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“What Hath Night To Do With Sleep?”: The Caregiving Context and Dementia Caregivers’ Nighttime Awakenings

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Abstract

Objectives: Care provision for persons with dementia can be rewarding yet may disrupt caregiver’s sleep health. Using the National Health & Aging Trends Study and the National Study of Caregiving, we examine care receiver and caregiver contextual factors, caregiver health and psychological well-being as predictors of caregivers’ nighttime awakenings.

Methods: The sample for this cross-sectional study included 451 caregivers for individuals with dementia surveyed by telephone.

Results: Nighttime awakenings (1 item measure of waking and not being able to return to sleep) almost every night were reported by 16% of caregivers and 10% reported that helping the care receiver caused their sleep to be interrupted most nights. In a multinomial logistic regression, caregivers’ greater nighttime awakenings were associated with caring for care recipients with higher fall risk, as well as caregiver characteristics of more chronic medical conditions and emotional difficulty of the care role.

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Conflict of interest: None.

**Title quote from John Milton’s Paradise Lost

Conclusions: Emotional caregiving difficulties were associated with nighttime awakenings even accounting for caregivers' health and care receivers' disability. Thus, interventions improving caregiver distress may improve sleep health.

Clinical implications: Clinicians should screen caregivers for nighttime awakenings so that evidence-based interventions and treatments can be implemented to prevent persistent sleep disturbances.

Keywords

nighttime awakenings; sleep disturbance; dementia; caregiver; care related distress

Introduction

An estimated 15 million Americans provide care for an individual with dementia, contributing approximately 18.1 billion hours of care (Alzheimer's Association, 2016). Some caregivers report positive effects of providing care, however, the negative impact of caregiving has also been well documented including increased stress, burden, depression, and even earlier mortality among caregivers for individuals with dementia (Beach, Schulz, Yee, & Jackson, 2000; Cohen, Colantonio, & Vernich, 2002; Schulz & Beach, 1999; Wolff, Spillman, Freedman, & Kasper, 2016). Another area of potential negative impact of caregiving is on caregiver sleep.

On average, dementia caregivers only sleep about 6 and a half hours per night, thus less than the recommended 7–8 hours (Rowe, McCrae, Campbell, Pe Benito, & Cheng, 2008). Strikingly, female caregivers report sleep problems of similar severity to adult women with insomnia (Wilcox & King, 1999). In a study comparing caregivers of individuals with dementia with non-caregiver controls, caregivers self-reported more nighttime sleep problems and daytime impairment from sleep deprivation (McKibbin et al., 2005). Caregivers of individuals with dementia are most often an aging spouse or a middle-aged child and these age groups tend to have a more chronic course of insomnia and a higher likelihood of recurrence than younger adults (Buysse, 2004). In addition, caregivers' sleep problems have been found to persist even following the institutionalization or death of the care recipient (Carter, 2005). Of concern, while up to two thirds of dementia caregivers report problems with their sleep (McCurry, Logsdon, Teri, & Vitiello, 2007) and empirically validated sleep treatments exist, little is known about the association of characteristics of caregivers or individuals with dementia on such sleep problems that may help to identify caregivers in need of additional support and intervention.

Cohabiting individuals impact each other's sleep patterns, and as many caregivers live with their care-recipient this association may be amplified in a caregiving context. One common factor that contributes to caregivers' sleep disturbances is the nocturnal behavioral disturbances or awakenings of the care recipient (McCurry, Gibbons, Logsdon, Vitiello, & Teri, 2009; Teel et al., 1999; Wilcox & King, 1999). For example, Creese and colleagues (2008) found that nocturnal disruptions by the care receiver (e.g., wandering or getting up to use the bathroom) interrupted the sleep of a majority of spousal caregivers (63%). Caregivers may be hyper-vigilant ("sleep with their eyes half open") to be able to respond to

their care recipients' nighttime disturbances or to prevent possible injuries (e.g., falls) (Rowe & Fehrenbach, 2004). Thus nocturnal disturbances may result in nighttime awakenings wherein a caregiver is unable to return to sleep. However, night is only half of the equation when it comes to sleep. Activities and caregiving stressors that occur during the day, as well as specific characteristics of the caregiver, may all contribute to how one is able to sleep at night.

Prior research suggests that older age, female gender, and caregivers' own chronic medical conditions and depressive symptoms put them at risk for sleep disturbances (Beaudreau et al., 2008; McCurry et al., 2009; McCurry et al., 2007). However, the caregiving context provides its own factors that may precipitate or perpetuate caregivers' sleep disturbances. McCurry and colleague's (2009) review of the literature suggests that care recipients' higher levels of functional disability and memory impairment along with caregivers' stronger appraisals of caregiving stress were associated with poorer sleep quality among caregivers. Consistent with stress process models, it may be that caregivers' subjective appraisals of their care situation and stressors matter more for their sleep health than do the stressors themselves (Pearlin, Mullan, Semple, & Skaff, 1990), however this needs further study.

Sleep disturbances and insomnia symptoms are common among dementia caregivers and have the potential to be chronic problems that can put caregivers at risk for a host of negative outcomes (ex. cardiovascular disease, stroke, depression, decision to institutionalize relative) (Elwood, Hack, Pickering, Hughes, & Gallacher, 2005; Johnson, Roth, & Breslau, 2006; Phillips & Mannino, 2007; Vitiello & Borson, 2001). Yet a full understanding of predictors for caregivers' sleep problems including a range of both care partners' characteristics and aspects of the caregiving context still requires further exploration. Just as sleep deprivation can impair one's ability to drive safely, it may have adverse implications for the care a caregiver is able to provide. Thus, understanding risk factors of nighttime awakenings can lead to targeted and adaptive interventions to aid in the improvement of sleep health for caregivers of individuals with dementia. In the current study, we seek to examine caregiver and care receiver characteristics that may be associated with caregivers' nighttime awakenings. We hypothesized that caregivers' greater medical burden, greater emotional caregiving difficulties, and high levels of disability among care recipients will be significantly and independently associated with more nighttime awakenings among caregivers.

Methods

Procedures and Sample.

Data were drawn from the 2011 National Health and Aging Trends Study (NHATS; care receiver data) and the 2011 National Study of Caregiving (NSOC; caregiver data). NHATS is a nationally representative sample of Medicare beneficiaries aged 65 and older. Participants were sampled from a Medicare enrollment file with older individuals and African Americans oversampled; data was then collected through in-person interview. Dementia was classified as probable, possible or no dementia NHATS participants based on any of the following: 1) self-report of a dementia diagnosis; 2) a score indicating dementia on the AD8 Dementia Screening Interview; and 3) performance on cognitive tests of memory, orientation and

executive function (described in full detail in a technical paper by (Kasper, Freedman, & Spillman, 2013a). For the current analysis, we included individuals from NHATS with probable or possible dementia and not living in an assisted living facility, which was 717 (8.7%) of 8,245 NHATS participants (5 care receivers were living in some form of supervised home other than an assisted living or continuing care retirement community). Of the 717 care recipients, 281 (39%) had their data submitted by a proxy respondent (80% of proxies were a spouse or child). Reasons provided for having a proxy respondent included the care recipient having dementia (65%), a speech impairment (8%), hearing impairment (17%), language barrier (4%) being ill (23%), or other reason (7%).

The caregivers of NHATS participants were eligible for NSOC if they (the NHATS participant) had an unpaid family or non-family helper who provided them with assistance on mobility, household chores, or self-care activities. NHATS participants provided the names of those who helped them with care tasks and as many as five caregivers could be included in NSOC (if more than 5 were listed, 5 were randomly selected for NSOC). The 717 individuals with dementia in NHATS had 1,063 caregivers participate in NSOC, with data collected through a 30-minute telephone interview. Given our interest in how caregiving is associated with sleep, we selected only those caregivers who resided with the individual with dementia because these caregivers had more opportunities for care-related nighttime awakenings. Hence, the analytic sample included 528 same-household caregivers for 442 individuals with dementia. Based on University of Michigan policies, ethical approval for this study was not required as only publically available secondary data was utilized with no individual identifiers.

Measures.

Care Receiver Predictors.—Care receiver's age, gender, history of falls, activities of daily living (ADL) and instrumental activities of daily living (IADL) disability, and number of chronic medical conditions other than dementia were considered as predictors. Fall history indicates whether the care recipient fell in the last month. A sum of 12 difficulties including getting around both in and outside, getting out of bed, eating, bathing, toileting, dressing, laundry, shopping, meal preparation, banking, and medication management was created to reflect the level of ADL/IADL disability. A count of care receivers' number of diagnosed chronic conditions other than dementia was also included: heart disease, high blood pressure, arthritis, osteoporosis, diabetes, lung disease, and cancer.

Caregiver Predictors.—Caregiver predictors included age, gender, education, relationship to the care receiver, chronic medical conditions, and level of care-related emotional difficulties. Education was categorized as college or higher degree, greater than high school, or less than high school. Relationship to the care receiver was classified as spouse, child, or other. A count of chronic medical conditions included caregiver's self-report of: heart attack, high blood pressure, heart disease, arthritis, osteoporosis, diabetes, lung disease, cancer, serious difficulty seeing and serious difficulty hearing. Finally, caregivers were asked whether they experienced emotional difficulties in the care role. Caregivers who reported difficulties then indicated their extent from 1 (*a little difficult*) to 5 (*very difficult*). These two items were combined such that caregivers who did not report

emotional difficulties were assigned a zero and caregivers who reported emotional difficulties were given a score based on their degree (0 = *no difficulty* to 5 = *very difficult*).

Outcome.—In NSOC, caregivers' nighttime awakenings were assessed using a single 5-point scale item (1 *never*, 2 *rarely*, 3 *some nights*, 4 *most nights* to 5 *every night*) asking, "In the last month, on nights when you woke up before you wanted to, how often did you have trouble falling back asleep?". Descriptive information was also provided for the items "In the last month, how often did helping the care recipient cause your sleep to be interrupted?" (*never, rarely, some nights, most nights to every night*) and "You are exhausted when you go to bed at night" (*not so much, somewhat, very much*). A caregiver's sleep interruption due to care provision was also included as a covariate of nighttime awakenings in a post-hoc analysis.

Statistical Analysis.

First, descriptive statistics were determined for all study variables. To examine our primary research question of caregiver and care receiver predictors of caregivers' nighttime awakenings, we fit a multinomial logistic regression in SAS version 9.4 (Hardin & Hilbe, 2003). In this model (Model 1), care receiver characteristics of age, gender, last month falls, IADL and ADL disability, and chronic medical conditions, in addition to caregivers' age, gender, education, relationship to the care receiver, chronic medical conditions and emotional difficulty of care were included as predictors of nighttime awakenings. In a post-hoc analysis (Model 2), we further considered whether interrupted sleep due to care provision was associated with nighttime awakenings. The NSOC caregiver sampling analytic weight was applied to the models to account for differential probabilities of sample selection and survey design (Kasper, Freedman, & Spillman, 2013b). Additionally, we accounted for the clustering and stratification of the sample design in the model so that standard errors would be computed properly. Goodness of fit of the model is described using the Wald F test. Listwise deletion removed 77 caregivers from the regression model due to missing data. Thus, our analytic sample included 451 caregivers.

Results

On average, caregivers were in their late 50s, with 61% being female, and in terms of their relationship with the care recipient, 41% were a child, 35% were a spouse and 24% were another friend or relative (Table 1). In terms of the care recipients with dementia, they were on average in their early-80s, had more than 5 IADL and ADL support needs, and had more than 2 chronic medical conditions. Approximately 20% of caregivers said they were "exhausted" when they went to bed at night as a result of their care duties and 10% said caregiving caused their sleep to be interrupted most days or every day. The primary outcome of nighttime awakenings was commonly experienced by caregivers: 7% said this happened every night, 10% reporting it happened most nights, and 31% reporting it at least some nights.

A combination of care receiver and caregiver characteristics were revealed by the logistic regression analysis as predictors of caregivers' sleep nighttime awakenings. Demographic characteristics of both the care receiver and caregiver were not significantly associated with

nighttime awakenings. However, caring for a care recipient who had fallen in the last month ($OR = 2.33$, 95% CI [1.4–3.9, $p < .01$]) was significantly associated with caregivers' greater nighttime awakenings. Additionally, for caregivers, more chronic medical conditions ($OR = 1.33$, 95% CI [1.2–1.5, $p < .001$]) and higher reports of the emotional difficulty of the care situation ($OR = 1.2$, 95% CI [1.0–1.4, $p < .05$]) were significantly associated with more nighttime awakenings. Full multinomial logistic regression results can be found in Table 2 (Model 1).

In a post-hoc analysis (Table 2, Model 2), we considered whether interrupted sleep due to care provision was associated with nighttime awakenings. Indeed, caregivers whose sleep was interrupted due to care provision reported greater nighttime awakenings ($OR = 1.49$, 95% CI [1.2–1.8, $p < .001$]). Further, this mediated the association between the emotional difficulty of care and nighttime awakenings as emotional difficulty was no longer significant with interrupted sleep in the model.

Discussion

We found that nighttime awakenings were common among caregivers for individuals with dementia in the NSOC. Care receivers' fall risk, as well as caregivers' own health and greater reported emotional care-related difficulties were significantly linked to caregivers' nighttime awakenings. As a whole, these findings suggest that the characteristics of both members of the care dyad have distinct implications for sleep health among dementia caregivers. Of note, however, the caregiver's relation to the care recipient and other demographic factors were not associated with nighttime awakenings, in contrast with prior literature (Beaudreau et al., 2008; McCurry et al., 2009; McCurry et al., 2007). Different from other caregiving studies which commonly sample for a primary caregiver, the NSOC methodology did not limit recruitment to primary caregivers. Our proportion of adult children caregivers compares similarly to national reports, though the proportion of spouses may be diluted by the inclusion of multiple caregivers in NSOC (e.g., an adult child or sibling serving as a secondary caregiver) (Hunt & Reinhard, 2015). As all caregivers lived with the care-recipient in our sample, co-residence may have mattered more than one's relation to the care recipient. For example, prior work suggests spousal and adult child caregivers co-residing with the care recipient report similar levels of care-related strain, but strain differs among resident versus non-resident caregivers of the same relation (e.g. co-resident adult children report more activity restrictions) (Deimling, Bass, Townsend, & Noelker, 1989).

Co-residence is important as nocturnal disruptions stemming from the individual with dementia may interfere with caregivers' sleep (McCurry et al., 2009). For example, wandering, nighttime trips to the bathroom, or other nocturnal disturbances are commonly reported in prior research (Creese et al., 2008). It follows that these common disturbances may be especially likely to disrupt caregivers' sleep following a recent nighttime accident or fall. Supporting this possibility, caregivers in this study reported more nighttime awakenings when their care recipient had fallen in the past month. Consequently, caregivers' fear of another fall may be one factor that keeps them awake in the night. This is critical to the caregiving context as disturbances are cited as one of the top reasons a caregiver decides to

place their relative in a long-term care facility (Hope, Keene, Gedling, Fairburn, & Jacoby, 1998).

In addition to the concerns caregivers may have for their relatives' nighttime behaviors, their own health challenges were strongly associated with nighttime awakenings. This finding is consistent with prior research showing that multimorbidity is a risk factor for sleep disturbances in caregiving and non-caregiving community dwelling populations (McCurry et al., 2009). For example, insomnia is commonly experienced by individuals with chronic illnesses such as cancer or heart disease and is considered to be one of the most distressing symptoms (Berger, 2009; Berger & Mitchell, 2008; Bower, 2008; Carpenter et al., 2004; Taylor et al., 2007; Wielgus, Berger, & Hertzog, 2009). It may be prudent for health care professionals to screen caregivers with multi-morbidity for insomnia symptoms, as these symptoms can take a chronic course and put caregivers at risk for other health problems such as depression or anxiety (Buysse, 2004; Elwood et al., 2005; Johnson et al., 2006).

Finally consistent with prior research on caregiver burden (McCurry et al., 2009; Willette-Murphy, Toderò, & Yeaworth, 2006), caregivers' self-reported emotional difficulty of care was associated with more sleep problems. It is plausible that heightened emotional caregiving difficulties include a range of negative reactions such as worry and rumination about the care situation. Worry and rumination may perpetuate sleep disturbances such as nighttime awakenings; thus interventions that reduce caregivers' emotional distress may have a positive impact on caregivers' sleep health (McCurry et al., 2009). The effect of emotional distress was no longer significant, however, in a post-hoc analysis (Model 2) where care-recipient-related sleep interruptions were included in the model. Given that care recipient nocturnal disruptions lead to caregiver nighttime awakenings by default, it follows that a strong association between the two may account for some of the variance explained by caregiver emotional distress. Caregivers whose nighttime routines are more frequently interrupted by a care receiver may also be more likely to report emotional distress related to caregiving. Yet, the nocturnal disruptions are most proximal to nighttime awakenings and account for the variance otherwise explained by emotional difficulty of care. Of note, the care receiver's falls were significantly associated with caregivers' greater nighttime awakenings, even with the inclusion of nocturnal disturbances in the model. Therefore, falls may represent a particularly stressful time for the caregiver and may increase sustained fear of a future fall, potentially leading to interrupted routines and sleep.

Limitations

Our study takes advantage of a large and nationally representative sample of caregivers drawn from the NSOC, which provides a wealth of detail about caregiving for older adults with functional limitations in the United States. The study was not, however, designed specifically to assess care receivers with dementia or caregivers with sleep concerns. Therefore, the measure of sleep is limited to one item and is not a validated scale, though it does show convergent validity in this study (significant bivariate correlations in the expected direction with study descriptive items regarding caregiver exhaustion upon going to bed and awakenings due to care provision for the care recipient; $r=.2$ to $.3$, $p<.01$). Further, other research studies using single item sleep measures have found them to be associated with

other predictors in the same way as more detailed measures of sleep (Burgard & Ailshire, 2009; Cappelleri et al., 2009; Leggett, Burgard, & Zivin, 2016). Sleep disorders such as sleep apnea were not assessed as part of the survey, which could confound caregivers' reports of nighttime awakenings.

Additionally, the NHATS dementia classification strategy likely classified some participants without dementia as "possible" or "probable" dementia (Kasper et al., 2013a). This means some of the NSOC caregivers included in our analysis may be caring for individuals with functional difficulty but without true dementia. However, the level of nighttime awakenings found and predictors identified are comparable to other studies of dementia caregivers (McCurry et al., 2009). Finally, caregivers have been found to have high night-to-night variability in their quality of sleep, and our cross-sectional design can only reflect an average and does not imply causality (Rowe et al., 2008).

The present results add to a growing body of literature suggesting that dementia caregivers commonly experience sleep problems linked to a caregiver's own health and emotional care-related distress, over and above stressors stemming primarily from the care receiver's dementia such as memory impairment or functional decline. Further, crisis events such as a care recipient's fall risk and a caregiver's provision of care that interrupts sleep are particularly salient factors that may keep caregivers awake during the night. Fortunately, nighttime awakening is a modifiable problem with empirically validated treatments. For example, respite care (e.g. Adult Day Programs for individuals with dementia), Cognitive Behavioral Therapy for Insomnia (CBTI), and exercise interventions have all been shown to improve caregiver sleep (King, Baumann, O'Sullivan, Wilcox, & Castro, 2002; Lee, Morgan, & Lindesay, 2007; McCurry, Logsdon, Vitiello, & Teri, 1998; Zarit et al., 2011). Other technologies such as bed monitors may also be useful to alert a caregiver about the nighttime mobility of their care receiver. In addition to targeting key risk factors for caregivers' sleep problems, future research should consider what constitutes meaningful improvement for a caregiver. Might a caregiver's perspective of their sleep quality, for example, be as meaningful as objective indicators of improvement in sleep quality? Furthermore, how a caregiver's sleep is impairing his or her daytime function and provision of care may be critical indicators of the long-term well-being of the care dyad. In sum, this study lays groundwork for future research to gain more nuanced knowledge of the dementia caregiving context and its implications for caregivers' sleep health.

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Clinical implications

- Nighttime awakenings are common among family caregivers for individuals with dementia.
- Caregivers' own health and psychological well-being along with their care receivers' lower disability are linked to caregivers' nighttime awakenings.
- Clinicians should screen caregivers for nighttime awakenings so that evidence-based interventions and treatments can be implemented to prevent persistent sleep disturbances.

Table 1.

Caregiver and Care Receiver Characteristics

Care-Receiver Characteristics	M (SE) or %	Caregiver Characteristics	M (SE) or %
Age	80.7 (0.4)	Age	59.1 (1.5)
Female	55.6%	Female	61.1%
Fall in last month	26.0%	Education	
		College or higher	17.2%
		Greater than high school	63.9%
		Less than high school	18.9%
IADL and ADL disability	5.8 (0.2)	Relationship to care recipient	
		Spouse	35.1%
		Child	40.6%
		Other	24.3%
Chronic medical conditions	2.6 (0.1)	Number of daily care hours	7.5 (0.5)
		Chronic medical conditions	1.8 (0.1)
		Adjustment to change	2.0 (0.5)
		Emotional difficulty of care	1.6 (0.1)
		Trouble falling back asleep	2.4 (0.1)
		Every day	6.5%
		Most days	9.8%
		Some days	31.0%
		Rarely	25.2%
		Never	27.5%
		Exhausted at night	
		Very much	20.1%
		Somewhat	32.2%
		Not so much	47.7%
		Care caused sleep interruption	2.0 (0.1)
		Every day	6.0%
		Most days	4.2%
		Some days	16.3%
		Rarely	27.4%
		Never	46.1%

Note. Demographic characteristics are weighted with the sample person and caregiver analytic weights respectively and account for the stratification and clustering of the sample.

Table 2.

Care Receiver and Caregiver Demographic, Health, and Psychological Covariates of Caregiver’s Sleep Trouble

	Nighttime Awakenings					
	Model 1			Model 2		
	B	OR	CI	B	OR	CI
Care Receiver Characteristics						
Age	0.01	1.01	0.98–1.04	0.01	1.01	0.98–1.05
Male	0.15	1.17	0.65–2.09	0.05	1.05	0.60–1.85
Fall in last month	0.85**	2.33	1.40–3.87	0.82***	2.26	1.43–3.57
IADL and ADL disability	–0.02	0.98	0.92–1.04	–0.06	0.95	0.89–1.01
Chronic Medical Conditions	–0.01	0.99	0.87–1.13	–0.03	0.97	0.85–1.10
Caregiver Characteristics						
Age	–0.01	0.99	0.97–1.01	–0.01	0.99	0.97–1.01
Male	–0.21	0.81	0.53–1.24	–0.34	0.71	0.46–1.11
Education						
College or higher	0.26	1.30	0.64–2.64	0.31	1.36	0.65–2.83
Greater than high school	0.31	1.36	0.78–2.39	0.30	1.35	0.78–2.34
Less than high school (ref)	--	--	--	--	--	--
Relationship to Care Receiver						
Spouse	0.14	1.15	0.41–3.21	–0.02	0.98	0.35–2.76
Child	0.29	1.34	0.72–2.48	0.17	1.18	0.64–2.20
Other (ref)	--	--	--	--	--	--
Chronic Medical Conditions	0.28***	1.33	1.16–1.52	0.29***	1.34	1.17–1.53
Emotional Difficulty of Care	0.16*	1.17	1.02–1.35	0.10	1.10	0.97–1.24
Care provision interrupted sleep		--		0.40***	1.49	1.21–1.84
Goodness of Fit						
Wald F Test		3.1(13,55)**			5.19(14,53)***	

p<.001

**
p<.01

*
p<.05

B= beta estimate, OR= odds ratio, CI= 95% confidence interval; The sample for this analysis includes 451 same-household caregivers of care receivers with dementia. Model 1 presents results of the original hypothesized model and Model 2 presents a post-hoc test where a variable reflecting whether care provision for the care receiver interrupted the caregiver’s sleep was also included.