Palliative Care Considerations for Patients With Head and Neck Cancer With Children at Home

Verna L. Hendricks-Ferguson, PhD, RN, CHPPN, FPCN, FAAN; and Rebecca Ott, RN, BSN

Adult patients diagnosed with head and neck cancer (HNC) who may have contact with children in the home setting are at risk of experiencing distress because of embarrassing and challenging oral symptoms often associated with an HNC diagnosis and the side effects of required treatments. This article features a case study involving a patient diagnosed with HNC and details how oncology nurses can provide patients with HNC and their caregivers with resources and support.

At a Glance
- Patients with HNC often experience pain and embarrassment because of oral and body image side effects during and after radiation treatments.
- Homecare management stress is commonly reported by caregivers of patients with HNC.
- Oncology nurses are particularly well positioned to offer psychosocial-focused palliative care support to patients with HNC and their caregivers during radiation treatments.

Prior to her diagnosis of head and neck cancer (HNC), K.C., a 57-year-old female patient, noted a nonhealing sore on her tongue. After sharing this oral physical change with her dentist, K.C. received a comprehensive oral evaluation. Next, K.C. was examined by an ear, nose, and throat (ENT) medical specialist; this resulted in an oral biopsy being performed during her first appointment. The pathology revealed a squamous cell carcinoma of the tongue. She was then referred to an oncologist and a surgeon for further evaluation and treatment planning. The surgeon conducted a resection of the tongue tumor with a left lateral partial glossectomy and left selective neck dissection. The tumor was classified as a stage II tumor with a good prognosis after radiation therapy. The radiation treatments were planned and coordinated by a radiation oncologist and ENT physician in the radiation oncology clinic. K.C. received external beam radiation therapy directed at the affected tongue area five days a week for seven weeks in an outpatient radiation center.

K.C. resides in a rural town. As a result, she had to travel about two hours each day for her radiation treatments. She received homecare support from her immediate family also includes six grandchildren and a great-grandchild. Prior to and after diagnosis, she received daily visits from her 26-year-old daughter and 2-year-old grandson. However, K.C. did not have any family members or friends who were able to make a commitment to accompany her and provide psychosocial support during her daily radiation treatments because of other personal commitments (e.g., work, family responsibilities).

Following surgery, K.C. was concerned about her difficulties with speaking clearly and felt embarrassed about her altered facial appearance. Her speech was difficult for others to understand because a portion of her tongue had been surgically removed, and new dentures were put in place. K.C. initially did not want to call or have conversations with family members, and because of her speech difficulties, scheduling follow-up medical appointments was overwhelming for her. Over time, she began to cope with her altered form of verbal communication and became comfortable with having slower ability to pronounce words. K.C. had significant concerns about her postsurgical appearance because she feared the reaction of her 2-year-old grandson. However, with time, her fear and worry lessened because her grandson accepted her altered speech. Also, K.C. became more relaxed at home and in public settings after her initial facial swelling from surgery subsided.

Head and Neck Cancer

In 2016, adults diagnosed with HNC are estimated to constitute 3%–7% of all
diagnosed malignancies in the United States, with a total of 61,760 patients (45,330 men and 16,430 women) expected to be diagnosed; about 13,190 deaths are estimated to occur annually from HNC (American Society of Clinical Oncology, 2015; Ridge, Mehr, Lango, & Galloway, 2016). Most patients with HNC undergo an array of uncontrollable oral symptoms and body image changes (e.g., facial disfigurement) related to surgery and radiation treatments that place them at risk of experiencing a significant loss in quality of life (QOL) (Albornoz et al., 2013; Chen et al., 2009; Haisfield-Wolfe, McGuire, & Krumm, 2012; Haisfield-Wolfe, McGuire, Soeken, et al., 2012). Long-term consequences of patients’ facial disfigurement may include difficulties with uncontrolled oral secretions and swallowing, as well as oral communication limitations.

Alterations to Body Image and Oral Abilities

HNCs represent a group of cancers that originate in the squamous cells in the head and neck of the body, such as the esophagus, larynx, lips, nasal pharynx, and oral cavity (Khuri, 2012). Oncology treatments for patients with HNC often involve invasive surgical procedures, radiation, and chemotherapy within a few months after diagnosis. Because of the unique location of HNCs, patients with this type of cancer often have very visible and embarrassing body image alterations compared to patients with other types of cancers (Precious, Haran, Lowe, & Rogers, 2012). Therefore, the body image alterations associated with HNCs potentially have a profound effect on the affected patients’ QOL (Bond, Hawkins, & Murphy, 2014; Chen et al., 2009; Haisfield-Wolfe, McGuire, & Krumm, 2012; Haisfield-Wolfe, McGuire, Soeken, et al., 2012; Llewellyn et al., 2013). For instance, physical alterations and unpleasant oral symptoms (e.g., swallowing difficulties, uncontrolled oral secretions) often occur before and after radiation treatments and may result in embarrassment, social isolation, and emotional distress for patients, family members, and caregivers (Murphy, 2009; O’Leary & Kinsley, 2013).

Coping Responses Among Family Members

Limited research has focused on the impact of these changes on caregivers, family members, and children of patients with HNC. Among published studies on this topic, one study focused on the concerns of patients with HNC related to caregiver burden and reported the following: (a) caregiver burden was nearly twice as high for men compared to women, (b) caregiver burden was not related to age, (c) the patient’s spouse was most often the primary caregiver, and (d) patients with poor function felt that they were a burden to their caregiver (Precious et al., 2012). A second qualitative study found that patients with HNC with children in their care had fears related to living with the expected physical consequences of HNC treatments, missing the child’s milestones because of death, and explaining diagnosis and preparing children for the body image changes associated with HNC treatments (Semple & McCance, 2010).

Homecare Management

Following oncology treatments, patients with HNC are expected to have homecare needs that exceed the needs of patients diagnosed with other types of cancer (Albornoz et al., 2013; Bornbaum et al., 2012; Precious et al., 2012). These needs may include the inability to conceal the effects of oral symptoms (e.g., drooling), embarrassing facial disfigurement, and communication difficulties and limitations (whisper and/or unclear voice tone). Patients with HNC may also need to adjust to changes in their speech or their ability to swallow and taste, as well as cope with noticeable alterations in facial appearance. Such factors support the need to intervene with patients with HNC who have undergone radiation therapy other than oncology treatments must adjust to more long-term, unpredictable, and emotionally challenging stressors than patients with other types of cancer (Bornbaum et al., 2012).

Implications for Oncology Nurses

Oncology nurses are well positioned to provide education and psychosocial support to the family caregivers of patients with HNC. They can equip family caregivers with the knowledge to provide supportive home care. In addition, oncology nurses can offer anticipatory guidance to family members by providing education on the developmental and cognitive differences in children and how they may react to a family member with HNC. For example, oncology nurses possess advanced knowledge and training to provide education and support that would help minimize potential psychosocial concerns experienced by K.C., her daughters, and her grandchildren. This was particularly important when family members were present while K.C. was displaying uncontrolled oral symptoms or speech problems. Specifically, the psychosocial concerns identified by the oncology nurse in this case study were related to each family member’s coping reactions and responses to K.C.’s oral secretions and facial alterations after surgery, as well as each person’s acceptance of K.C.’s long-term speech limitations and changes in body image.

Conclusion

Oncology nurses can offer patients with HNC and their families information about resources for psychosocial support (e.g., counseling, support groups) and help them develop positive coping strategies during cancer treatment. In this case study, the radiation oncology nurse provided psychosocial support information to K.C. and her family members, resulting in positive outcomes. K.C.’s adult children became actively engaged in using psychosocial information resources and in attending a support group available at their community hospital. Formulating a plan of psychosocial support is also an example of integrating the palliative care philosophy into the care of all patients with cancer. Still, more evidence-based research is needed to help oncology nurses educate family caregivers about the delivery of symptom control mea-
sures and psychosocial support to patients with HNC. Ultimately, family caregiver support will help patients cope with difficult oral symptoms and fears regarding communication with children in their families.

References


