Support Needs of People With Head and Neck Cancer Regarding the Disease and Its Treatment

Mariëlle A.C. Peeters, MSc, Cora Braat, MANP, RN, Janet M.J. Been-Dahmen, MSc, RN, Gerda M. Verduijn, MD, Wendy H. Oldemenger, PhD, RN, and AnneLoes van Staa, MD, PhD, RN

OBJECTIVES: To provide insight into people’s experiences in dealing with the consequences of head and neck cancer (HNC) in daily life and their needs for self-management support.

SAMPLE & SETTING: 13 people with HNC who were successfully treated in the Department of Radiation Oncology at the Erasmus MC Cancer Institute in Rotterdam, the Netherlands.

METHODS & VARIABLES: Two focus groups and six individual interviews; data were analyzed with directed content analysis.

RESULTS: Most patients wished to receive professional support for dealing with post-treatment consequences. Apart from physical complaints, patients had difficulties in dealing with the emotional aspects of HNC and its treatment and struggled with building self-confidence to move on with their lives. Patients mentioned the importance of relatives being there for them but complained that their needs were not always met. Support from fellow patients was valued for their empathetic capacity.

IMPLICATIONS FOR NURSING: Nurses must provide self-management support that meets people’s integral needs inherent in living with the consequences of HNC, particularly in the initial post-treatment period. Practical interventions could be useful.

KEYWORDS head and neck cancer; consequences in daily life; self-management support needs; aftercare; nurses

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Head and neck cancer (HNC) is a relatively frequent type of cancer; it is the sixth most common cancer worldwide (Vigneswaran & Williams, 2014). Each year, about 63,000 people in the United States develop HNC (American Society of Clinical Oncology, 2017). In Europe, about 140,000 people are diagnosed with HNC every year (Perlay et al., 2013); of these, 3,000 are in the Netherlands (Netherlands Comprehensive Cancer Organization, 2017). Data from the Netherlands Cancer Registry show increasing incidence and survival trends of HNC (Braakhuis, Leemans, & Visser, 2014).

Although the number of HNC survivors has risen steadily because of better treatment, survival does not necessarily imply a life free of physical and psychosocial problems related to the disease and its treatment (Aaronson et al., 2014). Treatment usually involves a combination of radiation therapy, chemotherapy, and surgery, and may have several potential side effects, such as facial disfigurement; dry mouth; difficulties with speaking, chewing, and swallowing; and nutritional deficits (Wells et al., 2015). Apart from these physical discomforts, the psychological impact of HNC is significant. Patients may experience anxiety, depression, uncertainty, and hopelessness (Ledeboer, Velden, Boer, Feenstra, & Pruyn, 2005; Neilson et al., 2013; Shiraz, Rahtz, Bhui, Hutchison, & Korszun, 2014). The initial post-treatment period, when patients receive less support from healthcare providers (HCPs) than they did during treatment, is one of the most vulnerable periods in the HNC trajectory (Moore, Ford, & Farah, 2014; Semple, Dunwoody, George Kernohan, McCaughan, & Sullivan, 2008; Wells, 1998). Wells et al. (2015) demonstrated that in the first five years after the end of treatment, many HNC survivors continued to experience distress, fear of recurrence, and oral and...