Title

Sleep and Caregiving Experiences among Caregivers of Veterans in an Adult Day Health Care Program: A Pilot Study

Journal

Clinical Gerontologist, 41(2)

ISSN

0731-7115

Authors

Song, Yeonsu
McCurry, Susan M
Fung, Constance H
et al.

Publication Date

2018-03-15

DOI

10.1080/07317115.2017.1365795

Peer reviewed

HHS Public Access

Author manuscript

Clin Gerontol. Author manuscript; available in PMC 2018 March 12.

Published in final edited form as:

Clin Gerontol. 2018 ; 41(2): 167–171. doi:10.1080/07317115.2017.1365795.

Sleep and Caregiving Experiences Among Caregivers of Veterans in an Adult Day Health Care Program: A Pilot Study

Yeonsu Song, PhD, RN, FNP[a,b], **Susan M. McCurry, PhD**[c], **Constance H. Fung, MD, MSHS**[a,b], **Karen R. Josephson, MPH**[a], **Edmond Teng, MD, PhD**[a,b], **Michael R. Irwin, MD**[b,d], **Cathy A. Alessi, MD**[a,b], and **Jennifer L. Martin, PhD**[a,b]

[a]Geriatric Research, Education and Clinical Center, VA Greater Los Angeles Healthcare System, Los Angeles, CA

[b]David Geffen School of Medicine, University of California, Los Angeles, Los Angeles, CA

[c]Department of Psychosocial and Community Health, University of Washington, School of Nursing, Seattle, WA

[d]Cousins Center for Psychoneuroimmunology, Semel Institute for Neuroscience and Human Behavior, University of California, Los Angeles, Los Angeles, CA

Abstract

Objectives—This pilot study explored caregivers' attitudes toward core elements of a behavioral sleep intervention for managing sleep problems of older veteran care recipients and the caregivers, as an initial step for developing a dyadic sleep intervention program.

Methods—Five caregivers (all women, age range 66 to 75 years) participated in a focus group discussion. Data were collected at one Veterans Affairs, adult day health care program.

Results—Caregivers' poor sleep was not necessarily explained by their caregiving responsibility. Caregivers felt that behavioral recommendations regarding sleep compression scheduling, increased indoor physical activity, and outdoor light exposure would be acceptable sleep interventions for themselves and the care recipients. Some challenges to the sleep recommendation were identified and they included limiting naptime of care recipients and change of their current sleep schedule.

Conclusions—Caregivers are receptive to some key components of behavioral approaches to improving sleep. Tailored sleep recommendation strategy is needed to address potential challenges.

Clinical implications—If available within clinical care settings or delivered at the patient's home, caregivers of older veterans are likely to engage in behavioral sleep intervention programs.

Keywords

sleep; caregiver; behavioral sleep intervention; veterans

Address correspondence to Jennifer L. Martin, PhD, Geriatric Research, Education, and Clinical Center (11E), VA Greater Los Angeles Healthcare System, 16111 Plummer Street, North Hills, CA 91343. Jennifer.Martin@va.gov.

Conflict of Interest: No conflicts of interest have been declared by the authors.

INTRODUCTION

Sleep problems are common among caregivers of veterans (National Alliance for Caregiving, 2010; Rittman, Hinojosa, & Findley, 2009). More caregivers in this group are primary caregivers, spouses, living with veterans, and provide care for longer time periods than caregivers in general population (National Alliance for Caregiving, 2010), placing them at higher risk for poor sleep.

Sleep problems among caregivers in the general population are associated with depression (Rowe, McCrae, Campbell, Benito, & Cheng, 2008; von Kanel et al., 2012), poor physical function (Spira et al., 2010), low quality of life (Cupidi et al., 2012), and increased mortality risk (Mausbach et al., 2006). This negative impact may be even higher in caregivers of veterans than in caregivers of non-veterans.

Behavioral sleep interventions have been used for either caregivers (Carter, 2006; McCurry, Logsdon, Vitiello, & Teri, 1998) or patients who require caregiving (Martin et al., 2017; McCurry, Gibbons, Logsdon, Vitiello, & Teri, 2005; Simpson & Carter, 2010). Overall, these behavioral interventions have resulted in some improvements in sleep (Carter, 2006; Martin et al., 2017; McCurry et al., 2005; McCurry et al., 1998; McCurry et al., 2011; Simpson & Carter, 2010). However, sleep interventions targeting both members of the patient-caregiver dyad have not been studied in veteran or general populations. Targeting both dyad members may result in greater improvements because of the bidirectional nature of sleep in care-recipient/caregiver dyads where each individual's sleep affects the sleep of the other (Kotronoulas, Wengstrom, & Kearney, 2013). Given the evidence of potential synergistic benefits of dyadic interventions (Schulz et al., 2009), interventions that simultaneously address sleep difficulties in dyads may be highly beneficial.

The purpose of this study was to explore the unique experiences and needs of caregivers of veterans in managing their own and the veterans' sleep problems to inform development of a sleep intervention for the dyads. Findings were also intended to provide information on caregivers' perceived acceptability of components of behavioral sleep interventions used for older veterans (Martin et al., 2017) and training caregivers of vulnerable patients (e.g., those caring for dementia patients)(McCurry et al., 2005).

METHODS

Study Design and Participants

This was a qualitative study using a focus group. We recruited participants at one Veterans Affairs (VA) adult day health care (ADHC) program, using three methods. First, we mailed invitation letters to veterans who were enrolled in a previous study (Martin et al., 2017) and indicated they received assistance with activities of daily living. Second, we distributed study information to a caregiver support group at the ADHC. Third, the ADHC program director and staff referred interested caregivers to our study. Caregivers were screened for the following eligibility criteria: (a) age >21; (b) family caregiver for a veteran attending the ADHC program; (c) assisting with at least one activity of daily living (National Alliance for

Caregiving, 2010); (d) helping the veteran for at least 6 months, and (e) English-speaking. Among eight caregivers screened and eligible, three declined participation. Five caregivers were enrolled.

All five caregivers (mean age 72.0) were female, primary caregivers for an average of 10 years (range 3–26 years) and were spouses of care recipients. Three were providing care due to dementia. On average, caregivers had medium levels of perceived stress (Cohen, Kamarck, & Mermelstein, 1983); four had poor sleep quality (Buysse, Reynolds, Monk, Berman, & Kupfer, 1989) and fatigue due to poor sleep (Gradisar et al., 2007). Four caregivers took naps or dozed during the day (Carney et al., 2012).

Study procedure was approved by the Institutional Review Board of VA Greater Los Angeles Healthcare System.

Procedures and Measures

The audiorecorded focus group was facilitated by an experienced moderator (JLM), with two note-takers (YS and KRJ). The discussion guide focused on key questions: (1) caregivers' thoughts and experiences on managing sleep problems for themselves and the veterans, and (2) their reactions to components of behavioral sleep interventions (Martin et al., 2017; McCurry et al., 2005). As a part of the discussion, we shared one example of a sleep hygiene brochure (Centre for Clinical Interventions, 2008) to ask caregivers their thought and prior experiences on using this component. One caregiver was unable to participate in the group and was interviewed separately using the same discussion guide.

Data Analysis

Audiotapes were transcribed and reviewed for accuracy. A brief explanatory description of the transcribed text was summarized with key concerns under each key question. Three members of our research team (JLM, YS, and KRJ) discussed and compared notes to identify common issues/themes and key words used by caregivers to describe sleep concerns. Key findings for each key question noted by two or more of the team members were discussed. Following transcript review, themes were confirmed or adapted. Parts of the transcript not covered under key questions that were deemed important were noted and discussed. Frequency and intensity of caregivers' comments related to sleep and their reactions to the intervention components were sought. For example, we sought how many caregivers agreed that sleep was impacted by their care recipient's nighttime needs and behaviors, and how the language used by caregivers reflected the importance of their concerns.

RESULTS

Sleep difficulties among caregivers

Some caregivers attributed poor sleep to caregiving responsibilities at night. For instance, Participant 1: "…*He woke up at 2:30…and I need to keep an eye on him when he goes to the bathroom. And he came right back to bed and went to sleep, and I could not fall back asleep.*"

However, caregivers' sleep was not always interrupted by the veteran under their care. Participant 4: *"Well, my sleep issues have nothing to do with my husband…I mean we have many other issues that I'm dealing with, so that would keep me awake and when one would get resolved there'd be another one…right now I'm dealing with everything."*

Sleep difficulties among veterans

Four caregivers expressed that napping was routine and it was difficult to keep veterans active and awake during the day. *Participant 2: "When I know he can do something I find things sometimes for him to do, but at the same time it's so much work to direct them just like with a child".* Two caregivers reported caring for veterans with untreated sleep disorders.

Pharmacological strategies for sleep

In terms of sleep management for caregivers and care recipients, sleeping pills were reported, although caregivers did not view sleeping pill use favorably. Participant 1: "*I'm afraid to take sleeping pills because I feel like I'm on duty. I mean I have to be awake*". Participant 2: "*I gave my husband sleeping pills the doctor gave him, but he won't take those generally…he didn't like the way it felt.*"

Behavioral strategies for sleep

Other strategies that caregivers tried for their sleep included melatonin, nighttime reading, and some sleep hygiene practices. Participant 4: "*The only thing that helps me once in a while is I like to read and if I start reading late at night I do get tired. That helps a little, but then by the time I get up and go into the bathroom I'm wide awake.*" To help the veterans under their care, they had tried a new bed and changing bedtime early which they felt did not help.

Challenges of interventions

Three caregivers felt they had tried most sleep hygiene strategies, but did not find them helpful. Participant 3: "*…if you haven't been able to fall asleep, get up and do something else… I've heard this many times before. So I'm having a hard time falling asleep. So my husband's snoring. So I get up and I creep out of the bedroom, close the door ever so quietly, go into another room and turn on a lamp and just sit there to read. I can be there four minutes and my husband bursts in, "Why are you awake?…What's wrong?… It's like the enemy has crept by and woke him up in this foxhole…*"

All caregivers said increasing daytime light exposure and outdoor physical activity would be challenging if weather is unfavorable or due to physical limitations of veterans. They also did not prefer to use a lightbox indoors; however, four caregivers felt indoor physical activity or sitting outdoors on a patio or backyard area would be feasible and even enjoyable.

All expressed concern that changing their current sleep schedules would be disruptive, and limiting naps for veterans would be challenging. They viewed the veteran's naptime as their break time. Participant 3: "*I wouldn't know how to [keep his nap to only one hour]…his nap is an opportunity for me to wind down, so something I want to do, relax myself.…"*

Participant 1: *"I only let him sleep for one hour. I wake him up. And then we have to have an activity if I wake him."*

On using sleep compression (i.e., gradually reducing time in bed to improve sleep quality), all caregivers were willing to try this and felt it might be helpful but potential barriers were identified. Participant 1*: "I think that it may work. It can't work for [my husband] because if he stays up past a certain time, if he gets tired or he has like sensory overload, then he starts getting paranoid ideas."* Participant 4*: "We have a routine. He gets in that bed early… usually after dinner he'd go in and watch TV in the bedroom and I was always watching my programs out in the family room. So I don't even know what time he'd go to sleep… I go to bed late…"*

Best intervention

Caregivers felt the best program structure was face-to-face sessions in their home or at a clinic where veterans had other appointments. Participant 5: " *[I prefer] face to face and computer because he cannot hear very well, that's why…*" They did not feel it was necessary to engage veterans directly in most of the intervention since cognitive limitations would make their participation challenging. Participant 1: "*I wouldn't bring [care recipient] to this because he wouldn't get…he couldn't understand it*". They did feel providing support and encouragement for the veteran to adhere to the recommended behavioral plan would be helpful. They expressed no concerns with having up to 6 one-hour weekly sessions. They liked the concept of interventionists who understand the medical and cognitive complexity of veterans, such as trained nurses.

DISCUSSION

This is the first study that explored caregivers' thought on key components of behavioral sleep interventions targeting care-recipient/caregiver dyads. This study supports that some caregivers are receptive to behavioral sleep interventions.

Our findings suggest that caregiving responsibilities did not fully account for sleep problems. Some noted difficulties with sleep due to internal factors unrelated to caregiving such as worries. Demographics may contribute; namely, being a women and being older are well-known risk factors for sleep problems (Foley et al., 1995; Middelkoop, Smilde-van den Doel, Neven, Kamphuisen, & Springer, 1996).

Sleep compression, indoor physical activity, and light exposure were acceptable elements of a sleep intervention program, but having strict bed and rising time schedules were not. Keeping veterans awake during the day by limiting naps was considered challenging because of its impact on needed caregiver respite time and effort required to keep the veteran busy during the day. Caregivers had tried sleep hygiene strategies, however, it was unclear how long or how well they had done this.

Caregivers' positive attitude regarding a nurse interventionist suggests behavioral sleep interventions administered by healthcare providers with expertise in medical conditions and behavior change would be desirable. Previous sleep interventions administered by nurse or

nurse practitioner improved sleep in persons with insomnia (Buysse et al., 2011; Espie et al., 2007; Jungquist et al., 2010), providing support for this idea.

Our study, however, has weaknesses that included lack of pre-specified themes since only one focus group was conducted and the absence of objective sleep data for caregivers and veteran care recipients.

Acknowledgments

This study was supported by the Veterans Affairs Health Services Research & Development (HSR&D), Locally Initiated Project (LIP 65-154, PI: Song). Other funding support for authors include the VA Advanced Geriatrics Fellowship Program (Song), the Office of Academic Affiliations, Department of Veterans Affairs; the National Institute on Aging of the National Institutes of Health (K23AG055668, PI: Song); the National Institute on Aging of the National Institutes of Health and the American Federation for Aging Research (K23AG045937, PI: Fung). The content is solely the responsibility of the authors and does not necessarily represent the official views of the Department of Veterans Affairs, National Institutes of Health, or the U.S. Government.

The authors wish to thank ADHC program director Jo Ellen Baur, MSW, Maureen Burruel, MSW and all members of the ADHC staff for their support of this project. The authors also wish to acknowledge research staff members Stella Jouldjian, MSW, MPH, Alexandra Krall, Sergio Martinez, Simone Vukelich, and Terry Z. Vandenberg, MA.

References

Buysse DJ, Germain A, Moul DE, Franzen PL, Brar LK, Fletcher ME, … Monk TH. Efficacy of brief behavioral treatment for chronic insomnia in older adults. Arch Intern Med. 2011; 171(10):887–895. DOI: 10.1001/archinternmed.2010.535 [PubMed: 21263078]

Buysse DJ, Reynolds CF 3rd, Monk TH, Berman SR, Kupfer DJ. The Pittsburgh Sleep Quality Index: a new instrument for psychiatric practice and research. Psychiatry Research. 1989; 28(2):193–213. [PubMed: 2748771]

Carney CE, Buysse DJ, Ancoli-Israel S, Edinger JD, Krystal AD, Lichstein KL, Morin CM. The consensus sleep diary: standardizing prospective sleep self-monitoring. Sleep. 2012; 35(2):287–302. DOI: 10.5665/sleep.1642 [PubMed: 22294820]

Carter PA. A brief behavioral sleep intervention for family caregivers of persons with cancer. Cancer Nursing. 2006; 29(2):95–103. [PubMed: 16565618]

Centre for Clinical Interventions. Sleep Hygiene. Centre for Clinical Interventions, Department of Health, Western Australia; 2008. http://www.cci.health.wa.gov.au/docs/Info-sleep hygiene.pdf

Cohen S, Kamarck T, Mermelstein R. A global measure of perceived stress. J Health Soc Behav. 1983; 24(4):385–396. [PubMed: 6668417]

Cupidi C, Realmuto S, Lo Coco G, Cinturino A, Talamanca S, Arnao V, … Lo Coco D. Sleep quality in caregivers of patients with Alzheimer's disease and Parkinson's disease and its relationship to quality of life. Int Psychogeriatr. 2012; 24(11):1827–1835. DOI: 10.1017/s1041610212001032 [PubMed: 22652066]

Espie CA, MacMahon KM, Kelly HL, Broomfield NM, Douglas NJ, Engleman HM, … Wilson P. Randomized clinical effectiveness trial of nurse-administered small-group cognitive behavior therapy for persistent insomnia in general practice. Sleep. 2007; 30(5):574–584. [PubMed: 17552372]

Foley DJ, Monjan AA, Brown SL, Simonsick EM, Wallace RB, Blazer DG. Sleep complaints among elderly persons: an epidemiologic study of three communities. Sleep. 1995; 18(6):425–432. [PubMed: 7481413]

Gradisar M, Lack L, Richards H, Harris J, Gallasch J, Boundy M, Johnston A. The Flinders Fatigue Scale: preliminary psychometric properties and clinical sensitivity of a new scale for measuring daytime fatigue associated with insomnia. J Clin Sleep Med. 2007; 3(7):722–728. [PubMed: 18198807]

Jungquist CR, O'Brien C, Matteson-Rusby S, Smith MT, Pigeon WR, Xia Y, … Perlis ML. The efficacy of cognitive-behavioral therapy for insomnia in patients with chronic pain. Sleep Med. 2010; 11(3):302–309. DOI: 10.1016/j.sleep.2009.05.018 [PubMed: 20133188]

Kotronoulas G, Wengstrom Y, Kearney N. Sleep and sleep-wake disturbances in care recipient-caregiver dyads in the context of a chronic illness: a critical review of the literature. J Pain Symptom Manage. 2013; 45(3):579–594. DOI: 10.1016/j.jpainsymman.2012.03.013 [PubMed: 22926086]

Martin JL, Song Y, Hughes J, Jouldjian S, Dzierzewski JM, Fung CH, … Alessi CA. A Four-Session Sleep Intervention Program Improves Sleep for Older Adult Day Health Care Participants: Results of a Randomized Controlled Trial. Sleep. 2017; doi: 10.1093/sleep/zsx079

Mausbach BT, Ancoli-Israel S, von Kanel R, Patterson TL, Aschbacher K, Mills PJ, … Grant I. Sleep disturbance, norepinephrine, and D-dimer are all related in elderly caregivers of people with Alzheimer disease. Sleep. 2006; 29(10):1347–1352. [PubMed: 17068989]

McCurry SM, Gibbons LE, Logsdon RG, Vitiello MV, Teri L. Nighttime insomnia treatment and education for Alzheimer's disease: a randomized, controlled trial. Journal of the American Geriatrics Society. 2005; 53(5):793–802. DOI: 10.1111/j.1532-5415.2005.53252.x [PubMed: 15877554]

McCurry SM, Logsdon RG, Vitiello MV, Teri L. Successful behavioral treatment for reported sleep problems in elderly caregivers of dementia patients: a controlled study. Journals of Gerontology Series B: Psychological Sciences & Social Sciences. 1998; 53B(2):P122–129.

McCurry SM, Pike KC, Vitiello MV, Logsdon RG, Larson EB, Teri L. Increasing walking and bright light exposure to improve sleep in community-dwelling persons with Alzheimer's disease: results of a randomized, controlled trial. Journal of the American Geriatrics Society. 2011; 59(8):1393–1402. DOI: 10.1111/j.1532-5415.2011.03519.x [PubMed: 21797835]

Middelkoop HA, Smilde-van den Doel DA, Neven AK, Kamphuisen HA, Springer CP. Subjective sleep characteristics of 1,485 males and females aged 50–93: effects of sex and age, and factors related to self-evaluated quality of sleep. J Gerontol A Biol Sci Med Sci. 1996; 51(3):M108–115. [PubMed: 8630703]

National Alliance for Caregiving. Caregivers of Veterans - Serving on the Homefront: Report of study findings. 2010 Retrieved from.

Rittman M, Hinojosa MS, Findley K. Subjective sleep, burden, depression, and general health among caregivers of veterans poststroke. Journal of Neuroscience Nursing. 2009; 41(1):39–52. [PubMed: 19368070]

Rowe MA, McCrae CS, Campbell JM, Benito AP, Cheng J. Sleep pattern differences between older adult dementia caregivers and older adult noncaregivers using objective and subjective measures. J Clin Sleep Med. 2008; 4(4):362–369. [PubMed: 18763429]

Schulz R, Czaja SJ, Lustig A, Zdaniuk B, Martire LM, Perdomo D. Improving the quality of life of caregivers of persons with spinal cord injury: a randomized controlled trial. Rehabil Psychol. 2009; 54(1):1–15. [PubMed: 19618698]

Simpson C, Carter PA. Pilot study of a brief behavioral sleep intervention for caregivers of individuals with dementia. Res Gerontol Nurs. 2010; 3(1):19–29. DOI: 10.3928/19404921-20090731-02 [PubMed: 20128540]

Spira AP, Friedman L, Beaudreau SA, Ancoli-Israel S, Hernandez B, Sheikh J, Yesavage J. Sleep and physical functioning in family caregivers of older adults with memory impairment. Int Psychogeriatr. 2010; 22(2):306–311. DOI: 10.1017/s1041610209991153 [PubMed: 19943990]

von Kanel R, Mausbach BT, Ancoli-Israel S, Dimsdale JE, Mills PJ, Patterson TL, … Grant I. Sleep in spousal Alzheimer caregivers: a longitudinal study with a focus on the effects of major patient transitions on sleep. Sleep. 2012; 35(2):247–255. DOI: 10.5665/sleep.1632 [PubMed: 22294815]

CLINICAL IMPLICATIONS

- Caregivers are receptive of a sleep intervention program incorporating sleep compression, daytime light exposure and indoor physical activity.
- A dyad-based sleep intervention has the potential to improve sleep for veterans and their caregivers.