Research article

Sleepiness, sleep time, and depression of caregivers are linked with sleep and behaviors of their paired partners with dementia

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Abstract

Background: Sleep difficulties in people with Alzheimer's disease (AD) and their caregivers (CGs) have been documented. Additionally, sleep disturbances are a risk for AD indicating that poor sleep in CGs may place them at risk for AD. Little is known about the relationship between sleep in people with dementia (PWD) and their CGs.

Objective: This pilot study examines sleep in PWD and CGs dyads, and the relationship between PWD sleep and CG sleep, cognition, and burden. We explore whether disordered sleep, degree of dementia and PWD behaviors are related to CG sleep difficulties and burden.

Methods: We examined sleep using overnight polysomnography (PSG) and day/night activity using 14-day actigraphy in PWD/CG dyads form the Virginia Alzheimer's Disease Center Clinical Cohort. Dyad members received the Montreal Cognitive Assessment (MoCA), behavioral and mood assessments. CGs completed CG burden and preparedness assessments.

Results: Mean activity from actigraphy did not differ within dyad members. PSG measurement of total sleep time (TST), sleep onset latency (SOL), sleep efficiency (SEff), and wake after sleep onset (WASO) revealed that CGs had significantly decreased TST compared to their PWD and experienced greater SOL. Lower PWD MoCA scores were unrelated to CG sleep. However, PWD neuropsychiatric symptoms and CG burden correlated with worse CG SOL.

Conclusions: Our findings suggest that chronic rest and activity are linked within dyad members and that when separated, CGs experience shorter TST, lower SEff, and longer SOL than their partners. Additionally neuropsychiatric symptoms and CG burden were associated with worse CG sleep.

Keywords

Alzheimer's disease, caregiving burden, caregiver, dementia, sleep, sleep insufficiency

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Introduction

In the United States, people with dementia (PWD) are cared for by 16,000,000 unpaid caregivers (CGs).[1] These CGs provide the backbone of care provision for the more than 6 million PWD in the United States, and without these unpaid CGs, the system of care would crumble. These caregivers are often spouses or partners of the PWD and are of advanced age themselves. Unfortunately, CGs for PWD experience poor mental and physical health even when compared to other CGs[2] and higher mortality when compared to non-CGs of similar ages.[3] In addition to poor overall health, CGs of PWD are at greater risk for dementia themselves.[4]

Sleep disturbances including insomnia, poor sleep quality, and sleep fragmentation may play a role in the development and progression of Alzheimer's disease (AD) and related dementias in older adults.[5–10] There is mounting evidence that being a CG is associated with disrupted sleep. For example, overnight polysomnography

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(PSG), demonstrated that older CGs partnered with PWD with moderate to severe AD had shorter total sleep time (TST), lower sleep efficiency (SEff), and more frequent shifts from deep to lighter sleep than non-caregiver controls.[11] Actigraphy studies, measuring day and nighttime activity, demonstrated that CGs' sleep was influenced by their PWD bedpartners, and that daytime inactivity was more prevalent among PWD than among CGs or non-demented controls.[12,13]

The association between sleep disturbance and dementia, and additional evidence that being a CG is associated with decreased sleep, suggests that poor sleep in CGs may create health risks in the CGs themselves. Understanding the dyadic relationships between sleep-wake activity in PWD and their CGs may provide important information on CG well-being and potential interventions.

Our pilot study evaluates the sleep of PWD and CGs dyads, and the degree to which disturbed PWD sleep affects the sleep, cognition, and other aspects of CG well-being. We explore the possibility that CG sleep may be worsened by chronic exposure to the disordered sleep of their charges. Further, we explore the possibility that features of dementia in the PWD may be related to CG sleep and burden. This pilot study will guide further work on how best to protect CG health as mediated by sleep and the behaviors of PWD.

Methods

Participants/dyads

Seven dyads consisting of individuals diagnosed with dementia and their CGs were recruited from the Virginia Alzheimer's Disease Center (VADC) Clinical Cohort. Diagnosis of AD or other dementia subtype in the VADC cohort was made in a consensus conference examining neurological examination, neuropsychological testing, neuroimaging, and available biomarker data. PWD were excluded from this study if they had other neurological conditions that affected cognition, had been diagnosed with cancer (except basal or squamous cell carcinomas) within the last 5 years, or had any physiological impairments that would interfere with assessment. Inclusion criteria for the CG required that they self-identify as the primary, unpaid CG of their partner, had no cognitive impairments (as determined by Montreal Cognitive Assessment, MoCA), and had no physiological impairments that would interfere with assessments. Additional exclusion criteria for both groups were non-English speakers, presence of metal in the body, claustrophobia, and facial tattoos/permanent makeup. This study is in compliance with guidelines on human experimentation and the protocol was approved by the University of Virginia Health Sciences Institutional Review Board.

Sleep assessments

PSG (Natus Sleepworks, USA) was recorded for one night in an accredited sleep laboratory consisting of electroencephalography, electrooculography, submental electromyography, thoracic and abdominal respiration, airflow, electrocardiography, tibialis electromyography, and oximetry. PWD and CG slept apart. Records were scored according to the American Academy of Sleep Medicine criteria[14] for TST, sleep onset latency (SOL), SEff, and wake after sleep onset (WASO). Sleep stage proportions were calculated.

Non-dominant wrist actigraphy (Actiwatch, Phillips Respironics, NL) was started on the day after PSG and recorded for 14 days. Activity levels were measured by calculating the total volume of space moved during consecutive 5-min epochs, with overall activity for each period calculated as the sum of every epoch within the corresponding time frame. Since recording schedules of intended sleep and wakefulness were difficult for PWD, we evaluated actigraphy data (activity levels) divided into fixed activity (0600-2200) and rest (2200-0600) periods.

Survey assessments

Both members of dyads were administered independently the MoCA,[15] the Geriatric Depression Scale (GDS),[16] Epworth Sleepiness Scale (ESS),[17] and the Quality of Life in Alzheimer's Disease scale (QoL-AD).[18] CGs only completed the Preparedness for Caregiving Scale (PCS),[19] the Neuropsychiatric Inventory Questionnaire (NPI-Q)[20] and the Zarit Burden Interview (ZBI).[21] Both members of the dyad also completed the National Alzheimer's Coordinating Center (NACC) Uniform Data Set (UDS),[22] which included individual and family medical history.

Data analysis

Actigraphy. Paired t-tests compared actigraphy activity, rest, and the log-ratio of activity/rest within dyad pairs. F-tests of variance equality and unpaired t-tests were evaluated between CG and PWD groups.

PSG. Comparisons as above were evaluated for TST, SOL, SEff, and WASO activity/rest within dyad pairs and across CG and PWD groups. Sleep stage proportions between groups were compared with unpaired t-tests. Preliminary analysis with the use of nonparametric tests did not substantially change results.

CG sleep and PWD neuropsychological measures. We correlated TST and SOL from PSG against dyad partners' severity of dementia as represented by PWD MoCA score and by

Table 1. Correlations between aspects of CG sleep compared to caregiver outcomes.

	TST		SOL		Actigraph day count	
	cc	p	cc	p	cc	p
ESS	0.437	0.386	0.097	0.855	−0.829	0.041*
QoL-AD	0.076	0.903	0.834	0.079	0.138	0.825
PCS	0.471	0.345	0.337	0.513	−0.893	0.017*
ZBI	0.341	0.508	0.913	0.011*	0.029	0.956

cc: Pearson correlation constant; ESS: Epworth Sleepiness Scale; QoL-AD: Quality of Life in Alzheimer's Disease scale; PCS: Preparedness for Caregiving Scale; SOL: sleep onset latency; TST: total sleep time: ZBI: Zarit Burden Interview.

the total NPI-Q with the use of Pearson's correlations. Correlations between TST and SOL with CG burden (ZBI) were also measured (Table 1).

Results

Participants

Seven dyads were enrolled between August 2021 – November 2022 (Table 2). The majority of PWD were men and were older (about a decade) than CGs. Dyads were either bedpartners (n = 5), shared a room with different beds (n = 1), or slept in different rooms (n = 1). Six of the 7 dyads were spouses; 1 dyad was a PWD parent and a CG child. PWD had a diagnosis of AD (n = 4), nonspecific dementia (n = 1) or MCI (n = 2) and had mean clinical onset 7 years before enrollment. Six of 7 dyads completed neurocognitive data. As expected, mean MoCA scores were significantly lower in the PWD group. Depression (GDS), subjective sleepiness (ESS), and quality of life (QoL-AD) did not differ between CG and PWD groups.

Table 2. Characteristics of dyads of caregivers and their partnered people with dementia.

variable	CGs	PWD	p
age (y, mean ± SD)	60.5 ± 10.4	71.2 ± 9.15	0.093
sex (female %)	71.40%	28.60%	0.244
race (white %)	85.70%	71.40%	0.403
dementia duration (y, mean ± SD)	–	7.33 ± 4.62	–
MoCA (score, mean ± SD)	28.4 ± 1.71	12.0 ± 3.74	<0.0001*
GDS (score, mean ± SD)	1.29 ± 0.95	3.85 ± 4.30	0.166
ESS (score, mean ± SD)	3.17 ± 1.83	6.71 ± 4.54	0.095
QoL-AD (score, mean ± SD)	42.6 ± 6.47	39.3 ± 5.43	0.358
PCS (score, mean ± SD)	2.67 ± 0.69	–	–
ZBI (score, mean ± SD)	29.3 ± 15.3	–	–
N1 sleep (%)	8.35 ± 2.98	5.88 ± 4.54	0.292
N2 sleep (%)	58.8 ± 11.9	71.6 ± 10.5	0.076
N3 sleep (%)	21.7 ± 11.7	5.30 ± 4.82	0.007*
REM sleep (%)	11.2 ± 6.39	17.2 ± 8.01	0.178

CGs: caregivers; ESS: Epworth Sleepiness Scale; GDS: Geriatric Depression Scale, MoCA: Montreal Cognitive Assessment; PCS: Preparedness for Caregiving Scale; PWD: people with dementia; QoL-AD: Quality of Life in Alzheimer's Disease scale; REM: rapid eye movement ZBI: Zarit Burden Interview.
p values unpaired t-tests. *significant.

Actigraphy

Mean activity (0600-2200) and rest (2200–0600) per 24-h clock counts, as well as the log ratios of activity: rest, acquired for 14 days did not differ significantly within dyad members (Figure 1A–C). Neither variances nor means of actigraphy measures differed between PWD and CG. Although no differences occurred among dyads, day and night activity tended to be the same between dyad members. For example, when CGs are rank-ordered by daytime activity, their dyad partner remained in the near rank-order among PWD. In summary, chronic activity did not differ significantly between CG and PWD, and rest and activity appeared linked within dyads.

PSG

PSG results revealed a clear outlier dyad who showed that the PWD had a TST < 3 standard deviations below the group mean and SEff <50% of the group mean. This dyad consisted of the parent PWD and child CG who slept separately and therefore were excluded from further analysis. With the outlier excluded, paired comparisons within dyad partners showed that CGs had significantly decreased TST compared to their PWD and experienced greater SOL (Figure 1D, F). In overcall group comparisons, CGs experienced shorter TST (Figure 1D, borderline significance), lower SEff (Figure 1E), and longer SOL (Figure 1F). No significant differences within dyads or between groups was apparent with WASO (Figure 1G).

Sleep staging fell well into established patterns seen in dementia[23] with PWD having significantly less N3 sleep than CGs, and increased N2 sleep approaching significance (Table 2).

Relationships between CG sleep parameters and PWD neuropsychiatric measurements

Worse dementia, represented by lower PWD MoCA scores, was not associated with worse CG TST (Figure 2A). Worse behaviors, represented by PWD NPI-Q scores, correlated with worse CG SOL (r = 0.57, p = 0.18) (Figure 2B). CG SOL also correlated significantly with the degree of CG burden (represented by ZBI) (r = 0.913, p = 0.011) (Figure 2C).

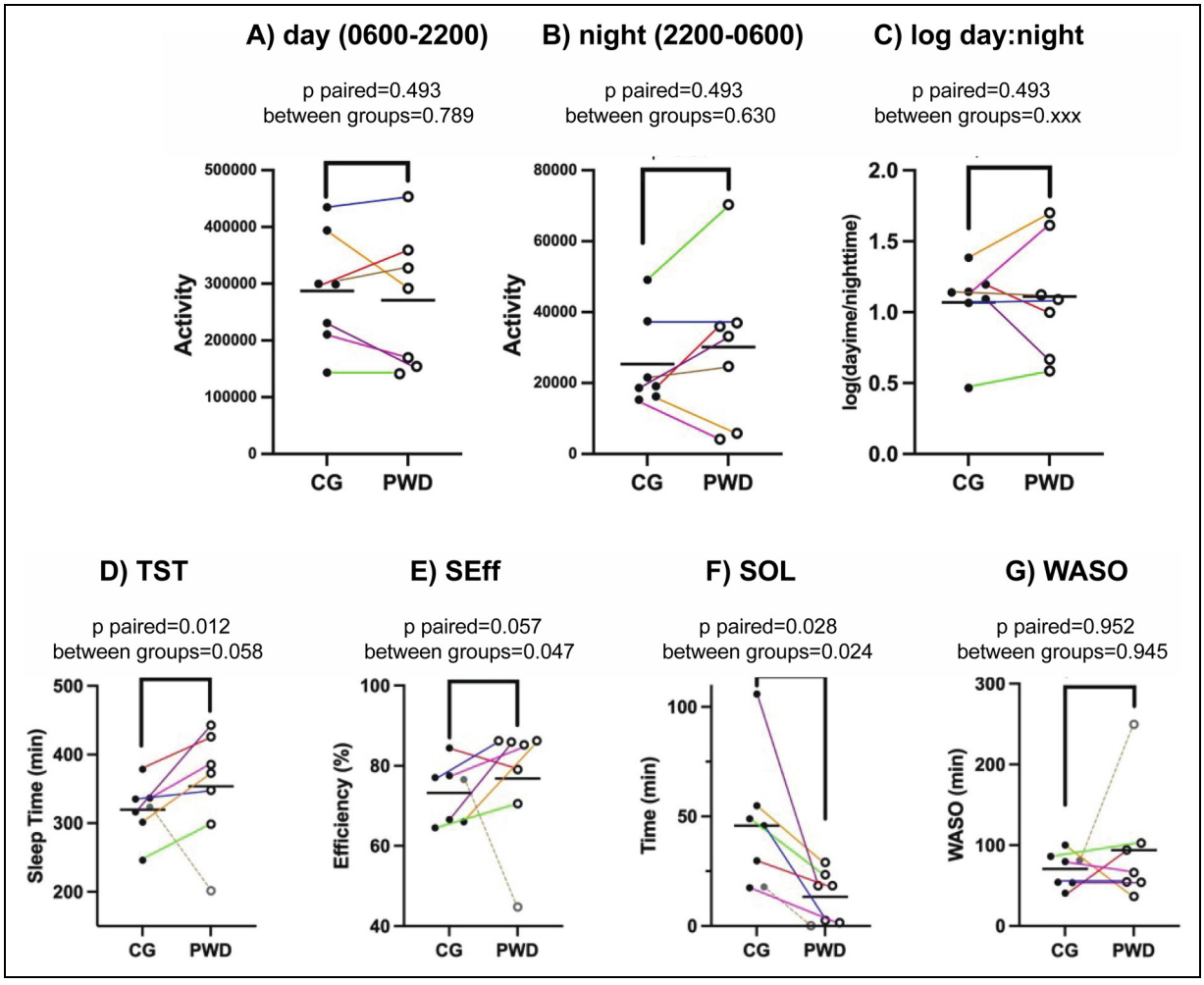

Figure 1. (A–C) Actigraphy recorded over 14 days in dyads of caregivers (CG) and people with dementia (PWD). (A) activity = daytime values recorded between 0600-2200, (B) activity = nighttime values recorded between 2200-0600, (C) log ratio daytime:nighttime. (D-G) polysomnography of CG and PWD when separated. Black lines indicate group means (between group p values). Lines join members of dyads (paired p values). TST: total sleep time; SEff: sleep efficiency; SOL: sleep onset latency; WASO: wake after sleep onset.

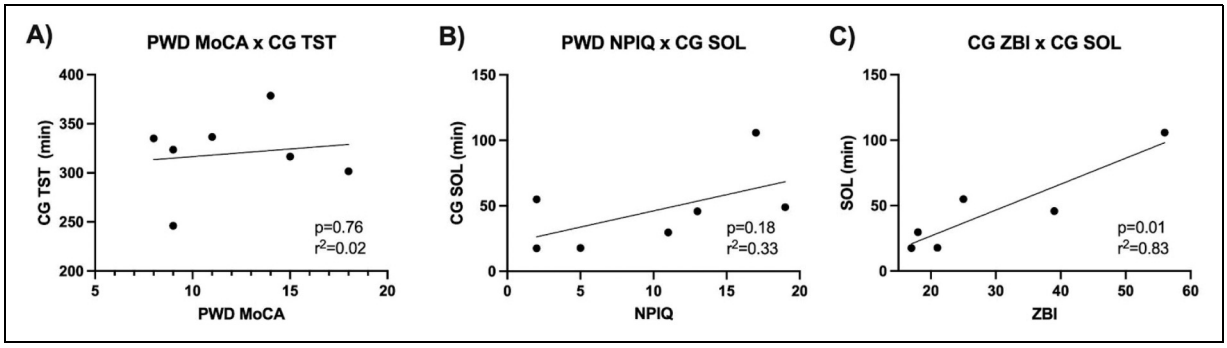

Figure 2. (A–C) Caregiver (CG) latency to fall asleep was not associated with (A) people with dementia (PWD) severity of dementia, but was associated with (B) neuropsychiatric behavior, and (C) perceived caregiving burden. TST: total sleep time; SOL: sleep onset latency; MoCA: Montreal Cognitive Assessment; NPIQ: Neuropsychiatric Inventory Questionnaire; ZBI: Zarit Burden Interview.

Discussion

In this pilot study of CG and PWD dyads, the sleep patterns of CGs and their paired PWD show that (1) chronic rest and activity does not differ consistently between partners and importantly appears linked between partners, (2) when separated, CGs experience shorter total sleep time, lower sleep efficiency, and longer sleep onset latency than that of their partners, and (3) the severity of their partner's dementia, represented by lower cognition scores was not associated with worse CG sleep; however, higher neuropsychiatric behavior scores were associated with worse CG sleep. Our study provides evidence that further evaluation of sleep patterns of dyads is merited with the goal of protection of CG health and quality of care for PWD.

The most striking finding was that, despite there being no consistent associations or differences of chronic rest: activity within dyads as measured by actigraphy, once separated, CG sleep was shorter, less efficient, and with longer latency than their PWD partners when measured by PSG. Our findings do not imply that the sleep of PWD was "normal"; consistent with other studies of patients with AD, our sample of PWD had more light sleep and less slow wave sleep than CGs.[24] However, our findings demonstrate that, when CGs are allowed to sleep separated from their partners, that difficulty falling and maintaining sufficient sleep follow. We do not know yet whether the CG sleep findings are limited to a single occurrence ("first night effects", or even the worry engendered by sleeping separately from a dependent spouse), or the PSG findings reflect a chronic, ongoing "brokenness" of CG sleep. Certainly, future work remains to clarify. Nevertheless, our findings agree with earlier data that chronic CG activity was influenced by their PWD partners.[12,13] Our data support earlier studies that showed that CG had shorter TST, lower SEff, and shifts from deep to lighter sleep than non-caregiver controls.[11] The type of dementia symptoms in the PWD matter more than the level of absolute dementia severity, as our findings show that deficits in CG sleep is proportionate to PWD neuropsychiatric symptoms not overall level of dementia. This finding is consistent with findings that neuropsychiatric symptoms create higher CG burden and hasten PWD placement to higher levels of care.[25] Our findings also extend earlier studies in that our CGs have worse sleep than their partners even when given the chance to sleep apart.[26]

The disruptions of CG sleep may result from concerns about caring for the PWD; our findings show that the burden of care is proportional to difficulty falling asleep (SOL) with higher CG burden associated with poorer CG sleep. We postulate that GC sleep abnormalities persist despite separation from affected partners because of psychological stressors associated with chronic caregiving. Further work may establish that the chronic stress of being a CG provides a lever by which repeated sleep disruptions lead, via classical conditioning, to the hyperarousal state of chronic insomnia.[27]

Limitations include the inherent small size of a pilot study. We propose that this study provides clear guidance in the design of a larger, prospective, and longitudinally assessed cohort. We anticipated CG and PWD difficulty in providing us with accurate sleep:wake schedules; therefore, we used fixed rest:activity time windows. Future work will concentrate on the timing of rest:activity schedules of CG in relation to PWD. We anticipate that expanded capabilities of ambulatory monitoring will permit robust associations between intended and measured rest:activity phases. Our single night of PSG could expose patients to "first-night effects",[28] but both CG and PWD had equal exposures. Future work should center on longitudinal assessments for both evidence of reproducibility and progression.

In summary, chronic rest:activity between CG and PWD appeared linked, but CG sleep was shorter in duration, delayed in onset, and less efficient than PWD sleep. Our pilot study suggests that examining CG/PWD dyadic sleep patterns provides a unique opportunity to develop interventions aimed at improving CG sleep which may preserve CG health, CG quality of life and the quality of caregiving. These interventions could directly target sleep, or target sleep via interventions on CG burden or PWD neuropsychiatric symptoms with the indirect effect of improving CG sleep.

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Statements and declarations

Author contributions

Carol Manning (Conceptualization; Formal analysis; Investigation; Methodology; Project administration; Supervision; Writing – original draft; Writing – review & editing); Anna Youngkin (Data curation; Formal analysis; Investigation); Mark Quigg (Conceptualization; Formal analysis; Investigation; Methodology; Writing – original draft; Writing – review & editing).

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Declaration of conflicting interests

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Data availability

The data supporting the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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