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The Feasibility of a Sleep Education Program for Informal Dementia Care Dyads: A Pilot Randomized Controlled Trial

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Abstract

Background: Untreated sleep problems in both persons living with dementia (PLWD) and their family care partners (CP) impact their health and quality of life. This pilot study tested a sleep intervention program for both dyad members.

Methods: Thirty dyads were randomized to a 5-session Care2Sleep intervention (n=15 dyads) or an information-only control group (n=15 dyads) delivered in-person or by video-telehealth by

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trained sleep educators. Care2Sleep is a manual-based program, incorporating key components of cognitive behavioral therapy for insomnia, daily light exposure and walking, and problem-solving for dementia-related behaviors. Adherence with Care2Sleep recommendations was assessed. Sleep outcomes included actigraphy-measured sleep efficiency (SE) and total wake time (TWT) for dyads; and the Pittsburgh Sleep Quality Index (PSQI) for CP. Other outcomes for CP included the Zarit Burden Interview (ZBI) and positive aspects of caregiving (PAC). Outcomes were measured at baseline, post-treatment, and 3-month follow-up. A 2 (group) by 3 (time) mixed model analysis of variance tested treatment effects.

Results: Study feasibility was demonstrated, with thirteen dyads completing Care2Sleep and 14 completing the control condition. In the Care2Sleep group, the dyads adhered to recommended sleep schedules 76% for bedtime and 72% for get-up time for PLWD, and 69% for bedtime and 67% for get-up time for CP. There were several nonsignificant trends in outcomes from baseline to 3-month follow-up between the two groups. For example, SE increased by 3.2% more for PLWD and 3.2% more for CP with Care2Sleep versus control. TWT decreased by 14 minutes more for PLWD and 12 minutes more for CP with Care2Sleep versus control at the 3-month follow-up. CP in Care2Sleep also showed non-significant improvement in the PSQI, ZBI, and PAC scores.

Conclusions: A dyadic approach to sleep improvement is feasible. Larger trials are needed to test effects of this intervention for PLWD and their family CP.

Keywords

poor sleep; dyads; behavioral intervention; caregiving; dementia

Introduction

Poor sleep is common among dementia care dyads and may affect more than 70% of persons living with dementia (PLWD)[1] and their family care partners (CP).[2] PLWD often presents difficulty falling asleep, multiple nighttime awakenings, excessive daytime napping, and early morning awakenings.[3,4] CP reports poor sleep quality, short total sleep duration, long duration of time awake after sleep onset, and difficulty in falling and staying asleep.[2] Sleep disturbances in PLWD are associated with lower quality of life, decreased social engagement,[5] functional decline, and shorter survival.[6,7] Poor CP sleep is associated with increased depressive symptoms, higher levels of caregiving burden[8] and increased inflammation,[9] leading to cardiovascular diseases. Untreated sleep problems among CP further impact the quality of care that they provide for their loved one and can lead to CP's inability to provide care for their loved ones and, therefore, deciding to admit them to long-term care facilities.[10] These findings suggest that poor sleep is an important target for both members of the dyad.

Behavioral sleep interventions are effective across age groups[11] and are usually based on cognitive behavioral therapy for insomnia (CBT-I) with adaptations for specific subgroups. Interventions focus on behavioral changes that may improve sleep, such as changing the sleep schedule and managing/eliminating behavioral or environmental factors (i.e., perpetuating factors) that interfere with good sleep. Such sleep interventions[12,13] administered by non-sleep specialists, such as nurses, have been successful.

Only a few studies of sleep management (i.e., light therapy or a combination of sleep hygiene, light exposure, and walking) have targeted both PLWD and their family CP.[14,15,16] However, they were lacking control group data or did not demonstrate existing sleep problems at baseline for both members of the dyads. Moreover, behavioral interventions focusing on improving sleep in both members of the dyad simultaneously are lacking. Dyad-based sleep interventions may have better effects on sleep and other health outcomes because of the reciprocal influence of PLWD sleep problems on their CP and vice versa.

This randomized controlled pilot trial tested the feasibility and preliminary effects of a dyadic sleep intervention program ("Care2Sleep") for dementia care dyads who experience sleep problems.

Methods

Participants and Settings

This study aligns with Stage 1B (feasibility and pilot testing) of the stage model for behavioral intervention development.[17] We recruited participants from two local healthcare systems and communities in Los Angeles, California, USA. Recruitment strategies included postal invitation letters, distribution of study flyers to dementia care services (e.g., adult day health care, caregiver support groups, outpatient geriatric clinics), study advertisement to local newspapers, and referral from health care providers. Eligibility criteria for PLWD included: (a) dementia diagnosis documented in the medical record, (b) community-dwelling, (c) ≥ 1 sleep problem ≥ 3x/week on the Neuropsychiatric Inventory Nighttime Behavior Scale[18], (d) able to ambulate with or without an assistive device, and (e) had an eligible CP. Eligibility criteria for CP included: (a) living with a PLWD, (b) age ≥ 21 years, (c) regularly assisting PLWD with ≥ 1 of 6 basic activities of daily living (ADLs)[19] or ≥ 1 of 8 Instrumental ADL (IADLs)[20] for the prior 6 months, (d) Pittsburgh Sleep Quality Index (PSQI)[21] total score > 5 indicating poor sleep quality, (e) Montreal Cognitive Assessment (MoCA)[22] ≥ 23, and (g) able to communicate in English. Of 168 dyads screened, 45 completed baseline assessment for the study and 30 were randomized to intervention or control (See the Figure 1).

Procedure

Written informed consent were obtained from CP and from PLWD or legally authorized representatives for PLWD. PLWD who do not understand the study were deemed unable to consent to participation. In such cases, the legally authorized representatives for PLWD agreed to the PLWD's participation and sign their written consent form. In all cases, the wishes of the PLWD to refuse participation in the study were honored and verbal assent from PLWD were obtained. Once written consents were obtained from both members of the dyad, they completed a baseline assessment, which included wearing a wrist actigraph for 7 consecutive days/nights and completing questionnaires on sleep health. CP completed sleep diaries for themselves and the PLWD while wearing the actigraph. Eligible participants were then randomized to Care2Sleep or the information-only control group, using sequentially numbered, opaque sealed envelopes. Participants and staff (except intervention staff) were blinded to group assignment. Research staff administered follow-up

assessments immediately and 3 months after the last intervention session. The study was approved by the Institutional Review Board (IRBs) at the two participating institutions. The study was conducted from October 2018 to January 2023.

Intervention

Care2Sleep is a manual-based sleep intervention program delivered over five weekly one-hour sessions by trained sleep educators.[23] The sleep educators had a study-specific manual that included participant materials and key points for each session. The content covered in each session was structured, but the educator did not follow a script and personalized the content based on the presentation of the dyad. It consists of key components of CBT-I (i.e., sleep hygiene, sleep compression [slowly decreasing time in bed to reduce time awake in bed at night], stimulus control [recommendations to decrease the association between bed and arousal], and relaxation), walking, natural light exposure, and the "A-B-C (i.e., Activator, Behavior, Consequence) problem solving" approach[24] for managing nocturnal dementia-related behaviors and treatment noncompliance issues. The sleep schedule goal included set bedtime and rise times. Daytime naps were instructed to limit ideally to 30 minutes or less unless PLWD already had set nap schedules. Goals for walking and natural light exposure during the daytime were also set. The sleep educators maintained a session-by-session checklist of information covered and recommendations made and progress notes that the researchers (YS, JLM, SM) reviewed during weekly meetings.

The control group received general information about sleep, aging, and dementia without specific or individualized recommendations. The control condition was dose-equivalent to intervention conditions (five, 60-minute weekly sessions). The PLWD was required to attend the first session and CP attended all five sessions. The interventions were designed for in-person delivery[23] and adapted for video-telehealth delivery during the COVID-19 pandemic after pilot testing in three dyads (not included here). Seventeen of the 30 randomized dyads received the study intervention using video-telehealth.

Measures

Primary outcome included sleep efficiency (SE: percent of the time in bed spent asleep at night based on sleep diary) among dyads measured by actigraphy (Micro Motionlogger^{R} watch, Ambulatory Monitoring, Inc, Ardsley, NY). SE has been used as a key parameter for evaluating effects of insomnia treatment.[25] Secondary outcomes included actigraphy-measured total wake time (TWT) at night among dyads and subjective sleep quality among CP (PSQI).[21]. Other measurements included demographics, medications, and sleep diaries for dyads; the Mini-Mental State Examination (MMSE to assess cognitive function)[26] for PLWD; and caregiving characteristics, Zarit Burden Interview (ZBI)[27] and Positive Aspects of Caregiving (PAC)[28] for CPs. The ZBI and PAC were used to assess possible non-sleep benefits. In Care2Sleep, adherence data[29] were collected from the CP's diary and interventionist's session notes for % days that dyad members met goals for: (1) sleep scheduling (i.e., bedtime and rising within 30 minutes of the recommended times), (2) limitation of daytime napping, (3) walking, and (4) daily light exposure.

Data analyses

Analyses were intention-to-treat. A 2 (group) by 3 (time) mixed model analysis of variance was used to test intervention effects. The effects at post-treatment were tested by a partial interaction comparing post-treatment versus baseline by group; the effects at 3-months were tested by a partial interaction comparing 3-month follow-up vs. baseline by group. Each outcome was tested separately using one-sided p-values with alpha at 0.20.[30] Pearson correlation was performed to test associations between the adherence and sleep outcomes. Analyses were conducted using Stata (version 17, Stata Corporation, College Station, TX).

Results

Attrition data

Characteristics of study participants are shown in Table 1. Twenty-seven out of 30 dyads attended all five sessions. Of 15 Care2Sleep dyads, one completed only one session due to CP's burden; another completed four sessions due to CP illness. Of 15 control dyads, one declined all sessions.

Adherence to intervention recommendations

Within Care2Sleep, the average % days the dyads adhered to their sleep schedules was 76% bedtime and 71% get-up time for PLWD and 68% bedtime and 67% get-up time for CP. The average % days that PLWD followed the nap duration plan was 75% and 92% for CP. The average % days the dyads met daily walking and light exposure for PLWD was 65% and 71%, respectively; and 68% and 70% for CP.

Sleep and other outcomes

Dyads who received Care2Sleep showed patterns of sleep improvement at 3-month follow-up compared to controls, although these findings were not statistically significantly (see Figure 2A–D). SE increased by 3.2% more for Care2Sleep PLWD (n=9) compared to controls (n=11, $p = 0.60$) and by 3.2% more for Care2Sleep CP (n=9) compared to controls (n=12, $p = 0.39$). TWT was also reduced by 14 minutes more for PLWD and 12 minutes more for CP with Care2Sleep compared to controls at 3-month follow-up ($p > 0.20$). Care2Sleep CP had non-significant improvement in PSQI and ZBI scores ($p > 0.20$) at the 3-months. Furthermore, CP in Care2Sleep reported more positive aspects of caregiving than controls group at both post-treatment and 3-months (both $p = 0.13$).

Intervention adherence and sleep outcomes

Care2Sleep PLWD adherence to recommended get-up time was significantly associated with CP SE measured with actigraphy ($r = 0.66$) and PSQI scores ($r = -0.62$) at posttreatment, but not with PLWD sleep outcomes. CP adherence to bedtime was significantly associated with CP SE ($r = 0.75$) and TWT ($r = -0.58$) at posttreatment, as well as with the PSQI scores at posttreatment ($r = -0.77$) and 3-month follow-up ($r = -0.75$). CP adherence to nap limitation was also significantly associated with CP TWT ($r = -0.74$) and PSQI scores ($r = -0.74$) at the 3-month follow-up (all p values < 0.05).

Discussion

The study findings demonstrate the feasibility of using behavioral strategies to improve sleep in dementia care dyads and provide preliminary evidence supporting intervention benefits. Particularly, following regular sleep schedules using sleep compression, which is a modified approach to sleep restriction, was realistic for dyads. Maintaining sleep schedules benefited sleep of CP, and better adherence to PLWD sleep schedules was associated with better sleep outcomes for CPs. This is consistent with previous studies which showed that higher levels of adherence to CBT-I recommendations were significantly associated with improvement in insomnia-related symptoms, decrease in nighttime wakefulness and sleep latency, and improvement in sleep efficiency.[31,32]

Overall adherence to a sleep schedule in our study participants was slightly lower than that in other studies of PLWD[29] or older adults[33] although different definitions of adherence have been used. Sleep schedule adherence among CP was lower than PLWD, perhaps because CP might experience increased burden in implementing sleep schedules for themselves and their loved ones or because CP wanted to use the extra time after the PLWD is in bed for themselves. Suggested delayed bedtime for PLWD created challenges for CP who would have preferred an earlier sleep schedule. Moreover, stimulus control (e.g., avoiding cell phone use in bed) and sleep compression recommendations (e.g., keeping PLWD awake until scheduled bedtime), and getting up at the same time each morning could be challenging for some CP. Future studies need to explore alternative strategies (e.g., acceptance and commitment therapy) to increase adherence to healthy sleep behaviors among these CP.

The overall pattern of results, regardless of statistical significance, suggests some improvement in sleep and caregiving related experiences with a behavioral intervention. That is, Care2Sleep showed sleep improvement among dyads and improvement in positive aspects of caregiving. This aligns with potential benefits of using nonpharmacological interventions (e.g., physical or social activities) to improve sleep among PLWD.[34] However, synergistic effect of targeting sleep issues of dyads is unknown, pending larger efficacy studies using standardized outcomes.

A limitation of this pilot study includes the small sample size which precluded subgroup analyses. We did not measure other factors such as depression or fatigue, which might affect sleep. In addition, the COVID-19 pandemic required study transition to telehealth delivery and likely increased caregiver stress. Nevertheless, these findings suggest dyadic intervention is feasible, and a fully powered clinical trial is warranted to evaluate the benefits of intervention on sleep for both members of the dyad and to both improve sleep and positive aspects of caregiving, which may ultimately allow PLWD to remain in the community.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Key Points

- It is feasible to train care partners using a dyadic sleep intervention for themselves and persons living with dementia.
- Trends suggest intervention may improve sleep and positive aspects of caregiving.
- Larger trials are needed to test the efficacy of a dyadic sleep intervention.

Why Does this Paper Matter?

Our dyadic program shows the feasibility of using behavioral strategies to improve sleep among persons living with dementia and their family care partners. This manual-based program can be used to coach health care providers without formal training in behavioral sleep medicine.

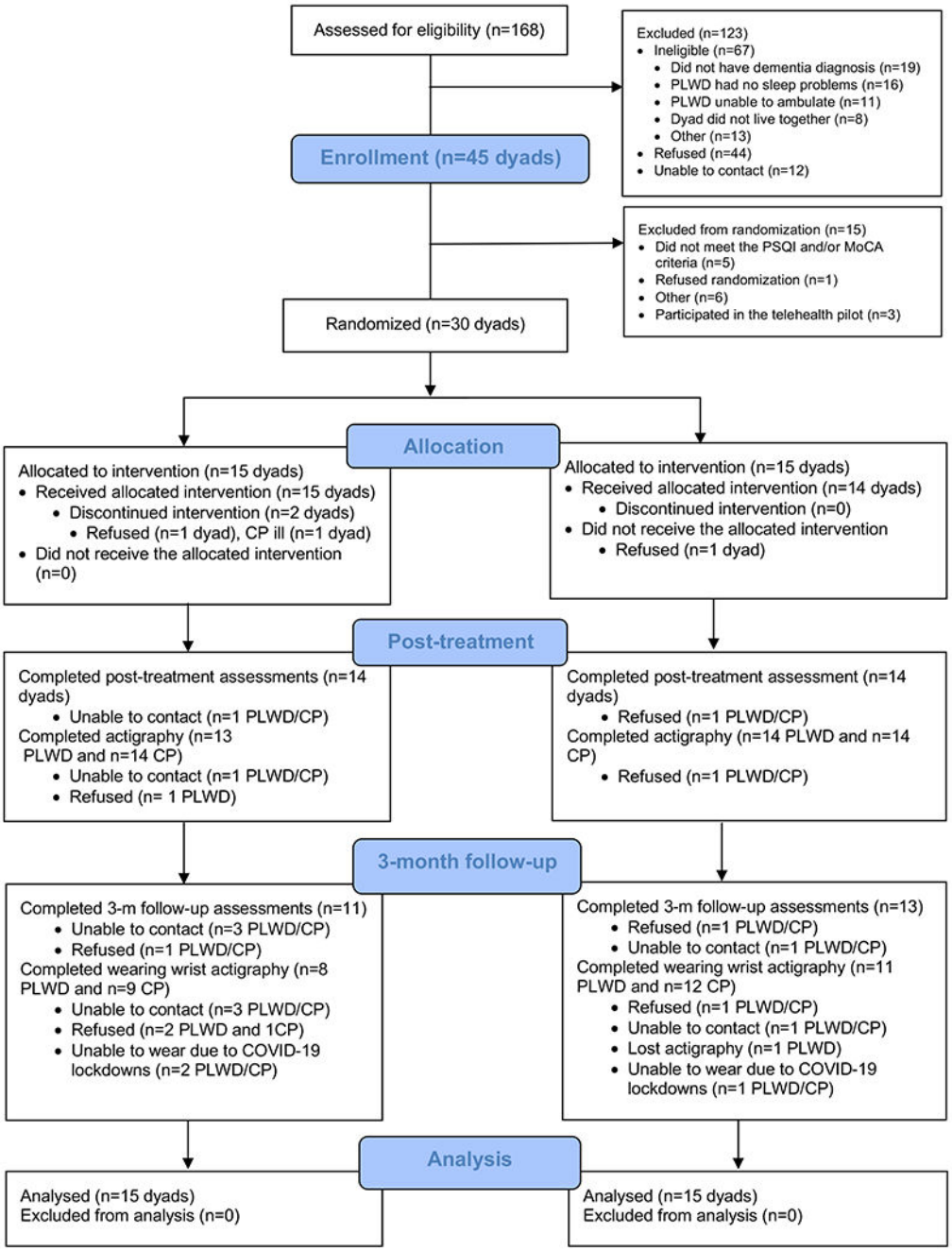

Figure 1.

Consort Flow Diagram

PLWD, persons living with dementia; CP, care partners

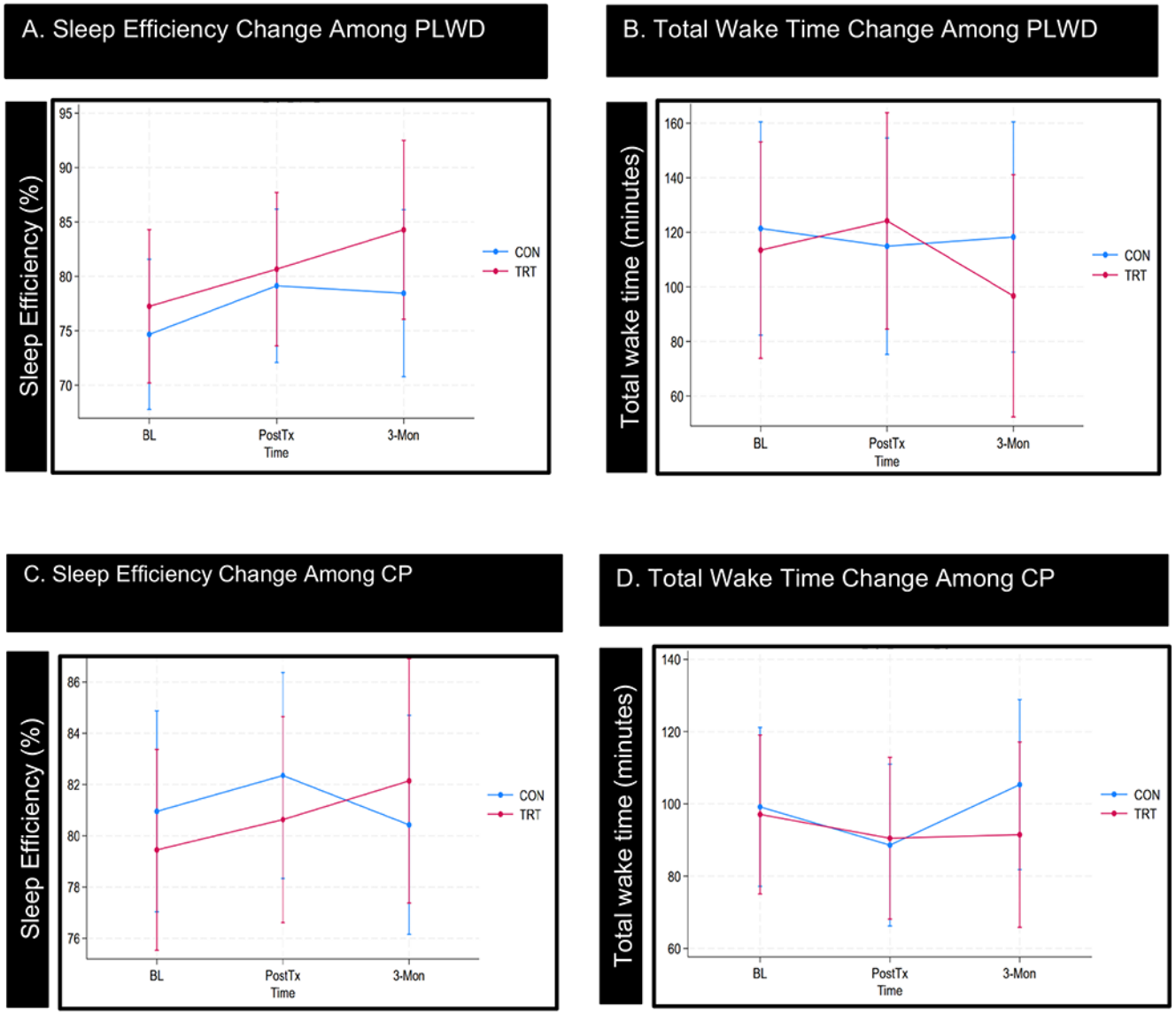

Figure 2.

Actigraphy-Measured Sleep Outcomes at Post-Treatment and 3-Month Follow-up Between Care2Sleep and Control Groups

TRT, treatment (Care2Sleep); CON, control; PLWD, persons living with dementia; CP, care partners

Table 1.

Baseline Participant Characteristics (N=30 dyads)

	PLWD	CP
	Mean (SD)/ frequency (%)	**Mean (SD)/ frequency (%)**
Age, years	82.9 (9.4)	67.0 (10.9)
Gender		
Male	19 (63.3%)	2 (6.7%)
Female	11 (36.7%)	28 (93.3%)
Race		
White	16 (53.3%)	17 (56.7%)
Black	7 (23.3%)	6 (20.0%)
Asian	4 (13.3%)	4 (13.3%)
American Indian/Alaska Native	1 (3.3%)	1 (3.3%)
Other	1 (3.3%)	1 (3.3%)
Unknown	0	2 (6.7%)
Ethnicity		
Hispanic	6 (20.0%)	7 (23.3%)
Non-Hispanic	24 (80.0%)	23 (76.7%)
Education level		
Less than high school	2 (6.7%)	0 (0.0%)
Some high school	1 (3.3%)	1 (3.3%)
High school graduate	2 (6.7%)	0 (0.0%)
Business/vocational school	2 (6.7%)	0 (0.0%)
Some college	7 (23.3%)	3 (10.0%)
College graduate	8 (26.7%)	8 (26.7%)
Graduate/professional education	8 (26.7%)	11 (36.7%)
Refused to answer	0 (0.0%)	7 (23.3%)
Relationship to PLWD	n/a	
Spouse or significant other		18 (60%)
Daughter		9 (30%)
Son		2 (6.7%)
Granddaughter		1 (3.3%)
Years of caregiving	n/a	7.8 (11.3)
Caregiving hours/week	n/a	41.4 (38.9)
Caring for another person (yes)	n/a	5 (16.7%)
Types of dementia		n/a
Alzheimer’s disease	16 (53.3%)	
Mixed dementia	5 (16.7%)	
Vascular dementia	4 (13.3%)	
Lewy body dementia	2 (6.7%)	

	PLWD	CP
	Mean (SD)/ frequency (%)	**Mean (SD)/ frequency (%)**
Unspecified dementia	3 (10%)	
*MMSE (range 0-30)	19.4 (5.4)	n/a
‡Total ADL score (range 0-6)	4.7 (1.7)	n/a
‡Total IADL score (range 0-8)	2.1 (2.0)	n/a
ZBI Total score (range 0-88)	n/a	38.7 (14.5)
PAC Total score (range 9-45)	n/a	35.6 (7.9)
PSQI total score (range 0-21)	n/a	7.8 (3.7)
†Sleep Efficiency by wrist actigraphy, %	76.0 (14.5)	80.2 (6.6)
†Total awake time by wrist actigraphy, minutes	117.7 (75.2)	98.1 (37.1)

PLWD, persons living with dementia; CP, care partners; MMSE, Mini-Mental State Examination; ADL, activities of daily living; IADL, instrumental ADLs; ZBI, Zarit Burden Interview; PAC, positive aspects of caregiving; PSQI, Pittsburgh Sleep Quality Index

*n=21,

†n=29,

‡higher score indicates higher levels of independence on performing ADL/IADLs; ADL and IADL total scores were significantly lower among PLWD in treatment group than those in control group (*P*-values <0.05). No significant differences in other characteristics were found between the group.