

Caregivers' Descriptions of Sleep Changes and Depressive Symptoms

Patricia A. Carter, PhD, RN, CNS

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, Sanderma, & 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

Patricia A. Carter, PhD, RN, CNS, is an assistant professor in the School of Nursing at the University of Texas at Austin. This study was sponsored by a research grant, supported by Bristol-Myers Squibb Oncology, from the ONS Foundation and by a Special Research Grant from the University of Texas at Austin. (Submitted September 2001. Accepted for publication December 20, 2001.)

Digital Object Identifier: 10.1188/02.ONF.1277-1283

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