



Human Papillomavirus–Related Oral Cancers: The Nurse’s Role in Mitigating Stigma and Dispelling Myths

Frank discussion is essential to both treatment and prevention.

ABSTRACT: The prevalence of human papillomavirus (HPV)–related oral cancers has been rising, the cancers occurring in adults at a younger age than HPV-negative oral cancers typically do and in men more often than women. Patients who are diagnosed often don’t understand the disease’s etiology. Because HPV is sexually transmitted, diagnosis with an HPV-related oral cancer may prompt feelings of shame, embarrassment, and guilt. There are currently three vaccines for HPV. It’s essential for nurses to educate patients on HPV transmission and HPV-related oral cancer, thus helping to mitigate the stigma and dispel myths, and to promote vaccination in at-risk populations, including children and young adults.

Keywords: human papillomavirus, oral cancer, oropharyngeal cancer, stigma

Until fairly recently, squamous cell carcinomas of the oral cavity, oropharynx, and larynx were associated with tobacco and alcohol use and occurred predominantly in men ages 55 and older.^{1,2} But since the 1980s, associations between oral cancers and human papillomavirus (HPV) have emerged.¹ HPV-related oral cancers are being found in younger adults, though still more often in men than in women, and appear to be associated with changes in sexual norms.² This link to shifts in sexual behavior is an important one. Because HPV-related oral cancers are sexually transmitted, their presence may be stigmatizing, causing distress to those who

are diagnosed unless they receive appropriate education and counseling. The association between oral cancers and sexual behavior further signals the need for prevention through education.

PREVALENCE AND RISK

According to one large national study by Gillison and colleagues, the overall prevalence of oral HPV infection among U.S. men and women ages 14 to 69 years is 6.9%; the prevalence of HPV 16, the strain most associated with oral cancer, is 1%.³ That study found there was a bimodal pattern with regard to age, with peak prevalences among people between the ages of

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30 and 34 years and between the ages of 60 and 64 years. This pattern is similar to one seen with anal and penile HPV infections,⁴ and may reflect an initial infection that either clears or becomes latent and then becomes reactivated at an older age. Gillison and colleagues also found that oral HPV infection was nearly three times as prevalent in men as in women (10.1% and 3.6%, respectively).³

HPV prevalence rates are much higher among people infected with HIV. In a two-cohort study among HIV-positive and at-risk HIV-negative people, the overall prevalence of oral HPV was 34%.⁵ HPV 16 was the most common type, with prevalences of 6.8% and 5.4% among HIV-infected men and HIV-infected women, respectively.

Risk factors. *Oral cancer.* Infection with HPV, particularly HPV 16, is a major risk factor for oral cancer. It's estimated that HPV causes between 20% and 25% of all head and neck cancers⁶; and among HPV-related head and neck cancers, more than 90% are caused by HPV 16.² Moreover, the rising incidence of HPV-related oral cancers in younger people may be largely attributable to changing patterns of sexual behavior. Oral sex has become more acceptable, as has having multiple sexual partners, and more people are having oral sex at a younger age.² Smoking, alcohol use, and poor oral hygiene are also

risk factors for oral cancer, though to a lesser extent.^{2,6}

HPV infection. Open-mouth kissing has been identified as a risk factor for acquiring HPV, with a four-fold greater risk for those who have open-mouth kissed five or more individuals.⁷ Having multiple sexual partners and having oral sex are also major risk factors for HPV. For both sexes, the risk of oral HPV infection increases with the number of sexual partners one has had.³ It's theorized that men may be at higher risk for such infection than women because of the greater prevalence of HPV in cervical tissue compared to penile tissue.² (There has been scant research among lesbian or bisexual women; their relative risk of HPV infection is unknown. One study did find that the prevalence of HPV in cervical tissue was about the same in heterosexual and bisexual women.⁸) Research further indicates that, compared with women, men are more likely to have more than five lifetime sexual partners (59.7% of men versus 41% of women, according to one large study) and oral sex partners (32.4% of men versus 17.6% of women in the same study).⁹ Poor oral health has also been shown to be a risk factor for oral HPV infection, independent of having multiple oral sex partners and smoking.¹⁰

It's worth noting that the partners of people with HPV-related oral cancers don't seem to be at higher

risk for HPV infection.¹¹ This may be because they were repeatedly exposed to the virus through their partners and were able to clear it.¹¹ That said, there is a case report of two women with HPV-related cervical cancer whose husbands were diagnosed with HPV-related nasopharyngeal cancer within three years of their wives' diagnoses; both couples engaged in oral sex.¹²

Among HIV-infected individuals, risk factors for HPV infection include having a higher number of oral sex partners and the severity of immunosuppression. Oral sex and oral–anal contact (“rimming”) are associated with higher risk of HPV infection; but in HIV-infected individuals, HPV infection may indicate reactivation of a latent infection secondary to immunosuppression rather than a new infection.¹³

CLINICAL FEATURES

Oral cancers usually present at stage III or IV, often with advanced nodal involvement.^{14–16} The tumors usually originate in the lingual or palatine tonsils and exhibit lobular growth with lymphocyte infiltration; the surface epithelium does not keratinize.¹⁷ Survival data suggest that HPV-related oral cancers have a far better prognosis than HPV-negative oral cancers; one large study found that, compared with patients with HPV-negative tumors, those with HPV-positive tumors had a much higher overall three-year rate of survival (52.1% and 82.4%, respectively).¹⁸ The researchers theorized that this reflects the greater sensitivity of HPV-positive tumors to chemotherapy and radiation.¹⁸ As Lozza and colleagues have noted, less aggressive treatment regimens in patients with HPV-positive cancers are “currently being evaluated and prospective trials may lead to stratified therapies based on tumor HPV status.”¹⁹ However, a history of smoking may alter response to treatment and reduce one’s chances for survival.¹⁸

without chemotherapy with cisplatin.² Since 2000, superior results have been seen with surgery and concurrent chemo- and radiotherapy, which can better preserve swallowing and speech functions.² Smoking and alcohol use should be avoided. Most of those diagnosed are relatively young with no comorbidities. As these patients usually survive for longer periods of time than patients with HPV-negative oral cancers, it’s important to minimize treatment-related toxicities to ensure a higher quality of life. Acute adverse effects of treatment can include dysphagia, xerostomia (dry mouth), and chronic fatigue. If radiation causes scarring of the pharyngeal muscles, there is increased risk of aspiration.² Dysphagia may warrant the placement of a feeding tube to maintain nutrition.² (For a more detailed discussion of clinical features and treatment, see “Human Papillomavirus–Related Oropharyngeal Cancer: A Review of Nursing Considerations,” August 2016.)

PREVENTION

Historically, efforts to prevent the transmission of HIV included promoting oral sex as less risky than genital sex.²¹ This, along with increasing social acceptance of oral sex, may have played a role in the rising incidence and prevalence of oral HPV infection, including infection with the oncogenic HPV 16 strain.²

Prevention efforts should include educating people on the importance of using condoms and dental dams to prevent HPV transmission during oral sex. This recommendation has obvious limitations; many people, especially women, resist using condoms and dental dams when they think such use will reduce sexual pleasure.^{22,23} And although condoms are readily available, dental dams are less so, and people may not know why dams are protective or how to use them.

The HPV vaccine probably offers the most effective means of protection from HPV infection, and

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There is no screening test for oral HPV. Because of the anatomic location of most HPV-related tumors—the tonsillar crypts—precursor lesions have not yet been identified, and these cancers are often difficult to detect and diagnose in the early stages.²⁰

TREATMENT

The standard of care for locally advanced oropharyngeal cancer is surgery with adjuvant radiation, with or

several types have been approved by the U.S. Food and Drug Administration (FDA) (see Table 1²⁴). Vaccination with the bivalent HPV 16/18 vaccine has been shown to reduce oral HPV infection in young women.²⁵ More recently, the FDA has approved the use of a nonavalent vaccine (effective against nine strains of HPV, including types 6, 11, 16, 18, 31, 33, 45, 52, and 58).²⁶ De Kok and colleagues have calculated that if both men and women received the HPV

vaccine, life years gained from the prevention of all HPV-related cancer would rise by 25%, with an increase of 26% in savings to the health care system and a cost-effectiveness ratio decrease of 21%.²⁷

The Advisory Committee on Immunization Practices (ACIP) and the Centers for Disease Control and Prevention (CDC) recommend that routine vaccination for both girls and boys begin at age 11 or 12 years (though the three-dose series can be started as early as age 9 years).^{28,29} Vaccination should continue through age 26 years for women and age 21 years for men “who have not been vaccinated previously or who have not completed the three-dose series.”²⁹ The vaccine is also recommended through age 26 years in men who have sex with men and in those with compromised immune systems.³⁰ There is no evidence that any of the vaccines is better than the other; that said, for men, the quadri- and nonavalent vaccines are recommended over the bivalent vaccine.²⁹

PUBLIC AND PATIENT EDUCATION

The public appears to be generally unaware of the risks of HPV infection, particularly as it relates to oral cancer. In a recent survey of more than 2,000 randomly selected adults in the United States, 66% reported being “not very” or “not at all” knowledgeable about head and neck cancer.³¹ Just 0.8% identified HPV as a risk factor for cancer of the mouth and throat, although 70% were aware of the HPV vaccines. More women than men were aware of the vaccines, probably because women are more likely to know of the connection between HPV and cervical cancer. In another survey among 303 adults, only 55% had ever heard of HPV and just 29.9% knew that HPV increases the risk of oral cancer.³² Of those who had heard of HPV, just 25.1% reported receiving information about HPV from a health care provider. It’s also concerning that 42.4% of the participants thought that HPV was the same as HIV. In a third survey of more than 600 gay or bisexual and heterosexual men, 79% of the gay or bisexual men and 62% of the heterosexual men had at least heard of HPV.³³ But 90% of all respondents reported knowing “nothing” or “little” about oral cancers. Only 23% knew that HPV can cause oral cancer; more respondents named tobacco use, genetics, and unsafe chemicals in food and water as causes.

Many people who are HPV positive don’t know it. It stands to reason that such lack of awareness makes behavior change in order to minimize further risks to oneself or one’s sexual partners less likely. In a study by Sivasithamparam and colleagues that included people with oropharyngeal cancer, 74% of these were HPV positive but only one-third knew their HPV status.⁶ And in a study by Milbury and colleagues of people with HPV-positive oropharyngeal tumors, 66% correctly disclosed their HPV status but only 35% knew that HPV was the cause of their cancer.³⁴

Table 1. Human Papillomavirus Vaccines²⁴

Name of Vaccine and Target Population	Type of Vaccine	Target Strain
Cervarix females only, ages 9 to 25 years	bivalent	HPV 16 and 18
Gardasil males and females, ages 9 to 26 years	quadrivalent	HPV 6, 11, 16, and 18
Gardasil 9 males and females, ages 9 to 26 years	9-valent	HPV 6, 11, 16, 18, 31, 33, 45, 52, and 58

It’s unknown to what extent health care providers are aware of the association between HPV infection and oral cancer. Dentists are particularly well positioned to promote both HPV vaccination and good oral health practices. But one survey among more than 200 dentists found that 92% were in the pre-contemplation or contemplation stages of readiness to discuss HPV with their female patients; only 9% reported actively having such discussions.³⁵

Infection with HPV, particularly HPV 16, is a major risk factor for oral cancer.

For people diagnosed with HPV-related oral cancer, education that includes accurate information about the risk of HPV transmission to sexual partners and preventive measures is vital, but often neglected. In the aforementioned study by Milbury and colleagues, only 23% of the participants felt informed about HPV transmission risks and precautions.³⁴ More than three-quarters (84%) reported that their oncologist either had not discussed HPV with them or had only “somewhat” done so. And in a study by Baxi and colleagues of 10 men diagnosed with and treated for HPV-related oropharyngeal cancer, the participants indicated feeling generally satisfied with the information provided by their providers.³⁶ Yet some of the men also reported that discussion of HPV was “often overshadowed by broader conversations about the cancer,” leaving them with unanswered questions.

PATIENT RESPONSES TO DIAGNOSIS

There is a paucity of research regarding how people respond when diagnosed with HPV-related oral cancer.

In a study conducted in 1992, Clarke and colleagues surveyed more than 450 adults infected with HPV about the impact of HPV on their lives.³⁷ The researchers found that 78% of the respondents felt anger, 76% were depressed, and 66% felt shame when they were diagnosed with HPV, although these percentages decreased over time. Moreover, 73% were concerned about transmitting the virus to a sexual partner, 72% felt less sexually desirable, and 57% worried about being judged negatively if they disclosed their HPV status.

In more recent studies, participants have voiced similar concerns. Baxi and colleagues found that three of their 10 participants felt “a sense of stigma or embarrassment” upon learning that they had HPV-related cancer.³⁶ Not knowing when they’d been infected with HPV led some of the men to feel anger, sadness, or helplessness. For several participants, diagnosis led to changes in sexual behavior: five men reported decreases in sexual activity and three completely eliminated deep kissing or oral sex, even with long-term sexual partners. Four men were worried about infecting their partners, and one expressed concern about whether his female partner could reinfect him. Participants in the study by Milbury and colleagues reported moderate levels of distress associated with having HPV-related cancer, albeit low levels of self-blame.³⁴

What should patients be told? Many clinicians who care for people with head and neck cancers are

accustomed to addressing alcohol and tobacco use as risk factors. But they may not be prepared to address HPV as a sexually transmitted infection, or to discuss behavioral risk factors such as having multiple sexual partners and oral sex. Yet omitting such vital information doesn’t serve patients or their sexual partners well. Avoiding such discussion can leave patients with unanswered questions and can adversely affect their health, their relationships, and their quality of life.

Fakhry and D’Souza have identified some common questions that patients diagnosed with HPV infection or HPV-related oral cancer often have, and offer suggested answers.³⁸ Topics include HPV transmission, the association between HPV infection and oral cancers, viral latency and activation, the risk of transmission to others, the persistence of HPV infection, prognosis, the implications of current or past tobacco use, and HPV vaccines. Their evidence-based answers form a useful framework for any discussion with a patient who has been diagnosed with an HPV-related oral cancer (see *Information for Patients*³⁸).

THE ROLE OF NURSES

Nurses have a vital role to play in teaching patients with HPV about HPV transmission and HPV-related oral cancers, as well as in encouraging vaccination to prevent new HPV infections. Like many other clinicians, some nurses may feel uncomfortable or insufficiently prepared to discuss issues related to sexually transmitted illness with these patients. But we must be able to answer their basic questions in order to educate, correct misinformation, and dispel myths—just as we would for any patient, regardless of the disease or its etiology. This means that we may first need to educate ourselves on HPV infection and HPV-related oral cancers, and to learn how to become more comfortable talking about sexual transmission. As always, it’s also important to ensure that information is provided in ways that are appropriate for culturally diverse populations and in language that the patient understands.

As the research indicates, many patients diagnosed with HPV-related oral cancer experience shame and embarrassment; offering them relevant, evidence-based information can help alleviate those feelings. For example, HPV infection is not an indicator of promiscuity or unfaithfulness.³⁸ Indeed, as noted earlier, Gillison and colleagues found that HPV is prevalent in about 7% of the general population,³ and most people will clear the infection within a year or two.³⁸ In most cases, the sexual partners of people with HPV-related oral cancer have already been exposed to HPV and are not at greater risk for developing such cancer.¹¹

Nurses in all settings can and should encourage HPV vaccination for boys and girls starting at age 11 or 12 years (or as early as age 9 years), as recommended by the ACIP and the CDC.^{28,29} Because no clinical trials testing HPV vaccination in the prevention

Information for Patients³⁸

Oral HPV Infection

- Oral HPV infection occurs more often in men than women.
- It is less common than genital HPV infection.
- It is more common in people who have engaged in oral sex.
- Most people who develop an HPV-related oral cancer were exposed to HPV many years earlier.
- Many people don’t know they have been infected with HPV.
- Most people clear the infection within a year or two.
- HPV can lie dormant for many years.

Transmission

- Oral HPV is not transmitted through casual contact.
- Partners of people with HPV-related oral cancers have usually been exposed to HPV before (from current or past partners) and have cleared the virus.
- Most people who have been treated for HPV-related oral cancer no longer have detectable viral levels, so the risk of transmitting HPV to a partner is slight.
- There are no HPV screening tests for partners.
- HPV infection is common. It does not mean that the individual or her or his partners have been promiscuous or unfaithful.

of oral cancer have been reported yet, we can't know whether it will be effective. But it's plausible that this will be the case, given that HPV vaccination has been shown to be effective in preventing cervical cancer.³⁹ Our active engagement in educating all patients on HPV vaccination will go a long way in preventing HPV infection and its associated cancers for future generations. ▼

For five additional continuing nursing education activities on the topic of human papillomavirus, go to www.nursingcenter.com/ce.

Anne Katz is a clinical nurse specialist at CancerCare Manitoba in Winnipeg, Manitoba, Canada. Contact author: anne.katz@cancercare.mb.ca. The author and planners have disclosed no potential conflicts of interest, financial or otherwise.

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