Pilot Study of a Brief Behavioral Sleep Intervention for Caregivers of Individuals with Dementia

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ABSTRACT

Informal caregivers of individuals with dementia experience higher rates of poor sleep quality and depression than the general population. Short-term behavioral interventions have been shown to improve sleep quality in other caregiver populations. The purposes of this study were to determine the feasibility of the CAregiver Sleep Intervention (CASI) in a small sample of caregivers of both community-dwelling and institutionalized individuals with dementia. The caregivers were given CASI, a 5-week behavioral sleep intervention combining relaxation, stimulus control, and sleep hygiene with personal goal setting, delivered at the caregiver’s convenience. Caregivers reported no increased burden with CASI. The intervention was well received, and sleep quality and depression trended toward improvement. CASI appears to be feasible and beneficial in this small sample and warrants further study in caregivers of individuals with dementia.

In the United States, more than 8 million informal caregivers provide care for a person age 50 and older with dementia (Family Caregiver Alliance, 2005). Prevalence estimates using the 2000 census projected a three-fold increase to 13.2 million people with Alzheimer’s disease (AD) (the leading cause of dementia) by 2050, with the greatest growth in the oldest age groups. The rapid growth of the population age 85 and older will result in a quadrupling of people with AD to 8 million by 2050 for that age group alone (Hebert, Scherr, Bienias, Bennett, & Evans, 2003).

As the aging population increases, the number of people with dementia will continue to grow, as will the demand for informal caregiving. Informal caregivers are currently and will continue to be the largest resource for long-term care (U.S. Department of Health and Human Services, 2003). The caregiving role does not come without consequences; it can extend over many years and has been described as a stressful career (Lindgren, 1993; Merrill, 1997; Skaff, Pearl-in, & Mullan, 1996).

Pearlin, Mullan, Semple, and Skaff (1990) presented a conceptual model of caregiver stress, depicting primary
stressors leading to secondary stressors, resulting in negative health outcomes. Research has supported the Caregiver Stress model, reporting that exposure to the continued stress of caregiving for individuals with dementia can result in depression and physical health decline among caregivers (Acton, 2002; Rose-Rego, Strauss, & Smyth, 1998; Schulz & Martire, 2004). Lack of quality sleep has also been correlated with negative cognitive and physical health outcomes (Dinges, Rogers, & Baynard, 2005). Caregivers of people with dementia experience a decrease in both perceived sleep quality and actual hours of sleep time (McKibbin et al., 2005; Wilcox & King, 1999). The Caregiver Stress model depicts mediators that buffer stress for the individual, thus reducing the negative outcomes. Improving sleep quality could be a potential mechanism for reducing the negative health outcomes experienced by caregivers of individuals with dementia.

LITERATURE REVIEW

Caregiver Sleep Quality

Poor sleep quality is a consequence of caregiving. At high levels of care, 51% of informal caregivers of individuals with dementia experience insomnia, which includes difficulty falling asleep, difficulty maintaining sleep, or arising too early (National Family Caregivers Association, 1998). Caregivers living with someone with dementia report the greatest amount of stress results from nocturnal awakening of themselves and other family members by the person with dementia (McCurry et al., 1999). The caregiver’s sleep quality is influenced by many factors, only one of which is the behavior of the person with dementia. In addition, caregivers report difficulty falling asleep, nocturia, and fragmented sleep as common disruptions (Wilcox & King, 1999). Long-term care placement does not mean the end of caregiving. The caregiving career continues through the transition to institutionalization and involves emotions such as loss of control, guilt, sadness, and sometimes relief (Kellett, 1999; Seltzer & Li, 2000). These feelings and worries can cause sleep disruption, and for the spousal caregiver, institutionalization means the loss of a life partner and bed partner, which can be disruptive to sleep.

Poor sleep quality results in complaints of impaired daytime and social functioning, decreased concentration and memory, and excessive daytime sleepiness (Semler & Harvey, 2005). Negative emotional outcomes of poor sleep quality have been studied in both caregiver and non-caregiver samples, with similar results. Both populations report increased anxiety and depressive symptoms and decreased quality of life as a result of their poor sleep quality (Carter & Chang, 2000; McCurry, Logsdon, & Teri, 1996, Riedel & Lichstein, 2000; Wilcox & King, 1999). Restorative sleep is necessary for emotional, mental, and physical well-being.

Caregiver Depression and Sleep Quality

Depression is strongly associated with caregiving stress as an outcome of the stress process (Pearlin et al., 1990). Approximately 8.2% of the general population older than age 18 experiences depressive symptoms, whereas 46% to 59% of caregivers report these symptoms (National Family Caregivers Association, 1998; National Institute of Mental Health, 2008). The relationship between depression and sleep quality has not been extensively researched in caregivers of individuals with dementia, but data exist. Wilcox and King (1999) examined sleep complaints using the Pittsburgh Sleep Quality Index (PSQI) and compared the scores with reference groups of healthy adults, sleep-impaired older women, and men and women with depressive disorders (i.e., major depression, dysthymia). The sleep scores of the 90 female caregivers studied were not similar to age-matched controls but rather were similar to older individuals with insomnia and people with depressive disorders (Wilcox & King, 1999).

Creese, Bédard, Brazil, and Chambers (2008) used a modified version the PSQI and found sleep quality, change in sleep quality over the past year, and nocturnal disruptions significantly correlated to depressive symptoms and overall mental health in 60 spousal caregivers of individuals with AD. Increased depressive symptom scores have been significantly correlated to objective measures of decreased sleep quality, such as longer sleep latency (time it takes to fall asleep) and number of awakenings after sleep is initiated (Rowe, McCrae, Campbell, Benito, & Cheng, 2008). These studies support the idea that poor subjective and objective sleep quality are associated with depressive symptoms in caregivers of individuals with dementia.

Sleep Interventions for Caregivers of Individuals with Dementia

Research testing the efficacy of sleep interventions on sleep quality and the impact of improved sleep quality on caregiver depression is limited. McCurry et al. (1996) conducted a small study with 4 spousal caregivers of individuals with dementia, and 1 caregiver showed a significant reduction in depression as sleep quality improved after participating in a 6-week group intervention. McCurry, Logsdon, Vitiello, and Teri (1998) replicated the intervention in a study with 20 caregivers. The behavioral intervention consisted of a combination of sleep hygiene, stimulus control, sleep compression, and relaxation techniques.
Education related to dementia, such as behavior management skills for use with the person with dementia and ways to cope with caregiver stress, were also included. Seven caregivers participated in the active intervention formatted in a 6-week group setting, while a second phase of the study provided one-on-one intervention for 12 caregivers over 4 weeks. Changes in intervention length and format were made because of participant feedback. The change increased accessibility for the participants and facilitated recruitment. In both groups, participants’ subjective sleep quality significantly improved and depression scores trended in the expected direction, reflecting a decrease; however, the findings were not statistically significant.

Behavioral sleep interventions have been successful in other caregiver populations. Carter (2006) found that small behavioral changes were effective in decreasing poor sleep quality and depressive symptoms in family caregivers of individuals with advanced cancer. The Caregiver Sleep Intervention (CASI) incorporates stimulus control, relaxation therapies, cognitive therapy, and sleep hygiene education with goal attainment scaling for behavioral goals set by the participant. In a sample of 15 family caregivers of a person with cancer, both global PSQI scores and depression scores decreased but were not statistically significant from the baseline scores until the third month of follow up, when global PSQI scores improved significantly.

These studies highlight that brief behavioral interventions for sleep can benefit sleep quality. However, further research is needed to develop this area of sleep research. No study was identified that addressed the sleep quality or sleep experience of caregivers of institutionalized individuals with dementia. Family members of institutionalized individuals with dementia continue to identify themselves as caregivers, are actively involved in the care of their loved one, and are not immune to the stress of caregiving. Supporting and promoting the health of caregivers of both community-dwelling and institutionalized individuals with dementia means exploring the format and delivery of the intervention to maximize the benefits for caregivers. Therefore, the questions are whether CASI will be effective in improving the sleep quality of caregivers of both community-dwelling and institutionalized individuals with dementia and whether improvements in sleep quality will be correlated to improvements in depressive symptoms if found in this population.

PURPOSE

The purposes of this pilot study were to determine the feasibility and efficacy of CASI in a population of informal caregivers of both community-dwelling and institutionalized individuals with dementia and to explore the impact of CASI on caregivers’ sleep quality and depression, as well as examine the relationship of sleep quality and depression in this caregiver sample. The significance of the knowledge gained will direct further research on how to best support informal caregivers of both community-dwelling and institutionalized individuals with dementia.

METHOD

Design and Sample

A 5-week, quasi-experimental, repeated measures design was used to explore the feasibility and efficacy of the CASI sleep intervention in a population of caregivers of individuals with dementia. Baseline data were collected at Week 1. The CASI intervention was delivered at Week 2, with a booster presentation done at Week 4. Follow-up data were collected at Week 3 (1 week after initial exposure to CASI) and Week 5 (3 weeks after initial exposure and 1 week after booster) to assess the impact of the intervention. At the final meeting, the caregivers’ experience with CASI was explored with open-ended questions about the process, content, and formats.

To be included in the study, caregivers were required to be older than age 21 and caring for a person with dementia who was living either at home or in assisted living (community dwelling) or residing in a local long-term care institution (institutionalized). Caregivers were excluded from the study if they were currently being treated or had been treated for a sleep disorder other than insomnia (e.g., restless legs syndrome, sleep apnea) or if they had been diagnosed with depression by a health professional or described experiencing symptoms of depression before the onset of caregiving. Caregivers were not excluded for experiencing symptoms of depression related to caregiving.

Ten caregivers living in the Austin, Texas, metropolitan area were recruited for this pilot study. The sample was recruited from a population of dementia patients serviced by a geriatric psychiatric practice that sees patients both in an outpatient clinic setting and within institutions. Potential participants were identified by the health care practitioners during the course of patient interactions and family communication.

The sample was predominantly women. Five caregivers were caring for their loved one at home, and 5 had placed their loved one in a long-term care institution. The caregivers of community-dwelling individuals with dementia consisted of 3 spouses and 2 adult children. The caregivers of institutionalized individuals with dementia consisted of
3 adult children and 2 spouses. Regarding race/ethnicity, 6 caregivers were not Hispanic or Latino/White, 2 were Hispanic/White, and 2 were not Hispanic or Latino/Black. Table 1 contains additional demographic and contextual information.

**Instruments**

**Demographic and Contextual Data.** An investigator-developed questionnaire was used to collect demographic data (i.e., age, gender, ethnicity, religion, education, income) and caregiver health status (i.e., self-reported illnesses and overall health ratings were rated on a scale of 1 = excellent to 5 = very poor). Other caregiver contextual information included identifying the relationship of the caregiver to the individual with dementia and capturing the total roles besides caregiving they experienced. Caregivers were asked to respond yes or no to whether they participated in caring for children in the home, employment, volunteering, or “other,” with an opportunity to describe that role. The total number of roles was recorded. The quality of the caregiver’s relationship (past and present) with the individual with dementia was captured by asking the caregiver to describe the relationship on a scale from 1 (conflict ridden) to 5 (harmonious).

Information about the individual with dementia from the caregiver’s perspective was also gathered. Caregivers were asked to respond yes or no to whether they had to help their loved one perform basic activities of daily living such as toileting, bathing, and eating during the past month. If yes, they were asked how often per day or per week. Caregivers were asked how many hours of the day they spend caring for their loved one. They were also asked to respond yes or no to whether the individual with dementia had experienced problematic behaviors, such as agitation, hallucinations, wandering, incontinence, sleeplessness/sundowning, or combativeness, during the past month. Total length of time caregiving and length of institutionalization, when appropriate, were also collected. For the community-dwelling individuals with dementia, caregiver sleeping arrangements were noted.

**Caregiver Sleep Quality.** Caregiver sleep quality was measured subjectively with the PSQI and objectively with the Motionlogger® actigraph (Ambulatory Monitoring, Inc., Ardsley, NY). The PSQI is a 19-item questionnaire that provides a global sleep quality score and seven subscale scores that include sleep quality, sleep latency (time needed to fall asleep after lights out), sleep duration (number of hours slept), sleep medication use, sleep efficiency (time asleep divided by time in bed multiplied by 100), sleep disturbances, and daytime dysfunction. A global score greater than 5 indicates poor sleep quality with a diagnostic sensitivity of 89.6% and specificity of 86.5% (Buysse, Reynolds, Monk, Berman, & Kupfer, 1989). Reliability scores, using Cronbach’s alpha coefficient, range from 0.83 to 0.89 in healthy people, chronically ill individuals, and family caregivers (Buysse et al., 1989; Carpenter & Andrykowski, 1998; Carter & Chang, 2000). Construct validity scores (r) range from 0.69 to 0.77 when correlated to related constructs, such as the sleep problem questions from the Symptom Experience Report or the restless sleep question from the Center for Epidemiological Studies Depression scale (Carpenter & Andrykowski, 1998).

Actigraphy is a reliable and valid method for detecting sleep in normal, healthy adult populations (Littner et al., 2003), with validation studies demonstrating strong correlations between actigraphic measures of sleep variables compared with polysomnographic measures (Jean-Louis, Kripke, Cole, Assmus, & Langer, 2001). The Motionlogger actigraph is a small, lightweight, portable accelerometer that is worn on the wrist of the dominant hand and records intensity and frequency of movement. Seventy-two hours is the recommended time frame for data collection to obtain an accurate assessment of sleep patterns (Ancoli-Israel et al., 2003).

Caregivers in this study wore the actigraph for 72 hours at baseline, Week 3, and Week 5. They also maintained a sleep log for the same 72 hours, recording their time to bed, time out of bed for the last time, number and kinds of disturbances, overall sleep quality, and daytime energy level. Caregivers also indicated nap times and any removal of the actigraph. The sleep logs were used to prepare the raw actigraph data for analysis by trimming the data to the period of interest, indicating down times (time in bed),

### Table 1

<table>
<thead>
<tr>
<th>Variable</th>
<th>Range</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>40 to 85</td>
<td>63 (14.85)</td>
</tr>
<tr>
<td>Education (years)</td>
<td>4 to 22</td>
<td>14.67 (6.37)</td>
</tr>
<tr>
<td>Subjective health rating&lt;sup&gt;a&lt;/sup&gt;</td>
<td>1 to 4</td>
<td>1.9 (0.99)</td>
</tr>
<tr>
<td>Number of other roles&lt;sup&gt;b&lt;/sup&gt;</td>
<td>0 to 3</td>
<td>1.4 (1.1)</td>
</tr>
<tr>
<td>Time spent caregiving (years)</td>
<td>1.5 to 14</td>
<td>6.25 (4.09)</td>
</tr>
</tbody>
</table>

<sup>a</sup> Rated on a scale of 1 (excellent) to 5 (very poor).

<sup>b</sup> Other roles included working, caring for children, and volunteering.
nap periods, and times when the actigraph was removed. Action 4 software, version 2.4 uses a sleep algorithm to interpret the Motionlogger data and calculates sleep latency, duration, efficiency, and wake after sleep onset.

Caregiver Depression. Caregiver depression was measured using the Quick Inventory of Depressive Symptomatology (QIDS) Clinician Rating tool. The QIDS is derived from the Inventory of Depressive Symptomatology (IDS-R) and contains 16 items rating the severity of symptoms of major depression. Each item is rated by severity from no problem (0) to severe (3), with a total possible score of 27. Scores of 5 or less are considered normal, scores of 6 to 10 indicate mild symptoms, 11 to 15 moderate symptoms, 16 to 20 severe symptoms, and 21 or greater very severe symptoms. Cronbach’s alpha coefficients range from 0.81 to 0.94, and total scores are highly correlated with the IDS-R (0.96) and the Hamilton Rating Scale for Depression (0.86) (Rush et al., 2003; Trivedi et al., 2004). The QIDS has been used to measure depressive symptoms in the general population (Kessler et al., 2003).

Procedure

Following approval by the University Institutional Review Board, advanced practice nurses (APNs) working with the geriatric patients identified potential participants and initially inquired about the caregiver’s interest in participation. If the caregiver agreed, his or her contact information was provided to the investigator. In the initial telephone interview, the investigator explained the research study, qualified the caregiver (i.e., probed for history of sleep disorders and experience of depressive symptoms), and obtained verbal consent to participate. All meetings were conducted at a time and place of the caregiver’s choosing, usually the caregiver’s home. Two caregivers found it more convenient to meet at the long-term care facility where their loved one resided.

During the initial meeting, the consent was reviewed and signed, demographic questionnaires were completed, and baseline data were gathered using the PSQI and QIDS. The actigraph was placed on the caregiver’s wrist, and the investigator provided verbal and written instructions about
the actigraph and how to complete the sleep log. Follow-up measurements of sleep quality (PSQI, actigraphy), and depression (QIDS) were gathered at Weeks 3 and 5.

Sleep Intervention

On Week 2, the caregivers were instructed in the CASI by the investigator, a master’s-prepared nurse. The sessions lasted 60 to 90 minutes. The original CASI, developed by Dr. Patricia Carter, is a combination of education and personal goal setting tailored to each caregiver’s identified sleep problems (Carter, 2006). Education on cognitive therapy, sleep hygiene, stimulus control, and relaxation elements was provided in both verbal and written formats. Caregivers were guided in creating measurable goals in behavioral changes that addressed the etiology of their poor sleep quality in the areas of environment, stimulus control, daily routine, and relaxation. Assessment was done by goal attainment scaling. An example of a goal for daily routine would be to exercise for 20 minutes 4 of 7 days per week. An example of relaxation would be to practice deep breathing exercises 5 of 7 days per week. Figure 1 provides an example of a goal worksheet.

In Week 4, a CASI booster session was administered, during which the content was reviewed and any barriers to current goals and experiences regarding the behavioral changes were discussed. Attainment of behavioral change goals was rated, and goals were adjusted if necessary. An adjustment might mean decreasing the frequency per week or changing the behavior to be modified. Attainment of sleep goals was assessed at Weeks 3 and 5.

The caregivers’ experience with CASI was assessed in the final interview at Week 5, following the last wearing of the actigraph. Caregivers were asked open-ended questions about the intervention process, content, and formats. The investigator documented notes after each meeting regarding the caregiver’s reaction to the measurement instruments, feelings about the intervention, and any noteworthy events described by caregivers (e.g., changes in the health of their loved one).

Data Analysis

The main focus of this study was the feasibility and efficacy of the CASI in this population of caregivers. Feasibility—issues of recruitment and retention, instrument use, and intervention administration—was assessed by exploring content from the investigator notes and final caregiver interviews. A secondary focus of this study was to explore the impact of the CASI on caregiver sleep quality and depression for the group of caregivers as a whole and then as subgroups. Data conformed to normal distribution, and paired t tests were used to assess improvements within the groups. A change score (baseline scores – Week 5 scores) was calculated, and an independent sample t test was used to provide a between-group comparison. The relationship between the variables of sleep quality and depression at baseline and at Week 5 was explored using Pearson’s correlations. Descriptive statistics (e.g., mean, standard deviation, frequency, percentage) were calculated for variables of interest to describe the experience of this sample. All statistical calculations were performed with SPSS version 15.

RESULTS

Caregiving Experience

Caregivers of community-dwelling individuals with dementia spent an average of 22.8 hours per day (SD = 2.68) with the person with dementia, whereas the caregivers of institutionalized individuals with dementia visited an average of 3.6 times per week (SD = 1.94). As a group, the caregivers had 1.4 (SD = 1) other roles besides caregiving; however, the subgroup of caregivers of institutionalized loved ones had an average of 2 (SD = 0.70) other roles, and caregivers of community-dwelling individuals with dementia had 0.8 (SD = 1.1) other roles.

The caregivers described the individuals with dementia as having an average of three behavioral symptoms, with incontinence, agitation, and sleeplessness reported most frequently. Seven (70%) of the individuals with dementia needed assistance with all basic activities of daily living 7 days per week. Six (60%) of the caregivers of community-dwelling individuals with dementia reported having to help their loved one at night one or more times per week. Of the 3 spousal caregivers of community-dwelling individuals with dementia, 2 still shared a bed with their spouse, but 1 had changed sleeping arrangements because the wife no longer recognized the caregiver as her husband.

Feasibility of CASI

The major purpose of this pilot study was to assess the feasibility of using the CASI in a population of informal caregivers of individuals with dementia. The areas assessed included recruitment and retention, instrument use, and intervention administration.

Recruitment and Retention. The APNs were able to easily identify 11 potential caregivers from their population of patients with dementia. Most caregivers were enthusiastic about participating, and 2 agreed to participate because the APN had recommended the sleep information. Of the 11 caregivers identified, 10 met the inclusion criteria; 1 was excluded be-
cause of a pre-existing diagnosis of sleep apnea. The 10 caregivers who consented to participate remained in the study for the full 5 weeks. Their comments about the process were favorable, such as “I appreciate being in the study but I could only do it because you came to my home. I can’t always go places.”

*Instrument Use.* The self-report instruments (PSQI, QIDS) were easy to administer in this population. The caregivers had quick comprehension of the questions and expressed no discomfort in answering. Data were not missing from these instruments because they were verbally administered to the caregivers. The actigraph performed well, with only one incident of lost data due to battery failure. In general, the caregivers found the actigraph easy to wear, with the exception of one caregiver with fragile skin feeling some discomfort. Skin irritation was resolved with a terry cloth wristband applied between the skin and actigraph. In debriefing, the caregivers stated that the forms, and particularly the sleep log, were easy to use.

*Intervention Administration.* Assessment of CASI as a behavioral intervention suitable for this population focused on caregivers’ openness to the content, ability to recognize their current behaviors that decreased sleep quality on the basis of the information provided, and willingness to perform activities to improve their sleep quality. All caregivers said the material was easy to comprehend and follow. Most caregivers found the sleep hygiene information to be new. One caregiver stated, “I had no idea there was so much to know about sleep. I just thought it was.”

Tailoring the intervention goal setting allowed caregivers to set realistic and achievable goals. Seven (70%) caregivers were able to identify three or four goals to work on to improve their sleep. In the category of improving environment, the most common (4 of 8 caregivers) goal was to use the bed only for sleep (or sex) and to watch television or read before bed in another location. The second most common (3 of 8 caregivers) goal was to turn the clock around to avoid watching the time during the night if awake or to avoid being disturbed by the light generated. Creating a daily routine to help prepare for sleep at night had caregivers setting goals of adding light exercise to their day, creating lists of things to be done, and building in time for relaxation (e.g., taking a warm bath, reading). Some caregivers had issues with stimulants and elected to decrease their caffeine intake late in the day or to decrease smoking before bedtime. Goals for relaxation involved deep breathing exercises, meditation, and listening to music. Seven of the caregivers met or exceeded 50% of their goals. Four caregivers met or exceeded 100% of their goals, 2 met or exceeded 75%, and 1 met or exceeded 66%. Figure 2 offers an example of how goals were assessed.

### Sleep and Depression: The Impact of CASI

As a group, the caregivers reported moderately poor global sleep scores and borderline normal depression scores at baseline. Although no statistical difference was found between the two groups’ sleep quality or depressive symptom scores at baseline, caregivers of community-dwelling individuals with dementia reported higher scores on both the PSQI and QIDS, representing worse sleep quality and more depressive symptoms than caregivers of institutionalized individuals.
individuals. At Week 5, both groups of caregivers reported lower scores on both the PSQI and QIDS, indicating improvement in both sleep quality and depressive symptoms (Table 2). The improvement in scores was not statistically significant within the groups (Table 3). A between-group comparison did not indicate a significant difference in the change in sleep scores or depressive symptom scores between the two subgroups of caregivers (Table 4).

The PSQI reflects the subjective perception of sleep, and in this sample, the average number of sleep hours reported was 6.15 (SD = 1.65). Objectively, actigraph measurements of recorded sleep time averaged 1 hour more than the subjective report. The objective sleep measurements did not show an improvement over time in this sample. Overall, the caregivers of institutionalized individuals demonstrated a better sleep percentage, shorter sleep latency, and fewer minutes spent awake after sleep onset than caregivers of community-dwelling individuals (Table 2).

Seven caregivers were able to meet or exceed more than 50% of the goals they established. For these 7 caregivers, their global sleep scores decreased from a mean score of 6.00 (SD = 3.56) to a mean score of 3.71 (SD = 1.7). The trend was positive, but the difference was not statistically significant (t = 1.753, p = 0.13). For this group, their depressive symptom scores decreased from a mean score of 3.57 (SD = 2.23) to a mean score of 2.43 (SD = 1.62) at Week 5. This change was statistically significant (t = 2.50, p = 0.05), but clinically, both scores fall within the normal range.

Finally, the relationship of sleep scores to depressive symptom scores were considered for the entire group and the two subgroups at baseline and after exposure to CASI. The correlation between sleep quality scores and depressive symptom scores were statistically significant at baseline (r = 0.71, p = 0.02) and at Week 5 (r = 0.910, p < 0.001) for the entire group. For the caregivers of community-dwelling individuals, the correlation of sleep scores to depressive symptoms was not statistically significant at baseline (r = 0.84, p = 0.07) but was significant at Week 5 (r = 0.95, p = 0.02). The relationship of sleep quality scores and

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**Table 3**

Within-Group Comparison of Sleep Quality and Depressive Symptoms for Caregivers of Individuals with Dementia

<table>
<thead>
<tr>
<th>Variable by Group</th>
<th>Baseline</th>
<th>Week 5</th>
<th>t Score</th>
<th>p Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sleep quality (PSQI)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregivers of community-dwelling individuals with dementia</td>
<td>10.40 (5.94)</td>
<td>7.0 (4.74)</td>
<td>1.21</td>
<td>0.29</td>
</tr>
<tr>
<td>Caregivers of institutionalized individuals with dementia</td>
<td>5.20 (1.92)</td>
<td>3.4 (1.95)</td>
<td>1.55</td>
<td>0.19</td>
</tr>
<tr>
<td>Depressive symptoms (QIDS)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregivers of community-dwelling individuals with dementia</td>
<td>3.60 (2.51)</td>
<td>2.6 (1.95)</td>
<td>0.73</td>
<td>0.51</td>
</tr>
<tr>
<td>Caregivers of institutionalized individuals with dementia</td>
<td>6.20 (6.03)</td>
<td>5.0 (4.12)</td>
<td>2.236</td>
<td>0.089</td>
</tr>
</tbody>
</table>

Note. PSQI = Pittsburgh Sleep Quality Index; QIDS = Quick Inventory of Depressive Symptomatology.

**Table 4**

Between-Group Comparison of Sleep Quality and Depressive Symptoms for Caregivers of Individuals with Dementia

<table>
<thead>
<tr>
<th>Variable</th>
<th>Change Score, Mean (SD)</th>
<th>t Score</th>
<th>p Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregivers of Community-Dwelling Individuals with Dementia</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sleep quality (PSQI)</td>
<td>3.4 (6.3)</td>
<td>1.8 (2.6)</td>
<td>0.528</td>
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<tr>
<td>Depressive symptoms (QIDS)</td>
<td>1.2 (3.7)</td>
<td>1.0 (1)</td>
<td>0.117</td>
</tr>
</tbody>
</table>

Note. PSQI = Pittsburgh Sleep Quality Index; QIDS = Quick Inventory of Depressive Symptomatology.
DISCUSSION

This pilot study of a behavioral intervention for caregivers of both community-dwelling and institutionalized individuals with dementia contributes new information to the body of knowledge regarding health promotion for caregivers. The CASI intervention is feasible in this population and was well received by the caregivers, as evidenced by the retention rate, participation in goal setting, and compliance with the behavioral intervention. CASI demonstrates the potential to positively affect the sleep quality of caregivers of individuals with dementia as evidenced by improvement in participants’ sleep quality and depressive symptom scores. Building on the knowledge gained by McCurry et al. (1998), one-on-one delivery, scheduled at a place and time convenient for the caregiver, maximizes caregivers’ ability to participate and to benefit from the material. The goal attainment scaling strategy also contributed to the success of the intervention. For the 7 caregivers who met or exceeded more than 50% of their goals, their depressive symptom scores showed statistical significance in change from baseline to Week 5 and their sleep scores showed a positive trend.

In the future, consideration will be given to modifying the CASI to include educational information for the caregiver about how to support sleep habits of those with dementia, given that 3 of the 5 caregivers of community-dwelling individuals had their sleep disrupted by their loved one. Evidence exists that similar behavioral interventions (e.g., sleep hygiene), as well as light therapy, can benefit the sleep patterns of Alzheimer’s patients (McCurry, Gibbons, Logsdon, Vitiello, & Teri, 2005). The sleep problems would need to be identified and the intervention tailored to the person with dementia, as the current CASI goal setting is designed for caregivers.

The caregivers of community-dwelling individuals with dementia experienced poor sleep quality similar to that reported by previous researchers (McKibbin et al., 2005; Wilcox & King, 1999); the caregivers of institutionalized individuals with dementia also experienced poor sleep. However, both sleep quality scores and depressive symptom scores showed improvement over the 5-week intervention. The changes were not statistically significant in either group, with the exception of the subgroup of caregivers who met or exceeded most of their behavioral change goals. Several factors could contribute to this. Regarding sleep quality scores, 5 weeks may be too little time to assess the benefit of behavioral change in a population that has been experiencing stress and disrupted sleep patterns for months or years. Future studies should extend data collection past the initial 5 weeks. Second, goal attainment scaling does appear beneficial, but goals were assessed only at Weeks 3 and 5. Perhaps providing feedback more frequently with either weekly monitoring or daily documentation would enhance the effect. However, providing more feedback needs to be considered in the context of increased demands on the caregivers’ time.

An unexpected finding was the relationship between sleep quality scores and depressive symptom scores in the caregivers of institutionalized individuals with dementia. The inverse relationship calculated at baseline was the result of 1 caregiver scoring an 8 on the QIDS compared with a PSQI score of 5 (i.e., PSQI scores were higher than QIDS scores for all other caregivers). The lack of robust relationship between sleep scores and depressive symptoms at baseline in this group \( r = -0.03 \) compared with the caregivers of community-dwelling individuals with dementia \( r = 0.84 \) is not as easily explained. It may be due to the rather normal depressive symptom scores of this small sample of 5 caregivers. In addition, other contextual variables not measured in this study may influence the relationship between sleep and depressive symptoms. Severity of the loved one’s dementia or satisfaction with facility staff and care are examples of variables that may provide more information about the stress caregivers experience and how it affects sleep and depression.

The evidence provided in this pilot study demonstrates that caregivers of institutionalized individuals with dementia experience poor sleep quality, just as caregivers of community-dwelling individuals with dementia do. A behavioral intervention is feasible for both groups, but further research is needed to better understand the experience of caregivers of institutionalized individuals with dementia.

LIMITATIONS

Several limitations exist for this pilot study. The small sample may have limited the ability to detect a statistically significant effect of the sleep intervention on outcomes in this analysis. The effect size, while moderate \( d = 0.58 \), resulted in low power \( (0.125) \), decreasing the probability the CASI intervention had a treatment effect on the basis of this small sample of 10 caregivers. The effectiveness of the CASI intervention will need to be tested in a larger sample to evaluate its ability to improve sleep quality and depression in caregivers of individuals with dementia.
The high retention rate may have been influenced by sample bias. Having two APNs identify potential participants, rather than randomly selecting from a patient list, may have introduced some internal validity issues. Finally, the sampling method and size make generalizability difficult. These limitations can be mitigated by duplicating this study with a larger sample and testing the intervention against an attention-control group.

CONCLUSION

Family caregivers will most likely be the largest source of long-term care for our society in years to come (National Family Caregivers Association, 1998). Maintaining the health of these caregivers and supporting them throughout their caregiving careers benefits not only the caregiver but the individuals with dementia as well. Health care providers must consider assessing and intervening for sleep quality in caregivers of loved ones with dementia to minimize the negative outcomes that can develop.

The role of caregiving does not end when the difficult decision is made to institutionalize the individual with dementia. Informal caregivers continue to provide care through their direct interaction with their loved ones, as well as their monitoring and overseeing of the care provided by the professional staff. The caregiving role can continue to be stressful, and as seen in this small sample, the caregiver can experience poor sleep. Nurses must not overlook the support and health promotion needs of this population of caregivers. This pilot study provides a foundation for future work that indicates cognitive-behavioral therapies with goal attainment scaling can improve subjective sleep quality and depressive symptoms for caregivers of individuals with dementia.

REFERENCES


