Effect of an Integrated Cancer Support Team on Caregiver Satisfaction With End-of-Life Care

Sara L. Douglas, PhD, RN, and Barbara J. Daly, PhD, RN, FAAN

The importance of attending to family needs as an integral part of quality cancer care has been recognized (American Cancer Society, 2014; National Cancer Institute, 2014). An increase in reports of intervention trials to support families has occurred, particularly when a family member has advanced cancer (Northouse, Katepalli, Song, Zhang, & Mood, 2010). The needs of family caregivers have been described as including emotional support or education and practical help in performing tasks of caregiving. Because the care of patients with cancer has increasingly moved to the home, families are taxed with demands for providing physical care, medication administration, and symptom monitoring (Glajchen, 2004). All of these needs have been noted to increase at the end of life (EOL) (Cameron, Franche, Cheung, & Stewart, 2002; Kim & Given, 2008).

Although the quality of care for patients with cancer at EOL has become a major focus of research and quality improvement initiatives, far less attention has been paid to the experience, needs, and satisfaction of family caregivers in the final phase of illness. A number of studies have been performed with mixed samples of families of patients with and without cancer, which have provided some important insights (Steinhauser et al., 2000; Teno, Casey, Welch, & Edgman-Levitan, 2001). Among the items consistently rated as important at EOL by a large sample of seriously ill patients, bereaved family members, and healthcare providers were pain and symptom management and preparation for death (Steinhauser et al., 2000). Others have identified five domains of EOL care that defined quality: physical comfort, control of decisions, relieving family members of the burden of being the constant advocate, education of family members to instill confidence in caring for the loved one, and emotional support of the family (Teno et al., 2001).

The study of effective interventions for family caregivers of people with cancer at EOL is complicated by the recognized influence of situational and individual psychodynamic factors. Presence of social resources and subjective appraisal of stress have been identified as significant predictors of caregiver depression and life satisfaction (Haley, LaMonde, Han, Burton & Schonwetter, 2003), and stress appraisal and coping resources have been identified as key mediating variables influencing caregiver outcomes (Northouse, 2005).

Purpose/Objectives: To test the effectiveness of an interdisciplinary cancer support team (CST) on caregiver satisfaction with end-of-life (EOL) care for family members with advanced cancer.

Design: Quasi-experimental pre- and post-test tandem design.

Setting: Outpatient clinics of a comprehensive cancer center in urban Cleveland, OH.

Sample: 106 family caregivers.

Methods: Participants were enrolled into the control or CST group. Caregiver mood state and social support were measured at enrollment as well as at 3, 9, and 15 months, and satisfaction with EOL care was measured eight weeks after the patient’s death.

Main Research Variables: Caregiver mood state, social support, and satisfaction with EOL care.

Findings: The intervention made no statistically significant contribution to caregiver mood state or perception of social support. The intervention group reported higher satisfaction with overall EOL care as well as five specific areas of EOL satisfaction (i.e., pain relief, information about managing pain, speed in treating symptoms, information regarding side effects, and coordination of care).

Conclusions: The CST yielded improved EOL satisfaction.

Implications for Nursing: Although the emotional impact of an impending loss of a loved one may not change with the provision of support, perception that a loved one was well cared for in the terminal phase of illness may have long-range benefits through the grieving process. Investigation of the long-range effects of satisfaction with EOL care on the grieving process is warranted.

Key Words: family caregivers; end of life; cancer