

Person-centered dementia care and sleep in assisted living residents with dementia: a pilot study

LI, Junxin, GRANDNER, Michael A., CHANG, Yu-Ping, JUNGQUIST, Carla and POROCK, Davina

Available from Sheffield Hallam University Research Archive (SHURA) at:

<http://shura.shu.ac.uk/14702/>

This document is the author deposited version. You are advised to consult the publisher's version if you wish to cite from it.

Published version

LI, Junxin, GRANDNER, Michael A., CHANG, Yu-Ping, JUNGQUIST, Carla and POROCK, Davina (2017). Person-centered dementia care and sleep in assisted living residents with dementia: a pilot study. *Behavioral Sleep Medicine*, 15 (2), 97-113.

Repository use policy

Copyright © and Moral Rights for the papers on this site are retained by the individual authors and/or other copyright owners. Users may download and/or print one copy of any article(s) in SHURA to facilitate their private study or for non-commercial research. You may not engage in further distribution of the material or use it for any profit-making activities or any commercial gain.

**Person Centered Dementia Care and Sleep in Assisted Living Residents with Dementia:
A Pilot Study**

Authors

Junxin Li, PhD, RN^{1,3}

Michael Grandner, PhD, MSTR, CBSM, FAASM¹

Yu-Ping Chang, PhD, RN^{2,3}

Carla, Jungquist, PhD, FNP²

Davina Porock, PhD, RN^{2,3}

Affiliations

1. Center for Sleep and Circadian Neurobiology, University of Pennsylvania
2. School of Nursing, University at Buffalo
3. UB Institute for Person-Centered Care

Junxin Li, PhD RN.

Email: Junxin.Li@uphs.upen.edu

Address: 3624 Market Street, Suite 201. Philadelphia, PA, 19104

Abstract

The sleep of people with dementia living in long-term care is known to be disturbed. This pre-post controlled pilot study examined the effects of a person centered dementia care intervention on sleep in assisted living residents with dementia. The three-month intervention included in-class staff training plus supervision and support in practice. The sleep-wake patterns were measured using actigraphy for three consecutive days at baseline and post-intervention. Sixteen residents from the intervention and six from the control groups completed the study. The intervention group had significantly more nighttime sleep at posttest. After adjusting for baseline, the intervention group exhibited significantly less daytime sleep and more nighttime sleep. Person centered dementia care may be effective for improving sleep of residents with dementia.

Keywords: Person Centered Dementia Care, sleep, dementia, long-term care

Introduction

The sleep of people with dementia living in long-term care facilities is known to be disturbed and severely fragmented (Lorenz, 2011; Martin & Ancoli-Israel, 2008; Ancoli-Israel & Ayalon, 2006). Residents with dementia experience excessive daytime sleepiness, at night difficulty falling asleep, increased duration and frequency of awakenings, and disrupted sleep-wake rhythms (Rose, & Lorenz, 2010; Song, Dowling, Wallhagen, Lee, & Strawbridge, 2010). Ancoli-Israel, et al (1989) has shown that residents with dementia were not totally awake or fully asleep in a single hour during a 24-hour period, and these residents with dementia, on average, fell asleep 22 times for a total of two hours during the daytime (Ancoli-Israel, Parker, Sinaee, Fell, & Kripke, 1989). Furthermore, for people with dementia residing in long term care facilities, poor sleep has been found to be associated with negative health outcomes, including: risk of falls, greater depression, poor concentration and memory, decreased physical performance and quality of life, and elevated mortality risk (Martin & Ancoli-Israel, 2008; Martin, Fiorentino, Jouldjian, Josephson, & Alessi, 2010).

Multiple factors are associated with sleep problems in residents with dementia in long term care settings (Ancoli-Israel, Ayalon, & Salzman, 2008; Lorenz, 2011). Increasing age and dementia contribute to the increased frequency of awakenings, decreased percentage of slow-wave sleep, excessive daytime sleep, and abnormal day-night sleep patterns (Rose et al., 2010; Vitiello & Borson, 2001). Increased physical and psychological health problems and multiple medication use may have negative impacts on the ability to sleep and the quality of sleep in elders with dementia (Ancoli-Israel, et al., 2008; Cole & Richards, 2007; Foley, Ancoli-Israel, Britz, & Walsh, 2004; Gaugler, Yu, Krichbaum, & Wyman, 2009; Roehrs & Roth, 2005; Zwakhalen, Hamers, Abu-Saad, & Berger, 2006). In addition to these factors, inactivity, the lack

of social activities, and the environment contribute to the prevalence of sleep disturbances in long term care settings (Martin & Ancoli-Israel, 2008; Naylor et al., 2000; Rose et al., 2010).

Managing sleep problems in residents with dementia living in long term care is challenging to clinicians. Medications, such as sedative-hypnotics and antipsychotics, are often used, but the many reported side effects seem to result in the exacerbation of insomnia and symptoms of dementia (Lorenz, 2011). Lack of physical and social activity during the day is documented in the literature as a major cause of excessively unintentional daytime sleep, which disturbs night-time sleep, in long term care residents with dementia (Richards, Beck, O'Sullivan, & Shue, 2005). In addition to the inactive life style in this environment, the ability to remain awake and become engaged in daytime activities are weaker in people with dementia than older adults without cognitive impairment. Therefore, interventions to consolidate the normal sleep-wake patterns of residents with dementia need to provide meaningful physical and social activity and to facilitate the engagement of these older adults in activities and thus promoting greater alertness.

Person centered dementia care (PCDC) is an approach used in this study to improve sleep in residents with dementia. It is a humanistic care model for people with dementia that was developed from Tom Kitwood's work (Kitwood, 1997). PCDC sees the person first rather than his/her dementia, and it discovers and enables the potential for greatest capacity in people with dementia by involving them in relationships and care, regardless of their level of cognitive and physical impairment (Brooker, 2007; Kitwood, 1997). Kitwood identifies five psychosocial needs (comfort, attachment, inclusion, identity, and occupation) above and beyond the physical needs. He describes how a "malignant social environment" is created for residents with dementia in the long term care settings through routinized task-oriented care with a focus on

physical care and how to resolve this issue with a “positive person work”. “Positive person work” provides a practical guideline for long term care providers of engaging these older adults through interactions during care practice (Brooker, 2007; Brooker & Surr, 2005; Kitwood, 1997).

In addition to Kitwood’s work, PCDC takes place in a system, which requires a person-centered physical environment and a supportive organizational environment (Li & Porock, 2014). It challenges staff in particular to reflect on their philosophy of care and care practices and to learn creative ways to interact using non-verbal as well as verbal communication. Learning to be person-centered is not simply a matter of changing a protocol and making sure everyone knows what to do. It is a process of total and holistic change, building respect, dignity, collaboration and team among care providers. It is also highly skills and action orientated. An intervention like PCDC needs to start with direct care staff training and then be carried out by the staff.

There are three reasons why PCDC may improve sleep in long term care residents with dementia. First, PCDC may decrease daytime sleep opportunity by providing and engaging residents with meaningful and purposeful daytime activities, which potentially enhances the homeostatic sleep drive and consolidates nighttime sleep. Second, the social stimuli and physical activities provided by PCDC may serve as external cues for residents to establish normal circadian rhythms. Third, the positive staff-residents interactions of PCDC may provide a more positive psychosocial environment, improve subjective well-being which may improve sleep.

The purpose of the pilot study reported here was to test the effects of a PCDC intervention on sleep in residents with dementia residing in assisted living facilities. Specifically, we hypothesized that the PCDC intervention will decrease daytime sleep and then consolidate

nighttime sleep by training direct care staff with the skills to provide meaningful and purposeful daytime activities and interact with the residents with dementia during activities of daily living.

Methods

Design

This pre-post controlled trial was nested within a larger study examining the impact of PCDC on multiple resident, staff, and family outcomes (Porock, Li, & Chang, 2014). This study was reviewed and approved by Social and Behavioral Sciences Institutional Review Board, University at Buffalo.

Setting

Secure dementia care units at two different assisted living facilities in suburban Buffalo were selected for the study. Both facilities provided person-centered care to residents in general, but had not been previously trained specifically on PCDC. Older adults living in the two study units had cognitive impairment and required assistance in activities of daily living, such as preparing meals or bathing, but could eat and walk (with or without walking device) independently. The two dementia units included one with 30 beds and the other with 18 beds, and were randomly assigned to be the intervention or control group. The staff to resident ratios in the intervention group and control group were 1:7 and 1:6 respectively. To be eligible for the study, the resident must have had a formal diagnosis of dementia; the score of Brief Interview for Mental Status equal to or less than seven, indicating severe cognitive impairment; be 65 years of age or older; and have had at least 60 days' residency to allow the resident time to have adjusted to the unit. Exclusion criteria applied to residents included diagnosis of Parkinson's disease or obstructive

sleep apnea, acute illness, being completely bed-bound, or expected to move or require hospice care within the 5-month study period.

The research team worked with the unit managers to ensure there was no coercion during recruitment of the study. Potentially eligible residents in each unit were first identified by the unit managers. The unit manager informed these potential residents as well as their designated representatives about the study, distributed letters of introduction to their designated representatives, and elicited their permission for a member of the research team to visit both the residents and their representatives to provide information about the study. After verbal agreement and arranging to meet, a member of the research team explained the study, answered questions, and obtained oral consent from the residents and written informed consent from their designated representative for participation. We recruited 18 residents from intervention unit and 10 from control units.

Measures

Actiwatch Spectrum (Philips Respironics, Andover, MA) is a small watch-like device worn on the non-dominant wrist to provide an objective estimate of sleep and the 24-hour sleep-wake rhythm and can detect circadian rhythm disturbances. It functions by measuring physical movement using motion sensors (Ancoli-Israel, Cole, Alessi, Chambers, Moorcroft, & Pollak, 2003; Buysse, Ancoli-Israel, Edinger, Lichstein, & Morin, 2006, Chesson, Coleman, Lee-Chiong, & Pancer 2007). It also has a light sensor to capture the participant's light exposure. In this study, participants wore this device for three consecutive days at baseline and post intervention to assess 24-hour sleep-wake patterns and light exposure.

The following variables were extracted from participants' actigraphy by Respironics Actiware 5.5 computer algorithms: daytime sleep, percent of daytime on sleep, nighttime sleep, percent of night on sleep, numbers of awakening, daytime physical activity, and day light exposure. The sensitivity for wakefulness on Actiware 5.5 was set at low, which is 20 counts/min. The arousal index was calculated from the number of awakenings and nighttime sleep. Sleep latency and sleep efficiency are not the points of interest of this study, because residents' exact bedtime and rise-time are unknown. Sleep-wake patterns in older adults with dementia are very complicated, with many awakenings and little consolidation (Rose et al., 2010). For that reason, we examined total sleep across the 24-hour period, coded as day or night sleep. Based on the common sleep schedule of residents living in the two units, 8am to 8pm is defined as daytime, and 8pm to 8am as nighttime. Minutes of daytime sleep and minutes of nighttime sleep were identified as the primary sleep outcome variables in this study. Daytime physical activity is represented by daytime activity counts from Actigraphy.

Participants' level of social engagement was measured by Dementia Care Mapping (DCM). DCM is a highly structured observation system which quantifies the behaviors, mood, and engagement of the residents with dementia in long term residential care settings. It was developed by Kitwood in the late 1990s and has been further refined by the Dementia Group at the University of Bradford, U.K (Brooker, 2007). In its latest version there are 23 behavioral category codes each with a mood and engagement score that is recorded every five minutes for several hours by a pair of certified dementia care mappers and producing an overall score of well-being versus ill-being. The 23 behavioral category codes, named alphabetically to aid recall during observations, include: "Articulation" (interacting with others verbally or otherwise), "Borderline" (being passively involved), "Cool" (disengaged), "Doing for self"(self-care),

“Expressive” (expressive or creative activities) , “Food” (eating or drinking), “Going back” (reminiscence), “Intellectual” (prioritizing the use of intellectual abilities), “ Joints” (exercise), “Kum and Go” (walking about), Leisure (leisure, fun and recreational activities), “Medication” “Nod Land Of” (sleeping, napping), “Objects”(displaying attachment to inanimate objects), Physical care (receiving care), “Religion” (engaging in a religious activity), “Sex”(sexual expression), “Timalation” (direct engagement of the senses e.g. aromatherapy), “ Unresponded to” (communicating without receiving a response) , “Vocational” (engaging in work or work-like activities), “Withstanding” (repetitive self-stimulation e.g. rocking, calling out), “Excretion”(Episodes related to excretion), “Yourself” (interaction in the absence of any observable other), and Zero option (when the behavior does not fit any other category).” The eight mappers including the PI in this study from UB Institute for Person-Centered Care were all trained and certified by the University of Bradford’s Dementia Group. All participants were observed for 12 hours by three shifts of paired mappers (8am-8pm) at both baseline and post intervention. Level of social engagement (Social activity) is an aggregate score of frequency of behavior codes that are related to social interaction and capture interactions between staff and resident, resident and resident, and resident and family including “articulation”, “expression”, “going back”, “intellectual”, “leisure”, and “religion”. In addition to being an outcome measure, participants’ baseline DCM was used to tailor the training of staff in the PCDC intervention. The inter-rater agreement of DCM behavioral codes from the paired mappers in this study was 92%.

Cognitive impairment was assessed using Brief Interview for Mental Status (BIMS) which is a scale embedded in the Minimum Data Set version 3.0 (MDS 3.0). Saliba et al. tested reliability and validity of the new score against the gold standard Modified Mini Mental State Exam and the previously used MDS-embedded Cognitive Performance Scale (CPS) (Saliba et al., 2012).

Scores range from 0 (no response) to 15 (no impairment). Scores between 8 to 12 indicate moderate impairment and scores from 0 to 7 indicate severe impairment. “For identifying any impairment, a BIMS score of 12 had sensitivity = 0.83 and specificity = 0.91; for severe impairment, a BIMS score of 7 had sensitivity = 0.83 and specificity = 0.92” (Saliba et al., 2012).

The participant’s comorbidity was assessed by using Cumulative Illness Rating Score for Geriatrics (CIRS-G) which was developed from the Cumulative Illness Rating Score (CIRS) and is a comprehensive recording of all comorbid diseases of older adults (Miller & Towers, 1991). CIRS-G has been validated and commonly used in geriatric residential population (Parmelee, Thuras, Katz, & Lawton, 1995). It has established good intrarater and interrater reliability (intraclass correlation coefficients of 0.83 and 0.81, respectively) in the literature (Salvi, et al., 2008). Participants’ comorbidity is represented by CIRS-G total score and the number of categories endorsed. The research team also used a standard data collection form to collect participants’ demographic information, diagnosis, and medication use.

Intervention

The PCDC intervention in this study was guided by Kitwood’s work on PCDC. The major strategies of this PCDC intervention and also the mechanism of PCDC on improving sleep in this study were to provide and engage residents with dementia with meaningful physical and social activities and to include residents with dementia in meaningful social interaction as much as possible. Staff training was provided by faculty from the UB Institute for Person-Centered Care over a three-month period, which comprised staff training, mid-intervention feedback, and staff practice. Staff training included three modules of in-class training plus in-service sessions.

Direct care staff (Registered Nurses, Certified Nursing Assistants, Personal Care Assistants and activity staff) from the intervention unit were allocated to small groups and received a total of eight hours training in three modules during the working day (or night) to initiate the process of change. Each training module involved didactic teaching integrated with active learning exercises and role play. The demonstration of sleep characteristics in residents with dementia, factors associated with poor sleep, and strategies to improve sleep in residents with dementia were introduced in the three modules.

Active learning exercises and role playing were used to help staff members to understand and develop the new skills. Examples were drawn from the many difficult situations on the unit observed during the baseline data collection, which made the training more relevant to staff's work experience and built on their existing knowledge of the residents. The aim was to train all direct care staff working on the intervention unit. However, it was very difficult to get every staff member to complete all three modules. We concluded our training modules with 82.6% staff (19 of 23) completing all three modules by the end of our fourth week of the intervention. Following the in class sessions, the trainers also worked with staff on the unit on the job by role modeling techniques and helping staff to think on their feet as they learned and tried to see the world from the perspective of the residents with dementia.

After the training modules and in-service sessions, we allowed two weeks for the staff to settle into the new practices with access to the trainers for consultation as necessary. At that time point, the trainers conducted a second dementia care mapping session on a randomly selected six residents for 4 hours. Insights from this mapping session were used as feedback to the staff to reinforce positive behaviors and identify negative or less desirable behaviors, so that information

could be used to further develop and hone their skills. Then staff practiced the skills with access to trainers for consultation for six weeks. The details of intervention are summarized in Table 1.

Procedure

Data were collected during a five-month period, which included one month baseline data collection (07/2013-08/2013), three months intervention (08/2013-11/2013), and one month post intervention data collection (11/2013-12/2013). Thus, the data related to the measurement of light was potentially confounded by seasonal variations in the day length, weather and the types of clothing worn during baseline and posttest data collection. Procedures for data collection at baseline and post intervention were the same. In both intervention and control group, we grouped six residents as a data collection unit. Each unit of data collection took five days. At the first day, the principal investigator (PI) collected data on standard data collection sheet and CIRS-G by reviewing the participants' medical and social records. The PI and another research team member assessed the participants for cognitive status (BIMS). On the next morning, the PI assisted the participants to put on the Actiwatch Spectrum before 8:00am, asked them to wear it for three consecutive days and nights, and took off the Actiwatch Spectrum after 8:00am on the fifth day of data collection. actigraphy data recording started at 8:00 on the first 'Actiwatch' day. DCMs with residents were conducted in one of the 'Actiwatch' day for 12 hours (8am-8pm) by three pairs of certified mappers.

In our baseline data collection, two residents in the control unit refused to wear the Actiwatch on the second 'Actiwatch' day and were excluded from the post-intervention data collection. Both of the two residents had frequent episodes of paranoid behavior as reported by the registered nurse in the control unit which were exacerbated by wearing the Actiwatch. Thus, all 18 residents from intervention unit and eight of ten residents from control unit completed the

baseline data collection. The three month PCDC intervention started after the baseline data collection. During the intervention period, we lost two residents from the intervention group (one moved to a skilled nursing facility and one died) and two from the control group (one moved to a skill nursing facility and one moved to home). Therefore, 16 residents in the intervention unit and 6 residents in the control group completed this study. Thus, the different attrition rates in the two study units were not related to the intervention or the variability between facilities. The three training modules were made available to staff members in the control group after concluding the post intervention data collection and completed by 11 of the 15 (73.3%) staff in the control unit.

Description of Data Analysis

The three-day actigraphy data from both baseline and post intervention were averaged. Statistical analyses were conducted with IBM SPSS statistics 21. Descriptive statistics (frequencies, percentages, range, means, and standard deviations) were used to describe participants' demographic and baseline characteristics. An independent t-test and a Chi-square statistic test were used to examine the differences in participants' demographic, comorbidity, medication use, and sleep variables between two groups at baseline. Descriptive statistics and a paired t-test were used to detect the change between baseline and post intervention within each group. Analyses of covariance using the variable' baseline values as covariates were conducted to evaluate the intervention effects between the groups. At last, numbers of participants who had better outcomes (simply the direction of change) at posttest between two groups was compared by using Chi-square statistic test. All statistical analyses were two tailed tests at .05 level of significance.

Results

Baseline Characteristics of Residents

In total, n=22 residents, including n=16 in the intervention and n=6 in the control group completed both baseline and post-intervention data collection. Baseline demographic and clinical characteristics of residents in the intervention and control groups are summarized in Table 2. Overall, all participated residents were white, nearly all (86.4%) were female, and all had severe dementia. Mean age was over 86 years, with mean number of comorbidities of five, and on a mean of six categories of medication. About 50% of residents were on psychotropic medications, including antianxiety agents, antidepressants, mood stabilizers, and antipsychotics. There were no significant differences in residents' demographic characteristics (age, gender, and race), baseline cognitive status, comorbidity, and number of medication used between intervention and control groups (Table 2).

Baseline sleep characteristics are presented in Table 3. Participants spent a mean of 35% of their day on sleep (246 minutes); they slept 73% of night time and woke up 13 times per hour during nighttime sleep. They were involved in some form of social activity for a mean of 160 (32*5) minutes during a 12-hour daytime period and were exposed to light over 1000 Lux for only 22 minutes. Four residents did not have any daytime bright light exposure (less than one minute of bright light or did not get any light exposure over 1000 Lux). There were no significant differences on most outcome variables at baseline. Residents in the control group had significantly more minutes of day light exposure over 1000 Lux ($p=.04$) than those in the intervention group at baseline.

Post-intervention effects on sleep

The comparisons of baseline to post intervention outcomes within each group and between the two groups are summarized in Tables 4 and 5

Within-group comparisons

The percentages of residents with improved outcomes (simply the direction of change) of daytime sleep, nighttime sleep, arousal index, physical activity, and social activity at the posttest for both groups were reported in table 4. In at least half of participants in the intervention group, nighttime sleep increased, and social activity increased. Changes were seen in at least 40% of the group for decreased daytime sleep and increased physical activity. This is in contrast to the control group, which saw minimal, if any improvements. Regarding continuous measures, Table 5 shows that the intervention group increased nighttime sleep and decreased mean light exposure over the course of the study, whereas no significant changes in measures were seen in the control group.

Between group comparisons

Table 5 shows that the intervention group had significantly less daytime sleep ($p=.01$) and more nighttime sleep ($p=.03$) than the control group, after controlling for baseline values. These results are partially reflected in Table 4, which shows that the percent of participants meeting threshold values for nighttime sleep was greater in the intervention group, and trends were seen for daytime sleep and physical activity ($p=0.05$).

Discussion

The present study evaluated the effects of a PCDC intervention on sleep in assisted living residents with dementia. Overall, the results support our hypothesis that PCDC improves residents' sleep in terms of decreasing daytime sleep and increasing nighttime sleep.

Distinguishable from traditional medical care, PCDC is a care approach which not only meets the person's physical needs but goes beyond physical needs to meet psychosocial needs. PCDC endeavors to maintain the personhood of the individual with dementia by facilitating social relationships, and making their day meaningful and enjoyable through personal engagement. The meaningful activities and social interactions in PCDC aim to keep the residents with dementia from unintentional daytime sleep with the potential then to consolidate nighttime sleep. The intervention in this study was delivered by direct care staff, who are trained with knowledge and skills of PCDC provided in the training modules and reinforced with role modeling on the job.

Our findings supports that person centered dementia care significantly increased participants' minutes of nighttime sleep (between and within groups) and decreased daytime sleep (between groups). Other variables failed to reach statistical significance, but since these analyses were underpowered to detect these differences, some findings may still have some clinical significance upon replication in a larger sample. For example, social activity and physical activity increased from baseline to post-intervention in 62.5% and 43.8% participants in the intervention group compared with in 16.7% and 0% participants in control group. These statistically and clinically significant findings suggest that the PCDC intervention had stimulated

staff to interact more often with residents and helped residents with dementia in the intervention group to stay awake during the day.

There are only three studies that have examined the effect of person centered care on sleep in long term care residents and in each of these sleep was a secondary outcome (Chang, Li, & Porock, 2013; Fossey et al., 2006; Matthews, Farrell, & Blackmore, 1996). Daytime and nighttime sleep was measured through staff reports (Fossey et al., 2006), questionnaire items (Matthews, Farrell, & Blackmore, et al., 1996), and Minimum Data Set 2.0 chart review (Chang et al., 2013). No objective measures for sleep were used in these studies. However, aligned with results in our study, two of three studies found person-centered care decreased residents' daytime sleep (Chang et al., 2013; Matthews et al., 1996). Matthews et al. found that resident's daytime sleepiness was significantly decreased at 6 to 8 weeks of the intervention (Matthews et al., 1996). Chang et al. used the minimum data set (MDS) 2.0 to measure the effects of person centered care on outcomes of residents (both with and without cognitive impairment) living in long term care settings (Chang et al., 2013). Sleep quality was measured by variables representing elders' daytime sleepiness in MDS 2.0. The daytime sleep of residents in PCC units significantly decreased compared with that of residents in traditional care units (Chang et al., 2013). However, no significant difference between the intervention group and the control group in terms of daytime sleep was found in Fossey et al.'s study (Fossey et al., 2006).

Previous research also reports that increased daytime physical and/or social activities are associated with decreased daytime sleep, increased nighttime sleep, decreased sleep fragmentation, and normal sleep-wake cycles (Alessi et al., 2005; Chen et al., 2010; Ouslander et al., 2006; Richards et al., 2005; Richards et al., 2011; Fetveit & Bjorvatn, 2005). Richards and colleagues conducted a series of studies to improve sleep in residents with dementia through

individualized physical activity, social activity or both and resulted in improvement in both daytime and nighttime sleep. Most other interventions provide structured activities in a certain timeframe of the residents' day. Interventions without adequate consideration for the person's individuality and preference, which is extremely important for people with cognitive impairment are more likely to be ineffective or problematic (Kitwood, 1997). For example, the time for structured activity, especially for group activity, is usually scheduled at a time convenient for activity staff and facility routine, rather than considering a time of each individual's preference in the group. Or it is very possible that the resident with dementia may not be interested in that particular activity and attends only because they are brought to the activity. As a result they do not engage positively in the activity nor are they engaged in an activity of their choice. These kinds of structured activities may not be meaningful to the residents, even though sometime favorable physical outcomes can be achieved at least while the activity is in progress. A PCDC intervention is embedded into residents with dementia's daily care with the aim of engaging the resident in physical and social activity at any possible moment of their day may be more beneficial, making life in long term care generally more enjoyable. These features make PCDC a healthy way to facilitate sleep for residents with dementia.

Daytime exposure to light is necessary for good sleep and for increased alertness (Ancoli-Israel, Martin, Kripke, Marler, & Klauber, 2002; Neikrug & Ancoli-Israel, 2010). However, residents in long term care are routinely exposed to significantly lower levels of daylight during the day and high levels of light throughout the night, compared to people living in the community in terms of intensity, duration and spectrum (Ancoli-Israel et al., 1997; Noell-Waggoner & LC, 2006; Shochat, Martin, Marler, & Ancoli-Israel, 2000). Ancoli-Israel and colleagues reported that 4% of nursing home residents with dementia were not exposed to any

bright light at all, and 47% were never exposed to light greater than 1000 Lux. In our study, about 17.4% participants at baseline and 47.8% at posttest were not exposed to light over 1000 Lux (Ancoli-Israel et al., 1997). At baseline, residents in the control group had significantly more minutes of day light exposure over 1000 Lux than those in the intervention group. Visible differences in physical features of the two study units that could contribute to this difference were not observed, such as windows or sunlight in residents' bedrooms, in the dining rooms, or in activity areas. However, there were more outdoor social activities observed in the control group than in the intervention group, which may lead the difference in day light exposure at baseline. In the didactic teaching of staff training in this study, daylight exposure was emphasized as an important element to consolidate normal sleep circadian rhythm in residents with dementia. However, daylight exposure in both groups dropped significantly from baseline to post intervention and intervention group dropped less than control group. Two possible reasons may contribute to the significant decrease in daylight exposure at posttest. First, our data collection for baseline was from early July to August and for post intervention was from November to December. Therefore, the significant decrease in daylight exposure may be attributable to the variation of natural light exposure in different seasons. Second, the Actiwatch Spectrum was placed underneath the clothes of many participants while data recording to reduce rejection of the equipment. The light sensor may not have accurately captured the daylight through the clothes, especially as the clothes got heavier as the seasons changed.

Actigraphy is commonly used as objective sleep measure in sleep research in older adults with dementia, however, the validity and reliability of actigraphy in this population are rarely reported. It is considered as an indirect sleep measure because the data is derived from movement rather than directly from brain physiology (David et al., 2010). Due to the decreased

movement and physical activity, actigraphy may overestimate sleep in older adults. One previous study reported that various modes of actigraphy systematically overestimated sleep in a population of community-dwelling older women compared to polysomnography (Blackwell et al., 2008). Some studies set up the nocturnal period in the software using caregiver recorded bedtime and rise time of older adults with dementia (Martin, Marler, Harker, Josephson, & Alessi, 2007; Richards et al., 2005). This method is more accurate than the software's automatic scoring of sleep and wake time (David et al., 2010). In this study, we did not have records of participants' bedtimes and risetimes. Nighttime was defined from 8pm-8am and daytime from 8am-8pm. The sleep and wake score were then extracted from participants' actigraphy by computer algorithms.

This pilot study had some limitations most of which are due to the larger study being conducted for feasibility and development of the intervention and not being powered for efficacy. The nesting of treatment group within facilities leads increased the risk for type I error. The small sample size exaggerates the deviation scores, decreases statistical power, and yields a greater potential for type II error. The unbalanced sample size magnifies the potential differences between two groups. Increased sample size would reinforce the findings and provide stronger evidence for the benefits of PCDC on sleep in long term residents with dementia and encourage long term care clinicians to provide PCDC. Second is the intervention fidelity. The intervention was extremely time intensive requiring the commitment and engagement of the staff. However, changing practice is not easy to achieve. The whole unit culture and approach must change in order to prevent/minimize the likelihood of a return to conventional behaviors over time. This intervention was delivered by the unit direct care staff after PCDC training and it is very likely that there would be some variation among staff member in terms of the magnitude of mastering

the knowledge and applying the knowledge in clinical practice. In addition, dementia care mapping was used to tailor the intervention; therefore, the mappers in this study were not blinded to the group assignment. As a result, the level of social engagement measured from dementia care mapping in this study might be susceptible to bias. Finally, actigraphy may have a low specificity in detecting wakefulness (Sadeh, 2011); therefore, the sleep time reported in this study might be overestimated and reflect participants' inactivity. Also, to fit within the limitations of a larger study in which this study was nested, actigraphy data were collected for three consecutive days which may not accurately capture the day to day variability of sleep. Extending length of actigraphy data collection and trying to keep a record of participants' bed schedule will ease these issues.

Conclusion

Sleep is important for health and well-being and this is no different for someone living in long term care. Older adults, and particularly those with dementia, often experience disrupted sleep, including difficulty reaching deep sleep. Poor sleep has been associated with an increase in distressing behaviors, such as pacing, agitation, aggression and depression. The findings of this pilot study suggest that PCDC may be beneficial for sleep in residents with dementia in terms of decreasing daytime sleep through providing individualized care, engaging them personally through communication and providing meaningful physical and social activities. PCDC may provide the caregivers in long term care a way to manage sleep disturbance in residents with dementia and may potentially decrease behavioral disturbance. More rigorous research with larger samples in multiple long term care settings is needed to further test the hypothesis that person-centered dementia care improves sleep for the resident with dementia.

References

- Alessi, C. A., Martin, J. L., Webber, A. P., Cynthia Kim, E., Harker, J. O., & Josephson, K. R. (2005). Randomized, Controlled Trial of a Nonpharmacological Intervention to Improve Abnormal Sleep/Wake Patterns in Nursing Home Residents. *Journal of the American Geriatrics Society*, 53(5), 803-810. doi: 10.1111/j.1532-5415.2005.53251.x
- Ancoli-Israel, S., Parker, L., Sinaee, R., Fell, R. L., & Kripke, D. F. (1989). Sleep fragmentation in patients from a nursing home. *Journal of Gerontology*, 44(1), M18-21.
- Ancoli-Israel, S., & Ayalon, L. (2006). Diagnosis and treatment of sleep disorders in older adults. *American Journal of Geriatric Psychiatry*, 14(2), 95-103.
- Ancoli-Israel, S., Ayalon, L., & Salzman, C. (2008). Sleep in the elderly: normal variations and common sleep disorders. *Harvard review of psychiatry*, 16(5), 279-286.
- Ancoli-Israel, S., Cole, R., Alessi, C., Chambers, M., Moorcroft, W., & Pollak, C. (2003). The role of actigraphy in the study of sleep and circadian rhythms. *Sleep*, 26(3), 342-392.
- Ancoli-Israel, S., Klauber, M. R., Jones, D. W., Kripke, D. F., Martin, J., Mason, W., . . . & Fell, R. (1997). Variations in circadian rhythms of activity, sleep, and light exposure related to dementia in nursing-home patients. *Sleep*, 20(1), 18.
- Ancoli-Israel, S., Martin, J. L., Kripke, D. F., Marler, M., & Klauber, M. R. (2002). Effect of light treatment on sleep and circadian rhythms in demented nursing home patients. *Journal of the American Geriatrics Society*, 50(2), 282-289.
- Blackwell, T., Redline, S., Ancoli-Israel, S., Schneider, J. L., Surovec, S., Johnson, N. L., . . . for the Study of Osteoporotic Fractures Research Group. (2008). Comparison of Sleep Parameters from Actigraphy and Polysomnography in Older Women: The SOF Study. *Sleep*, 31(2), 283-291.

- Brooker, D. (2007). *Person-centred dementia care: making services better*: Jessica Kingsley Pub.
- Brooker, D., & Surr, C. (2005). *Dementia care mapping: Principles and practice*. Bradford: University of Bradford.
- Buysse, D. J., Ancoli-Israel, S., Edinger, J. D., Lichstein, K. L., & Morin, C. M. (2006). Recommendations for a standard research assessment of insomnia. *Sleep*, 29(9), 1155-1173.
- Chesson Jr, M. D., Coleman, M. D., Lee-Chiong, M. D., & Pancer, D. D. S. (2007). Practice parameters for the use of actigraphy in the assessment of sleep and sleep disorders: an update for 2007. *Sleep*, 30(4), 519.
- Chang, Y. P., Li, J., & Porock, D. (2013). The effect on nursing home resident outcomes of creating a household within a traditional structure. *Journal of the American Medical Directors Association*, 14(4), 293-299. doi: 10.1016/j.jamda.2013.01.013
- Chen, K. M., Chen, M. H., Lin, M. H., Fan, J. T., Lin, H. S., & Li, C. H. (2010). Effects of yoga on sleep quality and depression in elders in assisted living facilities. *Journal of Nursing Research*, 18(1), 53-61.
- Cole, C., & Richards, K. (2007). Sleep disruption in older adults: Harmful and by no means inevitable, it should be assessed for and treated. *The American Journal of Nursing*, 107(5), 40.
- Fetveit A., & Bjorvatn, B. (2005). Bright-light treatment reduces actigraphic-measured daytime sleep in nursing home. *American Journal of Geriatric Psychiatry*, 13(5), 420-423.
- Foley, D., Ancoli-Israel, S., Britz, P., & Walsh, J. (2004). Sleep disturbances and chronic disease in older adults: results of the 2003 National Sleep Foundation Sleep in America Survey. *Journal of psychosomatic research*, 56(5), 497-502.

- Fossey, J., Ballard, C., Juszczak, E., James, I., Alder, N., Jacoby, R., & Howard, R. (2006). Effect of enhanced psychosocial care on antipsychotic use in nursing home residents with severe dementia: cluster randomised trial. *BMJ: British Medical Journal (International Edition)*, 332(7544), 756-758. doi: 10.1136/bmj.38782.575868.7C
- Gaugler, J. E., Yu, F., Krichbaum, K., & Wyman, J. F. (2009). Predictors of nursing home admission for persons with dementia. *Medical Care*, 47(2), 191-198. doi: 10.1097/MLR.0b013e31818457ce
- Kitwood, T. (1997). *Dementia reconsidered: The person comes first*: Philadelphia.
- Li, J., & Porock, D. (2014). Resident Outcomes of Person-Centered Care in Long-Term Care: A narrative review of interventional research. *International Journal of Nursing Studies*, 51(10):1395-415. doi: 10.1016/j.ijnurstu.2014.04.003.
- Lorenz, R. A. (2011). Sleep in adult long-term care. In Redeker, N. S., & McEnany, G. P.(Eds.), *Sleep disorders and sleep promotion in nursing practice*. New York: Springer Publishing Company.
- Martin, J. L., & Ancoli-Israel, S. (2008). Sleep disturbances in long-term care. *Clinics in Geriatric Medicine*, 24(1), 39-50, vi. doi: 10.1016/j.cger.2007.08.001
- Martin, J. L., Fiorentino, L., Jouldjian, S., Josephson, K. R., & Alessi, C. A. (2010). Sleep quality in residents of assisted living facilities: effect on quality of life, functional status, and depression. *Journal of the American Geriatrics Society*, 58(5), 829-836.
- Martin, J. L., Marler, M. R., Harker, J. O., Josephson, K. R., & Alessi, C. A. (2007). A multicomponent nonpharmacological intervention improves activity rhythms among nursing home residents with disrupted sleep/wake patterns. *The Journals of Gerontology*:

- Series A: Biological Sciences and Medical Sciences, 62A(1), 67-72. doi:
10.1093/gerona/62.1.67
- Matthews, E. A., Farrell, G. A., & Blackmore, A. M. (1996). Effects of an environmental manipulation emphasizing client-centred care on agitation and sleep in dementia sufferers in a nursing home. *Journal of advanced Nursing*, 24(3), 439-447. doi: 10.1046/j.1365-2648.1996.02102.x
- Miller, M., & Towers, A. (1991). A manual of guidelines for scoring the Cumulative Illness Rating Scale for Geriatrics (CIRS-G). Pittsburgh, PA: University of Pittsburgh.
- Naylor, E., Penev, P. D., Orbeta, L., Janssen, I., Ortiz, R., Colecchia, E. F., . . . Zee, P. C. (2000). Daily social and physical activity increases slow-wave sleep and daytime neuropsychological performance in the elderly. *Sleep*, 23(1), 87-95.
- Neikrug A.B., & Ancoli-Israel, S. (2010). Sleep disturbances in nursing homes. *Journal of Nutrition, Health & Aging*, 14(3), 207-211.
- Noell-Waggoner, E. (2006). Lighting in nursing homes—The unmet need. Paper presented at the Proceedings of the 2nd CIE Expert Symposium Lighting and Health, International Commission on Illumination Publication.
- Ouslander, J. G., Connell, B. R., Bliwise, D. L., Endeshaw, Y., Griffiths, P., & Schnelle, J. F. (2006). A Nonpharmacological Intervention to Improve Sleep in Nursing Home Patients: Results of a Controlled Clinical Trial. *Journal of the American Geriatrics Society*, 54(1), 38-47. doi: 10.1111/j.1532-5415.2005.00562.x
- Parmelee, P. A., Thuras, P. D., Katz, I. R., & Lawton, M. P. (1995). Validation of the Cumulative Illness Rating Scale in a geriatric residential population. *Journal of the American Geriatrics Society*, 43(2):130-7.

- Porock, D., Li, J. Chang, Y-P. (2014). Salivary cortisol, depression, agitation, and quality of life in residents with dementia Gerontological Society of America 67th Annual Scientific Meeting. Washington, DC. November 2014. Poster presentation.
- Richards, K. C., Beck, C., O'Sullivan, P. S., & Shue, V. M. (2005). Effect of individualized social activity on sleep in nursing home residents with dementia. *Journal of the American Geriatrics Society*, 53(9), 1510-1517.
- Richards, K. C., Lambert, C., Beck, C. K., Bliwise, D. L., Evans, W. J., Kalra, G. K., . . . & Sullivan, D. H. (2011). Strength training, walking, and social activity improve sleep in nursing home and assisted living residents: Randomized controlled trial. *Journal of the American Geriatrics Society*., 59(2), 214-223. doi: 10.1111/j.1532-5415.2010.03246.x
- Roehrs, T., & Roth, T. (2005). Sleep and pain: Interaction of two vital functions. Paper presented at the Seminars in Neurology.
- Rose, K. M., & Lorenz, R. (2010). Sleep disturbances in dementia: what they are and what to do. *Journal of Gerontological Nursing*, 36(5), 9.
- Sadeh, A. (2011). The role and validity of actigraphy in sleep medicine: an update. *Sleep Medicine Reviews*, 15 (4), 259-67.
- Saliba, D., Buchanan, J., Edelen, M. O., Streim, J., Ouslander, J., Berlowitz, D., & Chodosh, J. (2012). MDS 3.0: brief interview for mental status. *Journal of the American Medical Directors Association*, 13(7), 611-617. doi: 10.1016/j.jamda.2012.06.004.
- Salvi, F., Miller, M. D., Grilli, A., Giorgi, R., Towers, A. L., Morichi, V., ... & Dessì- Fulgheri, P. (2008). A manual of guidelines to score the modified cumulative illness rating scale and its validation in acute hospitalized elderly patients. *Journal of the American Geriatrics Society*, 56(10), 1926-1931.

Shochat, T., Martin, J., Marler, M., & Ancoli-Israel, S. (2000). Illumination levels in nursing home patients: effects on sleep and activity rhythms. *Journal of Sleep Research*, 9(4), 373-379.

Song, Y., Dowling, G. A., Wallhagen, M. I., Lee, K. A., & Strawbridge, W. J. (2010). Sleep in older adults with Alzheimer's disease. *Journal of Neuroscience Nursing*, 42(4), 190-198.

Vitiello, M. V., & Borson, S. (2001). Sleep disturbances in patients with Alzheimer's disease. *CNS Drugs*, 15(10), 777-796.

Zwakhalen, S. M., Hamers, J. P., Abu-Saad, H. H., & Berger, M. P. (2006). Pain in elderly people with severe dementia: a systematic review of behavioural pain assessment tools. *BMC geriatrics*, 6(1),

Acknowledgements

We thank Rhonda Rotterman, Bob Gaughan, Bonnie Patrick, Brenda Genewick, and Diane Braun from the UB Institute for Person-Center Care for their help in data collection.

This study was supported by Shirley D. DeVoe Nursing Research Support Fund and Sigma Theta Tau Gamma Kappa Chapter