

# Caregiver Burden and Symptom Distress in People With Cancer Receiving Hospice Care

Stephanie Crawford Andrews, MS, ARNP-C

**Purpose/Objectives:** To examine the relationship between caregiver burden and symptom distress in patients with terminal cancer who are enrolled in hospice.

**Design:** Descriptive, quantitative.

**Setting:** A large, metropolitan, nonprofit-based organization in west central Florida.

**Sample:** Convenience sample of 30 patient-caregiver dyads enrolled in hospice.

**Methods:** Caregivers completed the Caregiver Reaction Scale to measure the level of caregiver burden; patients completed the Adapted Symptom Distress Scale. Results were correlated using a Pearson correlation.

**Main Research Variables:** Symptom distress and caregiver burden.

**Findings:** The patient sample exhibited low symptom distress, and the caregiver sample exhibited moderate caregiver burden. A statistically significant moderate correlation existed between symptom distress and caregiver burden.

**Conclusions:** The significant moderate correlation confirms the idea that caregiver burden and patient symptom distress are related. Future studies are needed to obtain a more representative sample of caregivers of patients closer to death, even if those patients are nonresponsive.

**Implications for Nursing Practice:** This information can assist hospice nurses in assessing and formulating targeted care for symptom distress and caregiver burden in their patients.

The focus of care for patients with cancer has moved from the hospital into the home because of shortened hospital stays (Kurtz, Kurtz, Given, & Given, 1995). Laizner, Yost, Barg, and McCorkle (1993) stated that often at the point of discharge patients still view themselves as acutely ill. In addition, more treatments and procedures are being administered on an outpatient basis resulting in little or no time in the hospital. This leads to the family serving as the source of both acute and long-term care (Sarna & McCorkle, 1996).

With little or no training or nursing support, caregivers are asked to attend to the needs of people with cancer (Sarna & McCorkle, 1996). Caregivers help people with cancer with transportation, emotional support, physical care, managing illness-related finances, increasing housework, communication, mobility, medical/nursing treatments, coordinating/scheduling, psychological support, monitoring symptoms/progress, errands, and structuring/planning activities (Carey, Oberst, McCubbin, & Hughes, 1991; Given & Given, 1991; Harrington, Lackey, & Gates, 1996; Hileman, Lackey, & Hassanein, 1992; Kurtz et al., 1995; Laizner et al., 1993; Sarna & McCorkle, 1996; Silveira & Winstead-Fry, 1997; Stetz, 1987;

## Key Points . . .

- ▶ Caregivers take care of their loved ones with cancer with little or no training.
- ▶ Because caregivers are the center of support for the patient with cancer in hospice, if the caregiver fails, the patient suffers.
- ▶ Oncology nurses need measurable ways to identify individuals with high symptom distress or caregiver burden to target care plans.
- ▶ Increased symptom distress in patients with cancer receiving hospice care can predict a potential for increase in caregiver burden.

Yang & Kirschling, 1992). Furthermore, long-term caregiving is a dynamic process in that, over time, the burden changes (Elmstahl, Malmberg, & Annerstedt, 1996). This change may be more rapid among homecare patients who are in the terminal stages of an illness.

With increased responsibility on caregivers, strain may increase and lead to intensified caregiver need (Kurtz et al., 1995). The true impact imposed by this strain is not known. However, patient wellness, survival, and quality of life have been affected by supportive spousal and family relationships (Carey et al., 1991). Because the caregiver is the center of support for the needs of the patient with cancer, if the caregiver fails, the patient suffers (Siegel, Raveis, Houts, & Mor, 1991; Weitzner & McMillan, 1999; Weitzner, McMillan, & Jacobson, 1999). Therefore, more attention should be given to caregivers' needs.

A major part of caregivers' and patients' lives involves symptom management to prevent symptom distress (Stetz, 1993). Symptom distress is a growing problem because caregivers are taking care of these problems at home instead of in a hospital setting where nurses are readily available. Hospice services may help alleviate some of the distress from symptoms and help maintain the maximum amount of independence patients can achieve in their present condition. Hospice services also may lead to a decrease in the amount of

*Stephanie Crawford Andrews, MS, ARNP-C, is nurse practitioner in cutaneous and breast medical oncology programs at H. Lee Moffitt Cancer and Research Institute in Tampa, FL. (Submitted March 2000. Accepted for publication November 17, 2000.)*