Burden and Depression Among Caregivers of Patients With Cancer at the End of Life

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Purpose/Objectives: To examine the patient and family caregiver variables that predicted caregiver burden and depression for family caregivers of patients with cancer at the end of life.

Design: A prospective, longitudinal study was implemented with an inception cohort of patients and their family caregivers who were followed after the diagnosis and treatment of cancer.

Setting: Community oncology sites in the midwestern United States.

Sample: 152 family caregivers of patients with cancer who died during the course of the study.

Methods: Telephone interviews were conducted with patients at 6–8, 12–16, 24–30, and 52 weeks following diagnoses. In addition, patient medical records and state death certificates were reviewed.

Main Research Variables: Effect of caregiver age, gender, education, relationship to the patient, employment status, reports of patient symptoms, patient cancer type, stage of cancer, time from the patient’s diagnosis to death, caregiver burden, and depression.

Findings: Caregivers aged 45–54 reported the highest levels of depressive symptoms, and caregivers aged 35–44 reported the strongest sense of abandonment. Caregivers who were the adult children of patients with cancer and those who were employed reported high levels of depressive symptoms. Feeling abandoned (a portion of caregiver burden) was more prevalent in female, nonspouse, and adult children caregivers, and adult children caregivers of patients with early-stage cancer and patients with multiple symptoms reported a high perception of disruption in their schedule because of providing care. Caregivers whose patients died early following diagnosis reported the highest depressive symptoms, burden, and impact on schedule.

Conclusions: Caregivers reported levels of depression at thresholds for screening of clinical depression. The number of patient symptoms was related to levels of caregiver depressive symptoms. An association also was found between depression and employment status. Caregiver distress was not dependent on demands of care.

Implications for Nursing: Very little research exists that prospectively analyzes family caregiver experiences of burden and depression when providing end-of-life cancer care for a family member. Interventions aimed at decreasing caregiver depressive symptoms should be targeted to caregivers who are middle-aged, adult children, and employed. Interventions aimed at decreasing the burden associated with feeling abandoned and having schedules disrupted while providing care should be targeted to caregivers who are female, nonspouse, and adult children, and caregivers of patients with early-stage cancer and multiple symptoms.

The American Cancer Society (2004) estimated that 1,368,030 new cases of cancer will be diagnosed in the United States in 2004 and more than 563,000 Americans will die from the disease. The burden of providing care for the more than one million American patients with newly diagnosed cancer care is being provided in the home, with family members taking on the role of primary caregivers, assisting patients with activities related to everyday tasks and with medical procedures.

The effects of providing care for patients with cancer at the end of life on caregiver burden and depression have not yet been explored adequately.

Middle-aged, adult children, and employed family caregivers reported higher levels of depressive symptoms than their counterparts.

Key Points . . .

➤ Increasingly, cancer care is being provided in the home, with family members taking on the role of primary caregivers, assisting patients with activities related to everyday tasks and with medical procedures.

➤ The effects of providing care for patients with cancer at the end of life on caregiver burden and depression have not yet been explored adequately.

➤ Middle-aged, adult children, and employed family caregivers reported higher levels of depressive symptoms than their counterparts.

Goal for CE Enrollees:

To examine the patient and family caregiver variables that predicted caregiver burden and depression for family caregivers of patients with cancer at the end of life.

Objectives for CE Enrollees:

On completion of this CE, the participant will be able to

1. Identify caregivers of patients with cancer who report higher levels of depressive symptoms than their counterparts.

2. Identify caregivers of patients with cancer who report a high perception of feeling abandoned.

3. Identify caregivers of patients with cancer who report a high perception of disruption in their schedule because of providing care.

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