Title

Understanding Dyadic Sleep Association between Persons with Dementia and Family Caregivers: A Mixed Methods Study

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Understanding Dyadic Sleep Association between Persons with Dementia and Family Caregivers: A Mixed Methods Study

DISSERTATION

submitted in partial satisfaction of the requirements
for the degree of

DOCTOR OF PHILOSOPHY

in Nursing Science

by

Eunae Ju

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2023

DEDICATION

To

My husband Sung Won Park, my children Sungeun, Jiwoo, and Seohyun,
my parents Youngtae Joo, Imsik Min, Junsaeng Park, Heeja Kim,
my family, and my friends

in recognition of all their love and support for me to achieve this academic goal.

"When you pass through the waters, I will be with you;
and through the rivers, they shall not overwhelm you;
when you walk through fire you shall not be burned,
and the flame shall not consume you."
-Isaiah 43:2

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ABSTRACT OF THE DISSERTATION

Understanding Dyadic Sleep Association between Persons with Dementia and Family Caregivers: A Mixed Methods Study

by

Eunae Ju

Doctor of Philosophy in Nursing Science

University of California, Irvine, 2023

Associate Professor Jung-Ah Lee, Chair

Background: Alzheimer's dementia and related dementias (hereafter dementia) can affect sleep disturbance (e.g., nighttime awakening behaviors and poor sleep quality among persons with dementia (PWD). Estimates suggest sleep problems affect approximately 60-70% of PWD such as the difficulty of falling asleep and multiple wakes at night resulting in advanced cognitive impairment. In addition to the impact of sleep disturbance on PWD, sleep disturbance also is one of the foremost health problems affecting family caregivers of PWD. Family caregivers (e.g., spouses, partners, and adult children) experience the increased awakenings and demands of PWD at night which is associated with increased stress, depressive symptoms, and burden of caregivers. Little research has investigated dyadic interrelationships in sleep quality among PWD and family caregivers. PWD are often excluded from participation in sleep research due to memory deficits and impaired expressive language. Also, immigrant ethnic minorities (e.g., Korean Americans) are also understudied in sleep research. To fully understand sleep quality among PWD-caregiver dyads, we should include both perspectives together. **Purpose:** The specific aims of the study are (1) to describe dyads' sleep parameters (i.e., total/deep/REM/light sleep duration, awaken duration, latency duration, sleep efficiency) using wearable technology (i.e., smart ring) and sleep diaries, (2) to identify interrelationships of sleep parameters between PWD and caregivers, and (3) to describe lived experiences of sleep disturbances and sleep interrelationships of PWD and their family caregivers. **Methods:** An observational descriptive study design was used using mixed methods including quantitative and qualitative approaches using wearable devices' data (i.e., smart ring), daily sleep diaries, surveys, and individual interviews with cohabitating PWD and caregivers. Dyads were recruited in Southern California. Wearable technology (i.e., smart ring) monitored sleep parameters (i.e., total/deep/REM/light sleep duration, awaken duration, latency duration, sleep efficiency) for 4 weeks. Validated questionnaires assessed sleep disturbances and depressive symptoms for dyads, stress, and caregiving burden for caregivers. Thematic analysis was applied to dyads' interview data transcribed verbatim in English. Caregivers provided verbal consent, plus surrogate consent for their PWD. PWD provided verbal assent. All PWD were assessed for their decision-making capacity. **Results:** A total of 11 dyads (N=22) participated in the study: mean age of PWD was 82.7 years (SD=2.3); caregivers were 69.1 years (SD=10.2). Nine PWD (18.2%) were male, all caregivers (100%) were female, and 4 dyads (36.4 %) used the same bed. Sleep parameters of deep/REM/ awaken duration/ Sleep efficiency of PWD were significantly correlated with those of caregivers, respectively (All Ps < 0.05). Major themes included (1) linked sleep disturbances between PWD and caregivers, (2) sleep disturbances beyond control, (3) mixed attitudes about sleep quality in dyads, (4) language challenges within and outside the Korean American dyads, and (5) dyadic activity: strategies that improve sleep quality for dyads. **Conclusion:** Findings demonstrate PWD's sleep parameters (i.e., deep /REM sleep duration, awaken duration, sleep efficiency) were significantly correlated with caregivers' ones. Additionally, findings illustrate sleep disturbances of dyads (PWD - caregivers) connected to each other were beyond their control. The Korean American dyads (i.e., parent PWD and offspring caregivers) expressed communication challenges among them and also, they addressed limited community resources available in their primary language. A dyadic approach and wearable device used in this study show the potential to measure objective sleep quality for both PWD and their caregivers, particularly the immigrant population. Future studies should address special attention on dyadic approaches and cultural competency with large samples and diverse ethnic minorities.

PAPER 1

Sleep Quality of Persons with Dementia and Family Caregivers in Korean Americans: Wearable Technology to Study the Dyadic Association

Abstract

Background: Alzheimer’s dementia and related dementia (hereafter dementia) is associated with sleep disturbances among Persons with Dementia (PWD) such as difficulty in falling asleep and multiple awakenings at night resulting in advanced cognitive impairment and increased behavioral problems. Also, family caregivers (e.g., spouses or adult children) experience reduced sleep quality caused by PWD’ sleep disturbances. Relatively little is known about the interaction of sleep parameters in dyads (PWD-caregiver) as paired units among understudied immigrant minorities, particularly Korean Americans.

Objectives: To describe dyads’ sleep parameters (i.e., total/deep/REM/light sleep duration, awaken duration, latency duration, sleep efficiency) using wearable technology (i.e., smart ring) and sleep diaries, and to identify interrelationships among sleep parameters between PWD and caregivers.

Method: This one-group observational study of 4 weeks’ duration using wearable technology, a validated sleep survey, and self-report sleep diaries to explore sleep associations of KA dyads recruited from the community. Pearson correlations were performed.

Results: A total of 11 dyads participated: mean age of PWD was 82.7 years (SD=2.3); for caregivers 69.1 years (SD=10.2). Nine PWD (18.2%) were male, all caregivers (100%) were female, and 4 dyads (36.4 %) slept in the same bed. Sleep parameters of deep/REM/ Awaken/

Sleep efficiency of PWD were significantly correlated with those of caregivers, respectively (All p values were < 0.05).

Conclusion: Findings demonstrate PWD’s sleep parameters (e.g., deep sleep duration) were significantly correlated with those of caregivers’ ones. A dyadic approach and wearable device in this study shows the potential to measure objective sleep quality for both PWD and their caregivers particularly immigrant population.

Keywords: ***dementia, family caregiver, sleep disturbance, dyad, and wearable technology***

Introduction

Alzheimer's disease and related dementias (hereafter dementia) have increasingly affected individuals aged 65 and older, as well as their families and communities.[1] Among these older Americans, approximately 6.7 million were affected by dementia in 2023, and this is predicted to reach 12.7 million by 2050.[1] As the disease progresses, Persons with dementia (PWD) struggle with sleep disturbances (e.g., inadequate sleep, poor sleep, and circadian dysregulation) which are significantly associated with advanced cognitive impairment and increased behavioral problems.[2-4] Estimates suggest sleep problems affect approximately 60-70% of PWD.[1] PWD's sleep disturbances can likewise impact those of family caregivers (e.g., spouses, adult children) due to increased awakenings and needs of PWD at night.[5, 6] Sleep disturbances of family caregivers are one of the foremost health problems significantly associated with increased stress, depressive symptoms, and caregiver burden as well as other health problems.[5-7] This can lead to caregivers being unable to care for PWD at home, and increase the likelihood of PWD being admitted to long-term care facilities.[3, 8, 9] Little research has yet investigated in interrelation of sleep quality among PWD and family caregivers using dyadic approaches including PWD and caregivers together to gain an understanding of some ambiguous effects on either the caregiver's or PWD's side separately. Also, few studies directly assess PWD as well as the caregiver in terms of data collection.[10]

Most importantly, there are racial/ethnic sleep health disparities, and ethnic minorities, particularly Korean Americans, are generally underrepresented in research.[11, 12] Studies show that up to 83% of older Korean immigrants in the United States (U.S.) experience sleep problems.[11-14] Despite the growth of the Korean immigrant population in the U.S., little research has investigated the interrelation of sleep quality among PWD and their family caregivers in Korean Americans by including both in the study.[11, 14, 15] Most often, family caregivers were asked to answer PWD's questionaries. Previous studies denote the limitation of caregiver-reported outcomes in that caregivers tend to under-report or normalize sleep problems for themselves as well as PWD.[16, 17]

Wearable technology can be a critical tool for measuring objective and longitudinal physiological sleep parameters as well as understanding their relationship within the Korean American dyads.[18, 19] Some studies used accelerometers to measure sleep activity (e.g., sleep efficiency; ratio of actual sleep to total time in bed, total sleep hours) of PWD and caregivers at the same time and reported the sleep activity of each individually.[5, 20-23] However, these reports did not address the interrelationship between PWD and their family caregivers in terms of sleep. In addition, data collection was often short-term (1-2 weeks) limiting the ability to assess night-to-night variability. Moreover, systematic reviews report that despite actigraphy being proven helpful for basic wake-sleep assessment, it has limited accuracy on physiological parameters such as the sleep stages.[24]

Therefore, the overall purpose of this study is to explore objective physiological sleep parameters and associations for PWD-caregiver dyads, particularly Korean Americans. The specific objectives of this study are as follows: (1) to explore objective physiological sleep parameters of the dyads (patient-caregiver), (2) to compare objective and self-report sleep measure, and (3) to understand the interrelationships of objective sleep parameters between PWD and caregivers using data from wearable technology.

Methods

Study Design and Participants

This is a one-group observational study using wearable technology (i.e., smart ring), survey, and sleep diaries to explore sleep associations of PWD-caregiver dyads. Korean Americans was recruited by posting flyers in senior community centers, adult daycare centers, and caregiver support groups facilitated by non-profit organizations that serve Alzheimer's families in California. Snowball recruitment (word of mouth) methods were used to reach out to PWD-caregiver dyads. Eligibility for the study required that PWD participants be 1) aged 18 or older, 2) diagnosed with Alzheimer's disease or related dementia, 3) of mobility, 4) not receiving current cancer treatment and/or hospice care, and 5) able to wear a smart ring; The caregivers were required to be 1) spouse/partners, adult children, relatives, or significant others who live with PWD, 2) aged 18 or older, 3) able speak or understand English or Korean fluently, 4) willing to wear a smart ring, and 5) free of severe illnesses (e.g., cancer, hospice care, and cognitive impairment screened by Mini-Cog[25] if age is greater than 65). The University Institutional Review Board (IRB) approved the study protocol prior to the start of recruitment.

Consent process

For PWD, two different consent processes were conducted depending on their capacity for decision-making.[26, 27] The Decision-Making Capacity Assessment (DMCA) tool provided by the university IRB[28] was used to assess PWD's decision-making capacity. This tool elicits a response from potential subjects to a series of questions that demonstrates the subject's capacity to understand the study's goals, risks/benefits, and their choice to participate. If it was evident that PWD had a capacity for decision-making via the DMCA tool, informed consent was obtained from PWD after providing a sufficient explanation of the purpose and procedure of the study. If it was not evident that PWD had capacity for decision-making via the DMCA tool, consent was obtained from a surrogate (e.g., legal representative) who may be family caregivers or other relatives. The Surrogate Certification form provided by the university IRB[28] was used to obtain such consent from surrogate caregivers. Additionally, verbal assent was obtained from the PWD, demonstrating affirmative agreement expressed by the PWD.[26, 27] For caregivers, informed consent was obtained after explanation of the purpose and procedures of the study. Three PWD (27.3%) had limited decision-making capacity. Thus, their defined surrogates were family caregivers of PWD in our study provided consent for PWD and the PWD provided assent for voluntary participation in our study. Eight PWD (72.7%) and all caregivers (100%) provided consent for voluntary participation in our study.

Study Procedure

At the baseline, PWD and caregivers were provided with how to wear and use the smart rings and how to write sleep diaries for both. PWD and caregivers were asked to wear smart rings during day and night for 4 weeks, respectively. Baseline surveys including demographic information and sleep quality assessments were conducted with both PWD and caregivers. During the study period, follow-up phone calls were used to address any problems experienced with smart rings or sleep diaries. Upon the completion of the study, the dyads received $100 for their time to participate in the study.

Measures

Wearable device. Sleep parameters measured by smart rings included total sleep hours, sleep stages (deep, REM, light sleep), duration of sleep latency, awake duration, and sleep efficiency.[29-31]

Pittsburg Sleep Quality Index (PSQI). The PSQI is a validated survey that assesses subjective sleep disturbances. The possible total score range is 0-21, and greater than 5 indicates sleep disturbance (Cronbach α= 0.79).[32, 33]

Sleep diary. Two sets of diaries (separately for each PWD and caregiver) for 4 weeks were completed by caregivers.[34] Sleep diaries recorded bedtime, wake time, and self-reported sleep quality (ranging from 1, very poor to 5, very good). Based on sleep diaries, we calculated self-reported total sleep duration for the dyads.

Data Analyses

Descriptive statistics summarize the demographic characteristics, PWD's and caregivers' sleep parameters, subjective sleep disturbances, and sleep characteristics of sleep diaries as frequency (%) and mean with standard deviation (SD).

Linear mixed model (LMM) analysis via R software (version 4.1.3) using the lme4 package was used to test for significant time trends among each sleep parameter.[35] We included each sleep parameter as the dependent variable, individually, and added time variable as a fixed effect. We included random effects of each participant to capture the displacement of intercept from the average between participants. Additionally, we included random effects of slopes (e.g., changes of a sleep parameter over the time for 28 days between participants) to capture the level of heterogeneity within each participant's slopes. Significance was calculated using the lmerTest package,[36] which applies Satterthwaite's method to estimate degrees of freedom and generate p-values for mixed models. LMM can handle the variance associated with different intercepts and different changes over time between participants. LMM can deal with missing data using a full data set hence offering a simple alternative mean to handle missing data under missing at random without deleting any individual in a data set if they're missing data.[35-37]

In addition, Pearson correlation coefficients were calculated to identify associations between PWD's and caregivers' sleep parameters as paired data and to understand the directionality among variables between PWD and caregivers.[38]

Results

Participant Characteristics

Participants' demographic characteristics were presented in Table 1. PWD's average age was 82.7 years (SD= 2.3). The caregivers' average age was 69.1 years (SD= 10.2). Nine PWD (81.8%) were male, all caregivers (100%) were female. Average years of living in the U.S. was 41.3 (SD= 13.8). The PSQI total score of PWD was 6.6 (SD= 1.9) and caregivers were 8.2 (SD= 4.2). Ten PWD (91%) and 8 caregivers (73%) experienced sleep disturbances during study periods (all PSQI total scores > 5 out of 21).

Sleep parameters

The PWD's average total sleep duration was 384.0 minutes, average deep sleep duration was 55.9 minutes, average REM sleep duration was 52.5 minutes, average light sleep duration was 277.1 minutes, average duration of sleep latency was 20.7 minutes, average awake duration was 196.6 minutes, average sleep efficiency was 68.2%. Caregivers' average total sleep duration was 401.4 minutes, average deep sleep duration was 115.1 minutes, average REM sleep duration was 53.1 minutes, average light sleep duration was 233.2 minutes, average duration of sleep latency was 11 minutes, average awake duration was 68.1 minutes, average sleep efficiency was 85.8%. Sleep parameters measured from smart rings for 4 weeks were summarized in Table 2. The average number of days the PWD wore the smart ring during the study period was 21.3 (76%, SD= 5.2) out of 28 days. And for caregivers, it was 24.9 (89%, SD= 2.6) out of 28 days.

In the sleep diaries, the daily average of self-reported total sleep duration for PWD was 481 minutes, and for caregivers it was 478.9 minutes. PWD's average score of the self-reported sleep quality in the morning about the prior night's sleep was 4.0 (SD= 0.7) out of 5 and for caregivers, it was 3.9 (SD= 0.4) out of 5. (See Table 2.)

In the analysis of the linear mixed mode, during the study period, of 28 days. There was no significant change in all sleep parameters as time among PWD and caregivers. (See Table 3. and Figures 1-7.)

In the analysis of the Pearson correlation in PWD-caregivers paired dyads data, PWD's deep sleep duration was significantly correlated to/associated with caregivers' deep sleep duration ($r = 0.34$, $P < .01$). PWD's REM sleep duration was inversely associated with the caregivers' REM sleep duration significantly ($r = -0.24$, $P < .01$). PWD's awaken duration was significantly associated with the caregivers awaken duration ($r = 0.19$, $P < .01$). PWD's sleep efficiency was significantly associated with caregivers' sleep efficiency ($r = 0.22$, $P < .01$). (See Table 4.)

Discussion

To our knowledge, this is the first study to investigate physiological sleep parameters observed by wearable technology (i.e., smart ring) for both PWD and their family caregivers as dyad units among an ethnic minority, Korean Americans. We hypothesized that PWD's sleep parameters would be associated with caregivers' sleep parameters. We found that PWD's sleep parameters were significantly associated with their caregivers' counterparts which may reflect a complex relationship among sleep parameters in dyads. Several sleep studies were aligned with the dyadic approach of the study and included PWD and caregivers.[3, 7, 22, 39, 40] However, associations among specific sleep parameters captured by objective wearable devices have been rarely reported studies. Further, few studies targeted ethnic minorities, especially Korean Americans. Song et al., (2021) conducted a pilot study for non-Hispanic White individuals to develop tailored sleep interventions for PWD and caregivers using self-reported sleep outcomes[3]; Gibson et al., (2019) monitored the sleep patterns of PWD and their family caregivers non-Hispanic White using actigraphy[22]; and Sloane et al., (2015) tested light therapy to improve sleep quality for dyads in for non-Hispanic White individuals using actigraphy and self-reported outcomes.[7] Systematic reviews concluded that actigraphy was helpful for basic wake-sleep monitoring, however, there was a limitation in measuring sleep stages.[24, 41] Thus, to further understand interrelated sleep dynamics in Korean American dyads and gain more detailed sleep parameters information, leveraging wearable devices can allow assessment of sleep staging in longitudinal studies and monitor daily sleep variabilities in community dwelling dyads. Eventually, these data can inform interventions to support dyad sleep.

Moreover, our study focused on Korean American dyads in measuring their sleep quality using various methods. Based on our measures, the majority of PWD and caregivers in our study have sleep disturbances, including awakening for a long time at night, and decreased REM sleep, especially PWD. For example, PWD showed less than 85 % sleep efficiency, and longer than 3 hours of awaken duration at night, indicating PWD's sleep in our study may be a low level of sleep quality.[34,42] This was also supported by the PSQI score in our study. Oh et al., (2019) reported majority of Korean Americans reported moderate or severe sleep disturbances which were linked with mental health problems such as stress, loneliness, and suicide ideation.[11, 13 14] Although sleep disturbances are clearly a critical health problem, there is a dearth of research on in Korean American dyads with regard to improving their sleep quality.[11, 14, 15] Therefore, our finding emphasizes that future sleep research should be conducted with ethnic minority immigrant PWD-caregiver dyads to improve sleep quality for both and develop strategies for alleviating sleep disturbances.

Moreover, in our study, PWD's REM sleep duration was low in our study. The findings were aligned with several sleep studies to explore sleep stage characteristics in PWD. Emerging evidence suggests that changes in sleep architecture and patterns are significantly associated with dementia.[4, 43] Unlike sleep in normal aging, PWD exhibit less REM sleep duration compared to older adults without dementia.[34] One study reported that lower REM sleep percentage and longer REM sleep latency (time to get into REM sleep after sleep onset) were both associated with a higher risk of incident dementia.[44] Thus, monitoring sleep parameters can provide potential information to predict the relationship between REM sleep and dementia.

This study explored sleep parameters of Korean American PWD-caregiver dyads using wearable devices and sleep diaries. In our findings, there was a discrepancy between the data obtained using the wearable and self-reported data. In the wearable data, PWD's total sleep duration and caregivers' one was much lower compared to total sleep duration in sleep diaries reported by family caregivers. This finding was aligned with other studies, which have shown that participants tend to under-report or normalize their health outcomes resulting in masking of negative health outcomes such as sleep disturbances.[16, 17] The findings also suggested that a combination of objective measures with self-reported measures, rather than relying solely on self-reported measures, can be a consistent and accurate way to assess the sleep quality without self-report bias.

The study has some limitations for further consideration. The sample size is small, and convenient sampling was used to explore sleep parameters and sleep association in Korean American dyads. Therefore, caution should be exercised when generalizing the results beyond Korean immigrant dyads. With a total of 11 PWD and 11 caregivers, the power is limited to assess risk factors and correlates. To gain further reliable evidence, large-scale studies are needed to investigate sleep parameters' association among dyads in diverse ethnic minorities including Korean Americans.

Conclusion

This study investigated sleep association between Korean American PWD and their family caregivers using wearable technology. Wearable technology can be a feasible and acceptable way to monitor daily sleep characteristics for community-dwelling PWD-caregiver dyads. Findings highlight dyadic-based approaches for sleep quality using wearable technology has the potential to access objective sleep quality as well as may help guide effective dyadic sleep management and develop effective sleep interventions for ethnic minority immigrants. In addition, combined measures including objective wearable devices and self-reported data are recommended to provide consistent and reliable evidence.

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Table 1. *Characteristics of Family Caregivers and Their Loved Ones with Dementia*

Participants	Frequency (%) or Mean (SD)
Persons with dementia (n=11)	
Ethnicity/race: Korean	11(100%)
Gender (female)	2 (18.2%)
Mean age (SD) years	82.7 (2.3)
Health Insurance (yes)	11 (100%)
Medicaid only	2 (18.2%)
Medicare only	9 (81.8%)
Types of dementia	
Alzheimer's dementia	4 (36.4%)
Vascular dementia	6 (54.5%)
Frontal Temporal Dementia	1 (9.1%)
Stage of dementia reported by caregivers	
Early stage	6 (54.5%)
Middle stage	5 (54.5%)
Immigration to U.S. (Yes)	11 (100%)
Sleep disturbance score (PSQI)[a]	6.6 (1.9)
Decision making capacity (Yes)	8 (72.7%)
Caregivers (n= 11)	
Ethnicity/race: Korean	11(100%)
Gender (female)	11 (100%)
Mean age (SD), years	69.1 (10.2)
Spouse	75.9 (3.5)
Adult Child	57.2 (5.6)
Relationship with PWD	
Spouse (wife)	7 (63.6%)
Adult child (daughter)	4 (36.4%)
Education	
College/University	8 (72.7%)
Graduate degree	3 (27.3%)
Family monthly income	
$2,000 - $4,000	2 (18.2%)
$4,000 - $6,000	4 (36.4%)
More than $6,000	5 (45.5%)
Health insurance	
Yes	11 (100%)
Medicaid	1 (9.1%)
Immigration to U.S. (Yes)	11 (100%)
English proficiency, mean (SD)[b]	2.1 (1.1)

Spouse	1.4 (0.5)
Adult child	3.2 (1)
Years living in U.S mean (SD)	41.3 (13.8)
Comorbidity (Yes)	5 (45.5%)
Spouse (Yes)	4 of 7 (57.1%)
Adult child (Yes)	1 of 4 (25%)
Types of comorbidities	
Hypertension	3 (27.3%)
Diabetes	1 (9.1%)
High cholesterol	1 (9.1%)
Using the same bed with PWD	4 (36.4%)
Sleep disturbance score (PSQI)[a]	8.2 (4.1)

a. PSQI: Pittsburg Sleep Quality Index*;* The total score range is 0-21, and greater than 5 indicates sleep disturbance.

b. English proficiency measured with 5-Likert scale (4 =excellent, 0 = cannot speak English); all participants were immigrants to U.S.

Table 2. *Sleep Parameters from Wearable Device and Sleep Diary*

	Persons with Dementia (PWD) (n=11) Mean (SD)	Caregivers (n=11) Mean (SD)
Sleep parameters of wearable device		
Total sleep duration (min.)	384.0 (109.1)	401.4 (39.9)
Deep sleep duration (min.)	55.9 (37.7)	115.1 (32.8)
Deep sleep duration (%)[a]	14.8 (9.2)	29.0 (8.5)
REM sleep duration (min.)	52.5 (40.2)	53.1 (17.6)
REM sleep duration (%)[b]	12.6 (7.4)	13.2 (4.5)
Light sleep duration (min.)	277.1 (72.6)	233.2 (55.3)
Light sleep duration (%)[c]	73.4 (10)	57.7 (9.8
Sleep latency (min.)	20.7 (13.1)	11.0 (2.4)
Awake duration (min.)	196.6 (118.4)	68.1 (16.6)
Sleep efficiency (%)[d]	68.2 (14.3)	85.8 (2.8)
Self-reported total sleep duration (minutes) in sleep diaries	531.2 (91.7)	478.9 (55.4)
Self-reported daily sleep quality[e]	4.0 (0.7)	3.9 (0.4)

Note: Results are expressed as daily means (SD) for 4 weeks

a. Deep sleep duration percentage: deep sleep duration/total sleep duration * 100

b. REM sleep duration percentage: REM sleep duration/total sleep duration * 100

c. Light sleep duration percentage: Light sleep duration/total sleep duration * 100

d. Sleep efficiency (%): the ratio of actual sleep to total time in bed (1-100%)

e. Self-reported daily sleep quality in the morning after being awake: range from 1- 5, 1= very low, 5= very good

Table 3. *Linear Mixed Model: Time Effect on Sleep Parameters of PWD and Caregivers*

	Estimate (beta)	SE	df	t-value	P-value
PWD sleep parameters					
Total sleep duration (min.)	-0.31	0.68	11.62	-0.46	0.66
Deep sleep duration (min.)	-0.32	0.24	215.38	-1.37	0.17
Deep sleep duration (%)[a]	0.00	0.06	215.40	0.04	0.97
REM sleep duration (min.)	-0.28	0.29	10.06	-0.97	0.35
REM sleep duration (%)[b]	-0.10	0.05	9.83	-1.93	0.08
Light sleep duration (min.)	0.03	0.62	10.18	0.05	0.96
Light sleep duration (%)[c]	0.11	0.07	215.43	1.62	0.11
Sleep latency (mins)	-0.25	0.19	214.76	-1.31	0.19
Awake duration (min)	-0.07	0.96	11.96	-0.08	0.94
Sleep efficiency (%)[d]	-0.04	0.09	11.03	-0.40	0.70
Caregivers sleep parameters					
Total sleep duration (min.)	0.20	0.50	10.08	0.40	0.70
Deep sleep duration (min.)	-0.06	0.23	262.26	-0.26	0.80
Deep sleep duration (%)[a]	0.00	0.03	10.58	-0.08	0.94
REM sleep duration (min.)	0.09	0.17	11.18	0.53	0.61
REM sleep duration (%)[b]	0.00	0.03	262.30	0.12	0.90
Light sleep duration (min.)	0.18	0.44	10.73	0.41	0.69
Light sleep duration (%)[c]	0.01	0.07	9.55	0.12	0.91
Sleep latency (mins)	0.01	0.09	103.90	0.10	0.92
Awake duration (min)	0.22	0.26	263.12	0.84	0.40
Sleep efficiency (%)[d]	-0.03	0.05	16.49	-0.55	0.59

Linear mixed model (LMM) analysis in R (version 4.1.3) using the lme4 package was used to test if there were significant time trends among sleep parameters. We included each sleep parameter as the dependent variable, individually, and added fixed effects of time. We included participants and slopes as random effects.

* $P < 0.05$

a. Deep sleep duration percentage: deep sleep duration/total sleep duration * 100

b. REM sleep duration percentage: REM sleep duration/total sleep duration * 100

c. Light sleep duration percentage: Light sleep duration/total sleep duration * 100

d. Sleep efficiency (%): the ratio of actual sleep to total time in bed (1-100%)

Figure 1. *The Trend of Total Sleep Duration*

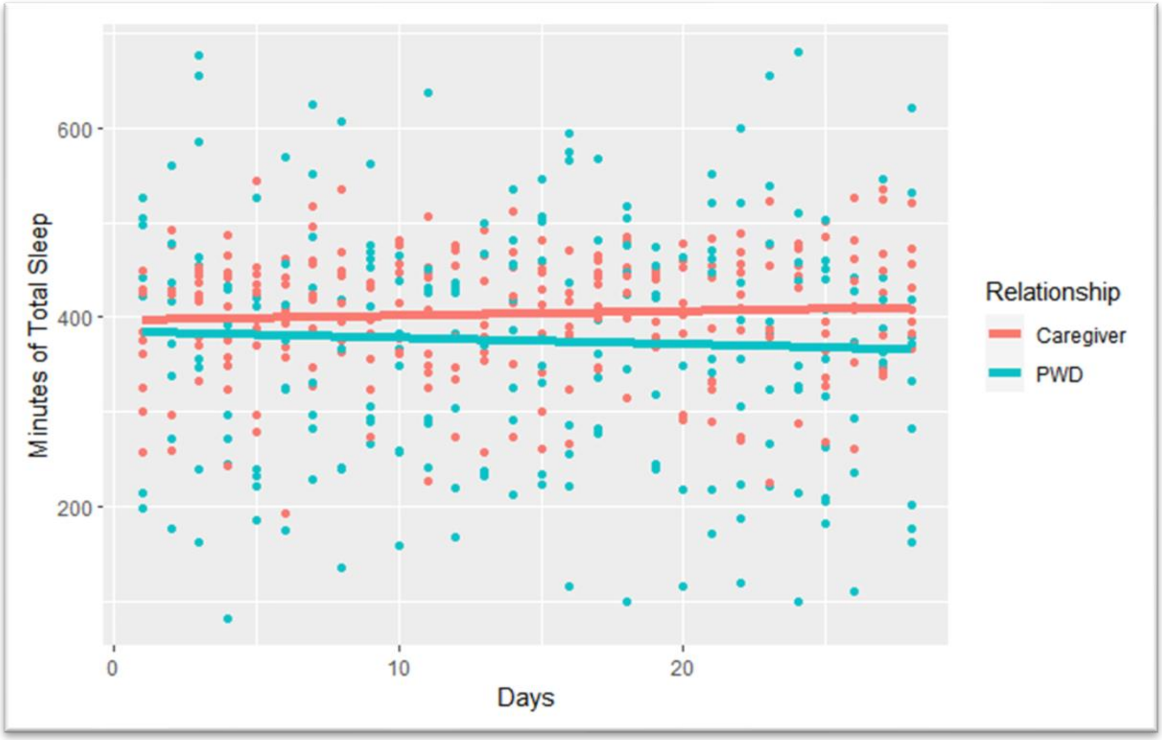

Figure 2. *The Trend of Deep Sleep Duration*

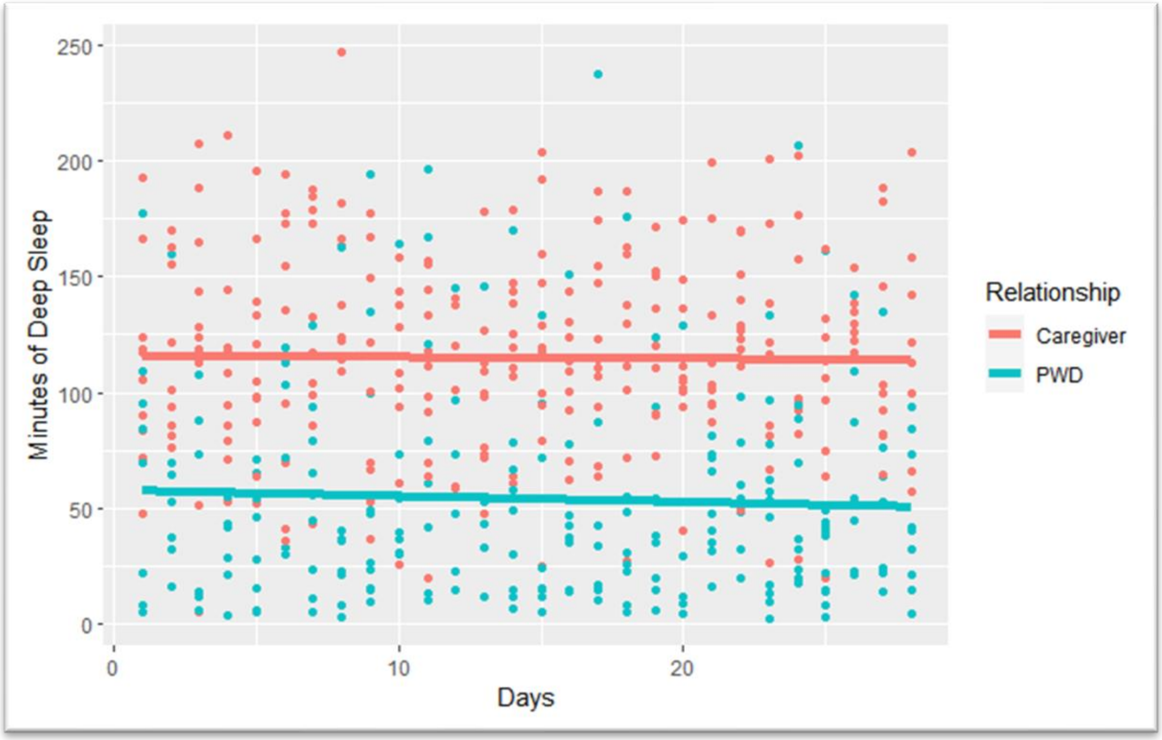

Figure 3. *The Trend of REM Sleep Duration*

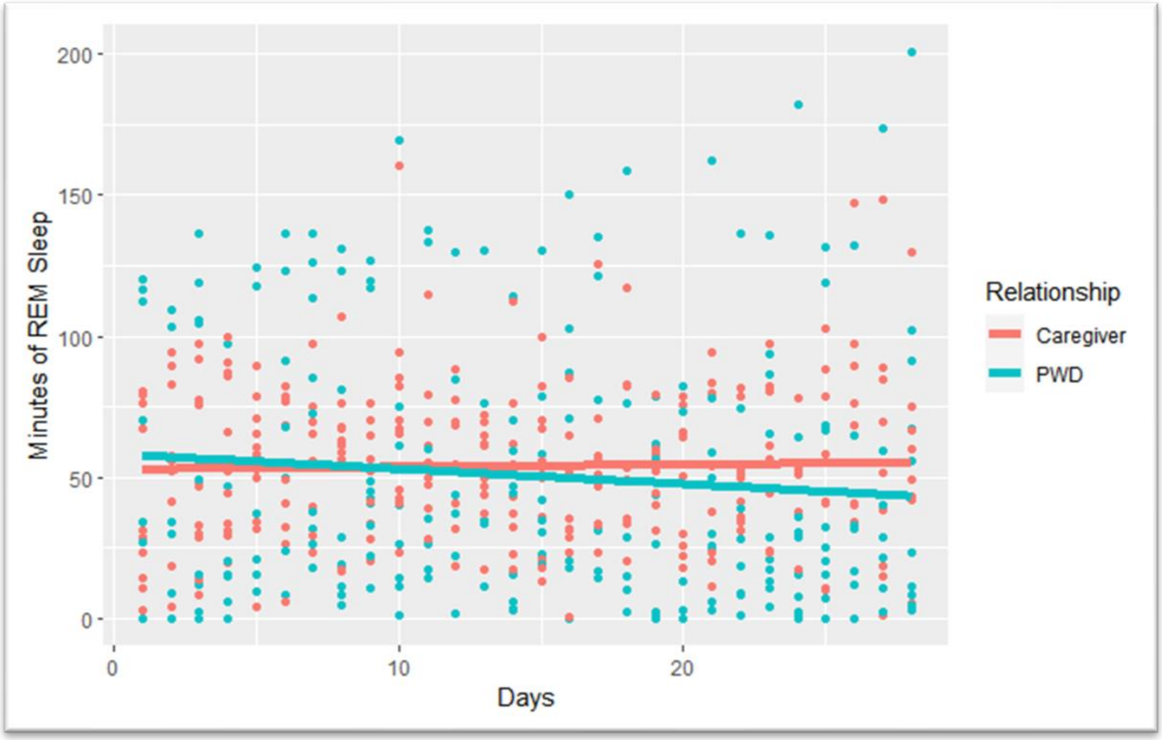

Figure 4. *The Trend of Light Sleep Duration*

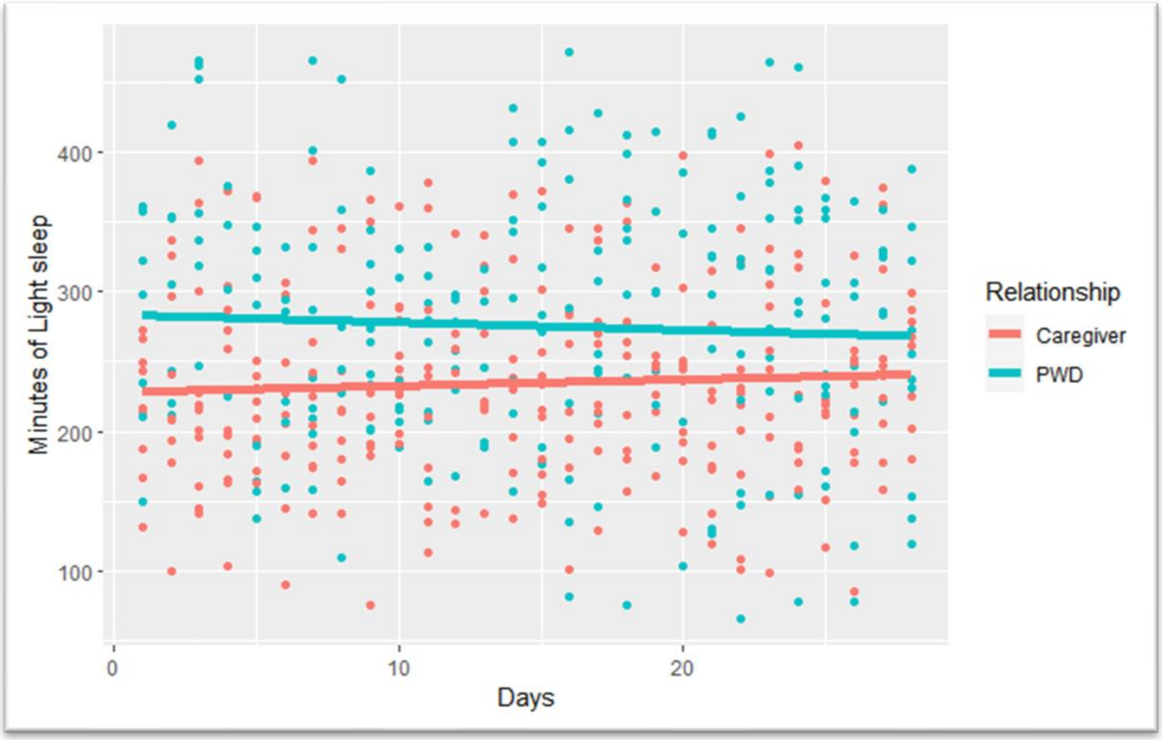

Figure 5. *The Trend of Sleep Latency Duration*

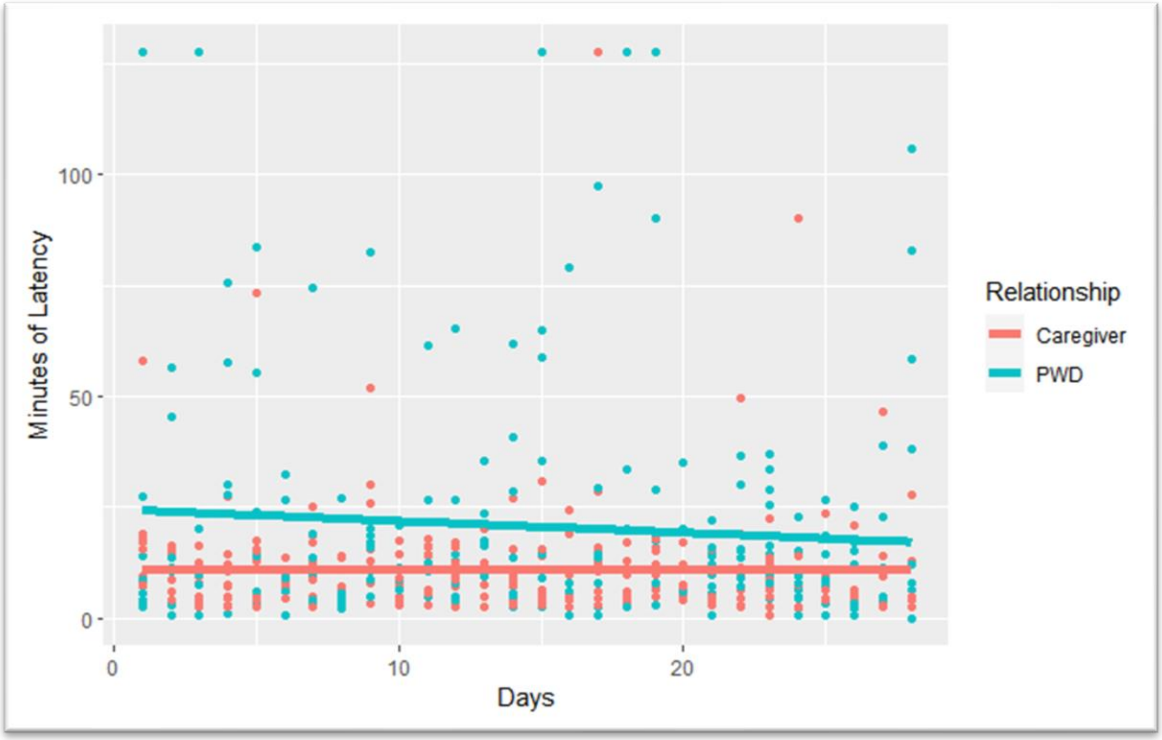

Figure 6. *The Trend of Awaken Duration*

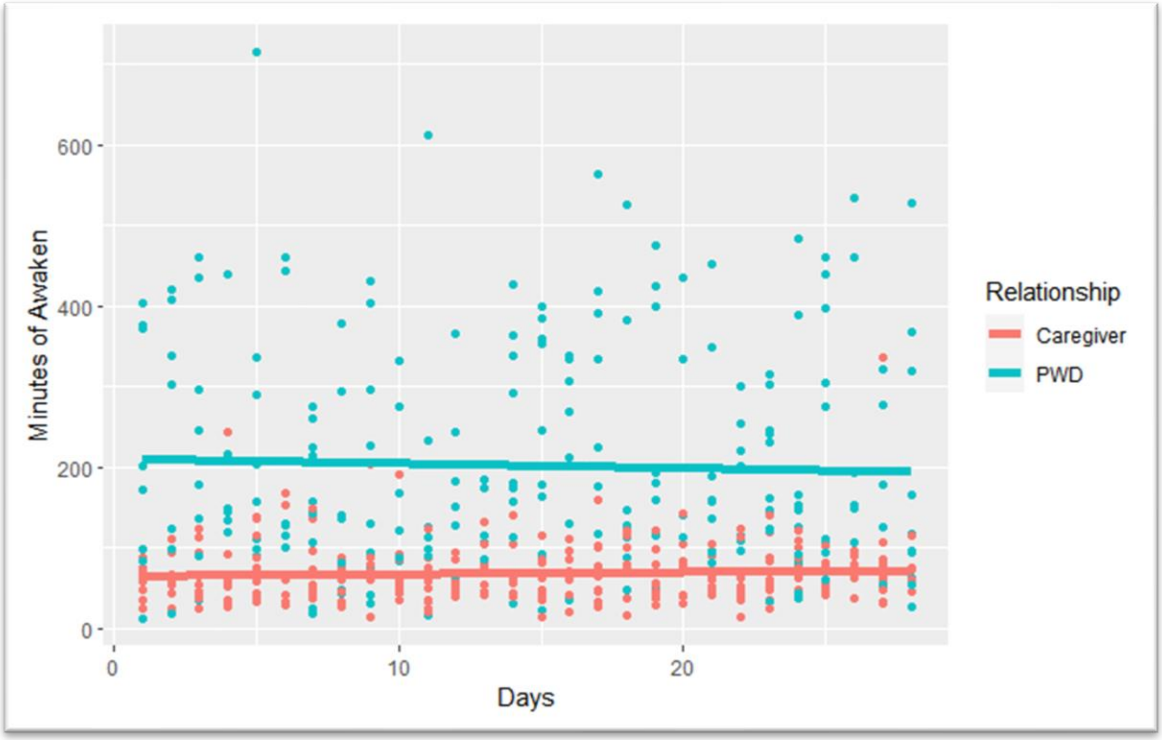

Figure 7. *The Trend of Sleep Efficiency*

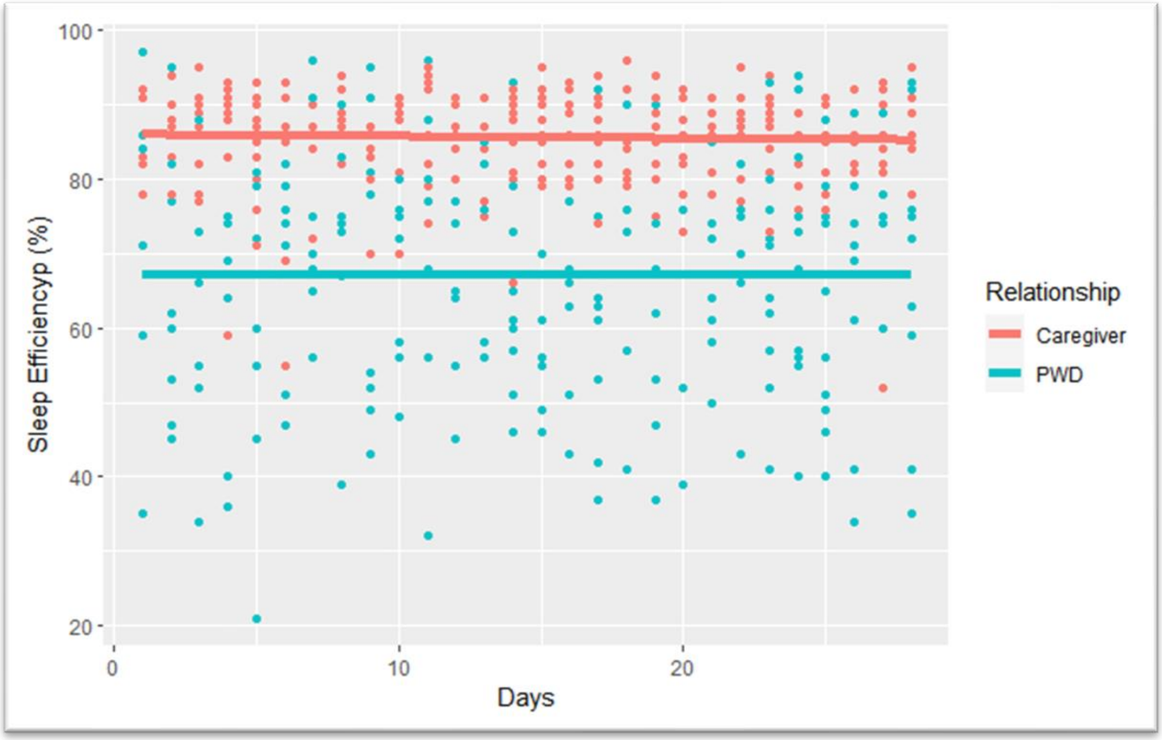

Table 4. *Pearson Correlation on Sleep Parameters in Dyads (PWD-Caregivers)*

PWD[a] / Caregiver	Total sleep duration	Deep sleep duration	REM sleep duration	Light sleep duration	Awaken duration	Latency duration	Sleep efficiency
Total sleep duration	-0.04	-0.08	-0.05	0.02	-0.068	0.01	0.03
Deep sleep duration	0.23	0.34*	-0.06	0.2	-0.05	-0.03	0.25
REM sleep duration	-0.17	-0.16	-0.24*	-0.02	0.34*	0.23*	-0.35*
Light sleep duration	-0.15	-0.22*	0.11	-0.09	-0.15	-0.06	-0.01
Awaken duration	0.06	-0.28*	0.29*	0.07	0.19*	0.05	-0.18*
Latency duration	-0.15	-0.14	-0.05	-0.12	-0.01	-0.01	-0.09
Sleep efficiency[b]	-0.07	0.25*	-0.26*	-0.06	-0.25*	-0.04	0.22*

Note: Pearson correlation coefficient; * P value < 0.01

a. PWD = persons with dementia

b. Sleep efficiency (%): the ratio of actual sleep to total time in bed (1-100%)

PAPER 2

Sleep Disturbances and Interrelationship between Persons with Dementia and Family Caregivers: The Lived Experiences of Korean American Dyads

Abstract

Background: Sleep disturbance is common among persons with dementia (PWD). Little research has investigated dyadic interrelationships in sleep quality between PWD and family caregivers, particularly among immigrant ethnic minorities, such as Korean Americans.

Purpose: The study aimed to describe lived experiences of sleep disturbances and sleep interrelationships between Korean American PWD and their family caregivers.

Methods: A descriptive study design was used using semi-structured interviews with cohabitating PWD-caregiver dyads recruited from California. Thematic analysis was applied. Interview data were transcribed verbatim in Korean and then translated to English. All PWD were assessed for their decision-making capacity. Caregivers provided verbal consent, plus surrogate consent for their PWD if necessary. PWD also then provided verbal assent.

Results: Eleven Korean American dyads participated in the study: the mean age of PWD was 82.7 years (SD=2.3), and that of caregivers 69.1 years (SD=10.2). Two PWD (18.2%) and all caregivers (100%) were female. Three PWD interviews were excluded due to limited ability of decision-making. Major themes included (1) linked sleep disturbances between PWD and caregivers, (2) interrelationship in dyads, (3) language challenges within and outside the Korean American dyads, and (4) strategies that improve sleep quality for dyads.

Conclusion: Findings demonstrated that sleep disturbances of dyads (PWD - caregivers) were connected to each other as an interactional unit where caregiving affects PWD sleep quality and the latter affects caregiver sleep quality. These Korean American dyads expressed that language barriers caused communication challenges and that there were limited community resources for support. Future interventions could address dyadic approaches to sleep improvement and cultural competency.

Keywords: ***Dementia Patient, Family Caregivers, Sleep Disturbances, Dyad Association***

Introduction

Alzheimer's disease and related dementias (hereafter dementia) have been increasing in older adults and are predicted to increase from 6.7 million in 2023 to 12.7 million by 2050 in the United States (U.S.)[1] In 2022, over 11 million family members provided unpaid care to persons with dementia (PWD) with progressive decline in cognitive functioning and difficult behavioral problems.[1]

Sleep disturbances are one of the foremost health problems in PWD and family caregivers living in the same household. Approximately 60-70% of PWD have been found to suffer from sleep disturbance, including difficulty falling or staying asleep as well as excessive daytime sleepiness or fatigue.[1, 4] Sleep disturbances may worsen the behavioral problems and cognitive impairments of PWD, leading to nighttime wandering, agitation, and increased memory loss.[2, 4, 45] For family caregivers, sleep is often affected by the demands of PWD at night; thus caregivers are more likely to experience nonrestorative sleep.[5, 46] Additionally, recent literature indicates that family caregivers of PWD lost an average of 2.4 - 3.5 hours of sleep a week over that of age-matched non-caregivers due to complex caregiving burdens.[5, 46] The sleep disturbances of caregivers are significantly associated with caregivers' stress, burden, and depression, which may hasten dementia patients' transitions to long-term care facilities.[3, 8, 47] There may be interrelated effects of sleep disturbances between PWD and caregivers either directly or indirectly as an interactional unit.

Although the Korean American population has been growing in the U.S., the group remains as one of the understudied ethnic minorities.[11, 12] Estimates suggest sleep problems affect approximately 80% of older Korean immigrants in the U.S.[12-15] However, little is known about the associated phenomenon of sleep disturbances between Korean immigrants with dementia and their family members, especially PWD-caregiver dyads. A dyadic-based approach includes the PWD-caregiver pair, and focuses on not only individuals or the family as a whole but the interrelationship of PWD and the caregiver as paired units.[48, 49] Findings from research using dyadic approaches support that dyadic perspectives were important in understanding dementia caregiving by considering both members of the adult patient–care partner dyad in the context of human illness.[10, 50]

The purpose of this study was to understand the lived experience of dyads' sleep disturbances and perceived sleep interrelationship for both PWD and caregivers among Korean Americans via a PWD-caregiver dyadic approach.

Methods

Study Design and Participants

This descriptive mixed-method study sought to understand the dynamic sleep association between PWD and caregivers. Participant recruitment began upon approval of the study protocol by the university Institutional Review Board (IRB). Potential participants in California were recruited using flyers in caregiver support groups, adult daycare centers, and senior community centers as well as snowball sampling. Study eligibility required that PWD participants should be (1) aged 18 or older, (2) diagnosed with Alzheimer's disease or related dementia, (3) not undergoing cancer treatment, and 4) not receiving hospice care; caregivers should (1) live with PWD, (2) be PWD's family, such as a spouse/partner, adult child, relative, or significant other, (3) be aged 18 or older, (4) speak or understand English or Korean, and (5) not have experienced severe illnesses (e.g., cancer, hospice care, and cognitive impairment screened by Mini-Cog[25] if age is greater than 65).

Consent process

A unique aspect of this study is the direct assessment of PWD as part of the dyadic approach. Obtaining PWD consent entailed two different processes depending on PWD's decision-making capacity.[28] All PWD participants were screened for their decision-making capacity using the 'Decision-Making Capacity Assessment (DMCA)' tool recommended by the university IRB.[28] The DMCA tool assessed whether PWD could understand the goals of the study, risks/benefits, and voluntary participation.[26, 27] If PWD showed evident capacity for decision-making, verbal consent was obtained. If a PWD did not show evident capacity for decision-making, we identified a surrogate (e.g., legal representative) such as a spouse, adult child, or other relative. In our study, all family caregivers of PWD were their surrogates, and we obtained surrogate consent from them using 'The Surrogate Certification' form recommended by the university IRB.[28] Additionally, we obtained PWD's assent and affirmative agreement of voluntary participation in the study. For the caregiver consent process, we provided a sufficient explanation of the study purpose, procedure, risks/benefits, and voluntary participation and then obtained verbal consent from caregivers. The university IRB approved the study without written consent as the study protocol presents minimal risk to participants. Three PWD (27.3%) were identified with limited decision-making capacity, and their family caregivers who were surrogates provided their consent. In addition, PWD's assent was obtained for voluntary participation in our study. Eight PWD (72.7%) identified with decision-making capacity provided verbal consent. All caregivers (100%) provided verbal consent for voluntary participation in our study.

Measures

Interviews. A semi-structured interview was conducted with both PWD and caregivers to explore the overall perceived sleep experience of the dyads. All interviews took place in the dyad's own home to encourage interaction and sharing of experiences by the dyads. Each interview was audio-recorded. Table 1 presents the semi-structured interview guides and sample questions.

English proficiency. English proficiency in this study was assessed based on the participant's subjective reporting. Family caregivers born outside of the US rated their own English proficiency on a single item with a 5-point Likert scale (4 =excellent, 3= very good, 2= moderate, 1= low, 0 =cannot speak English).

Sleep diary. Two diaries (one for PWD and one for caregivers) for the daily sleep experiences of both PWD and caregivers were logged by caregivers for four weeks.

Data Analyses

Thematic analysis. Thematic analysis was used to identify subcategories, categories, and themes via ATLAS.ti (8.0), a qualitative data analysis software.[51] The study followed Braun & Clarke's (2006) six-phase guide for inductive data management: (1) become familiar with the data, (2) generate initial codes, (3) search for themes, (4) review themes, (5) define themes, and (6) write-up.[52, 53] The audio-recorded interviews were transcribed verbatim. If participants used a language other than English (i.e., Korean), the bilingual principal investigator (E.J.) translated interview transcripts and sleep diaries into English and trained bilingual research assistants verified all translations. The principal investigator (E.J.) also reviewed all English transcripts multiple times with other qualitative researchers (J.L., J.K., CB). Additionally, all sleep diaries logged by caregivers were reviewed multiple times separately and concurrently with interview data.

Initial codes were generated through an open coding process, and similarities and differences identified among the created codes. Similar codes were grouped into sub-categories, and sub-categories identifying similar experiences were grouped into main categories. Interrelationships among the categories were discussed and initial themes identified. The research team refined the initial themes multiple times to reach consensus on the phenomenon of sleep disturbances and sleep association among the dyads.

Several methods were employed to ensure validity and reliability of the data analysis.[54] Credibility was ensured through peer reviews and triangulation of evidence from sleep diaries and interviews. This is one of the most successful strategies for validation of qualitative data.[55] Dependability was ensured through consistent use of an interview guide and audio recording to affirm the consistency of interpretations. To ensure confirmability, audio recordings, reflective notes, peer-reviewing, and the iterative process of data analysis were maintained to retain detail in the interpretation process. Transferability was bolstered through review of the analytical process and findings to ensure that conceptual dimensions are grounded by the data.[54]

Results

Participant Characteristics

Participants' demographic characteristics are presented in Table 2. PWD's average age was 82.7 years (SD= 2.3). The caregivers' average age was 69.1 years (SD= 10.2). Two PWD (18.2%) and all caregivers (100%) were female. Seven caregivers were wives of PWD, and four caregivers were daughters. Four dyads (36.4 %) slept in the same bed. The mean English proficiency of family caregivers born outside of the U.S. was 2.1 (SD= 1.1) out of 4 indicating moderate English proficiency. Seven spouse caregiver's English proficiency was 1.4 out of 4 indicating low English proficiency. Average years of living in the U.S. was 41.3 (SD= 13.8).

Themes

Four main themes were identified to describe dyad sleep disturbances and their interrelationship: (1) linked sleep disturbances between PWD and caregivers, (2) interrelationship in dyads, (3) language challenges within and outside the Korean American dyads, and (4) strategies that improve sleep quality for dyads. The themes reflect challenges that dyads experienced in their sleep environments and reveal dementia caregiving strategies that could improve dyads' sleep quality. Furthermore, the themes underscore the importance of treating the PWD-caregiver dyad as a unit of analysis rather than disparate PWD and caregiver cases. Themes, subthemes/ key findings, and example quotes are presented in Table 3.

Theme 1: Linked sleep disturbances between PWD and caregivers. Three sub-themes support how PWD and caregivers have linked sleep disturbances: (1) Influence of each other on their sleep quality in dyads, (2) Sleep disturbances beyond control, and (3) Mixed attitude about sleep disturbances in dyads.

Influence of each other on their sleep quality in dyads. First, most PWD-caregiver dyads discussed their influence on each other as an inevitability, especially sleep quality. In dyad descriptions, when caregiving for PWD was good, PWD acknowledged that their sleep quality was good. Many PWD described how attentive care improved their sleep. For example, on days when caregivers reminded PWD to exercise and cook healthy food, PWD had better sleep. One PWD-caregiver dyad described the impact of caregiving on the sleep quality of PWD that many other participants also expressed.

> PWD (82-year-old): Well, overall, I feel good. I'm good. I feel better in the morning before going out. When my daughter asks me to go out to exercise, I go out with her to work out. Going out to work out. I like it, I am fine…… Because my daughter took good care of me... of course. sure. It helps me get a good night's sleep.
>
> Caregiver (52-year-old daughter): What my plan is to take him out, mostly on the weekends, to keep him awake. That's my usual plan but sometimes it works and sometimes it doesn't. But when it does work, he [PWD] sleeps really well the next morning and he's in a better mood and a lot more alert. He's a little bit more cognizant of what's going on. For my sleep, well I exercise together with my father for an hour that helps us …, and he slept well and so I can sleep.

Additionally, most family caregivers reported sleeping well when PWD slept well. On the other hand, caregivers experienced sleep deprivation and decline in sleep quality when PWD suffered from sleep disturbances, exhibited nighttime behavioral problems, and required overcharging caregiving.

> Caregiver (61-year-old daughter): I have experienced that my mom's sleep patterns are directly linked to my sleep. My mom's sleep disturbance affected me, she came out of bed at night and tried to go outside and opened the refrigerator to find things. I was so tired that I lost up to 5 pounds, and it was so hard that anyone could tell me like that, looked sick. Now, now as my mother's symptoms improved... I got better too. I am at peace and sleeping comfortably at night in my room.

> Caregiver (75-year-old spouse): Sometimes, I don't get any sleep until 2 or 3 am at all. I have no chances to go to bed early resulting in decreased sleep. It has been 8 years caring for my husband. Sometimes, my husband screams explosively. These things make it harder for me, so I can't sleep any better.

Sleep disturbances beyond control. The frequency and intensity of sleep disturbances in PWD-caregiver dyads left them feeling that they had no control over their sleep. Significantly, many PWD-caregiver dyads described concerns and worries about their increased and uncontrolled sleep disturbances for both PWD and family caregivers. PWD and caregivers reported that sleep quality decreased when PWD experienced hallucinations/delusions, multiple awakenings at night, difficulty falling asleep, dozing off during daytime activities, and frequent/prolonged daytime naps. Some PWD experienced lasting nighttime hallucinations that required caregiver attention, and persisting hallucinations severely reduced the number of sleep hours for both PWD and caregivers in the dyads. Caregivers also faced challenges managing PWD during episodes of these sleep disturbances. Because caregivers needed to assume caregiving responsibilities to ensure PWD safety, episodic disturbances created sleep irregularities among caregivers. Additionally, caregivers experienced excessive fatigue resulting in frequent prolonged daytime naps. Many caregivers shared concerns about multiple awakenings, reduced amounts of total sleep time, and difficulty regaining energy even after a night of undisturbed sleep.

> PWD (80-year-old): Yes, I did. I thought that my wife was calling me at night…... It seems that my sleep affects my wife's sleep.
>
> Caregiver (73-year-old spouse): My husband would come to my room at night several times at 3 o'clock and talk strangely. Sometimes he comes to my room at night once or twice a week and asks, "Did you call me?" he said, [but I didn't] Basically, I don't sleep very well.

> PWD (85-year-old): Every day I lock my room before going to sleep because of the thief.
>
> Caregiver (63-year-daughter): The one problem is that sometimes, she hallucinates at night. I think that is the problem for my mom. My mother said there must have been a thief, she woke up at night and she was anxious. Then I woke up and calmed down my mother. But my mom keeps locking the door and wrapping the door handle around with a string. She wakes up frequently and stays awake at night.

Mixed attitude about sleep disturbances in dyads. When we discussed with PWD their sleep experiences, many insisted that their overall sleep quality was good enough irrespective of sleep disturbances and changes in sleep routines. This may be related to PWD's cognitive impairment and memory loss of nighttime sleep experiences. When PWD reported sleeping well, they often could not recall how they actually slept. Instead, their caregivers provided more detailed accounts of sleep experiences and disturbances.

> PWD (79-year-old): I'm someone who doesn't sleep for a long time. But I don't wake up at night. I usually sleep well at night. I don't even go to the restroom. I don't toss and turn in my sleep. I'm a good sleeper.
>
> Caregiver (70-year-old): Since my husband has such a strong idea stuck in his head that he is a person who does not sleep much, when he sleeps for 8 hours, without even remembering it, he says that he sleeps for only 5 hours. He tends to toss and turn, so the bed shakes a lot, and I can't sleep well. I hear my husband going to the bathroom about twice a night.

In some cases, caregivers were unaware of their own markedly poor sleep quality and how it could affect their physical and emotional health. Through the study, caregivers became more explicitly aware of their own sleep quality. They learned that they experienced nighttime sleep disturbances, yet many caregivers ignored their own sleep needs to care for PWD. For instance, a 75-year-old wife providing care for her husband did not realize that she only slept five hours per night until she had to log it in her diary for the study. She worried whether her forgetfulness and difficulties recalling past memories may be related to sleep deprivation. A 53-year-old daughter providing care for her father shared similar experiences and worries about her disturbed sleep.

> Caregiver (53-year-old): I realized [during the study], you know, I woke up so much in the middle, I wake up in the middle of the night all the time like him [father with dementia] that's not good. So, I told you I had some bad sleep for a long period of time. I don't like it. I don't want dementia to be my future.

These conflicting perceptions and unawareness of sleep disturbances in PWD and caregivers appeared to hinder both from having a clear understanding of their overall sleep disturbance. However, keeping a sleep log and reviewing it helps caregivers map their sleeping patterns, identify sleep disturbances, and assess their sleep quality with observable data rather than vague guesses and feelings.

Theme 2. Interrelationship in dyads; connected relationships in dyads. All dyads acknowledged themselves as a unit living together and affecting each other rather than as separate individuals living disparate lives. Within the unit, many PWD expressed their dependence on their caregivers. PWD appreciated their caregivers for providing good care, including food, exercise, and emotional comfort. An 83-year-old husband with dementia said, “I can’t live without my wife. She is an important person to me. So, I can’t be without her, it is comfortable with her. To me, she is a person I am grateful for.” Another 81-aged husband with dementia mentioned, “My wife takes good care of me, so I eat well and sleep well……, I can tell you. Now that my dependence has increased, she is like a mother, like an older sister, like a younger sister, like a nurse, like a doctor, and like a nutritionist.” Overall, the dyads described their lives as deeply linked. One dyad offers a glimpse of what linked lives between PWD and their caregivers look like.

> PWD (79-year-old): I can’t live without my wife. She’s a reliable person. I can’t live without my wife. I am able to be alone and can stay home by myself. When my wife goes to the grocery store, I am home alone, but it is okay because my wife is coming soon. She won’t run away.

> Caregiver (70-year-old wife): My husband relies on me a lot. Still, I feel lonely and unable to live without my husband. My husband is my emotional support. I wish we could live together like this for a long time.

***Theme 3. Language challenges*.** Language challenges consist of two sub-themes: (1) communication barriers within the dyad between PWD and caregiver and (2) between dyads and community resources.

Communication barriers within the dyad between PWD and caregivers. PWD and caregivers faced communication challenges between parent PWD and offspring caregivers. As the dementia progressed, some PWD forgot their second language (i.e., English) This made it difficult for caregivers who did not speak the first language as fluently to communicate with the PWD. Mainly, this challenge affected the second generation, offspring caregivers and their parent PWD. In one PWD-caregiver dyad, the caregiver kept talking to her PWD father in English, but he did not understand her words and hesitated to communicate with the daughter-caregiver. Another dyad mentioned:

> PWD (84-year-old): As I said earlier, I remembered even one English word well I knew before... but now I cannot remember. So, I'm afraid to speak [to my daughter].
>
> Caregiver (53-year-old daughter): I think a little bit he's nervous because he doesn't seem to understand my English, what's going on with me.

Between dyads and community resources. Additionally, there were limited community resources such as Korean education resources and Korean dementia utilization resources. Many PWD and caregivers described that when they felt that they had sleep disturbances, they wanted to learn how to deal with their sleep problems. However, with their limited English proficiency, it was difficult to find accessible education in Korean for sleep. Additionally, many caregivers stated that if they had respite from heavy caregiving responsibilities, it would help to relieve their stress and have good sleep, but that when they tried to find the resources such as adult daycare or senior center in Korean, there were limited resources. This forced caregivers to provide care for PWD around the clock, exacerbating sleep disturbances at night. Several quotes were selected to describe the challenges with the use of community resources due to the limited English skills.

> Caregiver (61-year-old daughter): Actually, when I think about how long I will take care of my mom. We can't know, don't know when it is going to end. So, you know what. I have nowhere to ask for help. It's so hard for me to stick to my mom and take care of her. I wish there were more community services with Korean that would take care of my mom all day long.

Theme 4. Strategies that improved sleep quality for dyads. Many PWD and caregivers described strategies that they adopted to improve their sleep quality together. Some of these included regular exercise, morning light exposure, keeping healthy sleep schedules, limiting liquid and food intake before sleep, and limiting the use of smartphones in bed. Additionally, most dyads expressed a desire to improve their sleep quality as a pair. Some wanted to find sleep programs that PWD and their caregiver could participate in together. Others mentioned that meeting other PWD-caregiver dyads was a great benefit for them to share their stories and build a community of support. The following quotes exemplify this theme.

> PWD (81-year-old): Also, my wife helps me to walk every day and sleeps well. I mean she helps me by checking if I walk outside or not…… I was well aware of the importance of taking good care of my body, walking well, and sleeping well. I have been walking with my wife.
>
> Caregiver (77-year-old wife): It was great to be able to check my sleep and my husband's sleep together. We work out regularly. I try not to take caffeine. Sometimes, I can't sleep at night. When that happens, I just relax and spend time doing what I like, reading a book, or listening to a song. To improve sleep... It's good to join the two of us on a program that we both participate in together. I think doing it together will be much more helpful because that way we can have a shared experience.

> Caregiver (70-year-old wife): I wake up early and always wake my husband up in the morning to create a regular habit or routine for him. I lift the blinds up on all windows in the morning. I make sure that I make the house filled with bright light every morning. I help my husband to exercise every day. He goes out at 3:30 pm to exercise every day. These days, his friend moved in, and they work out together…… There are two other dementia families that meet once a month. The women are family caregivers, and the husbands have dementia. I think it's good when couples get together. Caregivers talk with each other about caregiving, sleep, and food, and men [PWD] also have their own stories. I can also watch him from the side. I think it's good.

PWD-caregiver dyads demonstrated a desire to actively improve their overall quality of life using their sleep strategies. Although these strategies may not substantially improve the dyads' sleep quality, they include habits and routines that generally promote healthier lives. Many dyads suggested that addressing sleep challenges as a pair would be much more beneficial because their linked lives reinforce each other's experiences.

Discussion

To our knowledge, this is the first qualitative report of sleep disturbances and the bidirectional effect of sleep association in Korean American PWD-caregiver dyads. Here we provided an insight into the phenomenon of associated sleep disturbance between PWD and caregivers among Korean Americans as well as challenges and strategies addressing sleep quality of PWD-caregiver dyads. The main themes were linked sleep disturbances between PWD and caregivers, interrelationship in dyads. language challenges in Korean American dyads, and strategies for improving sleep quality for dyads.

Our findings offer a better understanding of sleep and sleep quality in PWD-caregiver dyads and highlight the importance of treating PWD-caregiver pair as an interactional unit.[10, 50] PWD and caregivers commonly described themselves as a unit living together with linked lives. Therefore, our findings reflect that to effectively promote sleep quality in dementia care, dyadic-based approaches involving both PWD and caregivers should be a top priority. Both PWD and caregivers would need to work together as a unit to improve sleep quality.[10, 56] This is consistent with several studies.[10, 56] Miller et al., (2019) examined the dyadic effects of well-being and underscored an assessment of both PWD and caregivers to allow us to understand a complete picture of dementia-related health outcomes.[10] We included both PWD and caregivers in our qualitative study to give voice to their sleep experiences and perspectives. Dyadic approaches in sleep research can thus synergistically identify ways of improving sleep quality for both PWD and their caregivers in a community-based environment.

Our findings also highlight unique challenges in ethnic PWD-caregiver experiences among Korean Americans, namely language and culture. The language gap between parent PWD and offspring caregivers in Korean American PWD-caregiver dyads can not only limit effective communication within the dyad but also produce an inappropriate caregiving environment. Another language-related challenge was the lack of useful and appropriate educational resources or limited availability of community resources in Korean with their limited English proficiency. Park et al., (2020) reported that Korean Americans experienced sleep disturbances due to sociocultural stressors such as language barrier and lack of community resources with cultural competency.[11, 13] Kim et al., (2019) identified that due to the language barrier, Korean American caregivers had challenges to find community resources.[57] Korean Americans' sleep disturbances were also linked with mental health problems such as depression, stress, and loneliness.[11, 14, 15] Therefore, our finding emphasizes that future sleep research should be conducted for PWD-caregiver dyads with special attention on cultural competency (e.g., PWD's native language) to bridge the immigrant generational gap and alleviate the language barrier in ethnic minority immigrants, especially Korean Americans.

Sleep disturbances among the PWD-caregiver dyads in our study were consistent with other studies that found low sleep quality in PWD due to difficulty falling and staying asleep as well as multiple awakenings, resulting in inadequate and/or poor sleep which was significantly associated with advanced behavioral problems.[2-4] Here, PWD and caregivers perceived these sleep disturbances as phenomena beyond their control resulting in stress worries. In addition, unawareness of sleep disturbance and forgetting sleep experiences among PWD may lead to deterioration of their sleep quality for both PWD and caregivers. Many PWD in our study mentioned that their sleep quality was good enough despite diary logs capturing sleep interruptions and poor sleep experiences. PWD's sleep disturbances negatively affected caregivers' sleep quality and their capacity to provide care. Without insight on PWD-caregiver dyadic sleep quality, their interrelated health problems may be neglected which can limit effective dementia caregiving.[58]

Caregivers' sleep in our study was frequently affected by the demands of PWDs at night and PWD sleep disturbances. Multiple studies have reported the same outcomes; caregivers' sleep quality is poorer when compared to those of the same age who are non-caregivers. Among spousal caregivers, sleeping together with PWDs is associated with increased rates of depressive symptoms and stress burdens related to nonrestorative sleep.[23, 59] Also, many caregivers struggle with high levels of stress, impaired mood, depression, and neglect of their own health care.[6, 60-62] Thus, it is important to improve sleep quality for both PWD and caregivers, and develop strategies to alleviate sleep disturbances as well as consider dyadic sleep association Korean American PWD-caregiver dyad.

This study has some limitations. First, our data were generated from small, convenient samples. Nonetheless, the findings indicate some of the potential implications of dyadic approaches for future interventions to improve sleep quality in community-dwelling families with PWD. Second, the findings cannot be generalized to other ethnic minorities or the entire dementia population. However, this study sheds light on an understudied population and suggests pathways for working with immigrant populations around dementia and sleep issues. Future research can focus on improving sleep hygiene by empowering PWD and their caregivers to reduce sleep problems of the dyads living together.

Conclusion

This study explored the dyadic sleep association between Korean American PWD and co-habiting family caregivers. This study has the potential to contribute to a greater understanding of the PWD-caregiver sleep dynamic and lead to the development of effective interventions designed to increase the quality of sleep for Korean American PWD-caregiver dyads. Dyadic appraisal, assessing both PWD and caregivers directly, can provide information on the relationship between PWD and family caregivers in terms of their sleep dynamics. In addition to dyadic appraisal, understanding the interrelated sleep quality and challenge/strategies offers an opportunity to promote healthier caregivers, which in turn allows better care for PWDs longer at home. Ultimately, if PWD can live in the community longer it has the potential to improve the quality of their lives.

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Table 1. *Semi-Structured Interview Guide and Sample Questions*

Domain	Example questions
PWD	
PWD's sleep	Can you tell me about how you are sleeping?
Perceived aids and barriers to sleep	What makes it difficult to have good sleep? Can you explain that further?
Caregivers	
Caregivers' sleep	Can you tell me about how you are sleeping?
Caregivers' perceived PWD's sleep	Can you tell me about - - - -'s sleep?
Sleep association between caregivers and PWD	How does - - - -'s sleep affect your sleep?
Perceived aids and barriers to sleep	What makes it difficult to have a good sleep? How did you try to solve your sleep problems?

Table 2. *Characteristics of Family Caregivers and Their Loved Ones with Dementia*

Participants	Frequency (%) or Mean (SD)
Persons with dementia (n=11)	
Ethnicity/race: Korean	11(100%)
Gender (female)	2 (18.2%)
Mean age (SD) years	82.7 (2.3)
Health Insurance (yes)	11 (100%)
Medicaid only	2 (18.2%)
Medicare only	9 (81.8%)
Types of dementia	
Alzheimer's dementia	4 (36.4%)
Vascular dementia	6 (54.5%)
Frontal Temporal Dementia	1 (9.1%)
Stage of dementia reported by caregivers	
Early stage	6 (54.5%)
Middle stage	5 (54.5%)
Immigration to U.S. (Yes)	11 (100%)
Decision making capacity (Yes)	8 (72.7%)
Caregivers (n= 11)	
Ethnicity/race: Korean	11(100%)
Gender (female)	11 (100%)
Mean age (SD), years	69.1 (10.2)
Spouse	75.9 (3.5)
Adult Child	57.2 (5.6)
Relationship with PWD	
Spouse (wife)	7 (63.6%)
Adult child (daughter)	4 (36.4%)

Education	
College/University	8 (72.7%)
Graduate degree	3 (27.3%)
Family monthly income	
$2,000 - $4,000	2 (18.2%)
$4,000 - $6,000	4 (36.4%)
More than $6,000	5 (45.5%)
Health insurance	
Yes	11 (100%)
Medicaid	1 (9.1%)
Immigration to U.S. (Yes)	11 (100%)
English proficiency, mean (SD)[a]	2.1 (1.1)
Spouse	1.4 (0.5)
Adult child	3.2 (1)
Years living in U.S mean (SD)	41.3 (13.8)
Comorbidity (Yes)	5 (45.5%)
Spouse (Yes)	4 of 7 (57.1%)
Adult child (Yes)	1 of 4 (25%)
Types of comorbidities	
Hypertension	3 (27.3%)
Diabetes	1 (9.1%)
High cholesterol	1 (9.1%)
Using the same bed with PWD	4 (36.4%)

a. English proficiency measured with 5-Likert scale (4 =excellent, 0 = cannot speak English); all participants were immigrants to U.S.

Table 3. *Themes, Subthemes, and Example Quotes*

Themes	Subthemes/ key findings	Example Quotes
Theme 1. Linked sleep disturbances between PWD and caregivers	Influence each other on their sleep quality in dyads: - Caregiving affecting the PWD's sleep	PWD (82-year-old): "Well, overall, I feel good. I'm good. I feel better in the morning before going out. When my daughter asks me to go out to exercise, I go out with her to work out. Going out to work out. I like it, I am fine…… Because my daughter took good care of me... of course. sure. It helps me get a good night's sleep." Caregiver (52-year-old daughter): "What my plan is to take him out, mostly on the weekends, to keep him awake. That's my usual plan but sometimes it works and sometimes it doesn't. But when it does work, he [PWD] sleeps really well the next morning and he's in a better mood and a lot more alert. He's a little bit more cognizant of what's going on. For my sleep, well I exercise together

	with my father for an hour that helps us …, and he slept well and so I can sleep.”
- Caregivers sleep well when PWD sleep well	Caregiver (61-year-old daughter): “I have experienced that my mom’s sleep patterns are directly linked to my sleep. My mom’s sleep disturbance affected me, she came out of bed at night and tried to go outside and opened the refrigerator to find things. I was so tired that I lost up to 5 pounds, and it was so hard that anyone could tell me like that, looked sick. Now, as my mother’s symptoms improved... I got better too. I am at peace and sleeping comfortably at night in my room..”
- Deprived sleep of caregivers due to overcharging of caregiving	Caregiver (75-year-old spouse): “Sometimes, I don’t get any sleep until 2 or 3 am at all. I have no chances to go to bed early resulting in decreased sleep. It has been 8 years caring for my husband. Sometimes, my husband screams explosively. These things make it harder for me, so I can’t sleep any better.”
Sleep disturbances beyond control: - Hallucinations/ delusions	PWD (80-year-old): “Yes, I did. I thought that I heard my wife calling me at night…... It seems that my sleep affects my wife’s sleep.” Caregiver (73-year-old): “My husband would come to my room at night several times at 3 o’clock and talk strangely, sometimes he comes to my room at night once or twice a week and asks, “Did you call me?” he said, [but I didn’t] Basically, I don’t sleep very well.” PWD (85-year-old): “I locked my room before going to sleep because of the thief.” CG (63-year-old daughter): “The one problem is that sometimes, she hallucinates at night. I think that is the problem for my mom. My mother said

	there must have been a thief, she woke up at night and she was anxious. Then I woke up and calmed down my mother. But my mom keeps locking the door and wrapping the door handle around with a string. She wakes up frequently and stays awake at night.”
- Frequent nighttime waking	CG (73-year-old wife): “He wakes up at least once or as many as three times a night to go to the bathroom. I wake up every time. I don’t sleep very well.” CG (61-year-old daughter): “For the past year, my mom has been waking up often in the middle of the night and she just was making a noise, looking for something, and walking around. Whenever my mom woke up and tried to get out of her bed, I told my mom it was still night. But keeping sleeping in the same room with my mom, I felt like I was about to die. My body was very tired because I couldn't sleep properly.” PWD (82-year-old): “I use the bathroom about 4 times.” CG (52-year-old daughter): “My father's dementia affects me sleep, yes, My dad wakes up every 3 hours. because he wakes up and then also, he’ll ask me, every time he wakes up, he looks at me and he goes, "where are we going today?" it's the same question…… So, I say the same thing over. This disrupted my sleep because then he goes back to bed, but I'm still lying in bed trying to sleep. I feel like my whole house has terrible sleep.”
- Difficulty of falling asleep	PWD (84-year-old): “Personally, it takes some time for me to fall asleep. Sometimes, it takes longer than I expected, and then I feel very difficult. It happens from time to time, you know, I cannot predict that. At that time, there was no way. I have no choice but lying in bed, lying like this, and lying like that.”
- Keeping falling asleep during daily activity	PWD (80-year-old): “Because I fall asleep while watching TV and reading books at evening [in the sofa], I do not wake up because I sleep soundly when I fall asleep. I can’t hear anything.”

	Caregiver (73-year-old wife): “He disrupts my sleep. Of course, I am not interrupted every day by my husband. Most of evenings, I wake him up when he’s sitting and sleeping on the toilet, wake him up when he’s sitting and sleeping on the sofa Because of those things, I’m annoyed and can’t sleep.”
- Frequent/prolonged daytime naps.	CG (75-year-old wife): “Yesterday, I only slept for 5 hours and I'm a little tired. On a day like this, I feel tired and sleepy around 5 pm and I doze off. When I started sleeping a little during the day, I slept for an hour or two. Even if I tried to sleep a little, it didn’t work.”
Mixed attitude about sleep quality in dyads - PWD did not recognize their sleep disturbances, but caregivers knew it.	PWD (79-year-old): “I’m someone who doesn’t sleep for a long time. But I don’t wake up at night. I usually sleep well at night. I don’t even go to the restroom. I don’t toss and turn in my sleep. I’m a good sleeper.” Caregiver (70-year-old wife): “Since my husband has such a strong idea stuck in his head that he is a person who does not sleep much, when he sleeps for 8 hours, without even remembering it, he says that he sleeps for only 5 hours. He tends to toss and turn, so the bed shakes a lot, and I can’t sleep well. I hear my husband going to the bathroom about twice a night.” CG (80-year-old wife): “I learned that he was not sleeping well most of the night. He spends a lot of time in bed and lays till late in the morning, so I thought he was sleeping well. But through this study, I learned that he wasn't sleeping deeply.”
- Despite the nonrestorative sleep of caregivers, they were unaware of their sleep disturbances resulting in ignoring their decreased health status.	Caregiver (75-year-old wife): “But this time, I found out I only sleep for 5 or 6 hours. If I drive, I always yawn. If I drive a car, I will yawn in about 10 minutes after I start driving. Recently, I have been forgetting memories from the past. I don't think I have a long -term memory. You know, all my friends can recall memories from the past, but I can’t.” CG (53-year-old daughter): “I realized [during the study], you know, I woke up so much in the middle, I wake up in the middle of the night all the time like

		him [father with dementia] that’s not good. So, I told you I had some bad sleep for a long period of time. I don’t like it. I don’t want dementia to be my future.”
Theme 2. Interrelationship in dyads: connected relationships.	Acknowledgement of PWD’s dependence on caregivers - They depend on each other in some ways.	PWD (81-age-old) “I can’t live without my wife. She is an important person to me. So, I can’t be without her, it is comfortable with her. To me, she is a person I am grateful for.” PWD (81-age-old) “My wife takes good care of me, so I eat well and sleep well……, I can tell you. Now that my dependence has increased, she is like a mother, like an older sister, like a younger sister, like a nurse, like a doctor, and like a nutritionist.” PWD (79-year-old): “I can’t live without my wife. She’s a reliable person. I can’t live without my wife. I am able to be alone and can stay home by myself. When my wife goes to the grocery store, I am home alone, but it is okay because my wife is coming soon. She won’t run away.” Caregiver (70-year-old wife): “My husband relies on me a lot. Still, I feel lonely and unable to live without my husband. My husband is my emotional support. I wish we could live together like this for a long time.”
Theme 3. Language challenges	Communication barriers within the dyad between PWD and caregivers - Communication barriers between parent PWD and second-generation offspring	PWD (84-year-old): “As I said earlier, I remembered even one English word well I knew before... but now I cannot remember. So, I’m afraid to speak [to my daughter].” Caregiver (53-year-old daughter): “I think a little bit he’s nervous because he doesn’t seem to understand my English, what’s going on with me.”
	Between dyads and community resource - Limited resources in Korean (e.g., Korean adult daycare center)	Caregiver (61-year-old daughter): “Actually, when I think about how long I will take care of my mom. We can’t know, don’t know when it is going to end. So, you know what. I have nowhere to ask for help. It’s so hard for me to stick to my mom and take care of her. I wish there were more community services with Korean that would take care of my mom all day long.”

Theme 4. Strategies that improved sleep quality for dyads.	Joining PWD and caregiver together to improve their sleep quality	PWD (81-year-old): "Also, my wife helps me to walk every day and sleeps well. I mean she helps me by checking if I walk outside or not…… I was well aware of the importance of taking good care of my body, walking well, and sleeping well. I have been walking with my wife." Caregiver (77-year-old wife): "It was great to be able to check my sleep and my husband's sleep together. We work out regularly. I try not to take caffeine. Sometimes, I can't sleep at night. When that happens, I just relax and spend time doing what I like, reading a book, or listening to a song. To improve sleep... It's good to join the two of us on a program that we both participate in together. I think doing it together will be much more helpful because that way we can have a shared experience." Caregiver (70-year-old wife): "There are two other dementia families that meet once a month. The women are family caregivers, and the husbands have dementia. I think it's good when couples get together. Caregivers talk with each other about caregiving, sleep, and food, and men [PWD] also have their own stories. I can also watch him from the side. I think it's good."
	And following general sleep hygiene - Regular sleep schedules - Light exposure in the morning - Regular exercise - Healthy diet	Caregiver (70-year-old wife): "I wake up early and always wake my husband up in the morning to create a regular habit or routine for him. I lift the blinds up on all windows in the morning. I make sure that I make the house filled with bright light every morning. I help my husband to exercise every day. He goes out at 3:30 pm to exercise every day. These days, his friend moved in, and they work out together."

PAPER 3

Severe Sleep Disturbances in Dementia Patients with REM Sleep Behavior Disorder and Family Caregivers: A Mixed Methods Case Study

Abstract

Coexisting dementia and rapid eye movement sleep behavior disorder can negatively impact both patients and their family caregivers living together. Little research has investigated the relationship of sleep disturbance in patient-caregiver dyads (dementia patients with RBD and their family caregivers). We aimed to address the impact of RBD symptoms on sleep quality of both dementia patients and their family caregivers and identify sleep interrelationships. The study used mixed methods including wearable devices (e.g., smart rings) to monitor dyad sleep for 4 weeks, semi-structured interviews, sleep diaries, and sleep quality surveys. This case study reported two dyads' sleep parameters and experiences. The findings demonstrate RBD symptoms of dementia patients affected sleep quality negatively (frequent awakening during the nights and shortened deep sleep). The findings highlight the importance of RBD assessment and management for dementia patients as it can help them improve both caregivers' and patient's sleep quality and well-being.

Keywords: ***dementia, caregiver, rapid eye movement sleep behavior disorder, sleep quality, sleep disturbance***

Introduction

Rapid eye movement (REM) sleep behavior disorder (RBD) is a unique clinical condition that manifests in recurrent abnormal behaviors associated with the loss of atonia during REM sleep.[63] Individuals with RBD show dreaming-driven acting out, including vigorous limb movements, punching, running, and jumping out of bed with potential injuries to self or/and their bedpartners.[63-66] Literature reported that RBD is associated with increased cognitive impairment and high risk for dementia.[67-69] Among older adults aged 40 to 80 with Parkinson’s disease and Lewy body dementia, the prevalence of RBD ranged from 35% to 75%.[70] In comparison, non-dementia older adults in the same age group had a much lower prevalence from 1.06% to 7.7%. [69-71] Despite longitudinal studies reporting Alzheimer's dementia (AD) and vascular dementia (VD) as a possible cause for RBD among some patients, little research had explored sleep problems caused by dementias including AD and VD.[69, 72]

Individuals with Alzheimer’s disease or related dementias (hereafter dementia) suffer from nocturnal behavior problems such as difficulty in falling asleep, multiple awakenings, and spatial and temporal disorientation at night.[40, 73] These sleep disturbances resulted in excessive daytime sleepiness and increased cognitive impairment in persons with dementia (PWD).[69] In addition, a systematic review reported family caregivers of PWD also had sleep disturbances.[5] Family caregivers experienced that their sleep was disrupted by the PWD’s demands leading to caregiving burdens and depressive symptoms.[8, 74] Moreover, PWD with co-existent RBD reported having sleep-related injuries at night, including abrasions, bruises, and lacerations with the potential risk of harm to self or/and their family members who live together.[65, 66, 72] Dementia patients with RBD and their family caregivers may be predisposed to sleep disturbance and caregiving burden because of PWD's coexisting dementia and RBD. However, limited research addresses sleep disturbance among both the dementia patient with RBD and their family caregivers living together to help them to manage sleep problems caused by dementia and co-existent RBD.[65, 66]

In this paper, therefore, we report two dyad cases, AD patient with RBD/caregiver and VD patient with RBD-like symptoms/caregiver, to identify sleep disturbance and sleep experiences. The purpose of this paper is to address severe sleep disturbance and interrelationships among dementia patients and family caregivers. We leveraged advanced wearable device, a smart ring, to collect physiological sleep data, including total sleep duration, sleep latency, deep/light sleep duration, REM sleep duration, awake duration, and sleep efficiency (percentage of actual sleep to entire duration in bed) for both the dementia patient with RBD or RBD like symptoms and their family caregivers. Wearable technology such as smart ring can be a valuable tool to continuously record physiological measures objectively.[75, 76] Data from wearable technology helps understand sleep relationships among dyads along with data from surveys and interviews with participants to gain comprehensive sleep information from them.

Methods

Study Design

This case study utilized mixed methods including quantitative and qualitative approaches using 4-week data from wearable devices (i.e., smart ring), daily sleep diaries, surveys, and individual interviews. This paper is part of a parent study that looked at sleep associations between dementia patients and their family caregivers. This presenting paper reports two dyads (patient-caregiver) cases including an AD patient diagnosed with RBD and his/her family caregiver as well as a VD patient who showed RBD-related behavioral episodes and his/her family caregiver.

Participants and Setting

Parent Study. The parent study recruited PWD and their family caregivers as paired cases to explore their sleep experiences and the bidirectional effect between them. Participants were recruited through community outreach in California. Eligibility for the parent study required PWD to 1) be aged 18 or older, 2) be persons with Alzheimer's disease or related dementia, 3) have mobility, 4) have not undergone cancer and hospice care, and 5) be able to wear a smart ring; caregivers to 1) be aged 18 or older, 2) live together with the PWD, 3) not have undergone severe illnesses (e.g., cancer, hospice care, and cognitive impairment), and 4) be able to wear a smart ring. The author's university Institutional Review Board (IRB) approved the parent study protocol.

Two paired PWD-caregivers were chosen from the parent study because two PWD showed typical RBD episodes through daily sleep diary logs and interviews. Their caregivers voluntarily reported sleep experiences related to dementia patients' RBD episodes. Caregivers provided informed consent for participation in the study. The research assistant screened dementia patients' decision-making capacity using a Decision-Making Capacity Tool required by the university IRB.[28] Depending on the PWD's capacity for decision making, dementia patients' verbal assent and caregiver's surrogate consent were obtained.

Measures

Wearable device. We provided smart rings[31] to both PWD and their family caregivers, and asked them to wear the rings during the day and night for 4 weeks. Sleep parameters measured by smart rings included total sleep duration, sleep latency, deep sleep duration, REM sleep duration, light sleep duration, awake duration, and sleep efficiency (percentage of actual sleep duration to the total sleep duration) as a daily mean for 4 weeks.[31]

Pittsburg Sleep Quality Index (PSQI). PSQI is a self-reported survey to assess subjective sleep disturbances.[32, 33] Both the caregiver and the PWD completed the survey at baseline. The possible total score range is 0-21, and greater than 5 indicates sleep disturbance.[32, 33]

Sleep diary. Caregivers were asked to write a sleep diary for themselves as well as their PWD over 4 weeks to collect 1) caregiver-reported sleep quality measured daily at wake-up time using a 5-point Likert scale, ranging from 1 (very poor) to 5 (very good), and 2) their sleep experiences at night using one open-ended question.[3, 77]

The Zarit Burden Interview. The survey measures the caregiver's burden regarding providing care for PWD. Scores were obtained at baseline. The possible total score is 0- 88. The total score can be interpreted as follow; 0 - 21 with little or no burden, 21 - 40 with mild to moderate burden, 41 - 60 with moderate to severe burden, and 61 - 88 with severe burden.[78]

Individual Interview. The dyads were interviewed at the end of the study in week 4. Semi-structured interview questions explored the sleep experience of both caregivers and PWD. One example question asks the caregiver, "Can you tell me about how you are sleeping?"

Interview questions included three categories: (1) RBD episodes and impact on PWD, (2) Impact of RBD on the caregiver, and (3) Strategies of caregiving on coexisting dementia and RBD.

Results

Dyad case 1 is a dyad of PWD diagnosed with RBD and spousal caregiver and dyad case 2 is a dyad of PWD with RBD-related episode and adult-child caregiver. Table 1 presents the demographic information and summary of surveys of each caregiver and PWD of the two cases. Sleep parameters measured from smart rings for 4 weeks were summarized in table 2. Trends of sleep parameters for 4 weeks are illustrated in Figures 1-5.

Dyad 1: RBD diagnosed AD patient and spousal caregiver

A spousal caregiver and her husband with AD were a married couple living together in their house. The PWD was 79 years old, diagnosed with Alzheimer's dementia, and had RBD for over 10 years. The caregiver was a wife, 74 years old. The caregiver and PWD used the same room and the same bed. The caregiver had been providing care for her husband with AD for over 3 years. The caregiver reported her husband was in the moderate dementia stage.

Based on the self-reported surveys on psychological variables, the caregiver reported no sleep disturbances (PSQI score = 4/21) and moderate to severe caregiver burden (ZB score = 53/88). For the PWD, the caregiver reported that her PWD had sleep disturbances (PSQI sore = 8/21).

In the wearable sleep measures, the PWD's average total sleep duration was 124 minutes, deep sleep duration was 16.3 minutes, REM sleep duration was 4 minutes, and sleep efficiency was 50.9%. Awake duration was not recorded. The caregiver's average total sleep duration was 436 minutes, deep sleep duration was 80 minutes, REM sleep duration was 77 minutes, awake duration was 67 minutes, and sleep efficiency was 87.4%.

In the sleep diaries, the caregiver logged 21 days for herself and 20 days for the PWD and the rest were not recorded. The daily average of PWD's total sleep duration was 619 minutes. PWD had naps for 18 out of 20 days, the daily average nap duration was 105 minutes. PWD's feeling in the morning after being awake was 2.9 out of 5. The daily average of the caregiver's total sleep duration was 481 minutes. She had naps for 10 out of 21 days, the daily average nap duration was 64 minutes. Caregiver's feeling in the morning about the prior night's sleep was 3.7 out of 5.

Three themes were identified from individual interviews with the caregiver and PWD: (1) RBD episodes and impact on PWD, (2) Impact of RBD on the caregiver, and (3) Strategies of caregiving on coexisting dementia and RBD. In dyad 1, only the caregiver was interviewed at the end of the study. PWD did not show enough decision-making capacity and was unable to be interviewed independently.

RBD episodes and impact on PWD. The PWD moved frequently while asleep. Sometimes the PWD threw pillows around, swung his arms in the middle of the air and soiled the bed. In his sleep, the PWD incorporated others and his environment into his dream. One day, the PWD acted out his dreams of playing basketball and knocking and throwing things around. The PWD also hurt himself by bumping his head on the edge of the nightstand and bleeding as a result. The PWD moved vigorously while napping as well and was unaware that he fell out of bed. The caregiver commented, "Throughout the week he had a REM sleep behavior disorder episode. He sleeps a lot, 10 hours at night and two hours of naps during the day. But he is always tired when he wakes up."

Impact of RBD on the caregiver. The caregiver noted that the PWD's nighttime episodes compromised her sleep quality. She referenced, "Because he does have REM sleep behavior disorder, his sleep disturbance absolutely affects my quality and quantity of sleep." The PWD moved actively in his sleep, sometimes threw objects such as pillows around, and kicked the caregiver. The caregiver also sensed the PWD's movement easily due to bed sharing, and RBD episodes resulted in the caregiver feeling sleep deprived. Awakenings at night from PWD's RBD episodes posed challenges for the caregiver to go back to bed, and the caregiver reflected, "My sleep was restless sometimes."

Strategies of caregiving on coexisting dementia and RBD. The caregiver developed strategies to reduce the harmful effects of her PWD's RBD. The caregiver and the PWD sleep on the same bed because the caregiver wants to be aware of when the PWD is having intense REM sleep behavior episodes to prevent him from hurting himself. The caregiver removes objects around the PWD's environment that he can potentially knock over while sleeping. Also, the caregiver puts a pillow between her and her PWD for protection. The caregiver reported that she did not wake her husband and touch him when he had RBD episodes because it can be dangerous to her. When the PWD was in the hospital, she disclosed to health providers that her husband had RBD so that they could keep an eye on him for his safety. The caregiver noted, "Recently, he had not been having intense REM sleep disorder episodes because we followed sleep hygiene (going to bed early, not eating late, avoiding caffeine, etc.) so that most nights helped him obtain more restful sleep, which in turn helped me obtain restful sleep as well. When we deviate from the protocol is when he tends to have REM sleep disorder episodes."

Dyad 2: Vascular dementia patient with RBD-related episodes and a family caregiver

A 42-year-old daughter caregiver cohabiting with her 84-year-old father with VD used different rooms for sleep. The caregiver reported PWD's history of dream enactment and suspected that he had RBD for over 10 years. The caregiver had been providing care for the PWD for over 1 year. The caregiver reported the PWD's stage of dementia was the early stage.

Based on the surveys for the PWD, the caregiver reported that her PWD had sleep disturbances (PSQI sore = 10/21). The caregiver reported sleep disturbances (PSQI score = 9/21). The caregiver experienced severe caregiving burden (ZB score = 70/88).

In the wearable sleep measures, the PWD's average total sleep duration was 296 minutes, deep sleep duration was 20 minutes, REM sleep duration was 12 minutes, awake duration was 406 minutes, sleep efficiency was 43%. The caregiver's average total sleep duration was 373 minutes, deep sleep duration was 106 minutes, REM sleep duration was 87 minutes, awake duration was 81 minutes, sleep efficiency was 83.2%.

In the diaries, the caregiver logged 28 days for herself and the PWD. On the other hand, she recorded only 2 days when she had naps and 4 days when PWD had naps, the rest of nap logs were not recorded. The daily average of PWD's total sleep duration was 476 minutes. The daily average nap duration was 61 minutes. PWD's feeling in the morning after being awake was 2.9 out of 5. The daily average of the caregiver's total sleep duration was 428 minutes. The caregiver’s daily average nap duration was 50 minutes. Caregiver’s feeling in the morning after being awake was 3.2 out of 5.

In dyad 2, the caregiver and the PWD were interviewed at the end of the study because the PWD had capacity for decision-making. Three themes were identified from individual interviews with the caregiver and the PWD: (1) RBD episodes and impact on PWD, (2) Impact of RBD on the caregiver, and (3) Unfamiliarity with the PWD’s RBD-like symptoms and limited sleep improvement strategies.

RBD episodes and impact on PWD. During the past year of caregiving, the caregiver noticed that her PWD had occasionally spoken loudly and yelled during the night. He also woke up late in the morning. The caregiver mentioned, “Sometimes his dream, his nightmares are so loud it wakes me up. He sleeps here [his room]. When I can hear him, I wake up and I go, and I always try to wake him up. So, he can snap out of it. Sometimes he goes through bad times with those bad dreams.” The caregiver reported that the PWD experienced an alarming episode two years ago. He woke up in the middle of the night, removed his clothes, went to the yard, and moved violently as though he was agitated or fighting. His wife was afraid [at that time his wife was alive and living together], and he showed limited comprehension of the situation. The PWD reported poor sleep quality. He recalled waking up some mornings thinking that he must have struggled or moved actively in his sleep. He found the blanket pushed back and sometimes found himself falling out of bed. He had frequent nightmares and mentioned, “My sleeping habits are not good while sleeping at night. I can’t remember what I did while I was sleeping. One day I must have struggled. The blanket was pushed back. Sometimes I would fall out of bed. And I dream at night. I have a bad dream too. I guess I can't sleep comfortably, quietly, and neatly. When I wake up in the morning, I don't feel very good. It's good if I'm in a good mood."

Impact of RBD on the caregiver. The caregiver expressed many concerns about her poor sleep quality. She mentioned that she woke up multiple times at night due to noise from the PWD having nightmares and using the bathroom. Sometimes, she could not fall asleep until 2 am for no apparent reason. She worried that she would develop dementia like her father because of her frequent sleep interruptions, resulting in severe stress for her. She commented, "I noticed I woke up. I wake up a lot and I don't like it. I don't like it. So, I have to do something to change. I don't know. I wonder to work on it. It's very interesting. I don't want dementia to be my future."

Unfamiliarity with the PWD's RBD-like symptoms and limited sleep improvement strategies. The caregiver was unfamiliar with RBD and unaware of her father's RBD-like sleep behaviors. The caregiver and PWD had misunderstandings about PWD's RBD-like symptoms. The pair mistook the symptoms as sleep episodes resulting from PWD's declining mental health or depression. Moreover, the caregiver was uninformed of specific guidelines to relieve RBD-related episodes, such as practicing bed safety by removing nearby sharp or breakable objects, not touching the PWD when he is acting out while asleep or removing items with potential risk of harm. In addition, both the caregiver and the PWD lacked information about general sleep hygiene including regular exercise, limited intake before sleep, and limited use of smartphones in bed. The caregiver described PWD's nighttime routine, "He learned to do YouTube and now he's totally addicted. He admitted it. He's always happy because he goes to his bedroom which is his safe place. He is watching his own TV and his iPad. I thought he used to go upstairs at like 8 pm. 8 o'clock. He is not going to sleep. He's going to it [view YouTube] for maybe 2 or 3 hours.

He also has some snacks. But I am not bothering him. I cannot see him anymore." The caregiver observed PWD's behaviors and his mood but did not recognize that the bedtime routine impeded his sleep quality. Although her father experienced sleep disturbances, the caregiver did not provide any support to the PWD to improve his sleep quality. She noted that she took on the caregiving role neither because she was qualified nor prepared but by default because no other family member remained. "He and I are the remaining people who can live together. I think I was more stressed with my father." The PWD worried about his worsening sleep problems, including restless sleep, multiple interruptions, and bad dreams. He mentioned, "I don't have good sleep... Sometimes it's very difficult because I can't fall asleep quickly. When I wake up, I open my eyes and stay still, but I can't get up right away because I'm tired. If I was in a good mood, I would have woken up right away. I seem to have all the bad sleeping habits." Despite these concerns, the caregiver and the PWD lacked awareness of RBD, had limited information about sleep hygiene, and as a result, did not have appropriate strategies to improve sleep quality.

Discussion

To our knowledge, this is the first case report to investigate the sleep disturbances experienced by an AD patient-spouse caregiver dyad and a VD patient-daughter caregiver dyad. Current literature has focused on RBD mostly in persons with PD and/or LBD, and few studies considered developing RBD features among persons with AD or VD.[63, 64, 68, 69, 79] In this case report, the dyad 1 patient was diagnosed with AD two years prior, and the dyad 2 patient was diagnosed with VD a year ago. The caregivers reported that they had sleep disturbance and observed RBD-related episodes in the PWD for over 10 years. Since the AD patient was diagnosed with RBD by a neurologist, the spousal caregiver in dyad 1 had sleep hygiene guidelines to follow for her husband’s RBD problems and had specific strategies to improve sleep quality for both. On the other hand, the adult-child caregiver in dyad 2 had no knowledge and information about RBD. Therefore, although the caregiver observed her father’s sleep disturbances, she could not make connections between her observations and RBD. While the VD patient recognized a noticeable change in his sleep patterns in recent years, progressively worsening sleep quality, and excessive fatigue, he simply attributed them to bad sleeping habits rather than RBD. Thus, the VD patient did not see a healthcare provider for the sleep disturbances and went undiagnosed despite exhibiting RBD symptoms. As a result, dyad 2 lacked information about managing sleep disturbance problems and advice from healthcare providers on sleep hygiene guidelines. These findings highlight the importance of RBD assessment and management for persons with AD or VD as it can help them improve their quality of life as well as their family caregivers’ sleep and quality of life.

Moreover, not only are the patients seriously affected by RBD, but their family caregivers are also pervasively affected. Caregivers reported a negative effect of RBD on overall sleep quality resulting in more caregiving burden. Their sleep was interrupted by PWD’s nocturnal behavioral problems. Caregivers could be at potential risk for harm caused by RBD episodes. Data from dyad 1 caregiver’s wearable device showed that the average awake duration at night was over one hour and almost two hours on the nights that PWD had acting out dreaming. In the sleep diary from the caregiver, she reported feeling sleep deprived when she spent more time awake at night due to the PWD’s RBD episodes (such as kicking, etc.). These findings are consistent with reports in the literature about the impact of patients’ RBD symptoms on their spouses.[65] Bed partners who take care of persons with RBD reported sleep disruptions and exposure to potential injuries caused by their patients with RBD.[66] They had insomnia, anxiety, and depressive symptoms, resulting in a more impaired quality of life.[65, 66, 72] Our findings consistently find that PWD's RBD behavior negatively affected their bedpartner and exposed them to the potential risk for harm. Additionally, caregivers who cohabit with the PWD and use a different room are also affected by PWD's RBD. Dyad 2 caregiver reported much higher sleep disturbances and more caregiving burden compared to caregiver 1 which was supported by PSQI and ZB scores. Dyad 2 caregiver confirmed that more RBD behaviors of her father affected her sleep quality. This emphasizes the need for a study to evaluate precisely the sleep problems of family caregivers of PWD with RBD and to develop proper interventions for improving their sleep quality and health.[74]

Lastly, our findings reported large discrepancies in total sleep duration between sleep diary and wearable device data for PWD. In the sleep diaries, caregivers reported that their PWD spent more time in bed and slept much longer compared to the wearable data. In the diaries, the total sleep duration of PWD 1 was 619 minutes; PWD2 was 476 minutes. On the other hand, in wearable data, the mean of total sleep duration of PWD1 was 123.6 minutes; PWD2 was 295.5 minutes. In the wearable data, there was a ton of movement at nighttime of PWDs, suggests that the PWD may toss and turn more frequently and for a long time, but they may be unaware of their movement during sleep. The wearable devices detected PWD's movement during sleep as being awake. Thus, the wearable data reported much fewer total sleep durations than what the caregivers reported in their sleep diaries. This is unique findings on movement throughout the overall sleep of PWD with RBD resulting in disturbed sleep quality. Little research has investigated the movement of PWD with RBD at nighttime.[63, 70] Further investigation is needed to explore nighttime movements and sleep quality for PWD with RBD.

The study has some limitations to consider. The study reported two cases to explore the sleep experiences of dyads related to PWD's RBD episodes. One case is RBD-diagnosed, while the other is a similar case without an RBD diagnosis from the parent study. One limitation of the current study is that the RBD-related experiences were reported by caregivers voluntarily in sleep diaries. Although we screened RBD episodes with existing works of literature,[63, 80] the primary purpose of the parent study did not involve exploring RBD specifically. Thus, the sleep diary and surveys did not include a specific assessment of RBD-related experiences. However, the 4-week sleep diary, which included daily sleep experiences and voluntarily reported RBD by caregivers, along with the results from the sleep quality survey and sleep data from smart rings, revealed poor sleep quality in the dyads. The utilization of different sources of data can provide new information to understand better sleep disturbances and the impact of RBD episodes on caregivers and their family members with AD or VD. Therefore, reporting these two cases was deemed worthwhile for exploring unique experiences of sleep among persons with AD/VD and RBD episodes, as well as the impact on their family caregivers.

Our findings uniquely contribute to the dearth of literature addressing PWD's RBD episodes and their family caregivers' sleep experiences. It implies that healthcare providers should evaluate PWD's sleep and screen for RBD and provide sleep hygiene guidelines for all caregivers of PWD. Our findings suggest that specific interventions should be developed for PWD-caregiver dyads to improve sleep quality, decrease the RBD episodes, and reduce harm for both the PWD and caregiver. In addition, the paper provides an alternative way to monitor sleep attributes using wearable technology to easily apply PWD and their family caregivers at the same time at their homes to capture day-by-day information about sleep. It suggests the possibility that technology can be a means to secure or replace the shortcomings of sleep monitoring in the sleep laboratory using Polysomnography which is the gold standard to recording sleep record.[34, 81]

Conclusion

RBD has been understudied in PWD and their cohabitating family caregivers. Given the limited knowledge about RBD among patients with AD and/or VD, the paper aimed to shed light on how to understand sleep problems caused by RBD of PWD and sleep experiences between PWD and their family caregiver through wearable technology and individual interviews. Future studies with large samples are needed to identify RBD-related sleep problems and bidirectional effects on both PWD and caregivers. The findings may guide us to develop effective sleep interventions with language specific guidelines for improving sleep quality leading to enhanced well-being of both PWD and their family caregivers particularly preventing and managing RBD-related sleep problems.

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Table 1. *Characteristics of Dyad Participants*

Participant characteristics	Dyad 1: AD[a] patient with RBD and caregiver	Dyad 2: VD[b] patient with symptoms of RBD and caregiver
PWD		
Gender	Male	Male
Language	English	Korean
Ethnicity/Race	Non-Hispanic White	Non-Hispanic Korean
Age	79	84
Health insurance	Medicare (e.g., private insurance)	Medicare (e.g., private insurance)
Type of dementia	Alzheimer’s dementia	Vascular dementia
Stage of dementia	Middle stage	Early stage
Years since dementia Diagnosis	2 years	1 year
Dementia-related medication taken	Yes	No
Sleep disorder diagnosis	Yes/ REM sleep behavior disorder	No/ report similar symptoms of the REM sleep behavior disorder
Comorbidity	RBD	Post stroke, Depression, Hypertension, Diabetes
Sleep disturbances (PSQI)	8	10
Caregivers		
Gender	Female	Female
Language	English	English/Korean
Ethnicity/Race	Non-Hispanic White	Non-Hispanic Korean
Age	74	42
Relationship with PWD	Spouse	Daughter
Education	Graduation Education	Graduation Education
Sleep disorder diagnosis	No	No
Comorbidity (Health Condition)	None	None
Sleep disturbances (PSQI)[c]	4	9
Caregiving burden (ZB)[d]	53	70
Family monthly income	More than $6,000	More than $6,000
Using same room/same bed	Yes/Yes	No/No

Note: a. AD=Alzheimer’s Disease

b. VD=Vascular Dementia

c. PSQI = Pittsburg Sleep Quality Index; the total score range is 0-21, and greater than 5 indicates sleep disturbance.

d. ZB = The Zarit Burden Interview; the total score range is 0 to 88, higher scores indicating a greater caregiving burden

Table 2. *Sleep Parameters from Wearable Device*

	Dyad 1		Dyad 2	
	Caregiver 1 Total number of nights = 21 Mean (SD)	AD patient with RBD Total number of nights = 6 Mean (SD)	Caregiver 2 Total number of nights = 21 Mean (SD)	VD patient with symptoms of RBD Total number of nights = 21 Mean (SD)
Total sleep duration (min)	436 (77.9)	123.6 (50.4)	373. (71.9)	295.5 (71.9)
Sleep latency[a]	9 (4.5)	13.9 (14)	14.8 (10.2)	54.9 (46.1)
Deep sleep duration (min)	79.7 (22.3)	16.3 (22.9)	106.4 (23.8)	20.3 (13.3)
Deep sleep duration (%)[b]	19 (6.3)	10.4 (11.9)	29.2 (6.9)	6.9(4.5)
REM sleep duration (min)	77 (26.8)	3.9 (3.3)	86.9 (30.1)	11.7 (21.1)
REM sleep duration (%)[c]	17.3 (3.9)	3 (2.5)	22.9 (5.1)	3.7 (6.1)
Light sleep duration (min)	279 (63)	108.4 (32.3)	179.8 (46.1)	263.8 (67.7)
Awake duration (min)	66.6 (50.5)	NA	81.4 (61.7)	405.5(138.4)
Sleep efficiency (1-100%)[d]	87.4 (6.6)	50.9 (9.2)	83.2 (8.1)	43 (10.2)

Note: Results are expressed as daily means (SD) for 4 weeks

a. Sleep latency: the time it takes to fall asleep.

b. Deep sleep duration percentage: deep sleep duration/total sleep duration * 100

c. REM sleep duration percentage: REM sleep duration/total sleep duration * 100

d. Sleep efficiency: the ratio of actual sleep to total time in bed

Figure 1. *Trend of Total Sleep Duration*

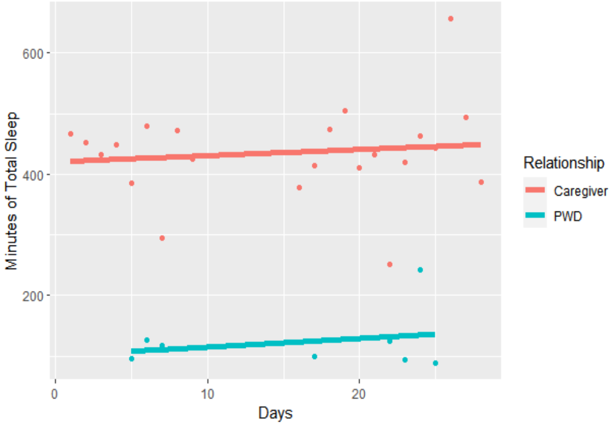
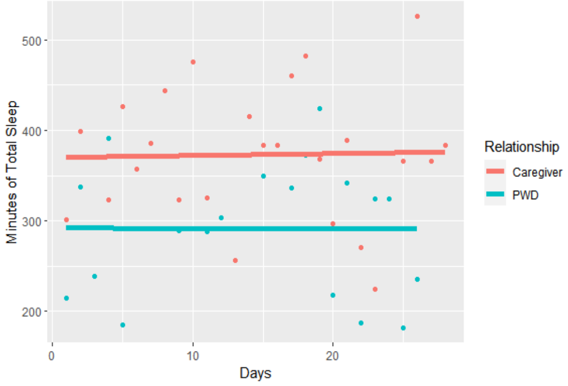
Dyad 1	Dyad 2
	

Figure 2. *Trend of Sleep Latency*

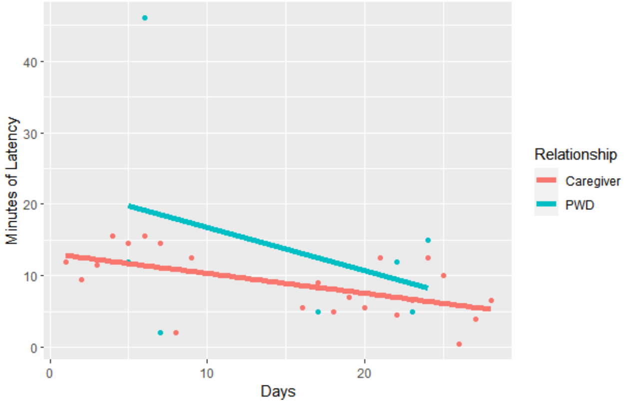
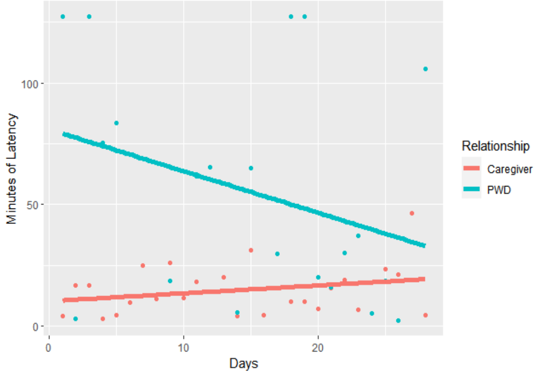
Dyad 1	Dyad 2
	

Figure 3. *Trend of Deep, REM, Light Sleep Duration*

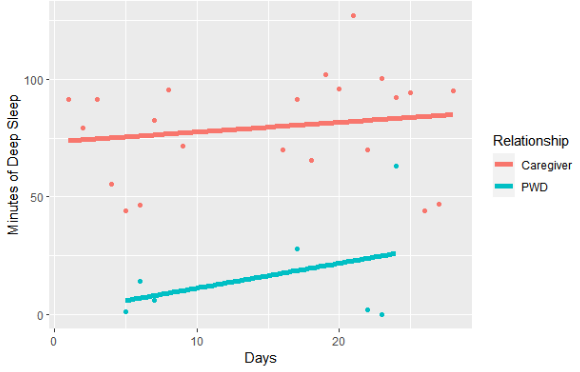
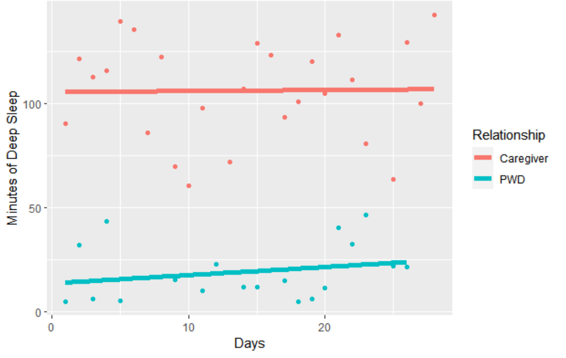
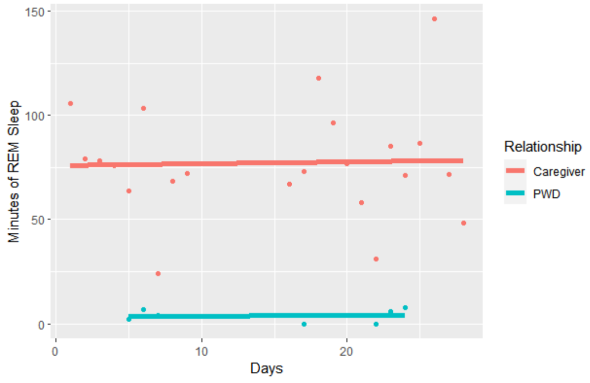
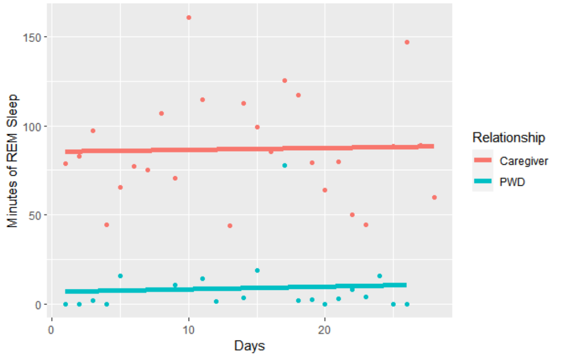
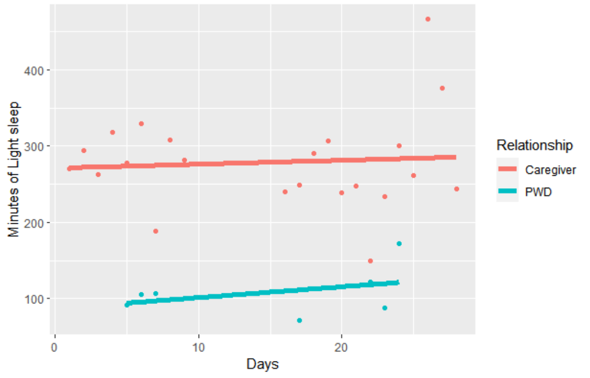
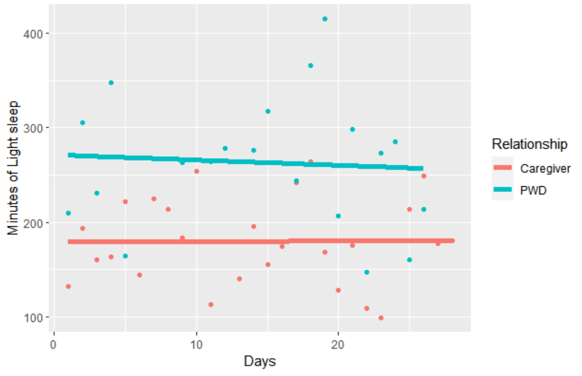
Dyad 1	Dyad 2
Trend of Deep sleep duration	
	
Trend of REM sleep duration	
	
Trend of light sleep duration	
	

Figure 4. *Trend of Awake Duration*

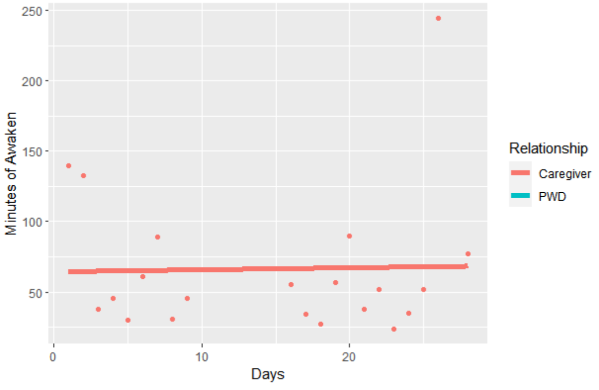
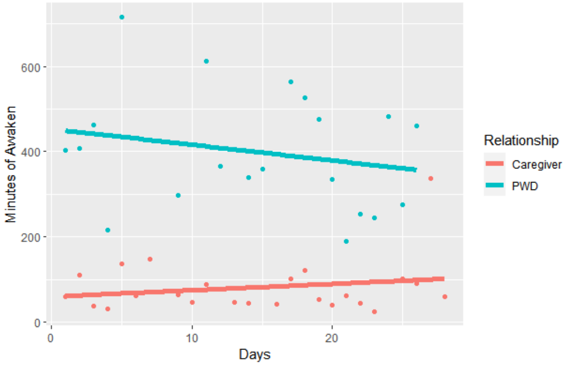
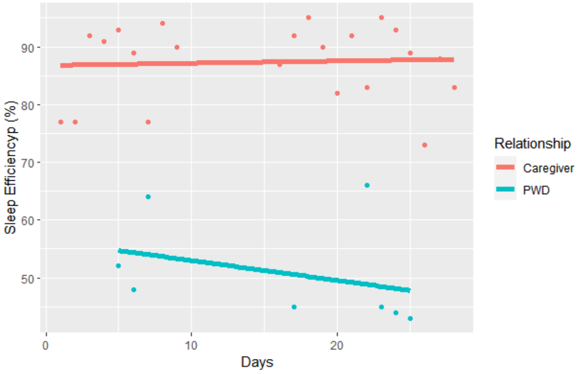
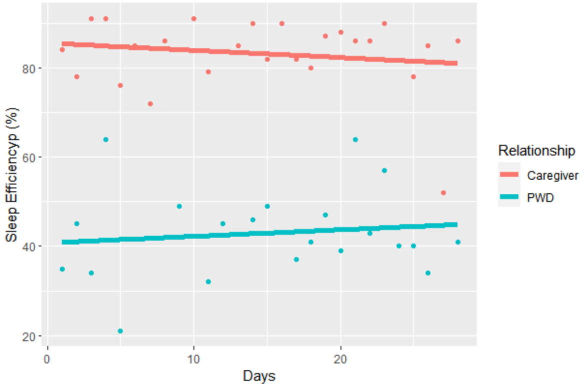
Dyad 1	Dyad 2
	

Figure 5. *Trend of Sleep Efficiency*

Dyad 1	Dyad 2
	

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