

A Survey of Information Needs and Preferences of Patients With Head and Neck Cancer

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OBJECTIVES: To determine the information needs and preferences of patients who had human papillomavirus-associated head and neck cancer (HNC) and who were aged 18–65 years in the post-treatment phase of recovery.

SAMPLE & SETTING: 205 patients who completed treatment for HNC at two large cancer centers in Western Canada.

METHODS & VARIABLES: A self-administered survey was completed in paper or online format. Participants were asked about information considered most important, sources of information used during recovery, and sources considered most helpful.

RESULTS: Participants wanted information on signs and symptoms of recurrence, cure rates, post-treatment rehabilitation, treatment and recovery time frames, and financial assistance. They identified healthcare providers as the most frequently used and helpful source of information, but also reported that the Internet was useful and that an online information resource would be helpful during recovery.

IMPLICATIONS FOR NURSING: Nurses can provide more personalized information for survivors of HNC by contributing to the development of reliable Internet-based resources. The developers of these resources could also consider creating ways to directly link healthcare providers and survivors of HNC who are experiencing problems stemming from diagnosis and treatment.

KEYWORDS head and neck cancer; human papillomavirus; information needs; Internet resources

ONF, 45(6), 761–774.

DOI 10.1188/18.ONF.761-774

In 2016, an estimated 5,660 people had been diagnosed with head and neck cancer (HNC) in Canada (Canadian Cancer Society, 2016). Of these 1,335 tumors originated in the oropharynx and were consistently associated with human papillomavirus (HPV) infection (Canadian Cancer Society, 2016). Although the incidence rates of HNCs have decreased, HPV-associated oropharyngeal squamous cell carcinomas have dramatically risen since the late 1990s (Canadian Cancer Society, 2016; Forte, Niu, Lockwood, & Bryant, 2012; Pytynia, Dahlstrom, & Sturgis, 2014). This shift in HNC etiology has the potential to impose a substantial economic burden on health systems and has changed the population characteristics of survivors of HNC (Coughlan & Frick, 2012; Pytynia et al., 2014; Reich et al., 2016).

The largest increase in HPV-associated HNC in Canada and the United States has been observed in men aged 40–59 years (Chaturvedi, Engels, Anderson, & Gillison, 2008; Forte et al., 2012). Although HPV-associated HNCs tend to be diagnosed at more advanced stages, individuals with HPV-associated HNC are younger than those with non-HPV HNC, respond better to treatment, have a decreased risk of recurrence, and have better survival rates than individuals with non-HPV HNCs (Heath et al., 2012; Marur, D'Souza, Westra, & Forastiere, 2010; Pytynia et al., 2014). Younger age at diagnosis leads to prolonged survivorship but also contributes to shorter productive work years, increased distress after treatment, and a diminished cancer-specific quality of life (QOL) (Johnson-Obaseki, McDonald, Corsten, & Rourke, 2012; Wells et al., 2015, 2016). Given the shifting demographic and clinical profile of those with HPV-associated HNC, this emerging population may experience a unique set of post-treatment needs when compared to survivors of non-HPV HNC (Powell & Evans, 2015).

For instance, literature that has focused on all HNC cancers suggests that, if employed prior to diagnosis