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Lack of Communication and Control: Experiences of Distance Caregivers of Parents With Advanced Cancer

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Distance caregiving, the experience of providing instrumental and emotional support to an ill loved one who is geographically distant from the caregiver, is a new and relatively unexplored phenomenon in health care, although its prevalence is increasing in the United States. Unlike previous generations in which family members cared for each other in their own homes or communities, many of today's adult children caregivers of parents with chronic illnesses are struggling with the demands of caregiving from a distance by themselves.

More than seven million Americans were distance caregivers in 1997, and the number was expected to grow as baby boomers and their parents aged (Wagner, 1997). According to the National Caregiving Survey conducted by the National Alliance for Caregiving (NAC) and AARP (2004), about 15% of adult children are distance caregivers for parents. The National Council on the Aging ([NCOA], 1997) projected that the number of distance caregivers will increase to 14 million by 2012. The literature on distance caregiving is very sparse and nursing research has been nonexistent, and trending data have not been evaluated nationally since the late 1990s. Although much is known about the effects of caregiving on local caregivers of patients with cancer, little is known about the impact of caregiving on adult children living at a distance. With the number of distance caregivers increasing, research is needed to understand the experience and develop interventions to include these caregivers in family-centered care (Mazanec, 2009; NCOA, 1997). This article presents the qualitative results of interviews with 14 distance caregivers of parents diagnosed with advanced lung, gastrointestinal, or gynecologic malignancies. The caregivers were part of a larger quantitative study exploring predictors of psychological outcomes of distance caregiving (Mazanec, 2009).

Purpose/Objectives: To explore the new and complex phenomenon of distance caregiving in the advanced cancer population.

Research Approach: Qualitative.

Setting: A large comprehensive cancer center in the mid-western region of the United States.

Participants: 14 distance caregivers of parents with advanced cancer.

Methodologic Approach: Patients with advanced lung, gastrointestinal, and gynecologic malignancies consented to have their distance caregiving adult children contacted to participate in the study. Responses to three open-ended questions guided the tape-recorded telephone interviews with the distance caregivers. Following transcription, content analysis with inductive coding was performed.

Findings: Two major themes, communication and control, and five subthemes, benefits and burdens of distance caregiving, dealing with uncertainty, direct action through information seeking, protecting, and staying connected, emerged from the data.

Conclusions: Distance caregivers experience some of the same stressors that local caregivers of patients with cancer experience. In addition, they have unique psychosocial needs related to the burden of geographic distance.

Interpretation: Distance caregivers could benefit from nursing interventions targeted at their unique needs. Innovative interventions using Web-based computer technology for improved communication, as well as supportive care interventions, may be helpful.

Background and Significance

Caregiving for a Family Member With Cancer

A diagnosis of cancer is a major life stressor for the patient and the family (Ferrell, Grant, Borneman, Juarez, & ter Veer, 1999; Given & Sherwood, 2006; Northouse, Kershaw, Mood, & Schafenacker, 2005). In the United