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Review

Discussing the diagnosis of HPV-OSCC: Common questions and answers

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SUMMARY

Human papillomavirus (HPV) is responsible for a rising proportion of oropharyngeal squamous cell cancers (OSCCs). HPV-positive OSCCs (HPV-OSCCs) are associated with oral HPV infection and sexual behavior. Patient questions regarding risk factors, prognosis and implications for past, present and future relationships often arise. This manuscript addresses frequently asked questions by patients with HPV-OSCC and their families. A framework for clinicians to address these conversations and the limitations of our present knowledge base is also presented.

HPV and its role in OSCC

Human papillomavirus (HPV), a sexually transmitted infection, is now responsible for the overwhelming majority of oropharyngeal squamous cell cancers (OSCCs) in the United States (U.S.). Historically, tobacco and alcohol use accounted for the majority of head and neck cancers. However, with the decline of tobacco use in the U.S., the incidence of smoking-related (HPV-negative) oropharyngeal malignancies has decreased [1]. The proportion of oropharyngeal cancers attributable to HPV (HPV-positive OSCC; HPV-OSCC) has risen substantially in the U.S. Indeed, while only 16% of OSCCs in the 1980s were HPV-positive, approximately 73% of tumors in the 2000s were HPV-positive. Not only is the proportion of OSCCs that are HPV-positive rising, but the incidence of OSCC is also rising. From 1988 to 2004, there was a 28% increase in incidence of OSCC in the U.S., which was primarily among younger men, ages 50–59 [1]. Currently, the incidence of OSCC in the U.S. is 6.2 per 100,000, and 1.4 per 100,000 among men and women, respectively [2]. There is also data emerging that HPV is etiologically associated with a smaller subset of oral cavity tumors [3].

HPV-OSCC has been recognized in the past 10 years as a distinct disease entity. These cancers are associated with oral HPV infection and sexual behavior (a surrogate for oral HPV exposure), although HPV-OSCC is diagnosed in many people who have a modest number of lifetime sexual partners. Individuals with HPV-OSCC, when compared to those with HPV-negative tumors, tend to be white, male, non-smokers and non-drinkers [4]. Patients with HPV-OSCC have significantly better prognosis than those with HPV-negative OSCC [5,6]. Given its prognostic significance, HPV tumor detection has been integrated into National Comprehensive Cancer Network (NCCN) guidelines in the diagnostic evaluation of patients with OSCC, thus establishing HPV detection as a clinical standard of care for oropharyngeal malignancy [7].

Nuances in discussing the diagnosis of HPV-OSCC with patients

Despite the recognition of a HPV-OSCC "epidemic" among head and neck oncology, the impact of providing a HPV-related diagnosis to OSCC patients has not been studied to date. This diagnosis is complex and multi-faceted. The diagnosis of HPV-OSCC imparts upon a patient a cancer diagnosis coupled with the diagnosis of a sexually transmitted infection (STI). The former part of the diagnosis is similar to diagnoses the oncologic team routinely provides and has been trained to discuss. However, the etiologic association of a STI and cancer is one that has emerged on the doorstep of the head and neck care team in the last decade, without education regarding the psychosocial ramifications of STI diagnoses. As opposed to gynecologic-oncologists, for instance, who discuss cervical cancer with patients routinely and are trained in diagnosing and treating STIs (cervical dysplasia, Chlamydia, etc.) head and neck surgical, radiation, and medical oncologists currently have no training in discussing STIs. Yet, the head and neck team is now in a position to not only discuss the etiology of a STI-related malignancy, but to counsel their patients and partners regarding

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complex social and behavioral questions outside the realm of oncology, as patients and partners wrestle with the knowledge that the malignancy was caused by a STI.

Clinically, the multidisciplinary head and neck cancer team is reasonably equipped to counsel patients on the link between tobacco, alcohol and cancer, as well as tobacco and alcohol cessation, although studies show low physician compliance and low levels of confidence to counsel patients [8–11]. The psychosocial distress of a cancer diagnosis has long been recognized, especially in the head and neck patient population [12]. By contrast, there is a paucity of head and neck literature regarding counseling of patients with a diagnosis of a STI-related cancer. Therefore, this manuscript is intended to address concerns of patients with HPV-OSCC and their families, and the behavioral questions that frequently arise among practitioners diagnosing, treating, and following this unique patient population.

Few resources currently exist to answer HPV-OSCC patients' behavioral questions about how, when, and why they got this cancer. The answers to these questions have implications for past, present, and future relationships and must therefore be carefully considered before providing advice to patients. Because these issues have not been well explored in an evidence-based method, it is important in discussions with patients to contextualize many of these answers with "*we do not know, however, initial evidence suggests that...*" Therefore, we present our best answers to these difficult questions with the caveat that in many cases, the answers to these questions are not yet established and can currently only be extrapolated from related research on anogenital HPV infection, initial oral HPV literature, and an understanding of the distinctions between oral and cervical HPV infection.

This manuscript addresses common patient concerns related to behaviors associated with HPV-OSCC and oral HPV infection, and reviews what is currently known and what remains unknown about oral HPV acquisition and transmission. A patient brochure with commonly asked questions and answers is also included (Fig. 1), which providers may give to their patients to supplement and reinforce their counseling regarding HPV-OSCC.

Discussing tumor HPV status in OSCC

Despite inclusion of HPV detection in NCCN guidelines for cancers of the oropharynx, there are no formal recommendations at present for when and how to discuss HPV test results with patients. Given that cervical HPV and cervical cancer literature has been used as the paradigm for oral HPV and HPV-OSCC research, until a similar body of literature is generated for HPV-OSCC, we can use the cervical HPV counseling messages created by the CDC as a starting point.

The cervical HPV counseling guidelines generated by the CDC suggest that physicians discuss the significance of cervical HPV infection and reasons for the test before performing the test [13]. In addition to the verbal conversation, the guidelines recommend that physicians provide patients with documentation in layman's terms to summarize HPV and how it is associated with cervical cancer [13]. When delivering HPV test results, physicians are recommended to summarize why the test was performed and contextualize a positive result in a neutral, non-stigmatizing fashion that reinforces the high prevalence and transience of HPV infection, as well as acknowledge potential concerns of transmission to partners. Providing information in print at the time of delivery of results is also recommended.

In delivering HPV results, communication style is highlighted to be as important as the content of the message. CDC guidelines have the following evidence-based recommendations for physicians delivering the diagnosis of cancer (not site-specific): recommend that clinicians slow down, adjust language to the literacy of the patient, supplement facts with stories, anecdotes or pictures, limit the topics covered at each visit, and use the so-called "teach back" method to assess the comprehension of patients at the end of a conversation [14,15].

By analogy, at the time of requesting HPV testing in OSCC, as with any diagnostic test, providing both verbal and print education may result in improved communication and understanding (see brochure provided in Fig. 1) [16]. When sharing with a patient that their OSCC is HPV-positive, providing both verbal and written education may be helpful in light of the questions that sometimes ensue after the initial relief of improved prognosis associated with HPV-OSCC, i.e. sexual intimacy, transmission, and/or infidelity.

Reaction to HPV-positive test

Patients may react differently to finding out their OSCC is HPV-positive, as some may experience anxiety and confusion about the behavioral aspects of infection (i.e. how, when or why they acquired the infection). The NCCN panel for head and neck cancers acknowledges that HPV testing of OSCC may lead to questions regarding prognosis and sexual history, which clinicians should be prepared to discuss [7]. In its discussion of HPV infection, the NCCN panel cautions "HPV information may add anxiety and stress for some patients. Alternatively, gaining an understanding of the etiology for one's cancer can result in reduced anxiety for some patients [4]."

Based upon the cervical literature, some patients presented with a diagnosis of cervical cancer (the overwhelming majority of which are HPV-related) have significant psychosocial sequelae including anxiety, depression, and sexual dysfunction [17]. It has been suggested that psychosocial counseling in this patient population may lead to improvement in quality of life [18]. Women who are diagnosed with a cervical HPV infection and/or premalignant lesions have been found to report self-blame, grief, concern, anxiety, shock, fear, shame, sexual dysfunction, and distress [19,20]. Commonly, women express concerns regarding disclosure of results to partner or partners, fear of future transmission, partner rejection, and questions over the source of infection [14,21,22]. Individuals report angst about the underlying infection that cannot be treated, the stigma of a STI, and questions regarding progression from infection to cervical pre-malignancy and/or malignancy. Along with clinical counseling, addressing patients' behavioral questions may help to reduce the aforementioned psychological sequelae of this complex diagnosis. Patients experience emotional reactions at the time of a cancer diagnosis which may interfere with comprehension [23], and these issues may be amplified with the additional diagnosis of HPV.

Below we discuss common patient questions and what is known and unknown in response to these questions.

How did I get an oral HPV infection?

- HPV is a sexually transmitted infection that can infect the epithelium of the oropharynx, oral cavity, and anogenital tract [24].
- Genital HPV natural history is well understood and serves as the paradigm against which we compare oral HPV natural history. Genital HPV infections, including cervical, vaginal, and penile infection, are common among sexually active young adults. More than 80% of sexually active young adults are infected with a genital HPV infection at some point during their lifetime, although many of these people will never know they were infected [25,26]. Most people clear these genital infections within a year or two on their own [25,27]. Among those who do not clear their infections, persistent infection can lead to pre-malignant and malignant genital lesions [28–30].