

Factors Associated With Caregiver Reports of Sleep Disturbances in Persons With Dementia

*Susan M. McCurry, Ph.D., Michael V. Vitiello, Ph.D.,
Laura E. Gibbons, Ph.D., Rebecca G. Logsdon, Ph.D.,
Linda Teri, Ph.D.*

Objective: *This investigation examined the relationship between caregivers' reports of sleep disturbances in persons with Alzheimer disease (AD) and actigraphic records of patients' sleep-wake activity, and explored the factors associated with discrepancies in this relationship. **Method:** Forty-six patients with AD living with their caregivers participated. Before study entry, all caregivers reported poor patient sleep quality using the Neuropsychiatric Inventory (NPI) Nighttime Behavior Scale. Patient sleep-wake activity was recorded for one week using an Actillum wrist-movement recorder. **Results:** Although all patients were reported by caregivers to have multiple sleep disturbances, 41% of patients had actigraphic sleep efficiencies in the normal range and 43% averaged eight or more hours of sleep nightly. In bivariate analyses, greater patient percent nighttime sleep (indicative of more discrepancy between subjective reports and objective outcomes) was associated with less patient cognitive, physical and functional impairment, lower self-rated depression, higher self-rated quality of life, and less daytime sleepiness. No patient variable significantly predicted total patient nocturnal sleep time. In both bivariate and multivariate analyses, greater patient percent sleep and total sleep time were also associated with caregiver factors, particularly greater use of criticism as a behavior management strategy. **Conclusion:** The study suggests that both patient and caregiver factors contribute to reported sleep problems in community-dwelling patients with AD, and that caregiver reports and objective sleep assessments frequently may not agree. Treatments should consider these dyadic contributions rather than focusing on caregiver reports of patient symptoms alone. (Am J Geriatr Psychiatry 2006; 14:112-120)*

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Received March 11, 2005; revised August 25, 2005; accepted August 29, 2005. From the Departments of Psychosocial and Community Health (SMM, RGL, LT), Psychiatry and Behavioral Sciences (MVV), and General Internal Medicine (LEG), University of Washington, Seattle, WA. Send correspondence and reprint requests to Susan M. McCurry, Ph.D., University of Washington, 9709 3rd Ave., N.E., Suite 507, Seattle, WA 98115-2053. e-mail: smccurry@u.washington.edu

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Caregivers frequently report sleep problems in their family members with dementia.¹⁻³ Persons with Alzheimer disease (AD) experience changes in sleep architecture, circadian rhythmicity, and thermoregulation compared with normal older adults.^{4,5} These changes are predominantly caused by degenerative changes in neuronal pathways that determine tendency toward sleep and wakefulness,⁶ but medical illness, primary sleep disorders, and psychiatric and environmental influences impact patient sleep quality as well.⁷⁻¹⁰ Clinicians who are faced with caregiver complaints that their demented family member is not sleeping usually treat the patients with AD accordingly, often with a sedating medication. However, is this necessarily the correct thing to do?

Because of the side effects and risks associated with the use of sedative-hypnotic medications in older adults, clinicians need accurate information about AD patients' sleep disturbances to treat them properly. This article explores whether caregivers accurately report the extent of their family members' sleep problems. "Sleep state misperception," a term coined to describe persons who report significant sleep difficulties in themselves that are not evident on objective sleep assessment such as polysomnography, is a fairly common phenomenon.¹¹ If self-reported sleep complaints do not always correspond with objective measurements of sleep quality, can we be sure that proxy reports of another person's sleep are always reliable? This investigation examined the relationship between caregiver subjective reports of sleep disturbances in family members with AD and actigraphic objective records of patient sleep-wake activity. It is the first study of which we are aware to identify factors associated with discrepancies between the objective sleep quality of persons with dementia and caregivers' subjective reports about patient sleep quality.

METHODS

Patients

Forty-six community-dwelling persons with probable or possible AD and their caregivers were en-

rolled in a study of sleep disturbances in dementia.¹² All patients were diagnosed with probable or possible AD confirmed in writing by their family physicians. Patients ranged in age from 63-93 years, were predominantly female (54%), white (87%), and had dementia for an average of 5.7 years (standard deviation [SD]: 3.2). Mean Mini-Mental State Examination (MMSE) score was 12.1 (SD: 8.9).

Caregivers

Caregivers were spouses or adult relatives who lived with the patient and could monitor nightly sleep and implement treatment recommendations. Caregivers' ages ranged from 21-87 years; 65% were female, 85% were white, and 54% were spouses.

Measures

Sleep. Caregivers' subjective impressions of patient sleep were reported using the Neuropsychiatric Inventory (NPI) Nighttime Behavior scale.¹³ The scale includes eight items that are rated as to how often they occurred during the past month. To be eligible for inclusion, caregivers had to endorse two or more items for the patient as occurring at least three to six times per week.

Objective sleep was based on one week of sleep-wake activity measured for all patients and caregivers using an Actillum wrist-movement recorder (Ambulatory Monitoring, Inc., Ardsley, NY). The Actillum is a matchbox-sized device worn on the wrist. It contains a piezoelectric linear accelerometer, a microprocessor, 32K-byte random access memory, and associated circuitry for the purpose of recording intensity and frequency of movement. This results in two variables: the sum activity (average of all activity movements per minute) and the maximum activity (the largest or maximum movement per minute). The Actillum also contains a log-linear photometric transducer that records illumination readings from a range below full moonlight to the brightest summer day at noon. The Action3 software package (Ambulatory Monitoring, Inc.), which incorporates Cole and Kripke's¹⁴ sleep scoring algorithm, was used to score sleep/wake based on sum and maximum activity. Sleep variables included total minutes of nighttime sleep, percent time asleep, number of awakenings, duration of time awake at night, total

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daytime sleep, and circadian rest–activity variables. Two actigraphic patient sleep variables—percent nighttime sleep (mean: 80.0%, SD: 13.1) and total nocturnal sleep (mean: 7.6 hours, SD: 1.9)—were the focus of this exploratory study, because it was judged that they provided the best comparison against caregiver subjective reports of patient sleep quality.

The night (in-bed) period was defined as “lights out” at bedtime until the final morning rising (out of bed). Sleep diary reports completed by caregivers were used in conjunction with Actillum activity and light data to create the in-bed (nocturnal sleep periods) and out-of-bed (daytime) periods for actigraphy sleep analyses. All Actillum sleep variables were derived from the sum activity channel, except daytime sleep hours, which were derived using the maximum activity channel because the increased sensitivity to movement decreased the likelihood that patients sitting quietly awake during the day would be recorded as asleep.

Secondary outcome measures. For this descriptive study, secondary outcome measures theorized to relate to patient or caregiver sleep or to caregiver coping with patient nocturnal disturbances were included. Assessments included patient self-ratings of mood and quality of life and caregiver ratings of patient physical and functional status, daytime sleepiness, and behavioral disturbance. Caregivers also reported on their own nighttime sleep, mood, health, stress, burden, and dementia management style. Baseline values for patient and caregiver secondary measures are shown on Table 1.

Patient Measures

1. The *Geriatric Depression Scale* (GDS)¹⁵ is a 30-item questionnaire that was used as a measure of patient self-reported depression.
2. The *Quality of Life in Alzheimer’s Disease* (QOL-AD)¹⁶ is a 13-item scale that was used to obtain patient self-ratings of their quality of life.

TABLE 1. Baseline Characteristics of Patients With AD and Caregivers (N = 46)

	Mean	SD	Range
Patient self-report			
Geriatric Depression Scale (GDS)	7.6	5.1	1–17
Quality of Life in Alzheimer’s Disease (QOL-AD)	35.6	5.7	26–48
Caregiver reports about patient			
Cornell Scale for Depression in Dementia	9.0	4.9	3–24
Epworth Sleepiness Scale (ESS)	14.2	6.1	0–29
Revised Memory and Behavior Problems Checklist (RMBPC)			
Memory	3.0	0.9	0.7–4.0
Depression	0.9	0.6	0–2.6
Disruption	1.0	0.6	0.1–3.1
Physical Self-Maintenance Scale (ADL)	14.5	5.6	6–25
Instrumental Activities of Daily Living Scale (IADL)	26.3	4.8	14–31
SF-36 Health Status Survey			
Physical Functioning	34.7	29.0	0–95
Physical Role Functioning	29.9	37.5	0–100
Caregiver self-report			
Pittsburgh Sleep Quality Index (PSQI)	8.6	3.6	1–18
Center for Epidemiological Studies Depression (CES-D)	13.4	9.4	1–36
Screen for Caregiver Burden (SCB)			
Objective	11.3	3.6	2–18
Subjective	21.0	9.4	2–48
Perceived Stress Scale (PSS)	19.8	9.2	0–47
Dementia Management Strategies Scale (DMSS)			
Criticism	23.5	6.3	12–43
Encouragement	26.7	5.7	16–38
Active management	35.7	5.1	24–43
SF-36 Health Status Survey			
Physical Functioning	81.0	21.6	10–100
Physical Role Functioning	63.6	42.1	0–100

SD: standard deviation.

3. The *Cornell Scale for Depression in Dementia*¹⁷ is a 19-item, clinician-rated scale of depression symptoms that was designed for use with dementia patients.
4. The *Epworth Sleepiness Scale* (ESS)¹⁸ provided caregiver estimates of patient sleepiness in eight everyday situations (e.g., watching TV).
5. The *Revised Memory and Behavior Problems Checklist* (RMBPC)¹⁹ provided caregiver reports of the average frequency of 24 dementia-related memory, depression, and disruptive behaviors.
6. The *Physical Self-Maintenance and Instrumental Activities of Daily Living Scales* (PSM, IADL)²⁰ provided a caregiver-rated assessment of patient functioning in 14 ADL/IADL activities.

Caregiver Self-Report Measures

1. The 19-item *Pittsburgh Sleep Quality Index* (PSQI)²¹ and the nine-item *Caregiver Sleep Questionnaire* (CSQ)²² provided caregiver ratings of their own sleep during the past month.
2. The *Center for Epidemiological Studies Depression scale* (CES-D)²³ assessed the frequency of 20 caregiver depression symptoms over the past two weeks.
3. The *Screen for Caregiver Burden* (SCB)²⁴ rated 25 items as to frequency of occurrence (objective burden) and level of distress each item caused the caregiver (subjective burden).
4. The *Perceived Stress Scale* (PSS)²⁵ is a 14-item self-report measure designed to measure nonspecific, appraised stress during the past month.
5. The *Dementia Management Strategies Scale* (DMSS)²⁶ rated the frequency with which caregivers use 28 critical, encouraging, and active management strategies to deal with dementia-related behavior problems in their patients.

Patient and Caregiver Health and Demographics (Caregiver-Rated)

1. The *SF-36 Health Status Survey* (SF-36) Physical Functioning and Physical Role Functioning subscales²⁷ were completed by caregivers to describe patient and caregiver functional health.
2. Demographic characteristics included patient and caregiver age, gender, ethnicity, education, relationship, patient MMSE score,²⁸ and dementia duration.

Statistical Methods

For this study, sleep misperception was defined as a discrepancy between caregiver subjective reports of patient sleep disturbances on the NPI and objective actigraphic sleep outcomes. This discrepancy was considered in two ways. First, patients were divided into two groups based on actigraphic estimates of percent nighttime sleep (ratio of time in bed versus time actually asleep) during the sampling week. Patients were considered "high percent sleep" if their average percent sleep was $\geq 85\%$, indicating that the patient was sleeping in the normal range for older adults.^{29,30} "Low percent sleep" patients were those with average percent sleep $< 85\%$ during the sampling week. Differences in caregiver reports of sleep problems on the NPI in the two percent sleep groups were compared using a Mann-Whitney test.

Second, linear regression was used to identify patient and caregiver characteristics that were independently associated with actigraphic estimates of percent nighttime sleep and total number of hours slept at night. Because caregivers had reported significant sleep problems in all subjects on the NPI, higher percent sleep (better sleep) and more hours of nocturnal sleep were considered indicative of greater discrepancy or more caregiver sleep misperception. For analysis purposes, the percent sleep scores were cubed to fulfill normality assumptions. Regression diagnostics indicated good fit for all models. Multivariate models for the two outcomes were built in a stepwise manner, selecting from all secondary outcomes, excluding those using patient self-report (because of missing data from patients who were unable to complete the GDS or QOL-AD) and those that were measuring sleep outcomes (the ESS, PSQI, and CSQ). The R^2 and R^2 -added were reported, indicating the percent of the variance that was explained by a variable.

RESULTS

Neuropsychiatric Inventory (Subjective) Sleep Ratings

All patients were reported by caregivers to have two or more sleep problems on the NPI that were occurring three or more times per week (mean: 4.2

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problems, SD: 1.5, range: 2–8). Getting up at night and awakening the caregiver were the most commonly reported problems (Table 2), and day/night reversal was the least frequently reported problem.

There were no significant differences between the high and low percent sleep groups in terms of caregiver age (t [44] = 0.14, p = 0.889), gender (Fisher exact, [42], p = 1.000), total PSQI (t [44] = 0.27, p = 0.787), or percent sleep (Mann-Whitney Z = 1.91, p = 0.056). However, caregivers of patients in the high percent sleep group reported significantly more problems with their patient awakening early on the NPI Nighttime Behavior scale than caregivers of patients in the low percent sleep group (Table 2).

Correlates of Sleep Misperceptions

Despite caregiver reports of frequent sleep problems, actigraphically measured patient sleep quality varied widely (Table 3). Forty-one percent of patients had estimated percent sleep $\geq 85\%$, and 43% of patients were averaging eight or more hours of sleep at night. Forty-seven percent of subjects who were sleeping eight or more hours per night also fell into the high percent sleep group.

In bivariate analyses, higher patient percent sleep (indicative of greater caregiver misperception) was significantly associated with more caregiver use of criticism as a behavior management strategy (F [1,40] = 13.52, p < 0.001) and more complaints about the

caregiver's own sleep on the CSQ (F [1,40] = 5.40, p = 0.025). Patient factors associated with higher percent sleep included significantly better patient scores on the SF-36 physical functioning subscale (F [1,40] = 6.11, p = 0.018), higher MMSE scores (F [1,39] = 5.26, p = 0.027), better IADL functioning (F [1,40] = 6.26, p = 0.017), and less daytime sleepiness reported by caregivers on the ESS (F [1,40] = 5.60, p = 0.023). Patients with higher percent sleep also scored significantly lower on self-reported depression on the GDS (F [1,21] = 4.60, p = 0.044) and had higher self-reported quality of life (F [1,24] = 7.18, p = 0.013).

When bivariate analyses were repeated using total nocturnal sleep time as the outcome instead of percent sleep, caregiver criticism was again the strongest predictor (F [1,40] = 15.07, p < 0.001). Objective caregiver burden was also significant (F [1,40] = 4.63, p = 0.038) with higher burden associated with longer sleep (greater misperception). No patient variable significantly predicted total nocturnal sleep time in the bivariate analyses.

In multivariate analysis, higher caregiver criticism and higher patient physical function were associated with greater percent sleep (F [2,39] = 13.83, p < 0.001). In building the model, caregiver criticism alone had an R^2 of 25% (F [1,40] = 13.52, p < 0.001). The R^2 -added for physical function was 16% (F [1,39] = 10.83, p = 0.002). Total nocturnal sleep time was associated with higher caregiver criticism and fewer

TABLE 2. NPI Nighttime Behavior Scale items (N = 46), Percent of Patients Reported to Have the Problem Occurring Three or More Times per Week During the Past Month*

NPI Items	All Patients (N = 46)	High Percent Sleep (SE $\geq 85\%$) (N = 19)	Low Percent Sleep (SE < 85%) (N = 27)	Mann-Whitney Test
Had difficulty falling asleep	30.4%	26.3%	33.3%	Z = -0.49; p = 0.624
Got up during the night (not counting routine bathroom trips)	80.4%	84.2%	77.8%	Z = 0.52; p = 0.604
Wandered, paced, or became involved in inappropriate activities at night	34.8%	42.1%	29.6%	Z = 0.85; p = 0.394
Awakened caregiver during the night	76.1%	73.7%	77.8%	Z = -0.30; p = 0.763
Awakened at night, dressed, and planned to go out thinking that it is morning and time to start the day	17.4%	15.8%	18.5%	Z = -0.22; p = 0.825
Awakened too early in the morning (earlier than was his or her habit)	32.6%	52.6%	18.5%	Z = 2.39; p = 0.017
Slept excessively during the day	60.9%	52.6%	66.7%	Z = -0.94; p = 0.349
Other nighttime or sleep-related behaviors that bothered caregiver	38.0%	31.6%	40.7%	Z = -0.61; p = 0.540

*Percent sleep groups based on Actilume estimates of patient nocturnal sleep versus time in bed. SE, sleep efficiency.

TABLE 3. Actigraphic Sleep Characteristics of Study Participants (N = 46 dyads)

	Patient		Caregiver	
	Mean (SD)	Range	Mean (SD)	Range
Actigraphy*				
Bedtime (pm)	21:34 (1:39)	17:55-01:55	23:09 (1:19)	20:20-02:53
Rising time (am)	7:50 (1:29)	03:42-11:46	7:11 (1:12)	04:38-10:35
Time in bed each night (hours)	9.6 (2.2)	3.6-14.0	8.0 (1.1)	6.0-11.1
Number of night awakenings	12.0 (10.0)	<1-41	6.5 (5.3)	1-25
Total sleep/night (hours)	7.6 (1.9)	1.8-13.1	7.0 (1.1)	3.4-8.9
Percent sleep	80.0 (13.1)	39.9-99.5	88.4 (10.6)	36.8-98.4
Daytime sleep (hours)	1.4 (1.4)	<0.1-5.2	0.5 (0.5)	<0.1-2.4

*Actigraphy sleep estimates are based on one week of wrist actigraphy; data presented are the mean of daily averages for each actigraphy variable. All estimates were derived from the sum (average) activity channel, except daytime sleep hours, which were derived using the maximum activity channel.

SD: standard deviation.

memory problems on the RMBPC ($F[2,39] = 10.3$, $p < 0.001$). Higher caregiver criticism alone had an R^2 of 27% ($F[1,40] = 15.07$, $p < 0.001$). The R^2 -added for memory problems was 7% ($F[1,39] = 4.37$, $p = 0.043$).

DISCUSSION

This investigation examined the relationship between caregivers' reports of sleep disturbances in persons with AD and actigraphic records of patients' sleep-wake activity. Almost half of patients who were reported by caregivers to be having multiple sleep disturbances occurring several times per week were actually sleeping well based on actigraphic estimates of percent nighttime sleep and total nocturnal sleep time. Patients who were objectively sleeping better were those who would be expected to do so based on their health and dementia status. Forty-seven percent of patients who were in the high percent sleep group were also sleeping eight or more hours per night, which may further explain why they were more likely to awaken early in the morning and less likely to be sleepy during the day. However, better patient sleep (i.e., more caregiver misperception) was also associated with caregiver factors, particularly a tendency to use criticism as a behavior management strategy. These findings suggest that perceived sleep disturbance in community-dwelling persons with dementia is a complex phenomenon that is affected by both patient and caregiver factors.

Better management of sleep and nighttime behavioral disturbances is a priority for persons with AD

and related dementias.³¹⁻³³ However, appropriate and effective treatment is dependent on accurate detection and diagnosis. The current study highlights a potential area of concern in dementia care, namely, that caregivers may not always be reliable reporters of nocturnal disturbances in their care recipients. In a worst case scenario, failure to appreciate the complexity of sleep disturbances in patients with dementia and the potential unreliability of caregiver reports could lead to aggressive pharmacologic treatment of someone who is, in fact, sleeping fairly well but who has a caregiver that is highly reactive to any patient nighttime wakefulness, regardless of its frequency or intensity.

Our findings can be considered in light of two separate bodies of research. The first has to do with the literature on sleep state misperception. The American Sleep Disorders Association divides persons with insomnia into objective or subjective subtypes depending on whether there is evidence that polysomnography (PSG) abnormalities support the sleep complaints.³⁴ There have been no large-scale, community-based studies examining the prevalence of subjective and objective insomnia subtypes in the general population. However, clinical reports suggest that misperceptions about one's inability to sleep are relatively common, that persons who fall into a subjective insomnia/sleep state misperception category may not respond to sleep interventions in the same way as their objective insomnia counterparts,¹¹ and that misperceptions about nighttime sleep may negatively influence patients' perceptions about daytime functioning as well.³⁵ Future research

is needed to determine whether caregiver misperceptions about their dementia patients' sleep quality are also common, and what implications this may have for patient and caregiver reactivity to sleep disturbances and their responsiveness to sleep interventions.

A second body of research relates to caregiver appraisals of general dementia-related behavior problems. Caregivers can be quite variable in how they react to, or appraise, patient behavioral challenges, and caregiver appraisal better predicts caregiver burden and patient institutionalization than does the actual frequency of patient behavior problems.^{36,37} A recent review of stress process theory posits that caregivers' appraisal of patient demands and of their own adaptive capacities influences their physiological and behavioral responses, thus altering caregivers' subsequent risk of physical and psychiatric disease.³⁸ Findings from the current study found that caregivers who were more critical of their patients' behavioral disturbances were also more likely to inaccurately report how well the patient with AD was sleeping at night. Future studies are needed to evaluate whether behavioral interventions that address caregiver appraisals of patient nocturnal disturbances are more effective than interventions that target patient health, sleep hygiene, or environmental factors alone.

Results of this investigation should be considered exploratory rather than definitive. The NITE-AD study, from which these data are taken, was not designed to answer the sleep misperception question considered here; rather, our interest in the question arose as we observed the perplexing phenomenon that substantial numbers of caregivers were enrolling patients into NITE-AD despite little actigraphic evidence that the patients were having sleep problems. Consequently, this study did not include measures selected to help clarify the sleep misperception question. The sample size was relatively small and included only patients who were reported by caregivers to be having difficulty sleeping. Furthermore, caregiver misperceptions are derived from actigraphic estimates of patient percent sleep and total nocturnal sleep time. The validity of actigraphy as an accurate measure of sleep/wake activity has been debated.³⁹ In normal adults, actigraphy tends to overestimate sleep compared with polysomnography because actigraphy cannot distinguish between

an individual lying quietly awake and one who is actually asleep.⁴⁰ It is unknown whether such overestimation contributed to apparent caregiver misperception in the "good sleepers" in this sample, but it seems unlikely that it would fully explain these study findings, because one would expect that patients who were lying quietly in bed would more often have their sleep disturbances overlooked instead of overreported. Future studies are needed to examine the factors that determine whether caregivers accurately report versus over- or underestimate sleep disturbances in their demented family members.

Despite its limitations, the current study raises interesting questions. Additional information is needed to examine whether particular nighttime behaviors are more disturbing to stressed caregivers or whether caregivers who experience infrequent and unpredictable nighttime disruptions actually have greater difficulty than those caregivers whose patients are more consistently disturbed. For example, caregivers whose patients get up nightly and rummage through their bedroom closet may be less disturbed than caregivers with a family member who occasionally wanders outside at night. Future studies using different criteria for separating good and bad sleepers based on a priori hypotheses that guide the selection of a particular instrument or cut point are also needed. Although we followed the convention of 85% as defining "normal sleep," alternative criteria are widely available in the literature,⁴¹⁻⁴³ and use of different cut points as well as different assessment tools or instruments might yield different results. Finally, additional research is needed to explore the relationship between depression and sleep disturbance in dementia. In this study, patients with higher percent sleep had lower self-rated depression, a finding that was not substantiated by the interviewer-administered Cornell depression scale. Further study could show if this discrepancy was due to the well-known tendency for patients with dementia to underreport their depression symptoms⁴⁴ or to the fact that the GDS was collected only on the subset of patients that were less cognitively impaired and able to complete it.

Ultimately, better procedures to assess and treat sleep disturbance in patients with dementia are needed. Our data suggest that caregiver misperception may not be a rare phenomenon, particularly for

patients with less cognitive and functional impairment whose caregivers are highly stressed. For the vast majority of patient-caregiver dyads seen in primary care settings, however, the use of polysomnography or even actigraphy to confirm caregiver reports may be impractical. Daily sleep logs are one inexpensive alternative that can provide information about patient and caregiver sleeping habits, environmental triggers for awakenings, and the actual frequency of nighttime disturbances. These logs, in combination with ratings of caregiver mood and burden, might help clinicians more accurately identify patients' and caregivers' sleep problems and evaluate whether these problems might be better treated by behavioral strategies, medications, or a combination of both.

In summary, the study provides preliminary data

that both patient and caregiver factors may contribute to reported sleep problems in community-dwelling patients with AD, and that caregiver reports and objective patient sleep assessments frequently may not agree. Treatments should consider these dyadic contributions rather than focusing on caregiver reports of patient symptoms alone.

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