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Bereaved Caregivers' Descriptions of Sleep: Impact on Daily Life and the Bereavement Process

Patricia A. Carter, PhD, RN, CNS

Purpose/Objectives: To describe how sleep and bereavement may be related in family caregivers.

Design: Descriptive and qualitative.

Setting: Participants' homes.

Sample: 9 adults with no previous diagnoses of clinical depression or sleep disorders who had been providing care to family members who died in the previous six months.

Methods: Participants provided narrative accounts of sleep quality, bereavement, and daily functioning since the death of their family members. Participants' sleep quality and depressive symptoms also were measured with the Pittsburgh Sleep Quality Index (PSQI) and Center for Epidemiological Studies—Depression Scale (CES-D).

Main Research Variables: Sleep quality, depressive symptoms, bereavement, and daily functioning.

Findings: Narratives revealed five themes: nightmares, wake after sleep onset, scheduling, daily life, and bereavement. Participants scored high on the PSQI and CES-D.

Conclusions: Sleep quality appears to affect bereavement and daily functioning. Participants reported severe levels of sleep disturbance and depressive symptoms.

Implications for Nursing: Studies are needed to explore sleep quality in bereaved caregivers and to examine the relationship between sleep quality and an individual's ability to accomplish the tasks of bereavement

ore than 2.4 million people died in the United States in 2003 (Hoyert, Kung, & Smith, 2005). Of those, about 2.2 million died from chronic, disabling conditions that compromised their ability to function independently prior to death. A typical death is preceded by an extended period of time during which one or more family members provide health care and support services to a disabled relative (Emanuel et al., 1999; Emanuel, Fairclough, Slutsman, & Emanuel, 2000). Almost one of every four households (23%, or 22.4 million households) is involved in caregiving for people aged 50 and older with chronic, disabling conditions. This number is estimated to increase to 39 million by the year 2007 (Family Caregiver Alliance, 2004). Although researchers have documented repeatedly the psychiatric and physical health effects of family caregiving (Schulz & Beach, 1999; Schulz, O'Brien, Bookwala, & Fleissner, 1995), caregivers rarely are followed after the

Key Points...

- Bereavement is a process that requires emotional, mental, and physical energy.
- ➤ Quality sleep includes sufficient restorative stage 3 or 4 sleep to provide emotional, mental, and physical energy.
- ➤ Bereaved caregivers suffer sleep disruption that appears to affect their lives following the death of their family members.

death of disabled relatives to assess the effects of death on the caregivers (Schulz, Newsom, Fleissner, DeCamp, & Nieboer, 1997). Similarly, bereavement researchers rarely explore the extent to which family members were involved in care prior to the death of their relatives as a factor affecting bereavement outcomes. Studies that have explored caregiver bereavement typically focused on emotional symptoms (e.g., depression, anxiety) and the impact on the bereavement process (Kelly et al., 1999; Kissane, McKenzie, & Bloch, 1997; Schulz et al., 2001; Wyatt, Friedman, Given, & Given, 1999). A few studies have begun to report the physiologic effects of bereavement, including changes in prolactin, growth hormone, cortisol, and epinephrine levels (Hall et al., 1998); an emphasis on in vitro correlates of cellular immunity (Irwin & Pike, 1993); and changes in the patterns of the level of sleep (Reynolds et al., 1993). A question not answered by these studies is how physiologic variables (e.g., sleep quality) affect the achievement of bereavement tasks and depression levels.

Further information is needed about how sleep quality changes from caregiving through bereavement and how the changes influence caregivers' quality of life, daily functioning,

Patricia A. Carter, PhD, RN, CNS, is an assistant professor of nursing in the School of Nursing at the University of Texas at Austin. This research was supported by a pilot research grant from the Center for Health Promotion and Disease Prevention in the School of Nursing at the University of Texas at Austin. (Submitted July 2004. Accepted for publication February 21, 2005.)

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physiologic health, and processes of bereavement. To begin to understand this complex process, researchers must interview caregivers who are having these experiences. Only through their eyes can researchers see how the road of bereavement is traveled and how sleep quality can influence the smoothness of that road.

The purpose of this descriptive study was to explore changes in caregiver sleep quality during caregiving and after the death of a family member. Family caregivers were asked to describe their caregiving experiences, changes in their sleep during caregiving, and how their sleep changed following the death of their family members. Caregivers also were asked to describe how their sleep quality influenced their daily functioning, quality of life, physical health, and bereavement processes.

Literature Review

Bereavement

Bereavement is defined as the time period in which a loss is experienced. During this time period, bereaved people experience a crisis of meaning (Steeves & Kahn, 1995; Steeves, Kahn, Wise, Baldwin, & Edlich, 1993; Steeves, Kahn, Wise, Sepples, & King, 1997). To reconstitute meaning, individuals who experience loss and bereavement must diffuse the emotional energy of the loss (grief), re-knit their social networks, and establish a new meaning of life without the deceased. Each of these three tasks of bereavement as described by Steeves and Kahn requires emotional, mental, and physical energy. Poor sleep quality can affect the amount of energy available to accomplish these tasks.

Sleep

People spend, on average, a third of their lives asleep. A basic physiologic need of all people, sleep is a dynamic behavioral state. During sleep, complex physical and biochemical changes occur in the brain and throughout the body. Hormones are released, and cells are nourished and restored (Mendelson, Gillian, & Wyatt, 1977). Integrative functions, repair, reorganization, and the formation of new connections occur in the neuronal system to support memory and learning. Also, sleep mediates stress, anxiety, and tension and assists people in regaining energy for concentration, coping, and interest in daily activities (Brown, 1999; Clark, Flowers, Boots, & Shettar, 1995). The brain and body follow oscillating cycles of different depths, some with the presence of dream activity. Sleep is divided into two categories, comprising a total of five stages. Non-rapid eye movement sleep (non-REM) includes stages 1, 2, 3, and 4. REM sleep is the fifth stage. A typical night includes four to six sleep cycles with as many as four sleep stages in each. Quality sleep provides individuals with emotional, mental, and physical energy needed to accomplish the tasks of daily living as well as to recover from the loss of loved ones. Poor-quality sleep, such as the insomnia experienced by the bereaved, saps individuals of such energies.

Bereavement and Sleep

Disrupted sleep is a normal reaction to bereavement and loss of a loved one; however, what is not well known is the relationships among sleep loss, poor sleep quality, disrupted sleep, and an individual's ability to function during bereavement. Some qualitative studies have begun to describe sleep in the bereaved. For example, Steeves (2002) reported that, during the process of bereavement, caregiver sleep quality changed several times, fluctuating with the "rhythm" of bereavement. Other researchers have explored sleep in the bereaved from a quantitative viewpoint. Researchers showed relationships among level of depression, number of losses, and negative sleep changes (increased sleep latency and wake after sleep onset [WASO] times and decreased REM sleep) (Pasternak et al., 1992, 1994; Reynolds et al., 1992, 1993). The link between sleep and the bereavement process is unclear. Irwin and Pike (1993) hypothesized a different relationship: that stress associated with bereavement (frequency of bereavementrelated intrusive thoughts and avoidance behaviors) leads to sleep disruptions (increased sleep latency and WASO times), which, in turn, lead to decreased immune function (natural killer cell functioning). Reynolds et al. (1993) suggested that preservation of sleep quality was associated with decreased depressive symptoms and a smoother transition through the bereavement process for caregivers.

The relationship between bereavement and sleep is far from being well understood. Ongoing quantitative studies, such as the examples provided earlier, are beginning to reveal the changes that occur in sleep architecture and patterns during bereavement; however, the impact that these changes have on bereaved individuals' daily lives and movements through the bereavement process still is unknown. These complex relationships can best be understood using a qualitative approach.

Methods

A descriptive design was used to explore changes in caregiver sleep quality during caregiving and after the death of a family member. Family caregivers were asked to describe their caregiving experiences, changes in their sleep during that time, and how their sleep changed since the death of their family members. Caregivers also were asked to describe how their sleep quality influenced their daily functioning, quality of life, physical health, and bereavement processes. Bereaved family caregivers were recruited from hospice bereavement services. Participants were required to be at least 21 years of age; have been living with and providing care for a family member who had died in the past six months; be able to read, write, and speak English; and freely consent to participate. Individuals were excluded from study participation if they had been diagnosed with a sleep disorder other than insomnia (e.g., sleep apnea, restless leg syndrome, periodic leg movements) or preexisting clinical depression.

Following approval from the university institutional review board, the principal investigator (PI) met with bereavement service staff at the hospice to explain the study purpose, methods, and design; to answer questions regarding the study; and to provide recruitment materials. Recruitment materials were distributed during bereavement support group meetings to all participants by the group facilitators. Individuals who were interested in learning more about the study were instructed to contact the PI by phone or e-mail. A study research nurse using a written script screened all potential participants for eligibility. If an individual was deemed eligible and provided verbal consent to participate, an interview meeting was scheduled at a time and location of convenience for the participant.

At the first meeting, the research nurse explained the study purpose, methods, and design and answered any questions the potential participant had regarding the study. The participant was provided with a copy of the consent form and was given time to read the document and ask questions. If the participant signed the consent form, he or she was given a copy of the form; then demographic information, self-report health status, sleep, and depressive symptoms data were collected. Participants were asked three open-ended questions and also were asked to provide any additional information about their experiences that they believed might be of interest to the researcher or other family caregivers. At the conclusion of interview 1, participants were asked if they would be willing to meet with the research nurse to review the interview transcripts in about one month. All participants agreed, and second interviews were scheduled.

At the second interview, approximately a month after interview 1, participants were provided with copies of their transcripts and were given time to read their answers. Participants were asked if they wanted to add to their answers or make any clarifications. All responses were tape recorded, transcribed, and added to the participants' files.

At the conclusion of each interview, each participant was provided with a \$20 money order as a thank you for their participation (total = \$40). All study-related interviews occurred in participants' homes. Following each interview, participants were given the opportunity to listen to the tapes and erase any portions of the tapes they chose. All audiotapes, transcripts, and questionnaires were kept in a locked file cabinet in the PI's office. Access to study materials was controlled strictly; only key personnel had access to study data. All key personnel completed human subject protection training prior to having access to participants or participant data.

Instruments

Demographics: Participants were asked to provide information about themselves and their caregiving experiences (age, gender, ethnicity, educational level, relationship to the deceased, duration of caregiving experience, and length of bereavement). They also were asked to provide information about the deceased (age at time of death, gender, and diagnosis).

Overall health: A single item was used to describe caregiver perceptions of personal overall health: "How would you rate your overall health at this time? Excellent, good, fair, poor or very poor?"

Sleep quality: Perceptions of sleep quality were assessed with the Pittsburgh Sleep Quality Index (PSQI) (Buysse, Reynolds, Monk, Berman, & Kupfer, 1989). Reliability alphas range from 0.83–0.89 in healthy and chronically ill individuals and family caregivers (Buysse et al.; Carpenter & Andrykowski, 1998; Carter, 2001, 2002; Carter & Chang, 2000). For the current study, the alpha was 0.92. The PSQI has 19 questions that are used to calculate seven sleep component scores (sleep quality, sleep latency [time to fall asleep upon going to bed], sleep duration, habitual sleep efficiency [time asleep ÷ time in bed X 100%], 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 are summed to produce a global sleep quality score. Global scores range from 0–21. Global scores greater than 5 indicate moderate sleep problems in at least three sleep component areas or severe sleep problems in two areas.

Depressive symptoms: The Center for Epidemiological Studies–Depression Scale (CES-D) (Radloff, 1977) was

used to measure caregivers' depressive symptoms. The CES-D is a 20-item, 4-point Likert scale. Respondents are asked to indicate how often they have experienced a particular symptom during the past week using a scale of 1 (never) to 4 (most of the time). Scores are summed, with higher scores indicating more depressive symptoms. A score greater than 16 is indicative of increased risk for clinical depression (Radloff). Empirical evidence indicates that the CES-D is a valid measure of depressive symptoms among caregivers. The CES-D has demonstrated high internal consistency (alpha = 0.85), and test-retest reliability (2 weeks r = 0.51; 8 weeks r = 0.59), supporting the CES-D's ability to measure current and immediate past symptoms (Bergman-Evans, 1994; Lawton, Moss, Kleban, Glicksman, & Rovine, 1991; Li, Seltzer, & Greenberg, 1997). For the current study, the alpha was 0.95.

Open-ended questions: Because the primary focus of the investigation was to elicit caregiver narratives to describe perceived relationships between sleep quality and bereavement experiences, three questions were used to elicit caregiver narratives. Participants were asked to describe sleep while providing care for their family members, sleep since the death of the family members, and how sleep influenced their daily functioning, quality of life, physical health, and bereavement processes. Standard probes (e.g., "go on," "tell me more," "that is interesting; can you give me an example?") were used to clarify and elicit further information from all participants.

Data Analysis

Descriptive data analysis was performed for quantitative measures (demographics, overall health, the PSQI, and the CES-D) using SPSS® (SPSS Inc., Chicago, IL). Frequencies, means, and standard deviations were computed to obtain a profile of the sample.

Narrative data were managed via the Ethnograph 5.0 (Qualis Research Associates, Amherst, MA) computer program to facilitate coding and analysis. All interviews were tape recorded and transcribed verbatim. The transcriptions were examined using the principles of content analysis described by Strauss and Corbin (1990). Analysis began with open coding that included extensive reading of the interview material, a line-by-line analysis search for words, phrases, or descriptions to uncover evidence of caregiver sleep and bereavement experiences to provide units of data. As the units of data were coded, each code representing one of the five conceptual clusters of sleep and bereavement was entered into the Ethnograph computer program.

Trustworthiness of the study findings was achieved through procedures to ensure credibility, consistency, dependability, and transferability (Sandelowski, 1986). Credibility (validity) was achieved by returning to the transcripts to confirm interpretations. Consistency (reliability) was attained by the PI conducting all interviews and by asking the same questions to all participants. Dependability (validity and reliability) was ensured by having a PhD-prepared coinvestigator familiar with qualitative analysis code 30% (n = 3) of the interviews along with the investigator. Coding procedures and resultant codes for themes were evaluated in a work session. A 95% agreement existed between the researchers regarding coded data. A consensus session was held to refine procedures for the disputed data. Transferability (generalizability) was attained by conducting the interviews in participants' natural environments.

Results

Demographics

A total of nine caregivers participated in the study. Caregivers were mostly female (78%), Caucasian (89%), and spouses of the patients (77%). The mean age of caregivers was 52 years, with a range of 28–67 years. Educational level ranged from 12–25 years, with a mean of 16 years. Patients' mean age was slightly older than the caregivers' (68 years), with a range of 36–89 years. Patients were diagnosed with a range of illnesses (cancer, cardiac, and respiratory), and caregiving ranged from days to months. Length of bereavement ranged from 1–6 months, with a mean of 5.5 months.

Three instruments were used to describe the sample: overall health, sleep (PSQI), and depressive symptoms (CES-D). Although the primary focus of the exploratory study was the participants' experiences, the context provided by a full description of the individuals was improved with the use of these instruments. Given the sample size, the quantitative findings are intended only to offer descriptive information about the sample.

Overall Health

Caregivers most frequently reported their overall health as good or fair (n = 6), two caregivers reported their health as excellent, and one reported having poor overall health.

Sleep

Caregivers reported a mean PSQI score of 12 (SD = 6.2). Scores greater than 5 indicate moderate to severe sleep problems in two or more of the seven component areas. Components where participants experienced the greatest sleep disruptions were latency, duration, and efficiency. Sleep latency scores ranged from 0-120 minutes, with a mean of 37 minutes (SD = 43). Sleep duration scores ranged from 1-7.5 hours, with a mean of 4.3 hours (SD = 2.2). Sleep efficiency scores ranged from 27%-87.5%, with a mean of 58.7% (SD = 18) for eight of the nine caregivers. With the exception of one caregiver who reported a sleep efficiency of 94%, the findings indicate that the participants in this sample were experiencing severe levels of sleep disruption. The American Academy of Sleep Medicine recommends that individuals have sleep latency below 15 minutes, duration of more than seven hours, and sleep efficiency of greater than 85% (Buysse et al., 1989).

Depressive Symptoms

Seven caregivers reported a mean score of 34.5 on the CES-D. Scores ranged from 11–55 (SD = 17.8). With the exception of two caregivers who reported CES-D scores of 0, the participants in this study were experiencing moderate to severe depressive symptoms. A score greater than 16 is indicative of increased risk for clinical depression (Radloff, 1977).

Caregiver Narratives

Interviews ranged in length from 1.5–2 hours each. Participants expressed that the interviews were helpful in that they provided an opportunity for catharsis in a safe and non-judgmental environment. Analysis of participant narratives revealed five themes: nightmares, WASO, scheduling, daily life, and bereavement.

Sleep was described by most caregivers as severely disrupted. Caregivers frequently spoke of having nightmares. The

nightmares took several forms. Whereas some caregivers expressed that their nightmares were focused on "re-living" the deaths of their loved ones, others stated that their nightmares centered on questions about "making the right decisions." In all cases, caregivers found the nightmares to be repetitive and severely disruptive to their sleep patterns. Some caregivers went as far as to say that they were afraid to try to sleep for fear that the nightmares would come. Caregivers gave the following descriptions of their nightmares.

- "Same dream . . . of not being able to breath . . . since that is how she died. . . . I wake up and I have to really work to catch my breath. I feel like I can't breathe."
- "I have a lot of nightmares and trouble staying asleep."
- "After my mom's death, every time [my husband] moved, I'd scream. And he'd say, 'Don't scream.' I said, 'I didn't know I'd screamed.' You know, because it was in my sleep."
- "I'm just so afraid to go to sleep. I have bad dreams, and they are so horrible. Everybody wants to have this happy dream about the person they loved; it hasn't happened."
- "Being the nurse in the family, I had all the pressure about making the right decisions; I had all these dreams about making the wrong decisions."

Natural sleep serves a restorative function for the mind and body. Sleep must occur in a regular pattern with only minimal disruptions to be fully effective in this function. WASO is a way to measure the frequency and duration (number of minutes) that an individual is awake during sleep episodes—roughly translating into the amount of restlessness experienced during sleep times. Individuals are expected to awaken for short, infrequent times during sleep episodes; however, the WASO experiences expressed by participants in the current study can be considered extreme. Participants described this experience in the following ways.

- "Sometimes I'll go to sleep and wake up an hour later, or 30 minutes later, then it'll take me another half hour to get to sleep, and then I'll wake up again . . . over and over."
- "What was hard was waking up suddenly for no good reason and then not being able to get back to sleep. Being in that [patient's] bed, in that room."

As mentioned earlier, sleep is most effective in its restorative functions when it follows a regular and predictable pattern. Small amounts of disruptions to sleep patterns can be tolerated and compensated for in the body; however, prolonged disruptions can result in negative physiologic, psychological, and sociologic outcomes. Family caregivers' sleep patterns frequently are dictated by the needs of patients. Once patients are deceased, the caregivers have no schedule to follow. This can result in experiences such as those expressed by the participants in the current study.

- "I don't have to be to work until nine, so I try to stay in bed until eight. Other nights it is about three or four [hours of sleep]."
- "My sleep pattern is very irregular. I can fall asleep immediately. I sleep for approximately one hour, then I'm up. I clean or something, and then I go back to sleep."
- "I nap a lot. I count five or six hours of nap time as my sleep, too. It's just about 20 minutes or so at a time."
- "My sleep is fairly bad, because it's been the two or three hours sleep and awake for two or three hours and then back to sleep for two or three hours. So, that to me is very bad."

Individuals' ability to successfully accomplish daily tasks often is dictated by the level of physical, emotional, and mental energy available. Sleep quality (latency, duration, efficiency, and WASO) determines the amount of energy available. Participants expressed how their lack of quality sleep often led to low energy levels, which, in turn, resulted in an overall inability to accomplish even the simplest of daily tasks.

- "I have trouble staying awake in church; isn't that awful? I have a real hard time."
- "At work I can get it done, but personally, no. I feel I'm not getting anywhere."
- "Every day it's a struggle getting out of bed. Every day!"
- "Physically, I feel just really drained. I don't feel like I'm giving 100% at work like I should be doing."
- "I'm just scattered. I mean, I'll start to do something and then forget what I was doing. . . . That's just lack of sleep as far as I'm concerned."
- "It's like going around in circles and trying to do something, but I just can't get it done."

Bereavement is a normal process resulting from loss. To move through the process, individuals must accomplish various tasks, all of which require energy. Many participants expressed that poor sleep left them with low energy levels. Two participants clearly articulated sentiments expressed by all participants about the relationship between low energy and movement through their bereavement.

- "I'm having a real hard time. I guess it's grief. I'm tired all the time, and I have no energy to get it done [sell mother's house]."
- "Inside, I think I am having a lot of turmoil, a lot of problems. I have a son to take care of, so I put on my happy face. But I'm having a rough time."

Discussion

The data presented in this article suggest that bereaved family caregivers suffer from severe levels of sleep problems and depressive symptoms. This supports the findings of other studies with the bereaved (Lavie & Berris, 1996; Reynolds et al., 1993; Steeves, 2002). The participants in the current study had been providing care to individuals with chronic illnesses who had died in the past six months. Research suggests that people in the first six months of bereavement are at the greatest risk of suffering from grief symptoms, including sleep problems and depression (Steeves). The findings from the current small sample seem to support this.

Sleep quality is influenced by several internal and external factors. The participants identified through their narratives several aspects of their daily routines that appeared to be contributing factors to their inability to obtain quality sleep. For example, participants stated that they did not have a routine time for sleep. Failure to have a routine sleep schedule has been shown repeatedly to affect sleep quality (Naitoh, Kelly, & Englund, 1990; National Sleep Foundation, 2005; Riedel & Lichstein, 2000). With prolonged sleep loss, an increasing drive to sleep develops. The drive to sleep can be over-ridden, resulting in a disruption of the sleep-wake cycle. If the sleep-wake cycle is disrupted, the body does not know when it is supposed to be asleep or awake, ultimately disrupting both states.

Poor sleep quality contributes to an inability to accomplish activities of daily living (Clark et al., 1995; Riedel & Lichstein, 2000). Participants expressed through their narratives

that poor sleep quality appeared to be affecting their ability to carry out their daily life tasks. Quality sleep provides the emotional, mental, and physical energy needed to function optimally during the day. Even one night of poor sleep can result in feelings of inability to concentrate or function optimally during the day (Naitoh et al., 1990). Prolonged sleep loss may affect decision making and physical response times, placing people at risk for injury.

Common in the bereavement literature are reports of night-mares (Steeves, 2002); however, existing literature fails to make a connection between nightmares and WASO episodes. The literature only mentions that nightmares are a common occurrence, without discussion of how nightmares may affect the overall sleep quality of the bereaved. The number of WASO episodes (frequency and duration) speaks to the fragmentation of sleep. Fragmented sleep results in less time spent in the restorative sleep stages (3 and 4). Sleep literature suggests that commonly used stimulus-control techniques might be helpful to allow caregivers to return to sleep without prolonged WASO periods. No studies to date have used stimulus-control techniques in bereaved caregivers.

Poor sleep is recognized in bereavement literature as a frequent occurrence during the bereavement process (Lavie & Berris, 1996; Reynolds et al., 1993; Steeves, 2002). What has not been explored but appears to be suggested in the current study's participant narratives is the impact of sleep quality on movement through the bereavement process. Participants expressed that poor sleep quality affected their ability to carry out their daily tasks, but they also mentioned that poor sleep quality impeded their ability to accomplish their bereavement tasks. Steeves and Kahn's (1995) qualitative work with bereaved individuals suggested that three tasks must be accomplished in bereavement (grief work, re-knitting of the social fabric, and finding meaning without the deceased). These tasks require emotional, mental, and physical energy. Without quality sleep, energy may not be available to accomplish the tasks of bereavement.

Implications for Nursing

Bereavement is a complex process that usually resolves with time. The author is not suggesting that a "good night's sleep" is all that is needed to move successfully through the process; however, this article raises the question, "Does improved sleep impact the available energy needed to accomplish the tasks of bereavement successfully?" The purpose of the descriptive study reported in this article was to begin to explore the relationship between sleep and bereavement in family caregivers. The findings suggest an important connection between sleep and bereavement; however, as is common in descriptive studies, more questions were generated than answered. Future directions include (a) longitudinal quantitative and qualitative explorations of sleep patterns during bereavement, (b) development and testing of a behavioral intervention to improve sleep quality for bereaved individuals, and (c) an exploration of the impact of sleep quality on physical and emotional health in bereaved family caregivers. Qualitative and quantitative methods are necessary for further studies, as the context is of great importance in understanding the relationship between sleep and bereavement outcomes.

Although the sample size was small (N = 9) and the data cannot begin to be generalized to the overall population, important information was generated, meeting the study's aim.

Qualitative and quantitative researchers who are interested in conducting research to evaluate and hopefully improve sleep quality in bereaved individuals can use the information as a starting point to design future studies. Sleep is a basic physiologic need that healthcare professionals are only beginning to understand. Bereaved individuals are under a substantial amount of stress; having quality sleep may provide the energy needed to accomplish the tasks of bereavement.

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Author Contact: Patricia A. Carter, PhD, RN, CNS, can be reached at pcarter@mail.nur.utexas.edu, with copy to editor at rose_mary@earthlink.net.

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