularity and participation in pleasurable, meaningful activity may have particular relevance to the prevention and treatment of chronic sleep disturbances in elderly dementia caregivers.

Practice points

1. Caregiver psychological factors, including depression, anxiety, reactivity to certain kinds of patient sleep-wake problems, and hyper-arousal or vigilance to nocturnal disruptions may all serve to precipitate or perpetuate caregiver sleep disturbances even if patient disturbances are reduced or eliminated.
2. There is little evidence to date supporting the use of antidepressants or other psychotropic medications for treating chronic insomnia in dementia caregivers, although they are widely used.
3. **Psychological** interventions have been shown to be effective for treating mood and sleep disturbances in dementia caregivers.

Sleep and declining health

The third factor that contributes to sleep disturbances in caregivers of persons with dementia is declining health. Medical co-morbidity is a known risk factor for insomnia. (70) By virtue of their age, older caregivers are at risk for developing many of the chronic illnesses that can directly impact sleep (71). Primary sleep disorders, including sleep disordered breathing (SDB) and obstructive sleep apnea (OSA), periodic leg movements in sleep (PLMS), and restless legs syndrome (RLS), are more common in older adults. Studies have shown that 45% – 62% of older adults have SDB, and 45% have PLMS, compared to prevalence rates of less than 10% in younger adults. (72) Primary sleep disorders are frequently undiagnosed in persons who complain of insomnia or excess daytime sleepiness and can have important functional and health consequences. (73–75) A number of serious health conditions which themselves can impact sleep, such as hypertension and cardiovascular disease, have also been linked to SDB, although the causal direction of the relationship has not been fully clarified. (76)

There is also a large body of research showing that dementia caregiving itself is associated with negative health effects. Caregivers perceive their health to be worse than non-caregivers. (34) Dementia caregivers have higher levels of stress hormones and lower levels of antibody responses. (77,78) Older caregivers are more likely to have a greater body mass index, (79) as well as elevated cholesterol, hypertension, insulin levels, and cardiovascular disease, all of which can adversely impact sleep. (80) Many medications used to treat these conditions also increase risk for development of insomnia, and many older adults take multiple medications, placing them at further risk for sleep disturbance. (44) These changes are greatest among caregivers with patients who are behaviorally disturbed, (81) and can persist long after active caregiving ends. (82)

The relationship between caregiving and health problems is complex, however, and is mediated by factors such as health habits, gender, and level of psychological distress. (83) Although health care providers treating caregivers should, of course, address underlying health problems that may be contributing to caregiver sleep complaints and encourage the practice of health-promoting behaviors, the additional fact that one is a caregiver makes medical management even of relatively straightforward health problems more complicated. For example, one population-based study of 3,000 married couples found that caregivers were more likely than non-caregivers to get insufficient rest, to neglect taking prescription medications, and to not take sufficient time to recover from illnesses when they occurred. (84)

Caregivers exercise less than their non-caregiving peers, (84–86) a fact that further increases their risk for age-related medical comorbidity, including sleep disturbances. Regular exercise not only reduces risk for developing many common disabling age-related illnesses, (87) it improves sleep and circadian rhythmicity in older adults, (88–90) and is included in the recommendations of most behavioral sleep programs. (17) King and her colleagues found that moderate-intensity exercise significantly improved blood pressure reactivity and sleep quality in a sample of 100 older women family caregivers. (91) Epidemiological studies as well as randomized controlled clinical trials have also found that higher levels of physical activity are associated with reduced depression prevalence in older adults, and with reduced incidence of depression over a 5-year follow-up period. (92–95) The relationship between sleep and exercise in depressed caregivers has not been investigated, but research has shown that depressed caregivers are less likely to initiate and maintain an exercise program than non-caregiving older adults. (96) In order to succeed in a regular exercise program, caregivers not only need someone to stay with their care-recipient while they exercise, but also need substantial encouragement, in some sense “permission”, from the health care providers, family members, and friends. (85)

Practice points

1. Many age-related medical conditions and their treatments can adversely impact caregiver sleep. Practitioners should target effective control of chronic illnesses and ensure that prescribed medications are not of themselves contributing to disturbed caregiver sleep.
2. The sedentary life-style, social isolation, and limited time available to most caregivers for pleasurable or health promotion activities can also indirectly impact caregiver sleep.
3. Regular exercise can be effective in ameliorating sleep and mood disturbances, as well as improving cardiovascular health and functional capacity in caregivers. Particular attention needs to be paid to ensuring that a support system exists that encourages adherence to exercise as well as other health care recommendations.

A real world example

We opened this paper by pointing out that sleep disturbances in dementia caregivers are complex, and typically involve an interaction between the effects of disrupted sleep/wake routines, caregiver burden and depression, and medical morbidity. Appreciating this complexity and evaluating which factors are important in any given specific situation is essential for developing a good treatment plan. The following vignette will demonstrate this interplay and will help us consider the implications for health care providers who are treating caregivers of family members with dementia.

Caregiver GW was an 82 year old, Caucasian woman who had cared for her husband with Alzheimer's disease until 4 months earlier, when she placed him in a nursing home. Mrs. GW's sleep had begun to deteriorate 2 years ago, which she attributed to the stresses of caregiving and her husband's nighttime wandering and incontinence episodes. Although he was no longer in the home, Mrs. GW's sleep had not improved. She had severe problems falling asleep at night, then would awaken in the very early morning and lay awake "thinking" for hours. She tried to overcome her exhaustion by sleeping in late and dozing in the recliner next to her husband's bed during her daily visits to the nursing home. In addition to her sleep complaints, Mrs. GW's depression and burden scores were elevated (Pittsburgh Sleep Quality Index score = 17; CES-D score = 32; Screen for Caregiver Burden objective burden = 9, subjective burden = 26). She was 30 pounds overweight, had high blood pressure, and poor control of her diabetes.

Shortly after enrolling in a research study treating sleep disturbances in dementia caregivers, Mrs. GW called and said her physician was going to hospitalize her if her sleep didn't improve immediately. The doctor prescribed a sedating antidepressant that she was to begin taking at bedtime. Mrs. GW withdrew from the study and we heard no more from her until several months had passed, when she unexpectedly called to say that her sleep was much better, and she thought we'd be interested in knowing what had happened.

Mrs. GW told us that she had discontinued the antidepressant after only a few weeks because she disliked the side effects. In the meantime, a favorite sister from out of town had come for an extended visit. The sister was up bright and early each morning with a list of things to do and places to see. Initially, Mrs. GW could barely force herself to get up and accompany her sister on the daily outings. At the end of each long, although enjoyable day, she would fall into bed exhausted. To her great surprise, after a relatively short time Mrs. GW found herself sleeping through the night. Her mood was better, she had more energy during the day, and her blood pressure improved. Mrs. GW attributed these positive changes to "my sister making me stick to a routine" and "giving me something to look forward to every day." However, her physician felt that the antidepressant had helped avert an imminent medical crisis, and urged

Mrs. GW to consider another medication trial when her sister returned home and Mrs. GW was once again living alone.

As is common, Mrs. GW attributed the initial onset of her sleep problems to her husband's nocturnal behaviors. However, by the time we had contact with her, her husband had been institutionalized and no longer was a precipitant for her sleep complaints. In the meantime, Mrs. GW had developed a number of habits that could be perpetuating her sleep complaints. She dozed at her husband's bedside throughout the day when she was visiting the nursing home. She had an inconsistent sleep-wake schedule; she often stayed in bed longer in the morning following a difficult night trying to "catch up" on her lost sleep. This combination of daytime napping, irregular morning rising, and a sedentary lifestyle had put her out of sync with other people and activities in the outside world, leading to a breakdown in the social cues that can help maintain circadian rhythmicity.

Mrs. GW also was quite depressed, as demonstrated by her CES-D scores, and reported high levels of subjective burden despite the fact that her husband was no longer in the home and his objective behavior problems had greatly diminished since the move. Her comment that she would lie awake at night for hours at night just "thinking" was consistent with the kind of anxious rumination associated with a depressive bereavement. Her physician recognized this and placed her on a sedating antidepressant in an effort to help both her depression and poor sleep. As in the case of Mrs. GW, however, not all older adults are willing or able to adhere to medication therapies, despite the fact that from her physician's subsequent perspective, the treatment had had an effect.

Finally, Mrs. GW was physically ill. Her hypertension, diabetes, and weight were poorly controlled. Presumably these conditions were being medically managed as well as possible, but that had not had a positive impact on her sleep, mood, or burden. What finally made the difference was a visit from Mrs. GW's energetic sister, who was able to provide the motivation and direction that Mrs. GW was lacking on her own. Mrs. GW attributed her sleep and mood improvement to consistent scheduling and involvement in pleasurable life events, which gave her "something to look forward to." Her physician was properly concerned that she would deteriorate again once the sister returned home. In this case, encouraging Mrs. GW to sustain her daily activity levels by connecting with a structured community exercise program that would also provide a social support system to replace the one her sister had created might be more efficacious than simply recommending a return to a medication therapy that had been originally rejected.

Summary

In summary, sleep disturbances in caregivers of persons with dementia are common. Estimates suggest that there are more than 10 million adult caregivers of persons with dementia, two-thirds of who experience some form of sleep disturbances during the course of their caregiving career. A complex set of precipitating, predisposing, and perpetuating factors, including the presence of caregiver disrupted sleep routines, caregiver burden and depression, and poor physical health are frequently associated with sleep complaints. If we are to develop a better understanding of caregivers' risk for developing and maintaining sleep disturbances as well as more effective interventions, evaluation of these interacting factors must be considered.

Practice Points

The case of Mrs. GW illustrates the complexity underlying the development, maintenance, and treatment of sleep disturbances in caregivers of persons with dementia. Health care professionals are in the best position to detect and address this significant public health problem. However, failure to evaluate the multiple factors that impact sleep quality in

caregivers may lead to treatments that are unsuccessful because they do not fully address the underlying causes of each specific caregiver's sleep complaints. Health care providers should keep the following points in mind:

- Caregiver sleep problems can exist both in response to, and independent of, patient nocturnal disturbances. Simply treating the dementia patient's nocturnal symptoms may not resolve the caregiver's sleep disturbances.
- Behavioral strategies should always be considered in treating sleep disturbances in elderly caregivers, either separately or in conjunction with pharmacological interventions.
- Disrupted caregiver sleep routines can become habitual and difficult to change. Asking caregivers to keep a daily sleep log (97) can be a useful and inexpensive tool to help determine whether the caregiver has fallen into potentially problematic but modifiable sleep behaviors such as spending excess time in bed at night or napping during the day.
- A sleep log can also help identify those caregivers with ruminating or intrusive thoughts that are keeping them awake. Such caregivers should be evaluated for depression, and their level of subjective burden assessed. Although a variety of cognitive-behavioral interventions have been used successfully with caregivers, those that enhance lifestyle regularity and increase social and physical activation may be of greatest benefit for improving both sleep and mood.
- Caregivers with sleep complaints should have a physical exam including a review of current medications to rule out medical causes for their insomnia. Caregivers should also be encouraged and offered assistance in developing a daily exercise program that would provide a structured routine and increased socialization as well as physical health benefits.

Although the above suggestions represent a reasonable clinical approach, based upon what we know about treating caregivers of persons with dementia who are experiencing sleep disturbances, empirical research on the development, maintenance, and treatment of sleep disturbances in this population is still quite limited. Large gaps in our knowledge remain to be filled by future research studies, however. We detail several of these crucial gaps in the accompanying Research Agenda.

Research Agenda

- Additional research examining the development and maintenance of sleep disturbances in vulnerable caregivers (e.g., caregivers with depression or co-morbid health problems) is needed. In particular, the phenomenon of continued sleep problems in caregivers once the care-recipient is no longer in the home or waking up at night should be investigated.
- Additional research is needed to evaluate the effectiveness of non-pharmacological treatments to improve sleep in dementia caregivers, including cognitive-behavioral strategies as well as other less well tested interventions such as light therapy, exercise, relaxation and biofeedback, and acupuncture or massage. These interventions need to be theoretically grounded, which would lead to better conceptualization and assessment of the complex mediating, moderating, and treatment process variables that influence caregiver sleep outcomes.
- Research is needed to examine how technology (e.g., telemedicine, the internet) can be applied in primary care settings to improve the detection, treatment, and follow-up of sleep disturbances in caregivers. For example, studies are underway exploring

how bed monitoring devices can be used to communicate to caregivers when cognitively impaired individuals leave their bed at night and to track their location if they wander. (98)

- Research is needed to help us more accurately predict what patients and caregivers are at risk for developing sleep disturbances, and to evaluate whether general health promotion programs that increase social and physical activation or that encourage good sleep habits can prevent their onset.

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Table 1

Prevalence rates of sleep disturbances in persons with dementia and their family caregivers

Caregivers	
McCurry & Teri, 1995 (2)	68%
Pruchno & Potashnik, 1989 (3)	22 – 41% (men), 53 – 67% (women)
Wilcox & King, 1999 (4)	67% (women only)
Persons with dementia	
Carpenter, et al., 1995 (99)	40%
Craig, et al., 2005 (100)	42 – 54%
Lyketsos, et al., 2002 (101)	20 – 27%
McCurry, et al., 1999 (26)	35%
Moran, et al., 2005 (27)	25%
Pang, et al., 2002 (102)	35 – 54%
Rabins, 1999 (103)	33%
Ritchie, 1996 (104)	19 – 44%
Thommessen, et al., 2002 (105)	25%