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Feature Article

Impact of Alzheimer disease patients' sleep disturbances on their caregivers

Philip Gehrman, PhD^{a,b}, Nalaka S. Gooneratne, MD, MSc^{b,c},
Glenna S. Brewster, PhD, CRNP^{b,d,*}, Kathy C. Richards, PhD^e, Jason Karlawish, MD^c^a Department of Psychiatry, University of Pennsylvania School of Medicine, USA^b Center for Sleep and Respiratory Neurobiology, University of Pennsylvania School of Medicine, USA^c Division of Geriatric Medicine, University of Pennsylvania School of Medicine, USA^d New Courtland Center for Transitions and Health, University of Pennsylvania School of Nursing, Philadelphia, PA, USA^e School of Nursing, University of Texas at Austin, TX, USA

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ABSTRACT

Sleep disturbance symptoms are common in persons living with Alzheimer disease (AD). However little is known about the impact of sleep disturbance symptoms in patients living with AD on caregiver burden and quality of life (QoL). The aims of this study were to determine the prevalence of symptoms of disturbed sleep in patients with AD, identify the care-recipient sleep disturbance symptoms that predict caregiver burden and QoL, and determine how care-recipient sleep disturbance symptoms compare to other caregiver and patient characteristics when predicting caregiver QoL. Caregiver burden was assessed using the Screen for Caregiver Burden. Sixty percent of the care-recipients had at least one sleep symptom. In 130 caregiver/patient dyads, nocturnal awakenings, nocturnal wandering, and snoring predicted caregiver burden. Multivariate modeling demonstrated that caregiver burden, caregiver physical and mental health, and caregiver depression were predictors of overall caregiver QoL. Treating disturbed sleep in care-recipients and caregiver mental health symptoms could have important public health impact by improving the lives of the caregiving dyad.

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Introduction

Persons living with Alzheimer's disease (AD) have disrupted sleep, with prevalence rates as high as 71%.^{1–3} They frequently have altered circadian rhythms that contribute to fragmented sleep and waking patterns.⁴ Persons with AD have significantly higher average frequency ratings on number of nightly awakenings, nightly sleep duration, time taken to fall asleep, time awake during night, waking up too early, and restless sleep.⁵ These sleep disturbance symptoms can also result in sleep disturbance symptoms for caregivers with up to 66% of caregivers of persons with AD reporting sleep disturbance symptoms such as longer sleep onset latency, longer wake after sleep onset, frequent awakenings and poor sleep quality.^{6–8}

In addition to experiencing sleep disturbance symptoms, caregivers also report high burden.⁶ One survey of 205 AD patients' caregivers examined the frequency and severity of burden caused by seven sleep-related patient behaviors.⁹ Roughly one-third of respondents had a "high disturbance" score, indicating that patients' sleep problems were a source of significant caregiver burden. However, Tractenberg and colleagues¹⁰ found that some sleep behaviors rated as the most frequent or severe were not associated with the highest ratings of burden. For example, daytime napping received one of the highest frequency ratings but the lowest burden rating. These results suggest that the presence of sleep disturbance in patients with AD does not necessarily increase the burden of caregiving and that the level of burden can vary considerably based on the type of sleep abnormality.

Research has also shown that caregivers also report lower quality of life (QoL).^{11,12} Caregivers are at greater risk for mental and physical health problems including depression,^{6,13,14} and overall poor health compared to age-matched non-caregiver controls¹⁵ which can contribute to their assessment of a poor QoL. Moon and colleagues¹⁶ reported that higher care-recipient activities of daily living (ADL) limitations were also associated with lower QoL.

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* Corresponding author. 3624 Market Street, Suite 205, Philadelphia, PA 19104-2676, USA.

E-mail address: glennabrewster@gmail.com (G.S. Brewster).

To elucidate the role that caregiver-perceived care-recipient sleep disturbance symptoms play in AD caregiving, we examined the relationships among caregiver reports of patients' sleep disturbance symptoms and caregivers' burden and QoL. The aims of the present investigation were thus to 1) determine the prevalence of symptoms of disturbed sleep in patients with AD, 2) identify the care-recipient sleep disturbance symptoms that predict caregiver burden and QoL, and 3) determine how care-recipient sleep disturbance symptoms compare to other caregiver characteristics, such as depressive symptoms and finances, and patient factors, such as functional status, when predicting QoL. We hypothesized that the caregiver-perceived sleep disturbance symptoms which involved caregiver awakening, i.e., nocturnal wandering, nocturnal awakening, and snoring, would predict caregiver burden; however, they would not be as important in predicting QoL when other caregiving factors are included in the model.

Methods

The study was a cross-sectional, secondary data analysis of data collected from caregivers of community-dwelling patients who met National Institute of Neurological and Communicative Disorders and Stroke/Alzheimer Disease and Related Disorders Association criteria for probable or possible AD.¹⁷ The survey was conducted during the semi-annual visit at the Penn Memory Center of the University of Pennsylvania's Alzheimer Disease Center. Caregivers provided written informed consent prior to completing the surveys, and the study was approved by the University of Pennsylvania Institutional Review Board.

Measures

In addition to demographics, caregivers completed questions about burden, QoL, physical and mental health status, depressive symptoms, care-recipients' ability to perform basic activities of daily living (BADLs) and instrumental activities of daily living (IADLs), and care-recipients' sleep. The physician assessed care-recipients' depression and cognitive impairment.

Demographics

Demographic information collected from the caregiver included the relationship with the care-recipient, education, employment status, and monthly household income.

Burden

Caregiver burden was assessed using the Screen for Caregiver Burden (SCB), a 25-item scale that measures level of caregiver distress from various patient behaviors.¹⁸ To calculate a burden score, the "no occurrence" and "occurrence, but no distress" response options were each assigned a score of 1, while the other response options retained their scoring (i.e., "occurrence with moderate distress" has a score of 3). The scores were then summed. Scores ranged from 25–100.¹⁸ The SCB has been found to be reliable with caregivers of persons with AD.¹⁹

Quality of life

QoL was assessed using a single item that asked caregivers to "Please rate your overall quality of life at present" and was followed by five Likert options ranging from "poor" to "excellent" (1–5, respectively).²⁰

Physical and mental health status

Physical and mental health status were assessed using the Medical Outcomes Survey Short-Form: Physical and Mental Composite Score [SF-12 PCS; SF-12 MCS]. The SF-12 PCS provides an

overall physical health rating (range: 0–100) with higher scores indicate greater perceived physical health. The SF-12 MCS provides an overall mental health rating (range: 0–100) with high SF-12 MCS scores indicating better overall emotional well-being.^{21,22} The SF-36 scale has been found to be reliable with older adults.²³

Depressive symptoms

Caregiver depressive symptoms were measured using the 10-item Center for Epidemiologic Studies Depression scale (CES-D 10).²⁴ A single score was computed as a sum of the individual questions (possible range 0–24), with higher scores indicating greater depressive symptomatology and scores ≥ 7 indicating significant depressive symptomatology.²⁴ The CES-D 10 has been found to be valid and reliable with older adults.²⁵

Care recipient's ability to perform basic activities of daily living (BADLs) and instrumental activities of daily living (IADLs): Caregivers responded to one question each that asked if the care-recipients needed assistance with BADLs and IADLs (yes or no response).

Caregiver perception of care-recipients' sleep

Caregivers rated several aspects of the care-recipients' sleep over the past month: sleep latency (the amount of time taken to fall asleep), average number of nocturnal awakenings, frequency of nocturnal wandering, frequency of loud nocturnal snoring, and average duration of daytime naps. Each question was followed by five to six Likert-style response options (Fig. 1). Care-recipients were considered to have symptoms of sleep disturbance if they were reported to have any of the following: a sleep latency greater than 30 min, three or more nocturnal awakenings per night, frequency of nocturnal wandering greater than once per month, frequency of loud snoring greater than twice per week, and/or spending greater than 1 h asleep during the day. These thresholds were based on criteria commonly used in clinical trials of interventions for sleep disturbance as well as clinical judgment.^{26–28}

Care-recipients' depressive symptoms

The 15-item Geriatric Depression Scale (GDS)-short form, administered to the patient by the clinician, rated the patient's depressive symptoms.²⁹ Higher scores (range of 0–15; scores > 5 suggest depression) indicate more severe depression. The 15-item GDS has been found to be reliable and valid with older adults.³⁰

Care-recipients' cognitive status

Care-recipients' cognitive status was assessed with the Mini-Mental Status Examination (MMSE), which has a range of scores from 0 to 30, with lower scores indicating more severe dementia.³¹ The MMSE has been found to be reliable and valid with older adults.^{32,33}

Statistical analysis

Descriptive statistics were computed to characterize sleep in the persons with AD. As part of this descriptive analysis, we examined the level of caregiver burden associated with specific sleep symptoms using univariate linear regression models. Individuals who responded "don't know" to specific sleep questions were excluded from the analysis related to that question. To correct for multiple comparisons, a conservative Bonferroni correction was used. We then examined the effect of the sleep disturbance symptoms on caregiver QoL. Factors significantly associated with caregiver QoL at a $p < 0.10$ were included in a multivariate stepwise linear regression analysis. All statistical analysis was done using SPSS v24.

Results

The initial study population consisted of 203 community-dwelling caregiver and care-recipient pairs. Data were not used if

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