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# THE RISE OF RELATED ORAL CANCER

Exploring the Dentist's Role in Preventing this Emerging Epidemic

By Kelly Rehan

n March 2007, Jeff Blackburn, DDS, FAGD, of Midlothian, Virginia, had all the energy in the world. He was a single dad of four kids, coached multiple baseball teams, completed sprint triathlons and was merging another dental business into his own busy practice. Then, one Sunday morning, he looked in the mirror and saw a lump the size of a large, unshelled peanut on his neck.

After visiting his physician, Blackburn was prescribed an antibiotic with instructions to call the office if the lump didn't go away in a week. The lump didn't go away, so Blackburn returned to his physician for a needle biopsy that revealed malignant cells.

"When you get the news, it hits you, and you go into shock," Blackburn says. "I always controlled everything in my life. In my egotistical way, I thought, 'I'm too busy for all this,' and as the nurse was telling me available appointment times, I realized I wasn't in control anymore."

Blackburn had oral cancer, but his doctors didn't know the cause or the primary source. Five weeks after the diagnosis, doctors discovered the source at the left base of his tongue, and all of the lymph nodes on his left side were infected. There was also a 50 percent chance that the lymph nodes on his right side were infected as well.

Blackburn's treatment of intense radiation and chemotherapy lasted seven weeks. He underwent 35 treatments of radiation and had chemotherapy once a week.

"The treatment was awful," he says.
"You can't eat or swallow. You lose your
voice and [sense of] taste. You shake
from the drugs and cough up blood;
ulcers are everywhere in your mouth and
throat. Your neck gets raw. You become
extremely tired, and you lose a lot of
weight. I ended up having to feed myself
through a tube inserted into my stomach.
I lost 21 pounds."

14 | AGD Impact | April 2017 | agd.org | 15

Blackburn was expected to miss up to four months of work, but he didn't miss a day. Six weeks after treatment ended, he completed a sprint triathlon.

Blackburn didn't have a history of tobacco or alcohol use, which are traditional risk factors for oral cancer. A few months after his diagnosis, his oncologist said new research was showing links between oral cancer and human papillomavirus (HPV) — the most common sexually transmitted infection in the United States today, which has become a major oral cancer risk factor.

### **Understanding HPV and Oral Cancer**

Cases of HPV-related oral cancers are rising. The number of oropharyngeal cancers linked to HPV has risen dramatically over the past few decades, according to American Cancer Society. HPV DNA (a sign of HPV infection) is now found in about two out of three oropharyngeal cancers and in a much smaller fraction of oral cavity cancers. A standard for prevention in dentistry is essential to curb this emerging epidemic.

On any given day, approximately 26 million Americans have an oral HPV infection, according to data from an ongoing National Health and Nutrition Examination Survey. Up to 80 percent of Americans will have HPV infections in their lifetime, and 99 percent will clear

# Three out of four people are infected with HPV at some point in their lives.

Oral Cancer Cause

these infections without consequence or even knowing that they had it, as it produces no noticeable symptoms, according to Centers for Disease Control and Prevention (CDC).

The HPV family contains almost 200 strains, and of all these, nine are associated with cancers. According to The Oral Cancer Foundation, of the nine that are high risk, only one is strongly associated with oropharyngeal cancer: HPV type 16 (HPV-16).

A small percentage of people with oral HPV infections develop oropharyngeal cancer, according to American Cancer Society. CDC reports that each year, on average, 8,000 men and 2,000 women in the United States are diagnosed with cancers of the oropharynx that may be caused by HPV. However, consider that 63 percent of oropharynx cancer cases in women per year is caused by any HPV type, according to CDC, while the percentage in men is

72 percent, making HPV the leading cause of oropharynx cancer.

Also consider the results of the 2011 study in *Journal of Clinical Oncology*, "Human Papillomavirus and Rising Oropharyngeal Cancer Incidence in the United States." The study found a 225 percent increase in HPV-related oropharyngeal cancers from 1988 through 2004, compared with a 50 percent decline of HPV-negative cancers over the same period.

The increase in incidence is only half the story — the other being *whom* HPV-related oral cancers are affecting. According to American Cancer Society, cancers of the oral cavity and oropharynx usually take many years to develop, so most patients with these cancers are older than 55 when first diagnosed.

However, people with cancers related to HPV infection now tend to be younger and less likely to be smokers and drinkers. While the American Cancer Society reports that the reason is unclear, some think that it could be because of changes in sexual practices in recent decades — in particular, an increase in oral sex.

To ensure more Americans are protected from cancer, CDC recommends that all adolescents who are 11 or 12 years old get the HPV vaccine. (See "HPV Vaccine Recommendations" sidebar on page 17.) In addition, it's important for dentists to talk with patients about HPV as a major oral cancer risk factor, as well as screen patients of all ages for oral cancer. Dentists should also be knowledgeable about HPV vaccines and be prepared to discuss them with parents of adolescent patients when the topic arises.

# TIPS FOR TALKING WITH PATIENTS ABOUT HPV AND ORAL CANCER

Consider these tips to improve dentist-patient communication about HPV and oral cancer:

- Make brochures or other educational literature on HPVrelated oral cancers available in your practice's reception area.
   Visit www.agd.org/factsheets to download AGD's latest oral health fact sheet on oral cancer to distribute to patients or use during your discussion.
- Establish your practice's philosophy on how to approach HPV and oral cancer, and make sure your team is comfortable broaching the subject with patients.
- Add a section to patient questionnaires that indicates whether the patient would like to speak with the provider in private about oral cancer concerns.

## Screening Patients for Oral Cancer

Of the estimated 49,750 Americans who are expected to be diagnosed with oral or pharyngeal cancer this year, only about 57 percent are expected to be alive in five years — a number that has not significantly improved in decades. When oral cancers are detected early, patients have an 80 to 90 percent survival rate, according to The Oral Cancer Foundation.

This is why, as an oral surgeon, John Alonge, MS, DDS, of Erie, Pennsylvania, performs oral cancer exams on every patient. Early detection is critical.

"We're taught how to do an oral cancer screen, but I'm not sure how many dentists do it on every patient or how thorough they are," he says. "I get a tongue blade and mirror, and I tell the patient what I'm doing. I can see more than what we'd be normally looking for. Dentists should put that in their repertoire; it only takes 20 seconds at best."

The gold-standard screening tools, at least currently, are a dentist's eyes and hands, Alonge says. He notes the emergence of systems such as VELscope® and ViziLite®, which have a role in detection but shouldn't be viewed as "magic wands."

"The newer adjuncts shouldn't be your sole screening source because they're not foolproof," he says. "They are not substitutes for your eyes and hands, which provide the best possible screen."

Alonge says the advantage of such screening devices is they may detect changes in the basement membrane, where HPV-related oral cancers start, so those who advocate for the tools say they can catch the cancer earlier. However, Alonge questions the validity of the results, as reports of lesions being "detected" by the devices have turned out to be noncancerous.

"Collectively, along with the gynecological and ear, nose and throat (ENT) communities, we will come up with an adjunct that could help with early detection," he says. "We're not there yet."

Alonge says when performing an oral cancer screening, dentists should look behind the tongue and tonsil area — sites beyond where dentists are typically trained to look for oral cancer. The infection typically manifests itself in the posterior third of tongue, tonsils and lateral pharyngeal walls, he notes, adding, "If you see something abnormal, you have to test, biopsy and refer."

Linda Miles, CSP, cofounder of Oral Cancer Cause, says first and foremost, patients and providers both need to be aware of the initial signs of oral cancer: a lump on their neck; a persistent sore throat; hoarseness; or a spot on the roof of their mouth, cheek or gums that won't heal.

The reasons many oral cancers aren't discovered until the late stage are because dentists are not recommending biopsies on early indicators, or patients are not following through by going to an oral surgeon or ENT doctor for a biopsy, she says.

"Doing complete oral cancer screenings is standard of care for all dentists, but sadly, fewer than 20 percent of all practices are doing an advanced two- to three-minute screening," says Miles, who adds that salivary testing is gaining popularity as a diagnostic tool.

"The real paradigm shift is that with salivary diagnostic testing, we can now determine who carries the HPV-16 and HPV-18 strains, which cause oral cancer," Miles says. "The salivary testing has been termed 'the liquid biopsy' by some."

Because more than 90 percent of HPV infections will go away within two years, the role of salivary testing is to identify patients who should be followed closely to determine if their immune system has cleared the infection, Miles says. Outside of screening every patient at every exam, she adds that dentists can prevent HPV-induced oral cancers and save lives by educating patients.

#### Desexualizing HPV: The Patient Education Approach

Because HPV is transmitted through sexual contact, dentists may find themselves in a challenging position when it comes to preventive discussions with patients. Striking a balance between maintaining a comfortable, professional relationship with patients and educating them about the disease can be difficult.

Jacquelyn L. Fried, RDH, BA, MS, of University of Maryland School of Dentistry, Baltimore, suggests reframing the conversation. HPV should be desexualized and instead viewed as an infection that could lead to head and neck cancer, she recommends.

The three HPV vaccines approved by the FDA have been recommended for children as young as 9 years old. Fried says many health care professionals consider early adolescence, such as 11 to 12 years old, a more appropriate time to broach the subject with patients and parents.

"There are no data to suggest that addressing the topic early encourages high-risk sexual activity among young

# HPV VACCINE RECOMMENDATIONS

Three vaccines are approved by the FDA to prevent HPV: Gardasil®, Gardasil 9 and Cervarix®. All three vaccines prevent infections with HPV-16 and HPV-18, though some formulations are approved for females only.

- All children girls and boys ages 11 or 12 should be routinely vaccinated for HPV. The vaccines may be started as early as age 9.
- All children and adults (males and females) ages 13 to 26 should be vaccinated if they haven't received the vaccine already.
- · The vaccines are most effective when given before they become sexually active. CDC recommends 11- and 12-yearolds receive two doses of HPV vaccine at least six months apart rather than the previously recommended three doses. Those who start the series later, at ages 15 through 26, will still need three doses of the vaccine to protect against cancer-causing HPV. For more information about CDC's "Preteen Vaccine" campaign, visit www.cdc.gov/vaccines/who/ teens/index.html.

Sources: American Cancer Society, CDC and National Cancer Institute

16 | AGD Impact | April 2017

adults," says Fried, who has spoken nationally and internationally on HPV and oral cancer. "Dentists and dental hygienists are ethically obligated to bring up the subject of vaccination."

Fried says each practice needs to establish its own philosophy on how to approach HPV and oral cancer with patients. For instance, as providers conduct their head and neck cancer screenings, they can address the subject. Another opportunity could be during a general conversation about wellness. Providers may feel more comfortable having the HPV conversation with longtime patients, or they may want to discuss the topic with parents of young adults, she suggests.

#### **ON-DEMAND WEBINAR:**

# HUMAN PAPILLOMAVIRUS (HPV) AND HEAD AND NECK CANCER

Visit www.agd.org/olc to view AGD's on-demand webinar, "Human Papillomavirus (HPV) and Head and Neck Cancer," presented by Eric R. Carlson, DMD, MD, FACS. After viewing this webinar, attendees will be able to describe:

- The increasing incidence of oral cancer in young people
- The molecular events involved in carcinogenesis associated with HPV, particularly with regard to the early proteins E6 and E7
- The social habits associated with tongue cancer
- The public health initiatives associated with HPV vaccination

This webinar is part of the members-only Free CE Program and was presented in collaboration with American Association of Oral and Maxillofacial Surgeons.

# Roughly one person every hour of every day is expected to die from oral cancer.

The Oral Cancer Foundation

"Telling a young person that high-risk sexual behaviors can lead to head and neck cancer is within the oral health professional's purview," Fried says. "One is not asking a patient what he or she did last Saturday night. The issue of transmission is a fact. Prying into a patient's private life is unnecessary. It is an educational discussion."

In her home state of Maryland, Fried says all dentists and dental hygienists received a letter from the Maryland Department of Health and Mental Hygiene, strongly recommending their involvement in encouraging the HPV vaccine. Such widespread statements

from government and professional associations may encourage more providers to be proactive about HPV, she says.

As with any sensitive topic, with some practice, providers will become more comfortable discussing it with patients, she says.

"There was a time when helping patients refrain from tobacco use was almost taboo, yet today it is and/ or should be a standard of practice," Fried says. "I liken the normalization of tobacco interventions to what I hope will occur with patient-provider discussions about HPV."

#### Providing Support for Patients with Oral Cancer

Nearly 10 years after his diagnosis, Blackburn is cancer-free and now uses his experience to give back to those who are fighting the disease.

Radiation oncologists in the Richmond, Virginia, area send patients his way. He makes sure each patient's mouth is "in incredible condition" prior to starting cancer treatment, as gum disease, tooth decay and other diseases can cause severe consequences during radiation, such as oral mucositis and difficulty

## GET INVOLVED DURING ORAL CANCER AWARENESS MONTH

April is Oral Cancer Awareness Month, and it's an opportunity for your dental practice to participate in community-wide education and prevention. "Educating communities can spread the knowledge faster and attract new patients to a practice," says Linda Miles, CPS, cofounder of Oral Cancer Cause. Here are some ideas to consider:

- Host cancer screening events at your office throughout the month.
- Sponsor a "fun run" to boost awareness and fundraise.
- Offer stickers for each patient to wear after they receive their oral cancer screening.
- If you're an AGD dentist in Nevada, volunteer to provide oral cancer screenings during AGD2017 in Las Vegas. Volunteer forms, which can be found at <a href="https://www.agd2017.org/the-agd-foundation.aspx">www.agd2017.org/the-agd-foundation.aspx</a>, must be submitted to AGD by June 15.
- Donate to the AGD Foundation or to its AGD2017 Electronic Silent Auction Fundraiser. Visit www.agd.org/agd-foundation/fundraising.aspx for more information.

eating, speaking and swallowing. And for patients who may be unable to pay, he performs the service free of charge.

"When someone learns they have cancer, I see them at their worst point," Blackburn says. "When they come in to see me, they see someone who knows what they are going through. They see someone who is positive, energetic, supportive, understanding and willing to give them a hug."

Blackburn's involvement in these patients' lives doesn't end with the pre-treatment dental exam. He mentors patients throughout the entire cancer treatment process by talking with them on the phone, sharing what they might expect from therapy and simply listening.

"We are in the business to cure disease and educate people so they have a better life — that's dentistry,"

Blackburn says. "In treating cancer patients, they may receive a lot from me, but I get far more out of it than they do because of the difference I've made in their lives." •



Kelly Rehan is a freelance journalist based in Des Moines, Iowa. To comment on this article, email *impact@agd.org*.

### The Importance of Early Oral Cancer Detection

By Linda J. Edgar, DDS, MEd, MAGD, AGD Foundation Vice President, AGD Past President

bout a year and a half ago, I was experiencing one of the most stressful periods in my life. I had been caring for my mother and was traveling back and forth from Seattle to Portsmouth, Virginia, every two weeks to organize and provide care, as I was her medical power of attorney. I was also practicing dentistry during this time and really felt as if I had a 24/7 job with everything combined.



In September 2015, I developed a fever blister on my inner lower lip. I thought it was probably due to stress, poor diet from traveling and lack of sleep. I purchased over-the-counter medications that did not help and then went to a dermatologist in December. She gave me a cream that was painful to use and made no difference.

The sore would ulcerate, then crust and fall off, and then ulcerate again. The area never fully healed. My husband, who is also a dentist, examined the sore and recommended a biopsy, which I had done in January 2016. The oral surgeon was a friend and rushed the report, which came back a week later with a diagnosis of squamous cell carcinoma of the lower lip. This diagnosis left me feeling very anxious because the determination of how much lip, face or jaw would have to be removed is not made until the surgery actually occurs. I left the oral surgeon's office shaking and called my office to cancel my afternoon appointments with patients.

I met with a well-known head and neck surgeon at the University of Washington, as well as the head of the oral medicine department, Dr. Edmond Truelove. He looked at the lesion and determined that a Mohs surgery could be done if it hadn't spread, and it hadn't. In March, the Mohs surgery was done, and the cancer cells were removed with two cuts. The second cut removed most of the lower lip, but they were able to save most of the vermillion border.

The next day was the reconstruction surgery, which took about five hours. Forty-two stitches later, I woke up in the recovery room with a large bandage across my whole lower lip that I had to wear for 10 days.

After the surgery, I wore a surgical mask at work and at home. I took about a week off from work. My lower lip remained swollen for about six weeks. My diet consisted of Jell-O, pudding, lukewarm soup and ice cream for about a month. My lower lip is still numb; it was painful to brush my teeth for about six months, and I often used a cotton swab. It still hurts to touch the area and apply lipstick. The area also is very sensitive to spices and sugar. I am constantly aware of the tingling in my lower lip.

So, why did this happen to me? The biggest reason probably was because I was a serious competitive runner and triathlete from ages 28 to 38, often running 120 miles a week and biking several 100-mile rides out in the sun. I have never smoked, rarely drink alcohol and have been with the same marriage partner for more than 50 years. I have never had Botox or anything injected into my lips or face.

I have been encouraged to tell my story as a reminder for dentists to screen more often and refer for biopsies for areas that are not healing in our patients' mouths. I also want to show how scary this positive diagnosis can be and the importance of early diagnosis.

The Academy of General Dentistry (AGD) Foundation's mission is to promote oral cancer awareness and education, as well as provide screenings. Of course, this mission has become much more personal for me. It would be my vision to see AGD take the lead in the country and have proactive action and education in every state to help prevent this disease. If each member donated \$25 to the foundation, we could accomplish this vision.

Donate to the AGD Foundation at www.agd.org/agd-foundation/make-a-donation.aspx.

18 | AGD Impact | April 2017