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Sleep Problems, Anxiety, and Global Self-Rated Health Among Hospice Family Caregivers

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Abstract

Background: While research has linked sleep problems, anxiety, and poor health outcomes among patients' family members in non-hospice settings, little is known about these often interrelated issues among hospice family caregivers.

Objectives: We sought to examine the relationships between sleep problems, anxiety, and global self-rated health among hospice family caregivers.

Methods, Setting, and Subjects: We conducted a secondary analysis of quantitative data from 395 family caregivers of hospice patients in the Midwest and Southeastern United States.

Results: Nearly one-third of the hospice family caregivers who participated in this study experienced clinically noteworthy levels of sleep problems and/or anxiety. Caregivers' symptoms of anxiety and sleep problems were strongly correlated. Caregivers who reported more frequent sleep problems and higher levels of anxiety reported poorer overall health.

Conclusions: Hospice providers, who are charged with attending to the needs of both patients and their family caregivers, may improve their practice by regularly assessing for sleep problems and anxiety among family caregivers and providing appropriate interventions or referrals.

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Keywords

caregivers; hospice; sleep; anxiety; health; end-of-life care

Introduction

In addition to providing care to patients with life-limiting illnesses, members of hospice interdisciplinary teams offer substantial support to patients' family members and friends, particularly those who are involved in managing patients' pain and other distressing symptoms.¹ Commonly referred to as "family caregivers," these individuals provide a substantial proportion of the daily care received by hospice patients, who are significantly more likely to receive services in the community than in an inpatient hospice unit.² While many family members cite positive aspects of caregiving, such as being able to reciprocate previously provided care and experiencing a strengthened relationship with the care recipient,³ hospice family caregivers typically face a wide variety of stressors,⁴ which can lead to a number of problematic physical and psychological outcomes.^{5,6}

Problems with sleep are commonly reported by family caregivers of seriously ill patients,⁷⁻¹⁰ including those receiving hospice services.⁴ In addition to being inherently problematic for caregivers themselves, poor sleep has the potential to negatively affect care provided to patients, as sleep-deprived caregivers may experience increased fatigue, cognitive impairment, and negative mood,¹¹ likely limiting their effectiveness. Research has shown that family caregivers' sleep problems are often accompanied by anxiety.^{4,12} For example, caregivers residing with a seriously ill patient may worry they will sleep through a medical emergency and be unable to assist their care recipient in accessing needed help,¹³ or they may lie awake worrying about other stressors, such as financial problems, interfering with their ability to fall asleep.

Sleep disturbances have been shown to place individuals at higher risk for numerous health problems such as cardiovascular disease,¹⁴ kidney disease,¹⁵ and impaired immune function.¹⁶ While compelling evidence has linked sleep loss, stress, and risk of chronic disease among family caregivers,¹⁷ research on sleep disturbances among individuals in specialized caregiving situations, such as hospice, is limited. Of the few studies that have specifically examined sleep disturbances among hospice family caregivers, most have focused on bereavement versus active caregiving and/or were conducted outside the United States (US),^{18,19} where hospice and family caregiving policies differ significantly from those in the US. Additional limitations of prior research on this topic include decidedly small sample sizes and inadequate investigation into the role of comorbid anxiety and sleep disturbance. Thus, we conducted the study described herein, the purpose of which was to examine the relationships between sleep problems, anxiety, and global self-rated health among hospice family caregivers. Based on existing research conducted with similar populations, we hypothesized that anxiety and sleep problems would be strongly correlated and that caregivers with less frequent sleep problems and lower anxiety would report better health than those with more frequent sleep problems and higher anxiety.

Methods

Data Sources

We performed a secondary analysis of data pooled from two separate original studies: a randomized clinical trial of a hospice family caregiver support intervention (National Institute of Nursing Research; Principal Investigator (PI): AUTHOR) and an observational study of hospice family caregivers' stress and coping experiences (Hartford Geriatric Social Work Scholars Research Grant; PI: AUTHOR). Both studies were reviewed and approved by the Institutional Review Board of the respective investigators' academic institutions prior to participant recruitment. Data collection for these studies occurred between 2008 and 2014 in partnership with community-based hospice agencies in the Midwest and Southeastern regions of the US. Detailed protocols for both studies have been published elsewhere (AUTHOR, in press; AUTHOR, 2015). To avoid capturing any intervention effects in our measurements, only baseline (i.e., pre-intervention) data generated during the randomized clinical trial were included in the analysis.

Measures

Caregiver and patient demographics.—Caregiver characteristics included age, gender, marital status, race, employment status (employed part- or full-time, not employed), relationship to patient (spouse/partner, adult child, other - which includes siblings, parents, in-laws, etc.), and residence (resides with the hospice patient, does not reside with the hospice patient). Patient characteristics included age, residence (lives in private residence vs. non-private residence), and primary diagnosis (cancer, dementia). Study site (Midwest or Southeast) was also examined.

Sleep problems.—The 9-item Patient Health Questionnaire (PHQ-9) includes a single item specific to sleep problems. Family caregivers indicated how often in the prior two weeks they had experienced having “trouble falling or staying asleep, or sleeping too much.” Responses ranged from 0 (“not at all”) to 3 (“nearly every day”).²⁰

Anxiety.—Family caregivers' anxiety was measured using the Generalized Anxiety Disorder 7-item (GAD-7) scale,²¹ which measures how often respondents experience symptoms of anxiety such as not being able to stop or control worrying, having trouble relaxing, and being so restless that it is hard to sit still. GAD-7 total scores range from 0 to 21; higher scores indicate greater anxiety. Total scores of 5, 10, and 15 represent thresholds for mild, moderate, and severe anxiety, respectively. Scores greater than or equal to 10 are generally considered clinically significant and signal the need for additional assessment and possible intervention.²¹ Previous studies have determined the internal consistency of the GAD-7 to be excellent (Cronbach's alpha = 0.92) and its test-retest reliability to be very good (intra-class correlation = 0.83).²¹

Global self-rated health.—Global self-rated health was based on family caregivers' responses to a single item asking them to rate their overall health as excellent, very good, good, fair, or poor. Use of a single item is a well-established approach to measuring global

self-rated health, and responses have been shown to be predictive of mortality risk in multiple studies.²² Higher values refer to the caregiver reporting better overall health.

Analysis—Descriptive statistics were examined for all patient and caregiver characteristics and outcomes for the full study population, as well as by study site. Chi square analyses (or t-tests for continuous variables) were utilized in an effort to examine differences between the two study populations. Additionally, a multivariable regression was used to model the associations between specific caregiver characteristics (age, gender, relationship to patient, residence, marital status, employment, anxiety levels, and sleep problems) and patient characteristics (age, residence, diagnosis) and with caregiver-reported levels of general health. All analyses were performed in SAS version 9.4.

Results

Patient and Caregiver Characteristics

The sample for the current study included 395 family caregivers, 43% of whom were from the Midwestern site (n = 171) and 57% of whom were from the Southeastern site (n = 224). Descriptive statistics for caregiver and patient characteristics overall and by study site are shown in Table 1. A majority of caregivers were female (82%), Caucasian (92%), and married (75%). Their mean age was 61 years (SD = 12.6 years). More than half (52%) of the caregivers reported residing with the patient, with a higher percentage reporting this from the Southeastern study site than the Midwestern study site (63% vs. 39%, respectively). Almost half (49%) of caregivers were adult children of the patient for whom they provided care, and 30% were spouses or partners. Thirty-four percent of caregivers were employed either full- or part-time, with caregivers at the Midwestern site having a higher rate of employment when compared to caregivers at the Southeastern site (42% vs. 29%, respectively).

Patients whose family caregivers were enrolled as study participants had a mean age of 79.4 years (SD = 12.8 years), and a majority lived in a private residence (67%). Thirty-seven percent of patients had a primary diagnosis of cancer, while 30% had a diagnosis of dementia. Patients at the Southeastern site had a significantly higher diagnosis rate of dementia ($p < .0001$) than those at the Midwestern site (45% vs. 11%, respectively).

The mean rating for the sleep item on the PHQ-9 was 1.1, corresponding to infrequent (i.e., experienced on half or fewer days within the prior two weeks) sleep problems. Sixty-nine percent of caregivers reported having had problems with sleep “not at all” or only on “several days” in the two weeks prior to their participation in the study, while 31% reported having experienced sleep problems “more than half the days” or “nearly every day.” No significant differences were found in caregivers’ reports of sleep problems between the Southeastern and Midwestern sites. With regard to anxiety, caregivers had mean GAD-7 scores of 7.3 (median score = 6, interquartile range = 0–21), with 33% of caregivers reporting moderate to severe levels of anxiety (i.e., GAD-7 scores equal to or greater than 10). Caregivers from the Midwestern site reported significantly lower levels of anxiety than caregivers from the Southeastern site [$\chi^2(2, 391) = 11.77, p < .001$].

Global Health among Hospice Family Caregivers

Caregivers had mean global health ratings of 3.3, with 82% reporting “good” to “excellent” health. Before adjusting for patient and caregiver characteristics, no significant differences were found in reports of general health by caregivers from the Midwestern and Southeastern sites. In order to examine the association of patient and caregiver characteristics with global health, a multivariable regression model was conducted (Table 2). As hypothesized, anxiety and sleep problems were found to be highly correlated ($r = 0.57$, $p < .0001$, $n = 391$) and, after adjusting for patient and caregiver characteristics, caregivers who had less anxiety [$\beta = -.14$, $t(360) = -2.35$, $p = .01$] and less frequent sleep problems [$\beta = -.19$, $t(360) = -3.24$, $p < .001$] reported better general health. In addition, caregivers were more likely to have better health ratings when they were married [$\beta = .14$, $t(360) = 2.75$, $p < .01$], employed [$\beta = .23$, $t(360) = 4.36$, $p < .0001$], or were from the Southeast [$\beta = .17$, $t(360) = 3.22$, $p < .001$]. Overall model fit was good [$R^2 = .18$, $F(13, 360) = 6.46$, $p < .0001$].

Discussion

Consistent with our hypothesis and the extant literature,¹⁷ we found a strong correlation between anxiety symptoms and sleep problems among hospice family caregivers. In addition, also as hypothesized, we found that caregivers who reported more frequent sleep problems and higher levels of anxiety reported poorer overall health. These findings highlight a number of opportunities for hospice teams to intervene to improve caregiver wellbeing, both emotionally and physically.

Research has previously identified an association between hospice caregiving and deterioration in physical health.⁵ If, as these data suggest, anxiety and sleep problems play a role in this physical decline, it is incumbent upon hospice providers to familiarize themselves with interventions designed to combat anxiety and promote restful sleep among family caregivers. Problem solving therapy, for example, has been found to be associated with decreased anxiety among hospice family caregivers,²³ while behavioral interventions have shown promise as a strategy to improve caregiver sleep.^{24,25} It is important to note, however, that caregiver sleep problems are often complex and attributable to a variety of different, potentially interrelated factors.⁹ Therefore, caregiver sleep interventions should be based on a thorough assessment of caregivers' sleep problems. If, for example, a caregiver experiences poor sleep quality because of nighttime caregiving responsibilities (e.g., administration of pain medication), the appropriate intervention may be quite different than if she struggles to initiate sleep due to worrying. Furthermore, the relationships between sleep, anxiety, and health are often bidirectional; while anxiety and poor sleep can lead to health problems, health problems can also cause anxiety and sleep problems.^{26,27} Thus, one of the first courses of action for a hospice provider working with a family caregiver experiencing anxiety or sleep problems may be to encourage the caregiver to schedule an appointment with a primary care provider, a preventive health behavior that caregivers often neglect due to competing demands on their time.²⁸ This will also broaden the intervention options available, as some potentially appropriate treatments (e.g., anxiolytics, sleep medications, continuous positive airway pressure) require a prescription to access. Regardless of the specific intervention approach ultimately adopted, these study findings

reveal an additional opportunity for hospice teams to support the family members and friends who provide often invaluable care to patients in their final days of life.

Study Limitations and Suggestions for Future Research

A number of study limitations warrant attention. First, both sleep and global health are complex constructs with an array of instruments available to measure them. The data available for this secondary analysis were originally collected via single-item, self-report measures of these constructs. Future research on sleep and health among hospice family caregivers would benefit from more comprehensive measurement strategies, potentially including biomarkers and/or sleep actigraphy to provide more objective data to supplement self-reports. Second, sleep is highly complex, and the etiologies of sleep disturbances among family caregivers vary widely.^{8,9,17,25,29} The available data did not allow us to distinguish between caregivers' experiences of insomnia and sleep apnea or other occult sleep disorders, which would point to different diagnostic and treatment approaches. For example, for caregivers whose sleep complaints take the form of excessive daytime sleepiness (e.g., increased likelihood of falling asleep in sedentary situations, such as at a traffic light or while watching television), polysomnography may be recommended to rule out sleep apnea or other occult sleep disorders. If sleep apnea is identified, the prescribed treatment may involve continuous positive airway pressure therapy,³⁰ whereas cognitive behavioral therapy is recommended as the first-line treatment for adults with chronic insomnia.³¹ This distinction is particularly relevant to this study population, which includes predominantly older females, given that sleep apnea rates increase with age and, for women, with menopause.³² Third, while data analyzed in this study were collected from samples in two different geographic regions of the US, these volunteer samples are not necessarily representative of all hospice family caregivers, limiting our ability to generalize study findings to other populations. Of particular note is that 92% of the caregivers in our sample were Caucasian. Additional research is needed to determine the extent to which the results of this study are applicable to caregivers of other racial groups. Further, it would be useful in future research to include data from non-hospice family caregivers to examine the role various factors (e.g., end-of-life stage of caregiving, receipt of hospice) play in problems with sleep, anxiety, and/or health. Finally, the item we used to measure sleep problems is one of nine items included on the PHQ-9, an instrument used to screen, diagnose, and monitor the severity of depression.²⁰ To avoid problems associated with multicollinearity in our analysis, we opted not to include the total depression score in our regression model, although important links between depression, sleep, and health are well-established in the literature.¹⁷ This further underscores the need for researchers to employ alternate sleep measures in future research on this important topic.

Conclusion

Sleep problems and anxiety are potentially serious issues experienced by nearly one-third of the hospice family caregivers who participated in this study. Hospice providers, who are charged with attending to the needs of both patients and caregivers, may improve their practice by regularly assessing for these conditions among caregivers and providing interventions, as appropriate to their scope of practice, or referrals to other healthcare

providers to address these concerns. Because the relationships among sleep problems, anxiety, and physical health are complex and often interrelated, hospice providers should encourage family caregivers to establish or maintain a relationship with a primary healthcare team.

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Table 1.

Characteristics of hospice patients and caregivers

	<i>Total</i>		<i>Study Site</i>				<i>p</i>
	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>	
<i>Overall</i>	395	—	171	43.3	224	56.7	—
<i>Patient Characteristics</i>							
Age, mean (SD)	392	79.4 (12.8)	171	79.2 (13.8)	221	79.5 (13.9)	.84
Has cancer	147	37.22	55	32.16	92	41.07	.06
Has dementia	119	30.13	19	11.11	100	44.64	<.0001
Lives in home (private) residence	263	66.58	102	59.65	161	71.88	.005
<i>Caregiver Characteristics</i>							
Age, mean (SD)	395	60.6 (12.6)	171	59.6 (12.4)	224	61.4 (12.7)	.16
Female	322	81.52	142	83.04	180	80.36	.55
White/Caucasian	362	91.65	155	90.64	207	92.41	.52
Lives with patient	207	52.41	66	38.60	141	62.95	<.0001
Employed	135	34.18	71	41.52	64	28.57	.005
Married	295	74.68	124	72.51	171	76.34	.34
Relationship to patient							.05
Spouse/partner	120	30.38	44	25.73	76	33.93	
Adult child	194	49.11	96	56.14	98	43.75	
Other	80	20.25	31	18.13	49	21.88	
PHQ-9 Item 3							
Trouble falling asleep/sleeping too much							
Mean (SD)	395	1.11 (1.08)	171	1.10 (1.01)	224	1.12 (1.13)	.85
Not at all	143	36.20	56	32.75	87	38.84	.07
Several days	131	33.16	64	37.43	67	29.91	
More than half the days	53	13.42	28	16.37	25	11.16	
Nearly every day	68	17.22	23	13.45	45	20.09	
<i>GAD-7 Anxiety Score</i>							
Mean (SD)	391	7.3 (5.6)	171	6.2 (4.9)	220	8.2 (6.0)	<.001
Severity, %							
Minimal (0–4)	150	38.37	78	45.61	72	32.72	.002
Mild (5–9)	111	28.38	52	30.41	59	26.81	
Moderate (10–14)	80	20.47	29	16.96	51	23.18	
Severe (≥15)	50	12.78	12	7.02	38	17.29	
Global Health Rating							
Mean (SD)	395	3.3 (0.9)	171	3.2 (0.9)	224	3.4 (1.0)	.08
Severity, %							
Poor	15	3.80	4	2.34	11	4.91	.06
Fair	55	13.92	30	17.54	25	11.16	
Good	158	40.00	74	43.27	84	37.50	

	<i>Total</i>		<i>Study Site</i>				<i>p</i>
	<i>n</i>	<i>%</i>	<i>Midwestern</i>		<i>Southeastern</i>		
			<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>	
Very good	120	30.38	49	28.65	71	31.70	
Excellent	47	11.90	14	8.19	33	14.73	

SD = standard deviation

Table 2.

Multivariable regression predicting general health among hospice family caregivers

	<i>General Health^a</i>			
	Estimate	Standardized Estimate	(95% CI)	P
<i>Intercept</i>	3.07	--	(2.60 – 3.55)	<.0001
Southeastern Site	0.17	0.18	(0.07 – 0.28)	<.001
<i>Patient Characteristics</i>				
Age ^b	0.01	0.07	(0.00 – 0.01)	.26
Cancer	0.09	0.04	(–0.13 – 0.30)	.41
Dementia	–0.12	–0.06	(–0.36 – 0.11)	.31
<i>Caregiver Characteristics</i>				
Age ^b	–0.01	–0.12	(–0.02 – 0.00)	.06
Female	0.22	0.09	(–0.03 – 0.46)	.07
Relationship to patient ^c				
Adult child	–0.07	–0.04	(–0.38 – 0.24)	.64
Other	–0.15	–0.06	(–0.50 – 0.19)	.38
Lives with parent	–0.14	–0.07	(–0.36 – 0.09)	.23
Married	0.33	0.15	(0.09 – 0.56)	<.01
Employed	0.47	0.23	(0.26 – 0.68)	<.0001
Anxiety ^d	–0.02	–0.14	(–0.04 – –0.00)	.01
Sleep problems ^e	–0.17	–0.19	(–0.28 – –0.07)	<.001

^aNotes. global health item, higher values equate to better health.^bpatient and caregiver age was righted at the mean^creference = spouse or partner.^dGAD-7 anxiety score, higher values equate to higher levels of anxiety.^ePHQ-9 item 3, higher values equate to having more frequent problems with sleep.