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# A feasibility study of a two-session home-based cognitive behavioral therapy–insomnia intervention for bereaved family caregivers

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## ABSTRACT

**Objective:** In 2008 over two million family caregivers will become bereaved. The vast majority of these caregivers have provided ‘round-the-clock care for a period ranging from months to years. Bereaved family caregivers report insomnia symptoms that persist beyond 1 year, longer than what is seen in bereaved noncaregivers, placing them at increased risk of depression and complicated grief. Despite some rewarding elements, caregiving is a stressful and exhausting role that often requires the caregiver to restructure his or her life around the needs of the patient. Once the patient dies, the structure is lost. Cognitive behavioral therapy interventions are effective in providing structure. This pilot study explored the feasibility of a two-session home-based cognitive behavioral therapy–insomnia (CBT-I) intervention for bereaved family caregivers.

**Method:** A 5-week longitudinal descriptive study design was used with 11 adult primary family caregivers of patients who died from cancer. A master’s prepared nurse delivered two CBT-I intervention sessions in participant homes. Data collection sessions occurred at baseline, 3, and 5 weeks. A debriefing session was held at Week 6.

**Results:** Participant evaluations of the intervention indicated that it was feasible and acceptable (e.g., 100% would recommend it to others); objective data further supported its feasibility (e.g., 100% completed the trial). In addition, when comparing baseline with Weeks 3 and 5, participants demonstrated improvement in insomnia and depressive symptoms.

**Significance of results:** The results of this pilot study suggest that the intervention is feasible and acceptable and produces promising effects on insomnia and depressive symptoms in bereaved family caregivers.

**KEYWORDS:** Insomnia, Bereavement, Family caregivers, Cognitive behavioral therapy

## INTRODUCTION

Currently, family members provide care to 52 million chronically ill loved ones in the United States (Family Caregiver Alliance, 2008). It is expected that 2.2 million of these patients will die each year (Centers for Disease Control and Prevention, 2008). Family caregivers provide ‘round-the-clock care, often

without assistance, for periods ranging from months to years depending on the patient’s diagnosis. The positive and negative outcomes associated with providing care to a chronically ill loved one have been well documented over the years. However, we are only beginning to understand what happens after the death of the patient. Bereaved spouses, if they have not been caregivers, fair better during bereavement than the majority of bereaved family caregivers. This may be because bereaved family caregivers enter their bereavement from a different place than bereaved noncaregivers. Family caregivers may have

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been actively grieving for a period of time prior to the death of the patient. The death of the patient is often described as “the final loss.” Caregivers have defined their lives and find meaning in their role (career) as caregiver. Once the patient is deceased, that role is no longer there, the structure that accompanied that role is no longer there, and the control and mastery that the caregiver felt is no longer there. These multiple losses often follow an intensely active end-of-life period. During end-of-life care the family caregiver is actively engaged in caring for the dying patient as well as any additional family members or attending professional caregivers. Sleep deprivation is inevitable and may continue for days. After the death there is intense silence, silence that is described as “deafening.” What caregivers need is rest; however, sleep often eludes them. Although transient sleep disturbances and feelings of depression are common during bereavement, persistent symptoms can increase the risk for a variety of negative health outcomes. The aging U.S. population will create growing numbers of bereaved caregivers, making this a significant and growing public health concern.

### Insomnia and Bereavement

Descriptions of sleep in bereaved caregiver samples are limited (Carter, 2005; Carlsson & Nilsson, 2007; Waldrop, 2007); however, studies with noncaregiver bereaved spouse samples report both subjective and objective sleep disturbances during bereavement. Pasternak et al. (1992) found bereaved spouses reported significantly greater disturbances in subjective sleep quality, as measured with the Pittsburgh Sleep Quality Index (PSQI), than age-matched nonbereaved controls. Subjective sleep complaints were consistent with insomnia symptoms (e.g., increased latency and decreased duration and efficiency). Reynolds et al. (1993) found bereaved spouses’ objective sleep changes, as measured with EEG, included increased sleep onset latency, wake after sleep onset minutes, decreased sleep efficiency, decreased delta wave activity during the first sleep cycle, and shorter REM latency as compared with age and gender-matched controls.

Further, investigations with other bereaved individuals report the increased incidence of insomnia symptoms. In a recent study with 815 bereaved college students, Hardison et al. (2005) reported that the rate of insomnia was significantly higher (22%) in the bereaved sample than in a nonbereaved comparison group (17%). Additionally, bereaved insomniacs reported higher complicated grief scores than bereaved noninsomniacs. Similarly, a recent study by Germain et al. (2005) found that persons with complicated grief symptoms reported significantly

disrupted sleep (PSQI scores averaged 9.4) and that comorbid depression worsened insomnia symptoms.

### Social Rhythm and Caregiver Sleep

Human behavior is structured into patterns that repeat themselves every 24 hours. These 24-hour patterns are largely determined by light cues (daylight/darkness cycle) and by family and work roles that set the temporal framework for daily activities. Caregivers’ lives are focused on and driven by the needs of the patient. For example, the patient may require medications or treatments to relieve symptoms (e.g., pain, dyspnea) at frequent intervals (every 2–4 hours) resulting in fragmented sleep for the caregiver. Similarly, the patient may require assistance with toileting several times throughout the day and night. The caregiver often provides this care without assistance for months to years. Consequently, the caregiver’s schedule is the patient’s schedule.

Following the patient’s death there is a remarkable absence of schedule that results for the caregiver. Theoretically, following the death of the patient the caregiver should feel relieved and be able to return to a “normal” sleep/wake pattern. However, unlike findings reported from studies with noncaregiver bereaved individuals, who report that both objective and subjective sleep disturbances dissipate with time (Brown et al., 1996; Monk et al., 2008), bereaved caregivers report increased sleep pattern disruption rather than a return to “normal” (Carter, 2005; Carlsson & Nilsson, 2007; Waldrop, 2007). Sleep pattern disruptions in bereaved family caregivers are reported to continue for years following the patient’s death (Carter, 2005). Prolonged insomnia symptoms have been associated with increased incidence of depression, which, in turn, can prolong the grief trajectory. Cognitive behavioral interventions are ideal for helping caregivers to restructure their lives and sleep.

The sleep/wake cycle is cued by light and social influences. Bereaved caregivers’ habits further influence their sleep/wake cycle. According to the 3-P model, the development of sleep disturbances is a multifaceted event that arises from a combination of predisposing, precipitating, and perpetuating factors (Spielman et al., 2000). For bereaved family caregivers, these factors can be independent of the caregiving situation as well as directly related to the influence of the care provided and death of the patient. *Predisposing*, independent risk factors for insomnia in bereaved caregivers include increasing age and female gender, both of which are associated with higher prevalence of sleep complaints (Foley et al., 1995; Middelkoop et al., 1996).

Following Spielman's 3-P model, sleep disturbances will occur when a person who is predisposed to poor sleep encounters some event that precipitates nighttime wakefulness. For bereaved family caregivers, the *precipitating* events are often death of the patient and the loss of the structure and control that came with the caregiving role. For a vulnerable caregiver, it can be very difficult to fall back asleep after being awakened by nightmares or "remembrances" of the patient death. Another precipitating factor may be the loss of structure from providing care that often dictates the sleep/wake schedule. *Perpetuating* factors are conditions or habits that accrue as the insomnia becomes chronic and helps to sustain the sleep disturbance. Frequently, the bereaved caregiver changes habitual practices in an attempt to cope with the sleep problem and inadvertently prolongs the problem. For example, bereaved caregivers will catnap to catch up on sleep, or they may increase their caffeine intake to stave off fatigue, or they may use alcohol to induce sleep. Each of these habits can perpetuate insomnia symptoms by disrupting the normal sleep/wake cycle. A number of clinical trials have shown that perpetuating factors for insomnia are responsive to cognitive behavioral therapy (Morin et al., 2006). The purpose of this study was to explore the feasibility of a two-session home-based cognitive behavioral therapy–insomnia intervention for bereaved family caregivers.

## METHODS

### Design

A 5-week longitudinal descriptive study design was used.

### Participants

Participants were the primary family caregiver of a person who died from cancer and who was at least 21 years of age. The primary family caregiver was self-identified as the person who assumed responsibility for and provided the majority of the assistance to the patient. Potential participants must have been serving as caregiver for a minimum of 6 months or

since the time of diagnosis if less than 6 months at the time of patient death. Participants could be of any ethnic/racial group, but they must have been able to communicate in English. Caregivers were excluded if they had a history a preexisting sleep disorder other than insomnia (e.g., periodic limb movement, restless legs syndrome, sleep apnea, narcolepsy, Gastroesophageal Reflux Disease).

### Procedure

Following institutional review board approval from the university, participants were recruited from outpatient oncology treatment care centers and bereavement support groups in the Central Texas area. Caregivers were given a flyer describing the study, including instructions to call the designated phone number if they were interested in learning more about the study. A trained research nurse using a detailed history and physical questionnaire screened potential participants for eligibility, obtained a verbal consent, and enrolled eligible caregivers in the study. Caregiver and patient demographic information was collected at the first meeting and subsequent meetings were scheduled. Depressive symptoms (Center for Epidemiologic Studies Depression Scale [CESD]) and sleep quality (PSQI, actigraphy, sleep logs, goal attainment scaling [GAS]) were assessed at baseline and 3 and 5 weeks. See Table 1 for a timeline of study activities.

### Intervention

A Master's prepared research nurse delivered the CBT-I intervention content in two 2-hour sessions (Weeks 2 and 4) in the participant's home. Participants were guided through a self-assessment of sleep/wake activities to identify habits that perpetuate insomnia symptoms. The intervention provided participants with the information, skills, and support necessary to identify and change insomnia perpetuating habits. The intent was to engage participants in assessing their present habits and setting meaningful goals for change. The emphasis was not on controlling the bereavement process, but on maximizing the participants' ability to improve their insomnia symptoms.

**Table 1.** *Timeline of Study Activities*

Activity	Baseline	Week 2	Week 3	Week 4	Week 5	Week 6
Data collection	X		X		X	
CBT intervention delivery		X		X		
Goal attainment		Set goals	Rate attainment	Rate attainment	Rate attainment	
Debriefing						X

The intervention included stimulus control, sleep hygiene, relaxation, and cognitive restructuring elements, complemented by personal goal setting and monitoring. See Table 2 for a summary of intervention components and major topics covered in each area.

## Instruments

### *Caregiver Demographic Characteristics*

Age, gender, ethnicity, religious preference, economic status, relationship to deceased, duration of caregiving, and overall health status were determined from caregiver reports.

### *Patient Demographic Characteristics*

Age, gender, ethnicity, length of illness, and time since death was recorded from caregiver reports.

### *Sleep*

*The Pittsburgh Sleep Quality Index.* The PSQI (Buysse et al., 1989) was used to measure participant subjective sleep quality. The PSQI has 19 questions that ask respondents about various aspects of their sleep and daytime energy levels. Instructions were modified from the original to have participants report on the previous 2 weeks. Items are used to calculate seven sleep component scores (sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, sleep medications, and daytime

dysfunction). Higher scores indicate more sleep difficulties. The possible score range for each sleep component is 0–3; the desired range is 0–1. Sleep component scores can be summed to produce a global sleep quality score. Global scores range from 0 to 21. Global scores >5 indicate moderate sleep problems in at least three sleep component areas or severe sleep problems in two areas. Chronbach's alpha for this study was 0.80.

*The Actigraph.* The Actigraph, manufactured by Ambulatory Monitoring, Inc. (Ardsley, NY), was selected as a measure of sleep patterns (latency, duration, wake after sleep onset [WASO], and efficiency) because it is a sensitive, noninvasive, easily applied, and widely used instrument. Movement was sampled 10 time per second and stored in 1-minute epochs. Zero Crossing Mode was used for this study. Raw Actigraph data were prepared for analysis using the Action W software (Edinger et al., 2001) and sleep logs (see description of logs below). Data were trimmed to the time period of interest (72 hours); downtimes (time to bed – time out of bed for the last time) were indicated and bad epochs (watch was removed for any length of time) were marked.

Activity data were recorded continuously for each of the three 72-hour periods. This time frame was used to decrease participant burden. To control for weekday versus weekend differences, the Actigraph was placed on the participant's wrist on Monday or Tuesday and removed 72 hours later for each of the three measurement periods (baseline, 3 weeks, and 5 weeks).

*Sleep logs.* While the participants were wearing the Actigraph, they recorded information about their sleep (time to bed, time out of bed for the last time, timing of disturbances during the night, types of sleep disturbances, overall sleep quality, and daytime energy level) for each of the 3 days (72 hours) in paper logs at each measurement point (baseline, 3 weeks, and 5 weeks). Additionally, participants were asked to indicate whether they removed the Actigraph and if so, to indicate the time removed, time replaced, and reason for removal. These logs were used along with the Action W software (Edinger et al., 2001) to prepare the raw Actigraph data for analysis. Participant sleep log comments were also used to describe sleep disturbances and daytime energy levels.

These sleep logs were designed by the first author and were used in previous caregiver studies. There was high agreement between what participants reported and what the Actigraph recorded on time out of bed, naps taken, and duration of sleep. The burden of keeping a sleep log must be acknowledged. In response to this burden, the sleep log used for this

**Table 2.** *Intervention Components and Major Topics Covered in Each Area*

Intervention components	Major topics
Educational	
Cognitive restructuring	Normal sleep Caregiving's impact on sleep Identify and address unrealistic sleep expectations
Stimulus control	Reassociate the bedroom with rapid sleep onset Curtailing sleep-incompatible activities
Sleep hygiene	Identification of maladaptive sleep habits: physical environment diet exercise
Relaxation techniques	Identify and practice techniques to address physical arousal cognitive arousal
Goal setting and monitoring	Identification of goals for sleep Rating of goal attainment



study was designed to limit the amount of narrative reporting required by the participant. In this and other studies, participants reported no difficulty or undue burden associated with filling out the sleep log. The sleep log was not intended to be used as a sleep diary but rather as a way to capture contextual factors during the Actigraph data collection.

**Goal attainment scaling.** GAS was used to assist participants in setting meaningful goals to change habits that perpetuate insomnia symptoms. Participants were asked to identify four goals, one for each of the following areas: environment, routine, stimulant use, and relaxation. The GAS process involves identifying a goal that is realistic to achieve in a given time (Kiresuk et al., 1994). This goal represents the 0 point on the GAS, and it must be precise and measurable. Next, a somewhat better than expected outcome is identified, and this becomes the +1 point on the scale. A much better than expected outcome becomes the +2 point, while a somewhat less than expected outcome becomes the –1, and much less than expected the –2 points on the GAS. The GAS enables comparison of individuals' relative success in achieving goals that are individually determined and therefore possibly different. Studies conducted with family caregivers confirmed the importance of carefully constructing the scales so that there are no overlapping points and no gaps between scale points and the scale's 0 point. To ensure that these guidelines were met, each research nurse was trained in setting and monitoring goals during a training session and the investigator reviewed each participant's goals.

### Depressive Symptoms

The CESD (Radloff, 1977) was used to measure participant depressive symptoms. The CESD is a 20-item, 4-point Likert scale. Instructions were modified, asking respondents to indicate how often they had experienced a particular symptom during the past 2 weeks using a scale of 1 (*never*) to 4 (*most of the time*). Scores are summed, with higher scores indicating more depressive symptoms. A cutoff of  $\geq 16$  is indicative of increased risk for clinical depression (Radloff, 1977). Chronbach's alpha for this study was .85.

### Sample

Eleven participants were enrolled in and completed the 5-week study protocol. All participants who began the study completed all measurement points. See Table 3 for a description of participants and deceased patients.

**Table 3.** Caregiver and Patient Demographics

	Number	Mean	SD	Range
Caregiver				
Age		56	11.77	42–80
Gender				
Male	4			
Female	7			
Ethnicity				
White	11			
Religion				
Christian	7			
Other	4			
Economic status (\$/year)				
$\leq \$50,000$	5			
$> \$50,000$	6			
Relationship to patient				
Spouse/partner	5			
Adult child	3			
Sibling	1			
Other	2			
Overall health status <sup>a</sup>		1.91	0.70	1–3
Duration of caregiving (months)		21.33	20.19	6–72
Patient (deceased)				
Age		69.36	12.1	53–90
Gender				
Male	4			
Female	7			
Length of illness (months)		21.33	20.19	6–72
Time since death (weeks)		8.36	9.58	3–36

<sup>a</sup>1 = excellent, 2 = good, 3 = fair, 4 = poor, and 5 = very poor.

## RESULTS

Participant narratives collected during the debriefing sessions and the research nurse reports of each session were used to explore the feasibility of intervention delivery protocols, data collection instruments, sample recruitment strategies, and acceptability of the intervention to bereaved family caregivers.

### Compliance with Components of the Intervention

Although treatment fidelity is a major challenge for psychosocial interventions, it remains central to the validity of the intervention study by reducing random and unintended variability (Dumas, Lynch, Laughlin, Smith, & Prinz, 2001; Bellg et al., 2004; Santacroce et al., 2004). We used methodological strategies recommended by the National Institutes of Health Behavior Change Consortium (Bellg et al., 2004) to enhance treatment fidelity. The principal investigator (PI) trained and supervised all

intervention team members to ensure that they followed condition protocols. Training included role-play with feedback on performance that assessed adherence to the intervention condition protocols (content fidelity) and communication skills (process fidelity) (Dumas et al., 2001; Bellg et al., 2004).

The research nurse delivered the intervention to participants. All sessions were audiotape recorded. The research nurse completed checklists, based on the condition protocols, after each session to minimize "drift" (Bellg et al., 2004). Adherence to the condition protocols was evaluated by the PI, who reviewed audiotaped intervention sessions and coded the sessions using a checklist that addressed both content and process fidelity. We reviewed both intervention sessions for each participant and discussed deviations from protocol with the research nurse. Retraining was to occur as needed; however, it was not needed during this feasibility study.

Participants' receipt of treatment addressed their ability to understand the content delivered and to perform the behavioral skills during the intervention (Bellg et al., 2004). Treatment fidelity strategies for monitoring receipt of treatment included reviewing goal achievement along with discussion about the CBT-I content and skills presented (Bellg et al., 2004). Participants' feedback during the exit interview (conducted at the end of the study) provided additional information about receipt of treatment and was used to refine the intervention protocol.

### **Feasibility of Data Collection Instruments**

We used two self-report measurements (PSQI, CESD), one objective sleep measurement (Actigraph with the sleep log), and one goal attainment measure. Self-report measures were administered by reading the questions to the participants while they followed along on a hard copy of the questions. All responses were recorded by the research nurse. This allowed for an opportunity to provide clarification of any questions to the participant and ensured that each question was filled out correctly. The Actigraph was placed on the participant's nondominant wrist at the data collection meeting (baseline, Week 3, and Week 5). The Actigraph was retrieved from the participant at the next meeting (Week 2, Week 4, and Week 6) and taken to the research laboratory to download the data. The sleep log was checked for completeness at the time the Actigraph was retrieved. All Actigraphs captured data at each time point for a total of 33 data measurements. There were no missing or lost data, as can sometimes occur with actigraphy instruments. The sleep logs provided the information needed (time to bed, time out of bed, removal of the actigraph) that allowed for the

preparation of the raw actigraph data. There was a high level of agreement between sleep log notations and the actigraph recordings. Goal attainment scaling was assessed by asking the participants to rate their ability to accomplish each of their four goals during the past 2-week period on a scale from  $-2$  to  $+2$ . Goal ratings were retrieved from the participant at each measurement period. Participants consistently rated their goals and reported the ease of use for the instrument as well as the positive feelings they had while using the goal scale.

### **Feasibility of Sample Recruitment Strategies**

Family caregivers are notoriously difficult to recruit for participation in research studies. Bereaved family caregivers are no easier to recruit. Possible factors contributing to low participation rates for active caregivers' center around the overwhelming needs of the patient leaving little time for anything else. For bereaved caregivers, low participation rates may be attributed to the loss of social networks. Bereaved caregivers become focused on increasingly complex care prior to the patient's death and become socially isolated following the death of the patient. During the caregiving process, caregivers often withdraw from prior social networks with noncaregiving friends and may instead establish networks with the patient's formal care providers. Following the death of the patient, the network with formal care providers is lost along with the patient. Thus the link with information about study opportunities is also lost. Similarly, bereaved caregivers may avoid bereavement groups because they "just don't have the energy to do that now," thus cutting off another source of information regarding research opportunities.

It must be noted that there are contradictory thoughts regarding the timing of the invitation to participate in a study following the death of a loved one. This feasibility study supported the need to engage family caregivers prior to the patient's death. Research has shown that talking with patients and their families about death is comforting (Emanuel et al., 2004). If the researcher is able to engage the caregiver prior to the death of the patient, this provides a bridge to care of the family caregiver during the end of life and after the death of the patient. Caregivers who come to be involved in the study after the death of the patient can also benefit, although they may be harder to engage. If it is not possible to engage the caregiver prior to the patient's death, the common timeline reported in many studies for approaching a potential participant following the death of a loved one is 4 weeks. When asked about the

appropriate timeline for an intervention study to promote sleep, participants in this feasibility study stated “the earlier the better for this type of study [CBT-I]. Being able to take control of your sleep helps you to get control of the rest of your life.”

Finally, engaging the support of the oncology clinic staff and bereavement support group leaders is essential in gaining credibility with family caregivers and their patients. Oncology staff become very close with their patients and families and can be very protective of them. If researchers can establish good relationships with the staff first, then they will have access to and credibility with the patient and family caregivers.

### **Burden and Acceptability of the Intervention**

#### *Objective Ratings of Participant Burden*

The research nurse and the bereaved caregiver met a total of six times for this study (three data collection, two intervention, and one debriefing sessions). Data collection sessions were 45 minutes for each of the three sessions (baseline, Week 3, and Week 5). The intervention sessions lasted 2 hours for each of the two sessions (Week 2 and Week 4). The debriefing session occurred at Week 6 and lasted on average 1.5 hours. At the debriefing session the participants were asked to comment on their experiences during the study, the burdens associated with their participation, the helpfulness of the data provided in the intervention sessions, the likelihood of them recommending this intervention to others, and any suggestions they had for improvements. All 11 participants in this study were able to complete the intervention, data collection, and debriefing sessions. All sessions were delivered in the caregiver’s home.

#### *Acceptability of the Intervention*

Participants were asked during the debriefing sessions to comment on the helpfulness or lack of helpfulness of the information provided during the intervention sessions. The narrative responses were content analyzed. Participants overwhelmingly supported the need for information to improve insomnia symptoms. One stated, “I had no idea how much what I do, or don’t do, affects my sleep.” Another said, “I used to just hope for sleep; now I know I can do something to make it happen.”

Similarly, caregivers were surprised to find that small changes to their behaviors during the day or upon awakening during the night could have such a significant and immediate impact on their sleep quality. One participant put it this way: “I slept! I can’t believe it, all I did was cover up the clock.” Participants

identified habits that perpetuated insomnia symptoms and set goals to change these behaviors. Some changes were easily accomplished, such as covering the clock, whereas others required more practice (e.g., thought stopping). However, each participant reported that he or she found the information provided in the intervention sessions to be helpful. One participant put it this way: “The skills I learned have helped me to improve my sleep. I now know what to do if I have a bad night’s sleep; mostly I know not to worry about it.”

Participants were asked about the timing of the intervention. Caregivers overwhelmingly stated that the information would have been helpful to have while they were providing care to the patient (actively caregiving), but that it was essential to receive as soon as possible after the patient’s death. One participant said, “I didn’t know how much my insomnia was keeping me from being able to move on with my life after my mother’s death. Now that I sleep, I can grieve, and I can get my life back. Every caregiver needs to know this and they need to know it immediately.”

In summary, the 11 participants in this study found the CBT-I information helpful, they were able to complete all measurement, intervention, and debriefing sessions, and the instruments performed as expected to capture sleep and depression data without undue burden being placed on the participants.

### **Efficacy of the Intervention**

Although the focus of this pilot study was to evaluate feasibility, preliminary data analyses suggest efficacy of the CBT-I with these 11 bereaved caregivers. Comparisons between baseline and Week 5 revealed improvement across variables.

#### *Sleep*

Sleep was reported at three time points (baseline and 3 and 5 weeks) and in two formats (by self-report with the PSQI and objectively with the Actigraph). PSQI total, latency, duration, and efficiency scores are presented in Table 4. On average, self-reported latency improved 5 minutes, duration increased 36 minutes, and efficiency increased 9 points to 88%. PSQI total scores decreased to 5.2.

Actigraph latency, duration, efficiency, and WASO scores are presented in Table 5. Although some improvements were seen in objective scores, as is commonly seen in brief studies, the self-reported sleep and objective sleep measures differed. It has been observed that self-report and objective measures tend to converge in longer studies.

Sleep logs were used to describe sleep disturbances and daytime energy levels. The most frequent reason given for sleep disruptions were dreams/nightmares



**Table 4.** *Self-Reported Latency, Duration, Efficiency, and Total PSQI Scores*

	Latency (minutes)		Duration (hours)		Efficiency (%)		PSQI (total)	
	Range	Mean (SD)	Range	Mean (SD)	Range	Mean (SD)	Range	Mean (SD)
Baseline	5–45	17 (12)	4–8.5	6.4 (1.4)	66–89	79 (8.8)	3–12	9 (2.5)
Week 3	5–45	19 (13)	5–8.5	6.7 (2)	60–94	84 (10)	2–12	7 (3)
Week 5	2–30	12 (10) <sup>a</sup>	6–8.5	7 (1) <sup>a</sup>	76–94	88 (5.5) <sup>a</sup>	1–11	5 (3) <sup>a</sup>

<sup>a</sup>Statistically significant improvement from baseline ( $p < .02$ ).

**Table 5.** *Actigraph Latency, Duration, Efficiency, and Wake After Sleep Onset (WASO) Scores*

	Latency (minutes)		Duration (hours)		Efficiency (%)		WASO (minutes)	
	Range	Mean (SD)	Range	Mean (SD)	Range	Mean (SD)	Range	Mean (SD)
Baseline	0.33–36	12 (12)	5.5–8.1	6.6 (0.8)	54–98	85 (13)	4.3–242	58.6 (67)
Week 3	7–142	33.5 (40)	4.1–8.4	6.1 (1.4)	59.5–95	81 (13)	7.5–182	55 (52)
Week 5	2.7–48.5	18.5 (16)	5.5–9.2	6.8 (1.2)	73–98	84 (9.5)	1.7–145	65 (49)

about the patient's death. Other common disruptions included mild physical pain ( $n = 5$ ) and needing to use the bathroom ( $n = 10$ ). Higher levels of daytime energy correlated with a good night's sleep, whereas lower levels were correlated with more insomnia symptoms. Participant's daytime energy levels improved as the study progressed.

#### Goal Attainment Scaling

Participants were assisted in identifying habits that perpetuated insomnia symptoms and were guided in setting meaningful goals for behavior change. Each participant set four individual goals, one each for environment, routine, stimulant use, and relaxation. The most common goals for each category are presented in Table 6. All 11 participants met or exceeded their goals at each measurement point (3 weeks and 5 weeks).

#### Depressive Symptoms

Participants' depressive symptoms were measured at three time points (baseline and 3 and 5 weeks).

**Table 6.** *Most Common Goals Set by Participants*

Environment	Routine	Stimulants	Relaxation
No TV in bed	Walk the dog	No caffeine after 3 p.m.	Meditation
Cover the clock	Create down time in the evening		Journaling
	Aromatherapy		Deep breathing

Baseline depressive symptom scores (CESD) ranged from 4 to 35 and averaged 17 ( $SD = 8.3$ ). At Week 3, 1 week after the initial intervention session, participants reported CESD scores that ranged from 2 to 28 and averaged 13 ( $SD = 9$ ). At Week 5, 1 week after the second intervention session, participants reported CESD scores that ranged from 0 to 18 and averaged 9 ( $SD = 5.8$ ).

## DISCUSSION

Although sleep complaints are common in newly bereaved individuals, studies support an eventual return to baseline sleep within 1 year in noncaregiver bereaved (Brown et al., 1996; Monk, et al., 2008). The few studies that have been conducted with bereaved family caregivers (Carter, 2005; Carlsson & Nilsson, 2007; Waldrop, 2007) report that insomnia symptoms begin prior to the death of the patient and persist for up to 5 years after death. Additionally, caregivers report their insomnia symptoms act as a barrier to their grief process. "I just don't have the energy to deal with it all when I don't sleep." Persistent insomnia symptoms have been linked to increased depression and complicated grief in noncaregiver samples (Ford & Cooper-Patrick, 2001; Hardison et al., 2005).

Bereaved family caregivers may be at higher risk for persistent insomnia symptoms due to a severely disrupted sleep/wake routine that begins as a result of patient needs and persists following the patient's death. Cognitive behavioral therapies have been shown to be effective in providing structure in order to establish a healthy and functional sleep/wake

routine (Edinger et al., 2001). The aim of this study was to explore the feasibility of a two-session home-based cognitive behavioral therapy to treat insomnia symptoms in bereaved family caregivers.

This study shows that a brief home-based CBT-I is feasible and acceptable for use with bereaved family caregivers. Participants found the information helpful. They were able, with guidance, to begin to use the skills to restructure their sleep/wake schedules, which often resulted in improved insomnia symptoms. These findings are not surprising, given that CBT-I is a widely used and empirically supported process of providing individuals with the information and skills to regain control of their sleep behaviors. What is surprising is that this is the first study that we could find that applied these techniques to a population of bereaved family caregivers.

Bereavement is a process, one that every person must move through at his or her own time and pace. However, in order to move through this process the individual must have the available energy to do the work. Insomnia robs the individual of the ability to do the work of bereavement and thus to move through it. Good sleep, however, gives the person energy and the ability to do the work of bereavement. This hypothesis was supported by the comments made by participants following the intervention.

### Limitations

The decrease in insomnia and depressive symptoms following the CBT-I intervention is promising, but the absence of a control group limits the interpretation of results; this is the primary study limitation. The single-arm design leaves open the possibility that improvements in insomnia and depressive symptoms seen in pre–post comparisons are due to nonspecific effects of the intervention or other confounding variables. For example, the bereaved caregivers may be seeing improvements in their insomnia and depressive symptoms as a part of the natural course of healing over time or as a result of the attention from the research nurse. The small sample size and homogeneity are limitations to generalizability of the results. These limitations are offset in part by the strengths of the study, including the minimal resources needed to provide a theoretically grounded intervention adapted to the special needs of bereaved family caregivers, the high rates of intervention delivery and participant retention, and the impact on important targets for bereaved family caregivers.

Behavioral interventions hold promise for active and bereaved family caregivers who are faced with challenges to their health and psychological well-being and may engage in habits that perpetuate

insomnia symptoms. This is one of the first studies to promote a brief (two-session) home-based CBT-I for bereaved family caregivers to provide skills and knowledge to improve insomnia and thus depressive symptoms. Individualized interventions, such as the one tested in this study, may be particularly attractive to healthcare professionals working to improve insomnia and depression in their patients' family caregivers both before and after the death of the patient. In future applications of CBT-I for bereaved family caregivers, it is suggested that the caregivers be engaged prior to the death of the patient. It is clear from the findings presented here and in previous studies that family caregivers suffer from insomnia symptoms both during and after the death of the patient and thus would benefit from receiving the information as soon as possible.

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