

# A Phenomenologic Study of Family Caregivers of Patients With Head and Neck Cancers

Ann E. Fronczek, PhD, RN

**W**ith the shift of caregiving responsibilities from the healthcare setting to the home, family members face what can, at times, be an overwhelming experience that is fraught with uncertainty about caregiving itself, as well as physical, psychosocial, and economic challenges. Caregivers require support as they balance the demands of everyday life with new caregiving responsibilities.

Family caregiver issues remain a domain of cancer research in need of further study, particularly with understudied populations, such as patients with head and neck cancers (HNCs) and their families (Longacre, Ridge, Burtness, Galloway, & Fang, 2012). Although HNCs are less prevalent than other cancers, many are diagnosed in advanced stages when treatment options require complex and multidisciplinary approaches, including a combination of surgery, radiation therapy, and chemotherapy (Menzin, Lines, & Manning, 2007). As a result, caregivers may need to cope with complex issues, including postoperative wound care, altered facial appearance, communication deficits, eating and swallowing problems, airway and pain management, changes in activities of daily living status, and the effects of myelosuppression (Baehring & McCorkle, 2012; Rodriguez & Blischak, 2010).

## Background

A paucity of literature specifically addresses the actual and potential needs of caregivers when caring for patients with HNCs, and much of it relates to emotional issues (e.g., fear, emotional distress, anxiety, depression). Hodges and Humphris (2009) found that caregivers have more concerns about the recurrence of the cancer than the patients themselves. These high levels of fear positively correlated with emotional distress and anxiety (Hodges & Humphris, 2009; Longacre et al., 2012; Watt-Watson & Graydon, 1995). Anxiety reached clinical levels that required treatment and

**Purpose/Objectives:** To describe and understand the lived experience of family caregivers of patients with head and neck cancers (HNCs).

**Research Approach:** Phenomenology using van Manen's human science approach.

**Setting:** Two hospital systems providing regional cancer care in upstate New York.

**Participants:** Nine family caregivers of patients with HNCs who had completed treatment.

**Methodologic Approach:** Qualitative analysis of semi-structured, conversational interviews about the lived experience of family caregivers.

**Findings:** Five major themes emerged related to the lived experiences of this sample of caregivers: (a) absorption of a large amount of information regarding diagnosis, (b) the importance of support from others, (c) adaptation to new routines and responsibilities, (d) a desire to be vigilant and protect a loved one from harm, and (e) feelings of fear, sympathy, and guilt.

**Conclusions:** Family caregivers of patients with HNCs play a fundamental role in the post-treatment phase of care, including meeting specific physical and psychosocial needs. Further investigation should explore the relationship between information needs and the experience of vigilance and fear.

**Interpretation:** Nurses must include caregivers in physical and psychosocial plans of care. Balancing and meeting information needs of caregivers to avoid undue emotional stress and recognizing their support needs are valuable components of care.

**Key Words:** head and neck cancer; family caregiving; qualitative research

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was higher than that of patients with cancer. This was particularly true in female caregivers of patients with HNCs (Baghi et al., 2007; Hodges & Humphris, 2009; Verdonck-de Leeuw et al., 2007).

Although adequate evidence exists regarding the fears of caregivers, little is available to explain the factors that contribute to these emotions and caregiving burdens. One study of caregivers of patients