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Development of a Dyadic Sleep Intervention for Alzheimer's Disease Patients and Their Caregivers

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Abstract

Purpose: This study aimed to refine a behavioral sleep intervention program targeting patients with Alzheimer's disease and their caregivers.

Methods: In this case series, key components of the sleep program were built upon previous intervention studies of patients with cognitive impairment/dementia. The intervention consisted of five weekly sessions covering sleep hygiene, sleep compression, stimulus control, daily walking/light exposure, relaxation/mindfulness, and caregiver training to manage patients' behavioral problems. The materials and structure were iteratively refined based on feedback from caregivers and sleep educators. Sleep diaries were used to evaluate sleep outcomes.

Results: Five out of six enrolled dyads completed the sessions. Several revisions were made during testing: the last session was changed from telephone to in-person; some components (e.g., sleep scheduling, mindfulness) were rearranged within or across sessions; sleep educator guidelines for sleep scheduling, light exposure, and walking were revised. After the fifth dyad, no additional issues were identified by the caregiver or the sleep educator. Four patients and three caregivers had improved sleep at the last session.

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Conclusions: The iterative refinement process was successful in finalizing the intervention program, with evidence of sleep improvements. Formal pilot testing of the program will provide further information on feasibility and effectiveness.

Keywords

behavioral sleep intervention; Alzheimer's disease; family caregiver

INTRODUCTION

Poor sleep in older patients with Alzheimer's disease is more common than in healthy older adults [1]. The prevalence rates of symptoms of sleep disturbances in Alzheimer's disease is up to 40% [2, 3, 4]. Common sleep problems in the population include multiple awakenings during sleep, disruption of diurnal sleep rhythms, difficulty falling asleep, early morning awakenings, sleeping more than usual, and excessive daytime sleeping [2, 3, 5, 6, 7]. These sleep disturbances may be due to neurodegeneration plus alteration in behaviors that are related to sleep habits (e.g., napping, less physical activity) [8]. Sleep disturbances are core behavioral and psychological symptoms of Alzheimer's disease and become significantly greater as the severity of dementia progresses [9]. Unmanaged sleep problems in Alzheimer's disease patients are significantly associated with lower quality of life [10] and shorter survival [11].

Caregivers' sleep is often interrupted due to nighttime disturbances or awakenings of patients with Alzheimer's disease [3]. Caregivers experience more difficulty falling and staying asleep [12, 13], lower self-reported sleep quality, longer duration of awakenings, longer time awake after sleep onset [13, 14], and shorter total sleep time [14, 15] than noncaregivers. Their poor sleep is significantly associated with increased depressive symptoms, higher levels of caregiver role burden [16], and increased inflammation (e.g., C-reactive protein, interlukin-6) [15, 17], which is known to increase risk for cardiovascular disease. Decline in caregivers' health may concomitantly impact the quality of care for Alzheimer's disease patients, which may contribute to the decision to seek institutional care for the patients [18, 19, 20]. This suggests critical needs of sleep management among both the patients and the caregivers.

Cognitive-behavioral sleep intervention programs for insomnia are effective in improving sleep disturbances across age groups [21] and in persons with a variety of physical and psychological comorbidities [22, 23, 24]. They focus on behavioral changes that have been successful in improving sleep such as changing the sleep schedule and managing/eliminating behavioral (e.g., watching television on bed) or environmental factors (e.g., turning light on in bedroom at night) that interfere with good sleep. Such sleep interventions administered by nonsleep specialists such as a nurse or a nurse practitioner have been successful [25, 26, 27].

Behavioral sleep approaches for cognitively impaired individuals, such as the Nighttime Insomnia Treatment and Education in Alzheimer's Disease (NITE-AD) program [28, 29] have significantly improved sleep (i.e., reduced number of nighttime awakenings and total wake time) and reduced depression in Alzheimer's disease patients. In the study of NITE-AD [29], trained interventionists worked with caregivers to set up bed and rising times,

provided individualized sleep hygiene education (e.g., consistent bedtime and rising time, reducing daytime naps, avoiding caffeine or alcohol in the evening), training in problem solving for challenging dementia-related behaviors (e.g., nocturnal wandering), and recommended daily walking and increased light exposure to help strengthen sleep/wake rhythms [30, 31].

In studies targeting sleep in caregivers of Alzheimer's disease patients [32, 33], interventions were also effective in improving caregivers' subjective sleep quality. However, only a few studies of sleep management targeted both the patient and the caregiver [34, 35] and these studies focused on somatic interventions such as increasing light exposure and exercise. No sleep interventions based on cognitive-behavioral therapy for insomnia strategies have been developed for treating sleep disturbances in both individuals of the Alzheimer's disease patient-caregiver dyad. Given the bidirectional relationship between sleep disturbances among Alzheimer's disease patients and caregivers and evidence of potential synergistic benefits of dyadic intervention programs in other patient populations [36, 37], interventions that simultaneously address sleep difficulties in Alzheimer's disease patient/caregiver dyads may be highly beneficial.

Following the National Institutes of Health/National Institute of Aging-Stage model for behavioral intervention development, this Stage 1 project aimed to finalize intervention materials to be used in a pilot randomized controlled trial (Stage 2)[38, 39]. The current study aimed to iteratively refine the sleep intervention program materials specifically tailored for Alzheimer's disease patient/caregiver dyads who both experience sleep difficulties, using feedback from both participants and sleep educators. The starting point for the intervention was the NITE-AD program with adaptations for use in a dyad-based intervention. The proposed intervention focuses on helping caregivers implement behavioral strategies to improve their own and the patients' sleep, using behavioral sleep management techniques. In this paper, we provide a brief description of two cases of dyad's experience with the intervention, highlighting modifications made during this Stage 1 project.

METHOD

Study Design and Participants

This was a Stage 1 study with a single-case experimental A-B design. We recruited potential participants by distributing flyers to caregiver services and locations (e.g., adult day health care program) where Alzheimer's disease patients received care at a local Veterans Affairs Healthcare System or University of California, Los Angeles health system. Study flyers were also distributed to community programs across the Los Angeles metropolitan area. Interested patients or caregivers were screened for eligibility when they called our research office. If the patients and caregivers were eligible based on telephone screening, a research assistant scheduled an in-person appointment and obtained written informed consents. Patients and caregivers who were capable of providing informed consent were asked to sign the written informed consent form. Patients who did not understand the study and deemed unable to consent to participation were asked to provide their verbal assent, and we obtained written consent from the patient's legally authorized representative. Study procedures were

reviewed and approved by the Veterans Affairs Greater Los Angeles and University of California, Los Angeles Institutional Review Boards.

Patients were eligible if they (a) had an Alzheimer's diagnosis OR probable or possible Alzheimer's disease as documented in electronic medical records and defined by the National Institute of Neurological Communicative Disorders and Stroke and the Alzheimer's Disease and Related Disorders Association [40], (b) were community-dwelling, (c) had ≥1 sleep problem ≥3x/week on the Neuropsychiatric Inventory (NPI)-Nighttime Behavior Subscale [41], (d) were aged ≥60 years, (e) had no previously diagnosed primary sleep disorders (e.g., sleep apnea, restless legs syndrome), (f) were able to ambulate with or without assistive devices, and (g) had an eligible caregiver. Caregivers were eligible for the study if they (a) lived with an eligible patient, (b) were aged ≥21 years, (c) had regularly assisted patient with ≥1 of 7 basic activities of daily living [42] (e.g., eating, dressing, toileting) or ≥1 of 7 Instrumental ADL [43] (e.g., using the telephone, preparing meals) for the past 6 months, (d) had a Pittsburgh Sleep Quality Index (PSQI) [44] total score >5, (e) had a Montreal Cognitive Assessment [45] score ≥23 [46], and (f) could communicate in English.

Nineteen dyads were screened via telephone, and six dyads were eligible. Five of the six dyads received the intervention sessions. One dyad was unable to finish the last session due to sudden death of the patient; however, data from first four sessions were available for this dyad.

Sleep educators

Sleep educators for this study included a social worker (DL), a registered nurse (JY), and a nurse practitioner (YS). The educators participated in a one-day training workshop to familiarize themselves with the draft manual and the various treatment components. Throughout the study, sleep educators completed field notes for each session, which were used in the interactive iterative refinement of the manual.

Intervention components

The intervention program adapted key components of cognitive behavioral sleep intervention programs (e.g., adjusting sleep schedules, sleep hygiene, stimulus control) that have been successful in previous studies targeting older adults with mild cognitive impairment [47] or Alzheimer's disease (i.e., NITE-AD) [28, 48]. Other treatment components included daily walking, light exposure, relaxation, and training in Activator-Behavior-Consequence (A-B-C) dementia-related problem-solving strategies [49, 50]. The intervention components and structure were also informed by feedback from a caregiver focus group [51].

We used a draft manual to train and guide the sleep educator in delivering the content. The manual contained detailed information about each session including session objectives, specific content, and participant handouts for each session. It also included guidelines for handling common issues that might arise during the sessions, such as interruptions or participant refusal to engage in selected program components.

Our initial intervention program consisted of five sessions: session 1 included both members of the dyad, while sessions 2–5 were with the caregiver only, who was better able to recall sleep patterns in the past week and was an essential partner in helping to implement new schedules and habits for both a caregiver and a patient. Session 1 ("How Sleep Works; Healthy Habits for Healthy Sleep") introduced program goals, importance of good night's sleep, why we need to sleep, and causes of sleep changes. This session also included stimulus control (i.e., limiting non-sleep activities in the bed), and sleep hygiene instructions. An initial sleep schedule was established for dyads based on their preference and routine. A sleep diary was introduced to the caregiver who completed it daily for both members of the dyad throughout the rest of treatment. The sleep diary data were used for the sleep educator to adjust the dyad's sleep schedule each week based on number of days they spent >30 minutes to fall asleep or to awaken through the night.

Session 2 ("Getting Solid Sleep; Walking & Light Exposure") introduced the concept of two processes of sleep regulation, limiting daytime naps, and sleep compression. Behavioral activation was used to help the caregiver identify idea for activities that could be used to delay bedtime as part of sleep compression. An initial plan for daily walking and light exposure was set up. The ultimate goal for walking was for both persons in the dyad to walk 30 minutes daily, ideally outdoors in natural light and at a time and place that were enjoyable so that walking was a pleasant shared experience. Potential activity limitations were assessed, and walking goals were tailored to ensure participants' safety and to fit their preferred time of day, location, and duration. We also educated caregivers about the importance of daytime light exposure and decreased light exposure at night as much as possible and helped them develop strategies to enhance appropriately timed exposure to light.

Session 3 ("A-B-C Problem-Solving Plan; Walking & Light Exposure Adherence") topics included training the caregiver on the "A-B-C problem-solving" approach for identifying "triggers" of nocturnal sleep disturbances and/or dementia-related problem behaviors, and for resolving treatment noncompliance issues. The goal of A-B-C problem-solving was to help caregivers learn to observe dementia-related mood and behavior challenges more creatively, and to develop effective strategies for managing them. The A-B-C problem-solving approach also guided a sleep educator to use for cases where using sleep compression would not be feasible (e.g., when prolonged caregiver's awakenings were due to helping a patient). In such cases, a sleep educator was instructed to help the caregiver to use the A-B-C problem-solving approach to help reduce the patient's awakening time.

Session 4 ("Being Healthy Caregivers") focused on stress and sleep management by different times (i.e., morning, afternoon, evening, and nighttime). The session began with following up on sleep schedules, walking, and light exposure plans, and the A-B-C plan from session 3. A sleep educator adjusted them as needed. Session 4 also introduced strategies to reduce caregiver stress each morning, afternoon/evening and at bedtime, and two types of relaxation techniques: 1) both patient and caregiver were taught to do diaphragmatic breathing [52]; and 2) the caregiver was taught a mindfulness practice [53] that encouraged them to notice their thoughts and inner experiences then let them go without

judgment or evaluation ("thoughts as leaves on a stream"). Such relaxation techniques are used to reduce physiological or cognitive arousal that may interfere with sleep [54].

Session 5 ("Healthy Sleep Habits for Life") was a brief (up to 30 minute) phone call designed to summarize and review the dyad's prior sleep recommendations and other plans. Brief feedback from both persons in the dyad about the intervention was also discussed, and a long-term sleep plan developed.

Intervention iterative refinement process

We tested the intervention components and structure with the first dyad. The sleep educator made notes after each session regarding the acceptability of the intervention to participants, and usability of the intervention materials for the educator. All intervention sessions were audio recorded and reviewed by the principal investigator (YS). Revisions to the program materials were discussed and implemented during intervention refinement team meetings, which included a clinical psychologist/behavioral sleep medicine researcher (JM), a family nurse practitioner/sleep researcher (YS), a social worker/sleep educator (DL), an experienced sleep educator (KJ), and a registered nurse (JY) in consultation with a second clinical psychologist and dementia/sleep researcher (SM). After revision, the intervention materials were used to deliver the intervention to the next dyad. This process continued (i.e., each dyad in sequence) until further revisions were no longer needed.

Measures

Screening Measures: To determine eligibility and gather feasibility data about outcome measures for future studies, we used the following validated questionnaires: The PSQI [44] was used to identify caregivers with sleep disturbance. It is a self-rated, 19-item questionnaire, which assesses sleep quality and disturbances over past month. High reliability and validity of the PSQI were reported in studies of various populations [55]. We used its total score > 5 as cutoff, which indicates poor sleep. The NPI-Nighttime Behavior Subscale [41] was also used to identify Alzheimer's disease patients with sleep problems. It is one of the twelve subscales of the NPI, which assesses types and severity of behavioral disturbances among dementia patients. The NPI-Nighttime Behavior Subscale contained eight items of sleep-related problems (e.g., difficulty falling sleep, nighttime awakenings). We asked a caregiver whether a patient experienced each type of sleep problem and if so, how many times each problem occurred per week during the past month. If the caregiver endorsed at least one type of sleep problems occurring at least three times per week, the patient was eligible for our study. This screening approach was adapted from previous studies of dementia patients [28, 56].

The Main study measures consisted of two parts: intervention outcomes and intervention refinement outcomes. Intervention outcomes were measured using simple sleep diaries that were modified from items on the Consensus Sleep Diary [57] for the purpose of our study. Caregivers were asked to complete the diaries during the intervention sessions. The diaries included 12 questions: bedtime; rise time; dichotomous variables of whether it took more than 30 minutes to fall asleep (yes/no), whether they were awake for more than 30 minutes total during the night after they fell asleep (yes/no), and whether they took a nap during the

day (yes/no); and duration of nap per day. The diaries also asked whether they went for a walk (yes/no) with further questions about when, where (i.e., outdoor and/or indoor), and how long they walked; and whether they received sunlight (yes/no) with further questions about when, where (i.e., outdoor and/or indoor), and how long they got sunlight.

A "good sleep" variable was calculated each week, defined as individual not taking longer than 30 minutes to initially fall asleep, and not spending more than 30 minutes awake during the night. Following sleep compression guidelines [47, 58], if the individual member of the dyad had "good sleep" for at least five nights in a given week, the sleep educator did not change the current sleep schedule. If a member of the dyad did not have good sleep (with <5 nights/week), the sleep educator was instructed to decrease time in bed by 15 minutes for that participant during the following week. The mean minutes of both walking and light exposure per day for each week were also computed.

Intervention refinement outcomes were measured using interventionist (i.e., sleep educator) field notes developed for the study. They included the acceptability of the intervention components to caregivers and the usability of the program materials for the sleep educator that were collected weekly throughout the intervention sessions. At each session, the sleep educator asked the caregiver whether topics discussed and suggested sleep recommendations were clear to understand (yes/no). If the caregiver indicated "no" (i.e., s/he had issues with the content clarity), then an open-ended question was used to elicit specific concerns. This information was discussed during the periodic intervention refinement meetings. The educator also self-rated clarity of information on each intervention component, ranging from 1 (poor) to 4 (excellent) and ease of delivery (yes/no).

Data Analysis

Descriptive statistics were used to calculate means, standard deviations, and sums for each variable for each dyad. We presented outcomes for each dyad individually. All analyses were performed using STATA Version 15.0 (Stata Corporation, College Stations, Texas).

RESULTS

Summary of sleep outcomes

After the intervention, three caregivers and two patients had no nights that it took >30 minutes to fall asleep, compared to 1–4 nights/week at baseline (i.e., week 1 of the intervention). Two other patients who did not experience problems falling asleep (> 30 minutes to fall asleep) at baseline maintained this after the intervention.

At baseline, dyads were awake >30 minutes at night for 1–6 nights/week; after all sessions, the numbers of nights they were awake more than 30 minutes were reduced 33–100% across dyads. For nap duration, three patients reduced their daily nap time (69, 61, and 114 minutes at baseline versus 29, 29, and 54 minutes, respectively at the end of five sessions). In week one, caregivers experienced an average of 1.6 nights of "good sleep" and patients experienced an average of 2.4 nights of "good sleep," which increased to 3.8 and 4.8 nights/week, respectively, in the last week of the program. Figure 1 shows each participant' sleep during the course of the intervention. Three caregivers showed patterns of improved sleep

after the last session, whereas two had no change of their sleep ratings. Four patients showed patterns of improved sleep after the last session, whereas one patient had no change in sleep ratings. After the program, minutes of walking increased for four caregivers (11, 19, 0, 0 minutes at baseline versus 100, 26, 4, and 20 minutes, respectively at the end of five sessions) and three patients (27, 39, and 12 minutes at baseline versus 56, 47, and 19 minutes, respectively at the end of the program). Minutes of light exposure also increased for three caregivers (17, 16, and 0 minutes at baseline versus 100, 22, and 9 minutes, respectively at the end of the program) and four patients (15, 42, 28, and 14 minutes at baseline versus 77, 45, 47, and 24 minutes at the end of the program). Details about how the pilot program was developed and modified is described in the following two selected case examples. Table 1 provides an outline of the topics covered in each session in the original protocol.

Case example 1 (Dyad 1)

A male patient diagnosed with possible Alzheimer's disease received care from his caregiver spouse. On the NPI-Nighttime Behavior Subscale, the caregiver indicated that patient had difficulty falling asleep, getting up during the night, wandering, awakening the caregiver, waking up too early in the morning, and sleeping excessively during the day. The caregiver's sleep was also poor (PSQI total score = 6). All five sessions were completed at the Veterans Affairs adult day health care program based on the caregiver's preference.

For this dyad, session 1 focused on personal goals and education: (a) having the patient get ready for sleep at a scheduled time with the patient's cooperation (caregiver's goal), and (b) having the patient cooperate with the caregiver (patient's goal). The dyad determined initially that a bedtime and rise time of 10 pm and 6:30 am, respectively, suited their preferences and routine. The sleep educator encouraged them to keep this sleep schedule through the week (sleep hygiene). The dyad agreed to reduce non-sleep activity in bed (stimulus control recommendations) by moving the cell phone and charger to outside the bedroom.

In session 2, check-in and review of the sleep diaries revealed that the caregiver had challenges keeping her 10:00 bedtime because she spent so much time helping the patient (her husband) get ready for bed. On the sleep diaries, the caregiver had only one night of "good sleep" and the patient had two nights of "good sleep" during the first week. An adjusted (reduced time in bed) sleep schedule of 10:30 pm for bedtime and 6:30 am for rise time was proposed (sleep compression recommendations), which was a more realistic bedtime schedule for their situation. Behavioral activation to identify activities to stay awake in the evening was not needed for this dyad as the caregiver was already assisting the patient in preparing for bed (e.g., changing a diaper).

The caregiver reported that the patient napped 60–90 minutes/day during the first week. Limiting daytime nap(s) was challenging because the patient fell asleep when he sat on a couch for watching television or resting. Possible solutions were discussed, including increasing daytime light exposure, playing with a dog, and turning on favorite/interesting television shows that might keep the patient awake during the day. The caregiver decided that it would be feasible to try limiting her husband's naps to 30 minutes 1–2 days per week.

Long-term daily walking goals were set in Session 2 to 30 minutes daily for both the patient and the caregiver, with a short-term goal of walking 10 minutes daily during the upcoming week (daily walking and light exposure recommendations). The initial light exposure plan was also set to 10 minutes per day. The caregiver felt that the best way to meet daily walking and light exposure goals was when the caregiver walked to and from the parking lot and the adult day health center, extending that time to a full 10 minutes and having the patient walk with her, rather than dropping him off at the entrance of the center. Sitting and playing with their dog in the backyard was also identified as a feasible plan for getting sunlight for the dyad.

In session 3, check-in and review of sleep diaries revealed that the patient's average daily nap duration during the previous week (based on sleep diary data) had been 68 minutes. Review of the walking and light exposure plan revealed that the dyad had met their short-term plans for daily walking and light exposure, and so was encouraged to keep the same 10 minutes/day plan during the next week. Limiting naptime for the patient was still challenging because the patient napped despite of the caregiver's encouragement to do other activities. The caregiver and sleep educator brainstormed a new plan, namely, that the caregiver could check in the patient for few minutes every hour to gently remind him to be awake. The adjusted nap plan was to have the patient's nap duration reduced by 10–15 minutes daily.

The caregiver had tried to follow the previously recommended bedtime schedule (10:30 pm) for both herself and the patient. For the next week, the same bedtime and rise time schedule was recommended for the dyad. The A-B-C problem solving approach was then introduced. A sleep problem that the caregiver wanted to target was that the patient awakened in the middle of the night. Sometimes nighttime awakenings were associated with incontinence, requiring a change in adult diaper or sheets, and sometimes the patient simply got up, went to the bathroom, and sat there for a long time. Activators for nighttime awakenings (what happened before he awakened) were brainstormed, as were consequences to the awakenings (how the caregiver responded to his incontinence or spending a long time in the bathroom). A plan was developed that included making sure that the patient changed into clean adult diapers when they became wet, finding different types of pads with better absorbency for the bed so the caregiver had an easier time cleaning up if incontinence did occur, and having the caregiver try not to show that she was upset or surprised when the patient wet the bed.

In session 4, during the check-in and sleep diary review, both had fewer than five nights of good sleep although the dyad had increased "good sleep" compared to their sleep on the first week of their sleep diaries. However, the caregiver requested to keep the same sleep schedule for one more week. Long-term goals of daily walking and light exposure had been achieved (30 minutes/day) for both members of the dyad, and they were encouraged to maintain this goal.

In discussing the follow-up of the A-B-C plan, the caregiver expressed that her husband seemed more receptive to her help when the caregiver showed a positive attitude when the patient wetted his bed. In session 4, the sleep educator also discussed positive and negative aspects of caregiving, and introduced strategies to reduce caregiving stress and chronic stress

(that are not related to caregiving responsibilities) during the daytime, evening, and nighttime. Behavioral activation was introduced to identify engaging activities for the evening hours to maintain wakefulness until scheduled bedtime and the activities included listening to music or watching favorite TV shows. At the end of the session, the dyad practiced a brief, breathing relaxation technique together, and the caregiver practiced mindfulness skills using "thoughts as leaves on a stream" [53].

In session 5, the caregiver described "unexpected benefits," to the program including feeling more rested, and having a positive experience with daytime sunlight and walking goals. The caregiver also felt she had more power and control over sleep issues and other problematic behaviors of the patient. The patient's reduced daytime napping (from an average of 69 minutes to 29 minutes) was also one of the benefits. Intervention sessions with Dyad 1 ranged from 30 minutes (session 5) to 90 minutes (sessions 1–4), with an average of 78.0 minutes.

Feedback and Modification

After completing all sessions with Dyad 1, intervention content that was redundant or confusing was eliminated. For example, the study introduction explanations about what constitutes a good night's sleep were shortened. A figure showing solid sleep versus disrupted sleep was eliminated. Additional information about the importance of consistent sleep scheduling was added to session 2. The A-B-C problem-solving plan was modified to focus on examples relevant to the caregiver. The stress discussion in session 4 was changed to emphasize evening/nighttime stressors that could impact caregivers' sleep. The brief "thoughts as leaves on a stream" mindfulness exercise was moved from session 4 to session 5. Session 5 was redesigned to be an in-person instead of telephone session. Content asking the caregiver to reflect on how our program impacted the dyad's life was also added to session 5 to encourage program feedback and to highlight the benefits of changes made during the program.

Case example 2 (Dyad 5)

A male patient diagnosed with probable Alzheimer's disease received care from his daughter. On the NPI-Nighttime Behavior Subscale, sleep problems of the patient included difficulty falling asleep, getting up during the night, nighttime wandering, awakening the caregiver during the night, and sleeping excessively during the day. The caregiver's sleep was poor (PSQI total score = 15). All sessions were delivered at our research office, per the caregiver's preference.

In session 1, the caregiver's stated goal for the program was to get at least 3–4 hours of solid sleep each night. The patient did not have any goals. Bedtime was set at 9:30 pm for the patient and 12:30 am for the caregiver. Rise time was set to 10:00 am for the patient and 7:30–8:00 am for the caregiver. The caregiver was encouraged to move non-sleep activities (paying bills, eating meals) into the dining room rather than doing them on the couch where she slept (stimulus control recommendations). The sleep educator incorporated several unique situational considerations when planning sleep recommendations. They included the

caregiver's physical limitations due to pain in her knee, the caregiver's use of a couch as her sleeping area, and the patient's nighttime wandering.

Session 2 was delayed by two weeks because of the patient's visit to an emergency room. In session 2, review of the sleep schedules indicated that the patient was going to bed later than it was originally scheduled, and the caregiver was staying in bed longer in the morning, mainly due to pain. Bedtimes were adjusted to 10:30–11:00 pm for the patient and 12:00 am for the caregiver. Rise time was set to 10:00 am for the patient and 9:00 am for the caregiver. Nap duration was set to one hour per day for the patient. When the daily walking was introduced, the caregiver stated that she could not walk more than 5–10 minutes/day due to right knee/ankle pain. Both the caregiver and patient used canes for walking. Long term goals for walking and daytime light exposure were set to 30 minutes per day for the patient (with caregiver observing) and 5–10 minutes for caregiver. Short-term goals for walking and light exposure were set to 5–10 minutes during the next week for both members of the dyad.

In session 3, review of the sleep schedule plans indicated that both the patient and the caregiver did not have any nights of "good sleep." Thus, sleep schedules for both were further tightened. The patient's schedule was set to 10:45 pm for bedtime and 9:45 am for rise time, which was a total compressed schedule of 30 minutes per night. The caregiver's schedule was changed to be more consistent with her actual schedule reported on the sleep diary the past week: 12:45 am bedtime and 8:45 am rise time. The recommended patient daily nap duration stayed the same (one hour limit). The dyad had no problems following the initial daily walking and light exposure plans, and the caregiver agreed to increase each to 10 minutes daily. When A-B-C problem-solving plan was introduced, the most challenging patient behavior identified by the caregiver was nighttime wandering and getting lost on the way back to his bedroom. Possible activators were brainstormed, including the caregiver reviewing the patient's medications with a physician to see if any could cause nocturia, and giving her father a protein snack before bed. The consequence that the caregiver planned to change was that she would reorient the patient back to the bedroom while using a calm tone of voice.

In session 4, the dyad's sleep schedules were reviewed. Bedtime was set to 10:45 pm for the patient and 12:45 am for the caregiver. Rise time was set to 9:45 am for the patient and 8:35 am for the caregiver. Falling asleep on a couch while watching television had been a routine for the caregiver. A possible plan (behavioral activation) for separating evening activities from bedtime was discussed: brushing teeth, changing to pajama 20 minutes before bedtime, and sitting up when watching television on the couch (i.e., her bed) and turning the television off at her scheduled bedtime. The recommended patient nap duration was kept the same (1 hour/day). The caregiver said there had been no problems following the daily walking and light exposure plans; both plans were thus increased to 15 minutes daily for the patient (with caregiver observing) and remained the same (10 minutes daily) for the caregiver.

In the final session 5, final recommended sleep schedule, napping, walking, and light exposure plans were established. Bedtime was set at 10:45 pm for the patient and 12:45 for the caregiver. Rise time for the patient was set to 9:45 am and 9 am for the caregiver. Nap

duration for the patient remained at one hour per day. The sleep educator encouraged keeping the same daily walking and light exposure plans as the previous week (session 4). The caregiver practiced a brief "thoughts as leaves on a stream" mindfulness exercise. "Benefits of this program" to the caregiver included that: (1) it gave her some time off from her caregiving responsibilities while participating in the sessions, (2) she felt that learning about meditation and relaxation techniques was helpful, and (3) she now has more tools to use when having sleep problems, stress, and other problems in the future.

Intervention sessions with Dyad 5 ranged from 45 minutes (session 1) to 80 minutes (session 2), with an average of 59.6 minutes.

Feedback & Modification

The caregiver from Dyad 5 did not identify any issues with treatment acceptability. The educator's perception after this case was completed was that both clarity of information and ease of delivery were excellent for all sessions. The only concern that arose was that the sleep educator (a registered nurse) was reluctant to initiate a daily walking plan when risk of falls was a concern. During discussion at an intervention refinement meeting, it was agreed that starting with very low baseline activity levels in the initial walking plans was critical for those with disability or chronic illness that may limit mobility and/or physical endurance. Encouraging participants to walk daily (rather than only certain days per week), and increasing walking duration very gradually based on the weekly progress were important and necessary components of treatment. No further modifications were needed on the intervention materials. The finalized intervention program is outlined in Table 1.

DISCUSSION

This study demonstrated the potential benefit of a dyadic sleep intervention program for Alzheimer's disease patients and their family caregivers. Our iterative refinement process for developing the intervention program allowed us to assess both caregivers and interventionists (i.e., sleep educators)' perceived acceptability on delivering each component of the program and to pilot test the revised version quickly. This approach was an effective way to capture complex situations involving dementia care and family caregiving and incorporate multiple needs of this population into our dyadic program.

Several areas in our program materials and structures were refined during the study. First, we changed the final phone call session to an in-person session and shifted some new content (mindfulness meditation) into Session 5. Questions asking about caregivers' perceived benefits of our program for dyads were also added to capture both expected (related to each dyad's initial goals) and unexpected achievements. Some of the key components such as sleep scheduling, stimulus control, caregiver stress, and mindfulness practice were rearranged within or across sessions for better flow based on sleep educators' feedback. We also created a structured method (use of the "good sleep" variable) to guide the sleep educators when to adjust sleep schedules (i.e., bedtime and rise time) on a simple sleep diary. Daily walking, light exposures, and A-B-C sleep problem-solving plan instructions were also revised in the interventionist manual, based on the interventionists' feedback about its use with the pilot cases.

Overall, our program showed positive patterns of improving self-reported sleep (i.e., reducing total wake time and sleep onset latency). Caregivers with physical limitations from medical comorbidities or worse baseline sleep quality (based on the PSQI score) showed less improvement in sleep or did not maintain sleep improvements to the end of treatment. Although this pilot study was not designed to test treatment efficacy, it did provide us with valuable information regarding issues that may arise when dealing with challenging cases.

Our findings supporting potential benefits of using nonpharmacological sleep intervention approaches are consistent with previous studies of sleep management (one study with light therapy and the other with a combination of sleep hygiene, light exposure, and walking) that targeted both patients with dementia and their family caregivers [34, 35]. However, both of the studies showed lack of evidence of existing sleep problems at baseline for both members of the dyads. Moreover, these studies had lack of control group in a pretest-posttest design. Variability (e.g., different type and stage of dementia, fluctuating nature of sleep problems, dementia-related behaviors) within the dyad [35] and relatively high dropout rates identified in these studies may be overcome by a more individualized program. Using a light box [35] may be less practical than using a strategy to increase exposure to ambient light in a daily life. Tailoring the intervention to accommodate each member of the dyad' unique situation would be a key to a successful program, for example by offering a home visit or adjusting some sleep recommendations at the individual's ability to follow. We are currently conducting a randomized controlled trial to pilot test the effects of our dyadic sleep program (NCT03455569).

Challenges regarding sleep educator training were identified during our study. One educator (a registered nurse) was reluctant to prescribe daily walking study participants with physical limitations because of concern about potential risk of injury or falls. Hospital-based studies [59, 60] have shown that inpatient nurses exert considerable influence over whether, when, and how often ambulation of patients occurs. Deferring decisions about initiating walking to other disciplines such as physical therapy or medicine is common. Fear of patient falls, nurse back injuries, and the absence of doctor's orders discouraged those nurses from walking patients [59]. This illustrates that training of future sleep educators needs to include elicitation of any potential barriers sleep educators might perceive related to prescribing walking, light exposure, or sleep behavioral recommendations, as well as education as to how these components can be introduced and monitored to ensure participant safety. This also suggests that engagement of medical providers who can evaluate fall risk factors is critical.

Our study has some limitations. Only five dyads participated in the study. However, this number was sufficient to refine intervention materials to the point that neither participants nor sleep educators had problems with their use. Sleep educators also had different backgrounds. One had previous experience delivering sleep education to older adults with insomnia, so feedback from this interventionist may have been different from those without previous experience. Future efficacy studies should include training evaluations and treatment fidelity monitoring of sessions to ensure that interventionist differences do not impact treatment outcomes. Unlike traditional cognitive-behavioral sleep interventions for insomnia, we did not have standard sleep diary measures that collect sleep diary information

needed to calculate total sleep time and sleep efficiency (i.e., the percentage of total time spent asleep while in bed), because our experience has been that complex sleep diaries are difficult for caregivers [51] and they cannot always capture reliable sleep data about the patient. We instead developed an algorithm based on our previous research [47] working with older adults with memory problems and other medical comorbidities. Although our program can be used within the health care systems that offer home visits, it may not be feasible at other settings that do not allow for a home visit. However, our program components can still be potentially further adapted for already existing programs (e.g., adult day care program, caregiver support program) for Alzheimer's disease patients or their family caregivers.

Despite these limitations, this was the first study developing a dyadic sleep education program targeting Alzheimer's disease patients and their informal caregivers when both persons in the dyad had sleep complaints. Pilot testing this program in a small-randomized controlled trial will provide further information about program feasibility, acceptability, and treatment effect size data that will help guide future larger effectiveness trials and program translation efforts.

Acknowledgments

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Implication for rehabilitation

- Our dyadic behavioral sleep program can be tailored to various types of sleep problems among patients with Alzheimer's disease and their family caregivers, with the goal of improving daytime function by reducing sleep disturbances at night.

- Caregiver training and participation of both members of the dyad in sleep management may benefit the patients' sleep and other health outcomes, reduce caregiver stress and burden, and ultimately delay or prevent institutionalization of Alzheimer's disease patients.
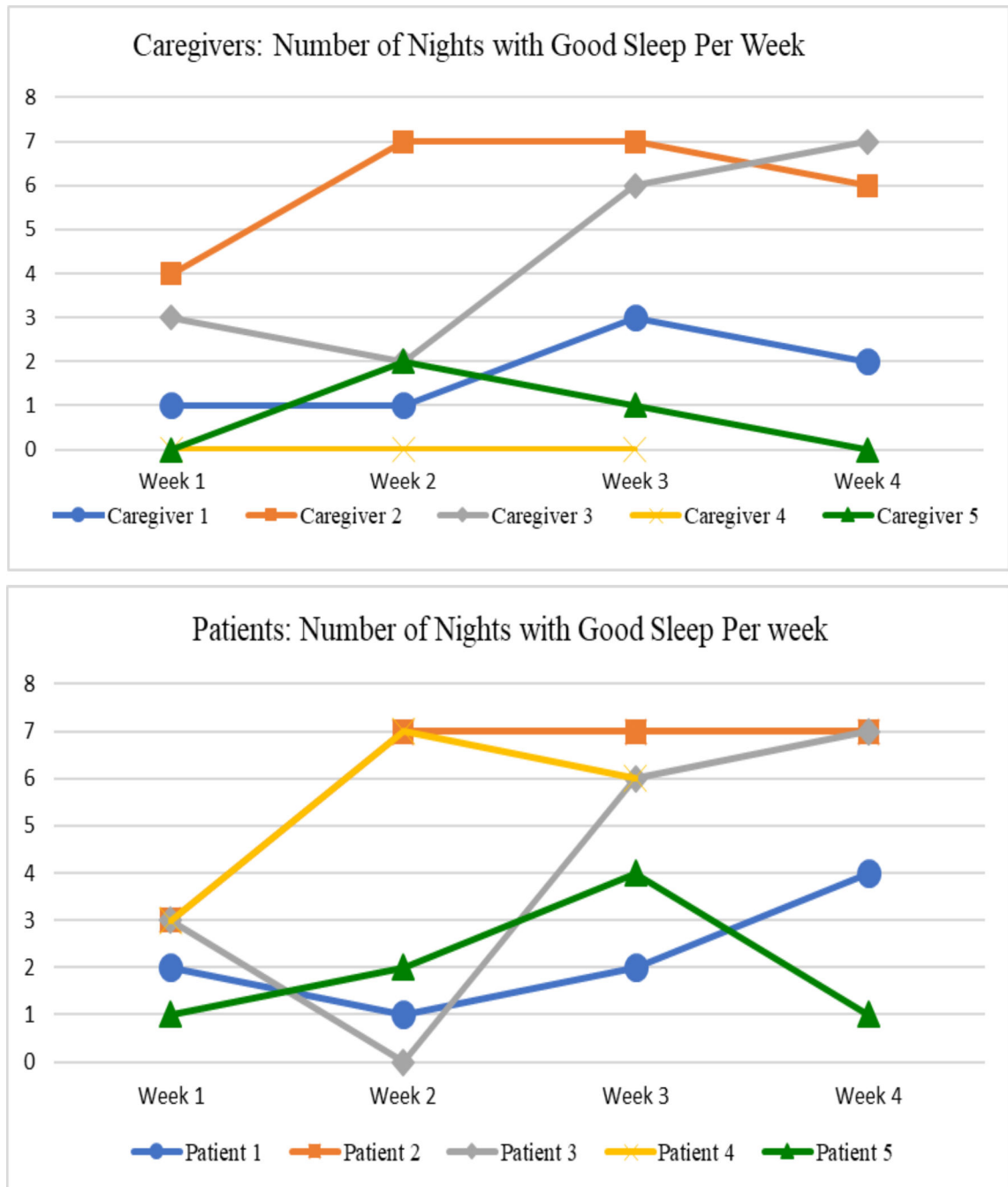
Figure 1.
Number of Nights with Good Sleep Per Week (N=5 Dyads)

Table 1.

Outline of The Finalized Dyadic Sleep Intervention Program

Topics covered	
Original protocol	**Final layout**
Session 1: How Sleep Works; Healthy Habits for Healthy Sleep (1 hour. Patient and Caregiver)	
• Personal goals for this program for both caregiver and patient • Education: why working together to improve sleep; why we need sleep; causes of sleep change; and healthy sleep • Stimulus control: limit nonsleep activities in the bed • Sleep hygiene: keep a regular sleep schedule • Introduction of sleep diary and initial sleep schedule established for dyads	• Personal goals for this program for both caregiver and patient, plus interventionist goal was to "understand specific situation of each dyad and how this program would be most helpful" • Education: why working together to improve sleep; why we need sleep; causes of sleep change; and healthy sleep • Stimulus control: limit nonsleep activities in the bed • Sleep hygiene; keep a regular sleep schedule • Introduction of sleep diary and initial sleep schedule established for dyads
Session 2: Getting Solid Sleep; Walking & Light Exposure (1 hour; Caregiver only)	
• Session overview • Check in and review sleep diaries • Education: sleep regulation (sleep drive & internal clock) and limiting daytime nap • Sleep compression: reduce time in bed by 15 minutes and adjust sleep schedule accordingly • Behavioral activation: identify idea for nighttime activities • Daily walking and light exposure • Summary and review	• Session overview • Check in and review sleep diaries: "Good sleep" variable was created to be used to guide sleep compression recommendations • Education: sleep regulation (sleep drive & internal clock) and limiting daytime nap (both time of naps and duration) • Sleep compression: reduce time in bed by 15 minutes and adjust sleep schedule accordingly • Daily walking and light exposure: Additional strategy for developing walking and light exposure plans • Summary and review
Session 3: A-B-C Problem-Solving Plan; Walking & Light Exposure Adherence (1 hour; Caregiver only)	
• Session overview • Check in and review sleep diaries • Review walking and light exposure plan and adjust plans (if indicated) • Education: overview of A-B-C plans; and two examples of how to apply the A-B-C plan • Use A-B-C approach to develop behavioral plan for solving a targeted problem • Sleep compression: revision of planned sleep schedule (if indicated) • Summary and review	• Session overview • Check in and review sleep diaries • Review walking and light exposure plan and adjust plans (if indicated) • Education: overview of A-B-C plans; and two examples of how to apply the A-B-C plan • Use A-B-C approach to develop behavioral plan for solving a targeted problem • Sleep compression: revision of planned sleep schedule (if indicated) • Summary and review
Session 4: Being Healthy Caregivers (1 hour; Caregiver only)	
• Session overview • Check in and review sleep diaries • Review walking and light exposure plan and adjust plans (if indicated)	• Session overview • Check in and review sleep diaries • Review walking and light exposure plan and adjust plans (if indicated)

Topics covered		
Original protocol	**Final layout**	
• Review the A-B-C plan • Education: caregiver stress and sleep; how to manage stress in the evening and at night; caregivers' chronic stress; and how to manage stress during the day • Behavioral activation: identify engaging activities for the evening hours to maintain wakefulness until scheduled bedtime • Deep breathing relaxation technique (both patient and caregiver) • Mindfulness ("thoughts as leaves on a stream") with a caregiver only • Sleep compression: revision of planned sleep schedule (if indicated) • Summary and review		• Review the A-B-C plan • Education: caregiver stress and sleep; and how to manage stress in the evening and at night • Behavioral activation: identify engaging activities for the evening hours to maintain wakefulness until scheduled bedtime; and identify idea for activities when having difficulty falling asleep • Deep breathing relaxation technique (both patient and caregiver) • Sleep compression: revision of planned sleep schedule (if indicated) • Summary and review
Session 5: Healthy Sleep Habits for Life (Caregiver only)		
• Phone-session (30 minutes) • Session overview • Check in and review sleep diaries • Review walking and light exposure plan and adjust plans (if indicated) • Review the A-B-C plan • Review benefits of the program to both patient and caregiver • Recommendation summary • Revise the sleep schedule and daily walks and light exposure to address long-term sleep plan		• In-person session (1 hour) • Session overview • Check in and review sleep diaries • Review walking and light exposure plan and adjust plans (if indicated) • Review the A-B-C plan • Education: caregivers' chronic stress and how to manage stress during the day • Mindfulness ("thoughts as leaves on a stream") with a caregiver only • Review benefits of the program to both patient and caregiver; and how our program impacts your life • Recommendation summary • Expect change in the future and use some of the strategies from the program