

Caregivers' Descriptions of Sleep Changes and Depressive Symptoms

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Purpose/Objectives: To describe caregiver sleep and depression using caregiver narratives. To compare qualitative descriptions with quantitative scores.

Design: Descriptive, one-time, open-ended interview followed by structured sleep and depression questions.

Setting: Interview conducted in person or via telephone at caregiver's preference.

Sample: 47 caregivers of patients with advanced stage cancer. Caregivers had a mean age of 54 years, and most were female (81%), Caucasian (82%), and spouses (61%). They provided care for a mean of 24 months. Patients' diagnoses were lung cancer (36%), colorectal cancer (13%), or recurrences (51%).

Methods: Two cancer care sites in southern California provided participants. After consent, the researcher conducted interviews. The Pittsburgh Sleep Quality Index (PSQI) and Center for Epidemiological Studies–Depression (CES-D) instruments were administered following interviews.

Main Research Variables: Sleep pattern changes and depression levels over time as defined by caregivers.

Findings: Caregivers described severe fluctuations in sleep patterns over time and how these changes affected caregiver depressive symptoms. PSQI and CES-D scores matched narrative comments.

Conclusions: Caregivers' narratives suggest they suffer progressive sleep deprivation that affects their emotions and ability to continue as caregivers.

Implications for Nursing: Nurses must recognize the severe sleep problems experienced by caregivers and respond with interventions to increase sleep quality and decrease depression.

Key Points . . .

- ▶ Family caregivers of patients with cancer suffer ever-increasing stress over the duration of their caregiving experience.
- ▶ The roller-coaster ride of caregiving challenges caregivers' endurance and coping abilities.
- ▶ Caregivers lose sleep, which leads to irritation and anger with the patients with cancer, ultimately resulting in caregiver depression.
- ▶ Nurses and other healthcare providers must understand the burdens that are placed on family caregivers and the outcomes of these burdens if they are to assist caregivers in keeping patients at home during their final months of life.

any possible correlation between caregiver narrative descriptions of sleep and depression with caregiver scores on widely used quantitative sleep and depression instruments.

Depressive symptoms (e.g., sadness, tearfulness, irritability, fearfulness) are feelings expressed by caregivers as a result of their caregiving experiences that would indicate the presence of or risk for depression. Depression is one of the most frequently studied caregiver outcomes (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Nijboer, Triemstra, Tempelaar, Sanderman, & van den Bos, 1999; Schwarz, 1999; Yates, Tennstedt, & Chang, 1999). Depression can have devastating effects on caregivers' health and their ability to continue to provide care for patients with cancer (Given, Given, Stommel, & Azzouz, 1999). Higher rates of depressive symptoms consistently have been observed among family caregivers compared to their same age peers who are not caring for ill relatives (Aneshensel et al.; Dura, Stukenburg, & Kiecolt-Glaser, 1990; Tennstedt, Cafferata, & Sullivan, 1992).

Several factors related to caregiver depression include time since diagnosis, type of diagnosis, patient age, patient

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Family caregivers suffer tremendous stress as a result of providing increasingly intense care to patients with advanced stage cancer. Caregivers report severe levels of depression that affect their daily functioning, quality of life, and ability to continue to provide care to their dying family members (Jepson, McCorkle, Adler, Nuamah, & Lusk, 1999; Wyatt, Friedman, Given, & Given, 1999). Depression is a normal response to the loss and grief that accompany a family member's diagnosis with a potentially fatal disease; however, other factors amenable to intervention (e.g., chronic sleep deprivation) may severely exacerbate the normal response. Few studies have addressed changes in family caregiver sleep patterns over time and how these changes affect caregiver depression levels (Carter, 2000; Carter & Chang, 2000; McCurry, Logsdon, Vitiello, & Teri, 1998; McCurry & Teri, 1995; Wilcox & King, 1999). In addition, few studies have explored

functional needs, social support, and relationship quality (Douglass, 1997; Given et al., 1999; Given & Given, 1992; Knop, Bergman-Evans, & McCabe, 1998; Kurtz, Given, Kurtz, & Given, 1994; Kurtz, Kurtz, Given, & Given, 1995). Most studies have relied on standardized instruments (e.g., depression inventories) to describe caregiver depression. Although these instruments are useful for quantifying caregiver depression and comparing it to other populations, they may not fully capture the depressive symptoms experienced by family caregivers because they limit family caregivers' responses to set alternatives. By allowing family caregivers to describe their experiences in their own words, the current study's researcher was better able to understand the essence of caregiver experiences that may have been lost using only structured questions.

For the purposes of this study, "sleep pattern changes" are the variations in caregivers' normal sleep patterns that result from providing care to patients with advanced stage cancer. Chronic sleep loss is a potential contributing factor to caregiver depression that only recently has been addressed in the scientific literature (Carter, 2000; Carter & Chang, 2000; McCurry et al., 1998; Wilcox & King, 1999). Research has shown that family caregivers' sleep is disturbed in several ways. For example, McCurry and Teri (1995) found that 68% of 136 family caregivers reported some form of sleep disturbance, sleep initiation, maintenance problems, or daytime fatigue. Bramwell, MacKenzie, Laschinger, and Cameron (1995) reported that a majority of 37 family caregivers of patients with terminal cancer were receiving more than four hours of sleep per night, but 59% appraised this amount of sleep as inadequate. Patients with cancer at the end of life often require 24-hour assistance with their personal needs; in addition, medications for pain and other symptoms must be given at regular intervals (e.g., every four hours) to be most effective. These needs necessitate caregivers being "on-call" during nighttime hours, as well as during the day. Family caregivers report to practitioners that they often are isolated and provide 24-hour care without assistance from family or friends. Given this clinical knowledge regarding chronic sleep loss among family caregivers, remarkably few studies have attempted to describe sleep pattern changes from the caregivers' point of view.

Purpose

The purpose of this article is to report the findings of an examination of the narrative descriptions of 47 caregivers' experiences. The specific aims of the study were to explore caregiver descriptions of sleep and depression and descriptions of connections between these two variables over time. Qualitative and quantitative sleep and depression findings were compared for discrepancies.

Framework

Family caregiving is a complex biopsychosocial process in which the outcomes are dependent on caregivers' perceptions of their experience, as well as their appraisal of their abilities to meet the demands presented by the caregiving situation. Pearlin, Mullan, Semple, and Skaff (1990) developed the Caregiver Stress Process Framework based on the earlier stress and coping work of Lazarus and Folkman (1984). This framework presents caregiving as a process in-

volving several stress factors, both past and present, that influence one another to result in physical and emotional outcomes for caregivers. Individuals assume the caregiver role and view the experience of providing care to a patient with advanced stage cancer in different ways based on their past experiences and several environmental and psychosocial stress factors that arise during the caregiving process.

The Caregiver Stress Process Framework allows for the exploration of the caregiving experience from individuals' frame of reference in a naturalistic setting. Researchers have demonstrated that the objective task being performed will not determine the degree of caregiver burden expressed. In fact, caregivers' perceptions or appraisals of the task determine the burden expressed and, ultimately, the negative or positive physical and emotional outcomes seen (McClenahan & Weinman, 1998; Nijboer et al., 1999; Schwarz, 1999; Yates et al., 1999).

A qualitative approach is needed to understand caregivers' experiences and, more importantly, their perception of their experience. The current study aimed to do just that. By asking caregivers to describe their experience, the investigator gained an understanding of the environmental and psychosocial factors influencing their perceptions of caregiving.

The Caregiver Stress Process Framework is used widely in caregiver research to identify and explore the relationships between factors influencing caregiver outcomes. Aneshensel et al. (1995), Pearlin et al. (1990), and Skaff and Pearlin (1992) used this framework with family caregivers of patients with dementia. Similarly, other researchers have used this framework with caregivers of patients with AIDS or cancer (Carter, 2000; Turner, Pearlin, & Mullan, 1998).

Methods

A descriptive, one-time, open-ended interview, followed by structured sleep and depression questions, was used to explore the main research aims.

Setting and Sample

Nonprobability convenience sampling was used to recruit family members or friends of patients who were being treated for advanced stage cancer at one of the two study sites in the southern California area. Individuals who met the inclusion criteria were invited to participate in the study. The following inclusion criteria were used: 18 years of age or older; self-identified as the primary caregiver of a patient with advanced stage cancer; coresiding with the patient with cancer; helping the patient for more than one month; preferring to read, write, and speak English; and willingness to participate in the study.

Procedure

After receiving approval from the university human subjects protection committee, the investigator met with the agency staff to plan participant recruitment. The investigator telephoned all potential participants identified by agency staff, explained the study, determined eligibility, and invited caregiver participation. Participants gave verbal consent, and telephone or in-person interviews were scheduled at the caregivers' convenience. During the interviews, the investigator read all questions aloud to participants. All interviews were audiotaped with the participants' permission. Following the interviews, participants were given the opportunity to

listen to and delete any sections of the audiotape recordings. All participants declined this opportunity. Audiotape recordings were transcribed verbatim. For the purposes of this study, all identifying information was removed from caregiver comments (i.e., names have been changed). All data were stored in a file cabinet; they were accessible only by authorized research associates in accordance with requirements for data confidentiality.

Instruments

Qualitative data were generated by a guided interview focusing on participants' experiences. The initial question was "What has it been like for you helping (name of person with cancer)?" Probe questions were asked to gain further information. Example probe questions included, "Can you tell me about your sleep since your family member's diagnosis?" and "Can you tell me about your mood since your family member's diagnosis?" Participants were encouraged to talk about any and all of their caregiver experiences. Probes such as, "Can you tell me more about that?" and "That is very interesting," were used as necessary to elicit additional information. Each participant was interviewed once either in person or by telephone at the caregiver's preference. Interviews ranged in length from one to four hours with a mean of two hours per interview.

Depression: Family caregiver depression was measured using the **Center for Epidemiological Studies–Depression (CES-D) scale**, a 20-item, four-point Likert scale ranging from 1 (never) to 4 (most of the time) (Radloff & Teri, 1986). Responses are summed, and higher scores indicate more depressive symptoms. Scores above 16 are considered to be indicative of increased risk for clinical depression. The CES-D was designed to measure depressive symptoms in nonpsychiatric subjects and has been used with caregivers. Li, Seltzer, and Greenberg (1999) reported an alpha reliability of 0.86 and 0.90 for 103 wife and 149 daughter caregivers, respectively. Lawton, Moss, Kleban, Glicksman, and Rovine (1991) reported an alpha of 0.90 in a sample of 632 caregivers of patients with Alzheimer's disease. Cronbach's alpha with this study population was 0.90.

Sleep: Family caregiver sleep problems were measured using the **Pittsburgh Sleep Quality Index (PSQI)** (Buysse, Reynolds, Monk, Berman, & Kupfer, 1989). This index has 19 self-rated questions that require participants to reflect back over the previous month and describe their sleep experiences. Items are combined into seven subscale scores (i.e., sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, sleep medications, and daytime dysfunction), each of which has a range of 0–3 points. In all cases, a score of 0 indicates no difficulty, whereas a score of 3 indicates severe difficulty. The seven subscale scores then are added to yield one global score, with a range of 0–21 points (0 indicates no difficulty, and 21 indicates severe difficulties in all areas). A global score greater than or equal to 5 indicates that a subject is having severe difficulty in at least two areas or moderate difficulty in more than three areas (Buysse et al.). In their study of 90 female caregivers of patients with dementia, Wilcox and King (1999) reported a Cronbach's alpha of 0.69. Cronbach's alpha for this study was 0.81.

Data Analysis

Qualitative data were managed via the Ethnograph, Version 5.0 (Seidel, 1998), computer program to facilitate coding and

analysis. All interviews were audiotape 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, which included extensive reading of the interview material and searching line by line for words, phrases, or descriptions to uncover evidence of caregiver sleep or depression to provide units of data. The units of data were coded, with each code representing one of the two conceptual clusters of sleep or depression that was entered into the 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 investigator conducting all interviews and asking the same questions of all participants. Dependability (validity and reliability) was ensured by enlisting a graduate nursing research assistant familiar with qualitative analysis in coding 20% ($n = 9$) of the interviews, along with the investigator. Coding procedures and resultant codes for themes were evaluated in a work session. A 95% agreement was found between researchers regarding coded data. A consensus session was held to refine procedures for the disputed data. Conducting the interviews in participants' natural environments attained transferability.

Descriptive statistics, calculated using SPSS® (SPSS Inc., Chicago, IL) for personal computers, were used to summarize demographic data; the scores on the CES-D and PSQI were used to obtain a profile of the sample characteristics. Cronbach's alphas were calculated as measures of internal consistency for each instrument.

Caregiver total scores on the CES-D and PSQI were compared to narrative caregiver comments coded as depression or sleep. This was done by dividing caregiver narrative segments coded as depression or sleep into categories that would appear to indicate either severe (high) or mild (low) depression or sleep problems. Caregiver comments from each group (high and low depression and sleep) then were compared with the CES-D and PSQI total scores reported by individual caregivers.

Results

Forty-seven family caregivers participated in this study. Caregivers were mainly wives (41%), followed by daughters (28%), husbands (20%), and other relatives and friends (12%). All participants identified themselves as caregivers and were living in the same home with the person with cancer. The duration of the caregiving experience ranged from 3–142 months, with a mean of 24.28 months. The hours spent with the care recipient ranged from 1–24 hours per day, with a mean of 15.78 and a mode of 24 hours.

Caregivers ranged from 26–75 years of age, with a mean of 53.65 years. Forty-one caregivers were female. Most of the caregivers were Caucasian (82%); however, Asian, Hispanic, and African American caregivers also participated in the study. The caregivers were well educated with 41 (80%) having some college education. Caregivers frequently were involved in other roles in addition to their caregiver role (e.g., employee, parent, volunteer). Fifty-five percent had at least one other role, whereas 27% reported having two or more

other roles. More than half of the caregivers were employed at the time of the care recipient's cancer diagnosis. Of those who were working, 15% stated they quit their jobs because of caregiving and 59% reported having to reduce the amount of hours that they worked. Twenty-two caregivers (43%) were retired at the time of diagnosis.

Individuals with cancer were diagnosed with primary lung (n = 17) or primary colorectal cancer (n = 6) or recurrences from other cancer sites (n = 24). All cancers were at advanced stages at the time of the caregiver interviews. All care recipients had received at least one type of conventional treatment (i.e., chemotherapy, surgery, or radiation), with 21 having had two of these three at some point during their illness. Patient gender was almost evenly split with just more than 50% being male. Patients' ages ranged from 19–89 years with a mean of 62.8 years (SD = 14.5), and most were Caucasian (84%).

Qualitative Findings

A total of 94 interview hours were generated from the 47 family caregiver interviews. Family caregivers related the sequencing of events from diagnosis to the point of interview, as well as their personal experiences and emotional and physical reactions regarding each of these events. During data analysis, several recurring themes were identified (e.g., problems and challenges, information needs, roles, losses); however, two of the most prominent of these were caregiver sleep problems and depressive symptoms. Additionally, caregivers discussed the links between chronic sleep loss and the subsequent development or worsening of their depressive symptoms. Only the themes of sleep loss and depression and the links between sleep and depression will be presented in this article.

Caregiver depression holds the attention of many researchers, healthcare providers, patients, and families. The comments regarding depressive symptoms from the caregivers who participated in this study were supportive of comments made by other caregiver samples. Some of the caregivers in this sample reported feelings congruent with mild depression, such as the following comment made by a wife caregiver: "I feel down, but not all the time; we still have some fun together."

Conversely, more frequent responses from these caregivers were congruent with moderate to severe depression. The following comments are representative of those made by more than 50% of the caregivers in this study.

You feel helpless because, it's like we're up against a stone wall and it's really difficult. I get so sad.

I get uptight because I can't do anything to help, and I'm so tired. I just get really, really uptight.

I've been falling into this spot where when I have my time to do something, I just like to close out everybody, just leave me alone.

I wanted to help her, and I was completely lost. What was I supposed to do, what was my role, and how do I go about it; it is terrible, absolutely horrible.

It's like a nightmare. Somebody wake me up. Somebody pinch me and tell me this isn't happening.

You just crawl on, not one step in front of another, but one knee in front of another.

Well, the future right now, I don't think about it. I can't deal with the present right now. I don't want to indulge in the future.

I'm always worried, the hardest part is that it is prolonged. If he would just die, I could deal with it. It would be less stress, he'd be gone. You deal with the things you have to.

In general, I feel sad on a constant basis.

All caregivers reported some change in their sleep since their family members' diagnosis of cancer. More than 95% of the caregivers in this sample reported moderate to severe sleep problems. Caregivers said, "I don't sleep. I mean, I shouldn't say I don't sleep, I sleep four hours, sometimes two, sometimes three," and "Oh, I'm so tired."

One of the origins of the caregivers' sleep problems, according to their comments, was the patients' own sleeping difficulties.

Four minutes and then a cough again and so he literally just never slept and neither did I.

Oh my God, I rarely sleep. He thrashes around a lot and I soothe him, but sometimes this will go on several times during the night, so I lie there waiting for the next earthquake and never sleep.

Another cause of caregiver sleep loss, revealed in the caregiver comments, was emotion focused.

My sleep is restless. I think I feel very tense when I sleep. I feel a lot of tension, like you know, I wake up with jaw pain.

Finally, caregivers attempted to explain or qualify their depressive symptoms by linking their symptoms with their chronic sleep loss. The following caregiver comments "explain" the link between chronic sleep loss and depressive symptoms.

When I have a bad night [sleeping], I don't have any patience. I just go off the deep end. I have good days and bad days. You can only get a grip for so long and that's it.

I suspect my sadness is probably aggravated when I don't get a lot of sleep.

If I don't sleep, then I cry all day. Some days I just turn off and I don't feel anything because if you start feeling, you just fall apart.

I notice in myself if I don't get enough rest then I am more stressed and I get more depressed.

Sleep deprivation is something. Yesterday and the day before were the first two days that I felt angry with her for getting me up . . . I felt so sad afterward. She can't help her disease.

I was going crazy, no sleep, and worried all the time.

A model of the connection between sleep loss and depression can be derived from the caregiver narratives. Family caregivers described the process as beginning with chronic sleep loss that leads them to feel irritable toward the patients with cancer. This feeling of irritability leads to anger with the patients with cancer and their ever-increasing needs for care. Anger leads to feelings of guilt in caregivers, and guilt leads to depressive symptoms. Conversely, caregivers described that

with a “good night sleep,” they were less irritable and better able to cope with the needs of the patients with cancer. Overall, feelings on days that followed good nights were less likely to be depressive.

Findings

In addition to the open-ended interview, caregivers answered a series of structured questions regarding their sleep (PSQI) and depression (CES-D). A full report of these quantitative findings can be found elsewhere (Carter & Chang, 2000), but a summary of the results is presented here.

Caregiver sleep problems: The sample, on average, reported a severe level of sleep problems ($\bar{X} = 11.4$, $SD = 4.4$). In fact, 95% of caregivers reported severe overall sleep problems. They reported moderate to severe sleep problems on six of the seven PSQI subscales (i.e., sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, and daytime dysfunction) (see Table 1).

Caregivers scored lowest or had the least problems with sleep medication. This appears to indicate that caregivers did not need to use sleep medications to aid in sleeping. During the interviews, several caregivers revealed that they had been prescribed sleep medication but were reluctant to take it because it prevented them from being able to monitor the patients’ needs during the night.

Caregiver sleep scores were explored further by dividing the sample by gender. These scores are presented in Table 2. Other studies with caregivers have found that male caregivers may respond differently than female caregivers when exposed to similar objective stressors (Yee & Schulz, 2000). These studies primarily explored indicators of caregiver burden (e.g., anxiety, depression). No studies to date, other than the one reported here, have attempted to describe possible differences in male and female caregiver sleep disturbances. In this study, male caregivers reported an overall sleep quality that was slightly better than the female caregivers (11 versus 11.53). Differences also were present between male and female caregivers’ responses to the sleep subscales, but none of these differences was found to be statistically significant.

Caregiver sleep scores were divided into spouse and non-spouse categories. Both groups reported similar scores; therefore, no statistically significant differences were noted.

Caregiver depression: Caregivers’ depression scores ranged from 0–44 ($\bar{X} = 19.3$, $SD = 11.1$). Twenty-seven caregivers (57%) scored at or above the standard population

cutoff of 16 for the CES-D, indicating that they were at risk for developing clinical depression. Caregiver depression scores were divided by gender. Male caregivers reported higher depression scores than female caregivers; however, the differences were not statistically significant. Depression scores also were divided into spouse and nonspouse categories. Spouse caregivers reported significantly lower ($p = 0.053$) depression scores than nonspouse caregivers. These findings are consistent with the findings of Li et al. (1999) and Raveis, Karus, and Siegel (1998) (see Tables 1 and 2).

Quantitative scores and narrative comments: Table 3 provides a sample of caregiver comments and the corresponding PSQI and CES-D scores reported by these individuals. Overwhelmingly, caregiver narratives (high and low sleep and depression problems) were congruent with the scores for the PSQI and CES-D.

Discussion

The plight of the family caregiver has captured the interest of researchers, healthcare professionals, and policy makers alike. With the aging of society and the increasing number of individuals being diagnosed with advanced cancer, family caregivers are being pushed into assuming a greater role in caring for the needs of this population. Although family members often are willing to take on this role, it does not come without a personal cost. Caregivers of patients with cancer suffer fatigue, sleep disruptions, physical injury, isolation, anxiety, and depression (Brody, Litvin, Hoffman, & Kleban, 1995; Kiecolt-Glaser, Marucha, Malarkey, Mercado, & Glaser, 1995; Pearlin & McKean, 1996; Vitaliano, Scanlan, Krenz, Schwartz, & Marcovina, 1996).

This study sought to add to the research knowledge by describing the sleep problems and depression experienced by caregivers of patients with cancer and exploring the relationship between these two variables within the stress process framework presented by Pearlin et al. (1990). Admittedly, the major limitation of the study was its restricted generalizability. Caregivers were caring for family members with a variety of advanced stage cancers and, therefore, descriptions of sleep and depression for caregivers of patients with specific types of cancer cannot be made. Caregivers, during the one-time interview, reflected back over the duration of their caregiving experience in providing their narratives. Scheduling multiple interviews over a period of time would have been preferable to assess and reassess sleep and depression. Additionally, multiple interviews would have allowed for assessment of how sleep and depression may change over the illness trajectory. All caregivers in this study were well educated and had an upper-middle-class income. Although this is typical of the geographic area where this study was conducted, it is not typical of the entire cancer caregiver population. Finally, the sample consisted of spouse, adult child, and other (e.g., sibling, friend) caregivers. Even though their experiences and burdens are similar and no significant differences were found in sleep between relationship groups in this sample, differences were found in depression scores. Future researchers should consider a more homogeneous sample and a longitudinal design.

Of the 47 caregivers included in this sample, more than 50% were experiencing depressive symptoms at a level that would suggest they were at risk for developing clinical depression. These findings are consistent with results reported by studies

Table 1. Descriptive Statistics for Caregiver Depression and Sleep Scores

| Variable | Range | \bar{X} | SD |
|-----------------------|-------|-----------|------|
| Depression (CES-D) | 0–44 | 19.3 | 11.1 |
| Sleep total (PSQI) | 2–21 | 11.4 | 4.4 |
| • Quality | 0–3 | 1.7 | 0.8 |
| • Latency | 0–3 | 1.6 | 1.2 |
| • Duration | 0–3 | 2.1 | 1.0 |
| • Efficiency | 0–3 | 1.3 | 1.0 |
| • Disturbances | 0–3 | 2.3 | 0.8 |
| • Medication | 0–3 | 0.9 | 1.2 |
| • Daytime dysfunction | 0–3 | 1.5 | 0.8 |

CES-D—Center for Epidemiological Studies–Depression; PSQI—Pittsburgh Sleep Quality Index

Table 2. Depression and Sleep Scores by Gender, Spouse, and Nonspouse Relationship

| Variable | Male (SD) | Female (SD) | Spouse (SD) | Nonspouse (SD) |
|-----------------------|---------------|---------------|----------------|----------------|
| Depression (CES-D) | 21.11 (11.26) | 18.79 (11.12) | 17.74 (10.67)* | 22.13 (11.58)* |
| Sleep total (PSQI) | 11.00 (3.71) | 11.53 (4.56) | 11.39 (4.25) | 11.50 (4.76) |
| • Quality | 1.89 (0.78) | 1.66 (0.78) | 1.68 (0.79) | 1.77 (0.77) |
| • Latency | 1.33 (1.22) | 1.63 (1.17) | 1.65 (1.17) | 1.44 (1.21) |
| • Duration | 1.89 (1.05) | 2.13 (0.96) | 2.03 (0.98) | 2.19 (0.98) |
| • Efficiency | 1.11 (1.05) | 1.37 (1.00) | 1.35 (0.95) | 1.25 (1.13) |
| • Disturbances | 2.56 (1.01) | 2.29 (0.65) | 2.29 (0.78) | 2.44 (0.63) |
| • Medication | 1.00 (1.22) | 0.92 (1.17) | 1.10 (1.19) | 0.63 (1.09) |
| • Daytime dysfunction | 1.22 (0.67) | 1.53 (0.86) | 1.29 (0.78) | 1.81 (0.83) |

*p = 0.05

CES-D—Center for Epidemiological Studies–Depression; PSQI—Pittsburgh Sleep Quality Index

of caregivers of patients with chronic illnesses other than cancer (Aneshensel et al., 1995; Dura et al., 1990; Given & Given, 1992; Kurtz et al., 1995).

Based on the reported caregiver sleep scores, more than 95% were experiencing moderate to severe overall sleep problems. Relatively little information describes sleep problems in caregivers; however, the results reported here are consistent with the reports of caregiver sleep problems by Bramwell et al. (1995) and McCurry and Teri (1995).

Throughout their narratives, caregivers described how their sleep changed and what types of things affected their ability to sleep well. Caregivers also described how their mood changed over time and how depressive symptoms surfaced. Third, caregivers described how chronic sleep loss set in motion the downward movement toward depressive symptoms. Caregiver narratives corresponded with the scores derived from the PSQI and CES-D.

These caregiver reports fit within the Caregiver Stress Process Framework (Pearlin et al., 1990). Caregivers experience environmental stressors (e.g., sleep loss, patient needs) that ultimately affect their emotional well-being (depression level). New insight has been gained regarding the importance that adequate sleep plays in caregivers' abilities to cope with the daily demands of caregiving. With "good sleep," caregivers found they could handle daily demands, but with "bad sleep" or "no sleep," caregivers were less able

to cope with stress day after day and more likely to experience irritability and anger and ultimately suffer depressive symptoms. In the Caregiver Stress Process Framework, Pearlin et al. suggested that coping serves as a mediating force between stressors and outcomes. These caregiver reports suggest that sleep quality may influence coping ability and thus, according to the Caregiver Stress Process Framework, caregiver emotional and physical outcomes.

Oncology nurses often are the first-line contact with patients and family caregivers. This study provides oncology nurses with information to support the importance of restful sleep and sleep interventions for caregivers. Further implications of these findings for oncology nurses include the impact that caregiver health and well-being may have on patient outcomes. Patients are receiving increasingly complex care at home delivered by their family caregivers. If caregivers are not well rested or if they are depressed, the quality of the care they provide may suffer. This study supports the need for family caregiver sleep interventions; however, further studies are needed to define what is the best sleep intervention for caregivers. Additionally, studies are needed to further explore the effects of sleep on coping and depressive symptoms.

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Table 3. Caregiver Narrative Comments and Corresponding Pittsburgh Sleep Quality Index and Center for Epidemiological Studies–Depression Scores

| Qualitative Comments | PSQI | CES-D |
|---|------|-------|
| "I say to myself, just don't worry about it. But it's just one of those things. It's to the point where I don't want to work or anything. I just want to shut the door and not deal with anything." | – | 37 |
| "I haven't slept—sleeping is a very big problem." | 17 | – |
| "(My husband's cancer) consumes my waking time and my sleeping time." | – | 16 |
| "Sometimes I wake up crying or I wake up scared or shaking or feeling nauseous, and it hasn't even been that long yet." | 7 | – |
| "Some days are better when I wake up, but some days I wake up, like this morning, crying, and I don't even know how it happened." | – | 30 |
| "I can't cope with him, because I can't even get any sleep. I have to get up and clean up stools, all over the floor from the bedroom to the bathroom. He's so restless, he's up and down, up and down, all night." | 17 | – |

CES-D—Center for Epidemiological Studies–Depression; PSQI—Pittsburgh Sleep Quality Index

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For more information . . .

- ▶ MEDLINEplus Medical Encyclopedia: Depression
www.nlm.nih.gov/medlineplus/ency/article/003213.htm
- ▶ Psychology Information: Depression and Depressive Disorders
www.psychologyinfo.com/DrFranklin/depression.html
- ▶ American Cancer Society
www.cancer.org/eprise/main/docroot/MBC/content/MBC_2_3X_Sleep_Problems?sitearea=MBC

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