Oropharyngeal Cancer and HPV
Measuring knowledge and impact among survivors of head and neck cancer

Sean Thomas Gallagher, RN, MSN, MA, OCN®, Allison M. Deal, MS, Deborah Ballard, RN, MSN, OCN®, and Deborah K. Mayer, PhD, RN, AOCN®, FAAN

BACKGROUND: Little is known about how survivors of human papillomavirus (HPV)-related oropharyngeal cancers (OPCs) learn about HPV, how knowledgeable they are, and how the diagnosis impacts their relationship with their sexual partner.

OBJECTIVES: This study aimed to describe survivors’ knowledge level regarding HPV-related OPCs.

METHODS: This qualitative study was developed as a non-randomized, single-center, cross-sectional study of individuals newly diagnosed with a HPV-related squamous cell carcinoma of the oropharynx and completed treatment at least three months prior to enrollment in the study.

FINDINGS: Thirty-four of the 64 surveys sent were completed. Respondents reported a strong interest in knowing about HPV but demonstrated low knowledge of HPV. Most reported that they were not taught about HPV at the time of diagnosis; Internet searchers were their primary source for information. Most reported that their relationship with their partner was not harmed by the HPV diagnosis, but most also reported decreased sexual intimacy with their partner.

KEYWORDS
head and neck cancer; oropharyngeal; human papillomavirus; knowledge

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DESPITE AN OVERALL DECREASE IN INCIDENCE OF HEAD AND NECK squamous cell cancers, oropharyngeal cancer (OPC) incidence rates are on the rise (Chaturvedi et al., 2011; Jemal et al., 2013). The growing incidence of OPCs is related to the rising incidence of human papillomavirus (HPV)-related OPCs, which have increased 225% from 1988–2004 in the United States (Chaturvedi et al., 2011). Historically, OPCs have been associated with tobacco use and, with the decreasing use of tobacco, the incidence of non–HPV-related OPCs has dropped 50% from 1998–2004 (Chaturvedi et al., 2011). However, the percentage of OPCs that are HPV-related has increased from about 16%–23% in the 1970s to 59%–79% in the late 2000s (Chaturvedi et al., 2011; Näsman et al., 2009; Wang, Thomas, & Zhang, 2012). Based on current trends, new diagnoses of HPV-related OPC will outnumber new diagnoses of cervical cancer, the most common HPV-related cancer, by 2020 (Chaturvedi et al., 2011).

With the rising incidence of HPV-related OPC, head and neck oncologists must increasingly incorporate education about HPV into their discussions with patients about the diagnosis of cancer. This conversation can be challenging, with important ethical issues being raised, including questions about disclosure to sexual partners (Shuman & Wolf, 2010). At the beginning of the conversation, many patients will not be aware of HPV (Marlow, Zimet, McCaffery, Ostini, & Waller, 2013). Women tend to have higher levels of awareness of HPV compared to men, but women aged 40–70 years are significantly less knowledgeable than younger women about sexually transmitted infections (STIs) (Montgomery, Bloch, Bhattacharya, & Montgomery, 2010; Montgomery & Smith-Glasgow, 2012). In addition, people who are aware of HPV are unlikely to know of the link to OPC (Allen, Fantasia, Fontenot, Flaherty, & Santana, 2009; Brewer, Ng, McRee, & Reiter, 2010; Dahlström et al., 2012; Reiter, Brewer, & Smith, 2010); therefore, basic education is required.

The diagnosis of HPV infection has been associated with significant anxiety and distress in women with HPV-related gynecologic health issues (Drolet et al., 2012; Kwan et al., 2011; Wang et al., 2010). Women diagnosed with gynecologic HPV infection report an immediate and strong need for information about HPV (Bertram & Magnusson, 2008). In the limited information available about men diagnosed with genital HPV infection, feelings of being upset and concern or worry are described as common (Daley et al., 2009, 2012).