

# Head and Neck Cancer Survivors

## Specific needs and their implications for survivorship care planning

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**BACKGROUND:** Head and neck cancer (HNC) survivors experience significant sequelae of treatment, including long-term physical side effects and ongoing cancer surveillance.

**OBJECTIVES:** The aim of this study is to understand patients' survivorship knowledge gaps and supportive care needs.

**METHODS:** Through an anonymous cross-sectional survey, the authors evaluated 41 HNC survivors' knowledge regarding post-treatment issues.

**FINDINGS:** Patients had undergone a variety of treatment modalities: radiation, chemotherapy, and surgery. Most had primary care providers, regular dental care, and caregivers. HNC survivors' correct responses to side effect knowledge questions were lowest for items regarding hearing loss, sleep, tiredness, and anxiety. About one-fourth correctly identified cancer risk with alcohol intake. The majority correctly linked tobacco products to cancer recurrence.

### KEYWORDS

head and neck cancer; survivorship; supportive care; post-treatment; side effects

### DIGITAL OBJECT IDENTIFIER

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**WITH AN ESTIMATED 436,000 HEAD AND NECK CANCER (HNC) SURVIVORS** in the United States (Cohen et al., 2016), long-term survival is increasingly common with multimodality therapy. Rates of remission for early-stage disease and human papillomavirus (HPV)-related cases are as high as 80%–90% (Cohen et al., 2016). The demographics of patients with HNC are shifting to younger ages with the rise of HPV-related cases and decline of alcohol- and tobacco-related squamous cell carcinoma (Young et al., 2015). Although cure rates are high, HNC survivors experience significant sequelae of treatment, including long-term physical symptoms that affect quality of life and societal functioning, such as difficulties with eating, drinking, and communicating, and pain (Funk, Karnell, & Christensen, 2012). In addition to managing chronic and late treatment-related toxicity, careful follow-up is necessary for surveillance of recurrence and secondary cancer development. Oral and eating problems, fear of recurrence, fatigue, and care coordination all have been cited as common unmet needs in this population (Giuliani et al., 2016; Wells et al., 2015).

Given the needs of this growing survivorship population, clinical guidelines have emerged to describe best practices for post-treatment care (Cohen et al., 2016; Nekhlyudov et al., 2017). Recommendations include delivery of survivorship care plans (SCPs), which aim to provide comprehensive treatment summaries and additional educational content to aid patients and their primary care physician when transitioning from acute oncology management. SCPs provide information about the treatment received, short- and long-term side effects, and guidance for follow-up monitoring (Institute of Medicine, 2006). SCPs are hypothesized to benefit patients through improved education. Oncology nurses are well-positioned to play an active role in SCP development and implementation (Corcoran, Dunne, & McCabe, 2015).

Few studies have specifically evaluated the educational and informational needs of the HNC survivorship population. One 65-patient study evaluated interest among patients with HNC in receiving information for certain topics (e.g., speaking and swallowing, coping with anxiety) and found that higher distress was associated with a greater informational need (Fang et al., 2012). A survey of 93 oral cancer survivors within one year of diagnosis found that