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Cancer survivorship care from the Memorial Sloan Kettering Cancer Center

Human Papillomavirus–Related Oropharyngeal Cancer: A Review of Nursing Considerations

A rise in head and neck tumors presents new challenges for patients and nurses.

ABSTRACT: The overall incidence of head and neck cancer—which includes laryngeal, hypopharyngeal, nasal cavity, paranasal sinus, nasopharyngeal, oral, oropharyngeal, and salivary gland cancers—has declined in the United States over the past 30 years with the concomitant reduction in tobacco use. Over that same period, however, the worldwide incidence of oropharyngeal cancer has escalated significantly, most notably among men and women under age 60 who live in developed countries. This epidemic rise in oropharyngeal cancer is largely attributed to certain genotypes of the human papillomavirus (HPV). In the United States, HPV prevalence in oropharyngeal tumors increased dramatically, from roughly 16% between 1984 and 1989 to nearly 73% between 2000 and 2004, and the annual incidence of HPV-positive oropharyngeal cancer is expected to surpass that of HPV-related cervical cancer by 2020.

This article provides an overview of head and neck cancer—its incidence, risk factors, treatment, and post-treatment sequelae—with a focus on HPV-related oropharyngeal cancer. Unlike other forms of head and neck cancer, HPV-related oropharyngeal cancer tends to affect younger patients with few or none of the traditional risk factors and has a distinctive presentation, histology, and natural course. In order to provide appropriate patient education and to help these patients monitor and manage late and long-term treatment effects, it is important for nurses to be aware of this disease and its treatment, and of the unique survivorship issues that arise for affected patients.

Keywords: head and neck cancer, human papillomavirus, human papillomavirus–related oropharyngeal cancer, oropharyngeal cancer

Marcus Atkins, a 46-year-old finance executive and father of two young children, was referred by his primary care provider to an ear, nose, and throat specialist (ENT) for evaluation of a painless, firm lump on the left side of his neck. (This case is a composite based on our clinical experience.) The ENT performed a biopsy and sent Mr. Atkins for a computed tomography scan of the neck to evaluate the lymph nodes and neck region. Testing revealed that Mr. Atkins had metastatic squamous cell carcinoma, originating in the left tonsil.

Mr. Atkins was divorced three years ago and is currently in a sexually exclusive relationship with

Sandra Weir, a 30-year-old woman with whom he shares a home. When biopsy results came in, the ENT met with Mr. Atkins and Ms. Weir to discuss test results and to refer Mr. Atkins to a team of radiation and medical oncologists for evaluation and treatment. In the meeting, Ms. Weir asked what might have caused this disease, since Mr. Atkins had always been very healthy and had never smoked. The ENT explained that the cancer may be associated with human papillomavirus (HPV) infection and that the tumor was currently undergoing HPV testing. (The tumor's HPV positivity was later confirmed.) Surprised, Mr. Atkins responded, "Isn't that a sex infection?" The ENT informed the couple that HPV is the most prevalent sexually transmitted infection worldwide and, in fact, almost every sexually active person in the United States has been exposed to HPV—with exposure often occurring many years, or even decades, before an HPV-related cancer is diagnosed. Ms. Weir then shared that her last Pap and HPV DNA tests were negative for HPV. The ENT informed the couple that they need not alter their sexual behavior since the risk of developing HPV-related oropharyngeal cancer from an established sexual partner with the disease is relatively low. The ENT also informed the couple that HPV-related head and neck cancers respond better to treatment than head and neck cancers associated with tobacco and alcohol exposure.

Mr. Atkins was treated with radiation therapy and concurrent chemotherapy, as recommended by the oncology team. Although his cancer treatment was successful (as indicated by posttreatment positron emission tomography–computed tomography scans showing that both the left tonsillar tumor and the left cervical lymphadenopathy had completely resolved), he experienced several adverse effects of treatment, both physical and psychological.

To provide patients like Mr. Atkins appropriate patient teaching while helping them monitor and manage late and long-term effects of treatment, nurses must be aware of the rising incidence of HPV-related oropharyngeal cancer, which affects a younger group of patients than other forms of head and neck cancer. These patients may have few or none of the traditional risk factors associated with head and neck cancer and their disease has a distinctive presentation, histology, and natural course. This article provides a general overview of head and neck cancer—its incidence, risk factors, treatment, and posttreatment sequelae—with a focus on HPV-related oropharyngeal cancer and the unique survivorship issues it creates.

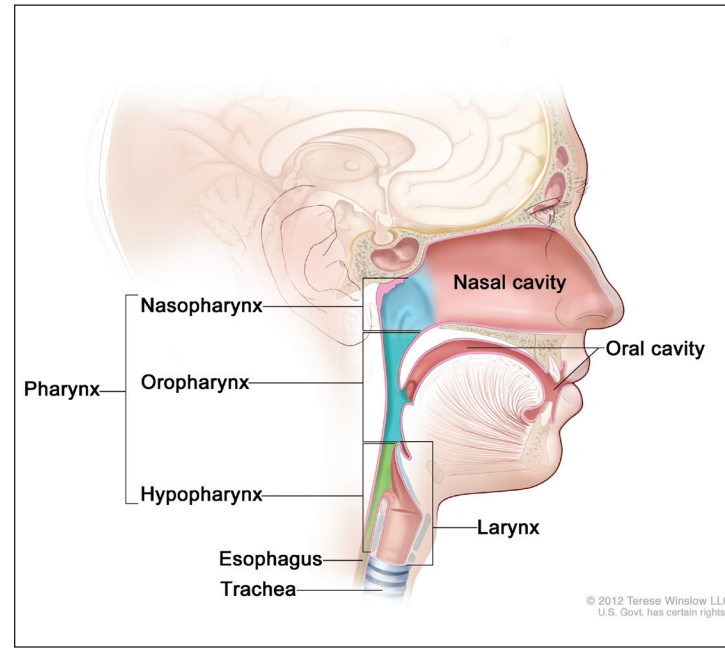

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Figure 1. Anatomy of the Pharynx

CANCERS OF THE HEAD AND NECK

About 3% of all cancers are cancers of the head and neck.[1] It's estimated that, each year, nearly 62,000 people in the United States develop some form of head and neck cancer, which includes laryngeal, hypopharyngeal, nasal cavity, paranasal sinus, nasopharyngeal, oral, oropharyngeal, and salivary gland cancers.[1] Together, head and neck cancers account for nearly 13,200 deaths per year.[1] Depending on the site, patients with head and neck cancer may present with a wide range of symptoms (see Table 1[2,3]).

More than 90% of head and neck cancers are squamous cell carcinomas that arise in the epithelial cells lining the oral cavity, pharynx, larynx, paranasal sinuses, nasal cavity, and salivary glands (see Figures 1 to 3).[4] If the tumor is confined to the superficial squamous layer, it is called carcinoma in situ; if it invades neighboring tissues, it is called invasive squamous cell carcinoma. Because both the major salivary glands (the parotid, submandibular, and sublingual glands) and the minor glands (those found throughout the upper aerodigestive tract) are made up of a variety of cell types, salivary tumors may be mucoepidermoid carcinoma, adenoid cystic carcinoma, and acinic cell carcinoma. The majority of salivary gland tumors, however, are benign.[5] Salivary gland cancers affect only one per 100,000 people in the United States annually.[5]

Risk factors for developing head and neck cancer include the following[1,6,7]:

- male sex (men are two to three times as likely as women to develop head and neck cancer)

Table 1. Common Presentations of Head and Neck Cancer by Site[2,3]

Sign or Symptom	Associated Site of Cancer
• Sore in the mouth or throat that doesn't heal in 2–3 weeks • Persistent sore throat • Ill-fitting dentures or loosening teeth • Dysphagia or odynophagia • Prolonged ear or jaw pain • Decreased mobility of the tongue with change in speech • New mass or lump in the neck (usually painless)	Oropharyngeal
• Continued hoarseness • Stridor or change in voice	Laryngeal
• Frequent epistaxis • Nasal obstruction	Nasopharyngeal
• Numbness of the tongue or other area of the head or neck (due to cranial nerve involvement)	Salivary (specifically, parotid) gland

- any form of tobacco use
- exposure to secondhand smoke
- excessive alcohol use
- combined use of tobacco and alcohol, which increases risk by 35 times over that of abstainers
- inhalation of wood or metal dust, asbestos, paint, or other chemical irritants
- a diet high in salt-cured fish
- exposure to Epstein–Barr virus (also known as human herpesvirus 4)
- poor nutrition (for example, a diet low in vitamins A and B)
- HPV infection

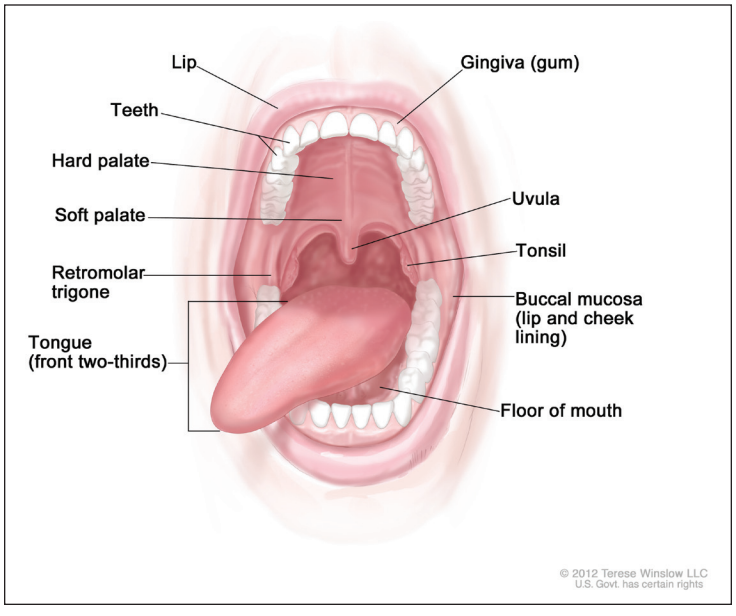

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Figure 2. Anatomy of the Oral Cavity

HPV-RELATED OROPHARYNGEAL CANCER

The United States has seen a decline in the overall incidence of head and neck cancer over the past 30 years, concurrent with the reduction in tobacco use.[1,8,9] Over that same period, however, the worldwide incidence of oropharyngeal cancer has escalated significantly, most notably among men and women under age 60 who live in developed countries.[8] Because the epidemic rise in oropharyngeal cancer is specific to younger adults in economically developed countries—among whom tobacco use is believed to be less common and sexual behaviors such as oral sex and multiple sex partners are believed to be more common—it has been largely attributed to certain HPV genotypes.[8,10]

HPV is a group of over 150 associated viruses.[11] The HPV viruses are responsible for a wide variety of infections, including common skin warts; genital warts; laryngeal polyps; and carcinomas of the anus, cervix and vagina, many of which can be spread by skin-to-skin contact.[12,13] Initially identified in head and neck carcinogenesis in the 1980s, HPV has recently been acknowledged as a risk factor for oropharyngeal cancer, specifically, squamous cell carcinoma of the tonsillar pillar and the base of the tongue.[13] In the United States, HPV prevalence in oropharyngeal tumors increased dramatically, from roughly 16% between 1984 and 1989 to nearly 73% between 2000 and 2004. The annual incidence of HPV-positive oropharyngeal cancer, which increased by 225% between 1988 and 2004, is expected to surpass that of HPV-related cervical cancer by 2020,[10] though it's hoped that HPV vaccines, introduced in 2006, may slow this disturbing trend. The National Comprehensive Cancer Network (NCCN) recommends that all oropharyngeal cancers be tested for HPV.[14]

Demographic characteristics. Traditionally, patients diagnosed with head and neck cancer have tended to be men in the seventh decade of life with

histories of excessive exposure to tobacco and alcohol.[15-17] By contrast, patients with HPV-related oropharyngeal cancer tend to be white, male, nonsmokers of high socioeconomic status who are in their fourth or fifth decade of life. HPV-related oropharyngeal infection, which precedes the development of HPV-related oropharyngeal cancer, is most likely to occur in people who had their first sexual encounter at an early age and who have had a large number of sexual partners, with more than five oral sexual partners.[18, 19]

Sexual transmission of HPV. Serologic studies of antibodies to HPV antigens suggest that the development of HPV-related oropharyngeal cancer is more likely to be linked to sexual behavior practiced more than 10 years before cancer diagnosis than to current sexual practices.[19] Furthermore, established sexual partners of patients diagnosed with HPV-related oropharyngeal cancer have been found to have a very low prevalence of oncogenic oral HPV (1.2%), similar to that in the general population (1.3%), suggesting that the risk of developing HPV-related oropharyngeal cancer from an established sexual partner with the disease is relatively low.[20] For these reasons, patients involved in exclusive established sexual partnerships need not alter their current sexual habits when diagnosed with HPV-positive oropharyngeal cancer.

Nurses can be instrumental in teaching patients and their partners about HPV transmission and in allaying their fears and confusion over related cancer diagnoses. If patients are not in an exclusive relationship, they should follow safe sexual practices such as using condoms and dental dams consistently. Although there is little evidence in the area of best practices for nonmonogamous patients with HPV-related oropharyngeal cancer, most practitioners treating patients with HPV-positive oropharyngeal cancer believe the underlying virus will be completely eradicated through the treatment and is unlikely to affect patients' partners.

Tumor characteristics. Compared with HPV-negative oropharyngeal cancers, the primary HPV-positive tumor is generally smaller, often under two centimeters, but is accompanied by greater cervical nodal disease.[21] Unlike HPV-negative tumors, HPV-positive tumors are not associated with epithelial dysplasia and are commonly nonkeratinizing and basaloid in appearance.[21]

Prognosis. Generally, patients with HPV-positive oropharyngeal tumors have better treatment outcomes and overall survival rates than patients with HPV-negative tumors. HPV-positive tumors have greater susceptibility to radiation therapy and chemotherapy[22, 23] and, unlike tobacco- and alcohol-related oropharyngeal tumors, are not associated with field cancerization (the process through which adjacent epithelial tissue that has been genetically altered by carcinogens engenders new invasive primary tumors).[24, 25] Patients with HPV-positive tumors who smoke, however, have significantly reduced survival rates, suggesting that tobacco modifies HPV biology.[26]

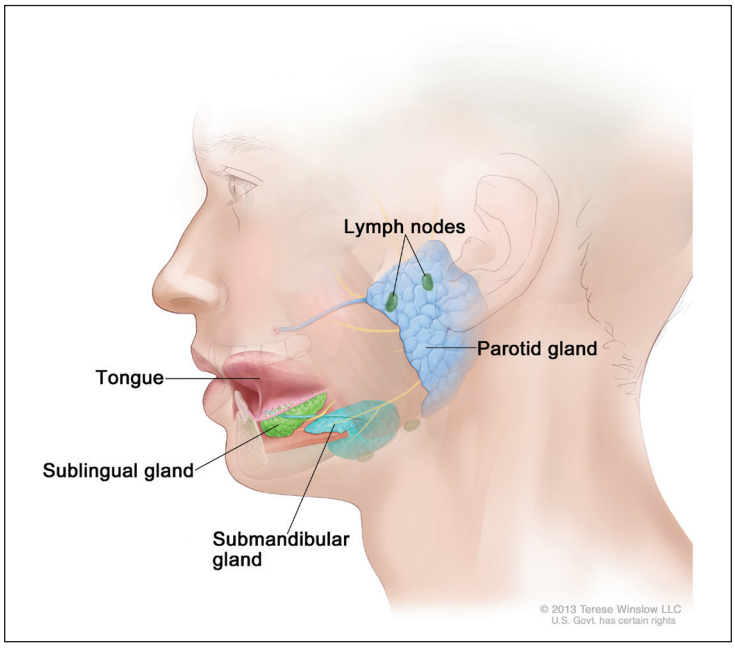

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Figure 3. Anatomy of the Salivary Glands

A retrospective analysis by Ang and colleagues demonstrated that three-year rates of overall survival for patients with oropharyngeal cancer can be estimated on the basis of HPV status, smoking history, tumor stage, and extent of nodal involvement.[26] Investigators determined that patients could be stratified into three risk categories:

- *low risk* (93% three-year rate of overall survival)–HPV-positive tumors, a smoking history of no more than 10 pack-years, and nodal stage N0 to N2a
- *intermediate risk* (71% three-year rate of overall survival)–HPV-positive tumors, a smoking history of more than 10 pack-years, and nodal stage N2b to N3; or HPV-negative tumors, a smoking history of 10 or fewer pack-years, and nodal stage N2b or N3 or tumor stage T2 to T3
- *high risk* (46% three-year rate of overall survival)–HPV-negative tumors and a smoking history of more than 10 pack-years; or HPV-negative tumors, a smoking history of 10 or fewer pack-years, and tumor stage T4

For an explanation of cancer, tumor, and lymph node staging, see *Oral and Oropharyngeal Cancer: Stages and Grades* at www.cancer.net/cancer-types/oral-and-oropharyngeal-cancer/stages-and-grades.

TREATING OROPHARYNGEAL CANCER

Treatment of oropharyngeal cancer does not differ significantly based on HPV status, but rather is

determined on the basis of the patient's functional status and tumor stage.[27] Stage I and II disease are usually treated effectively with surgery or radiation therapy. Because radical surgery can have severe adverse effects on speech and swallowing, disease at this stage is frequently treated with radiation therapy alone.[28] With the recent advent of transoral robotic surgery (TORS), however, patients with HPV-positive oropharyngeal cancer, who generally present with tumors at earlier stages (T1 and T2), now have a less invasive surgical option. TORS also reduces the need for intense adjuvant chemotherapy and radiation therapy while maintaining adequate treatment effects.[29] For stage III, IVa, and IVb oropharyngeal cancers, which are locoregionally advanced (meaning they involve either the lymph nodes or larger primary tumors), treatment generally includes at least two therapy modalities, such as surgery followed by radiation or chemotherapy and radiation given concurrently. In certain high-risk cases, all three modalities may be used.

Most patients with HPV-positive oropharyngeal cancer present with locoregionally advanced disease. Concurrent chemotherapy and radiation usually includes three cycles of cisplatin, administered every 21 days during a seven-week course of radiation therapy. While there are other agents such as cetuximab (Erbitux) or carboplatin with paclitaxel that can be used in place of cisplatin as a radiation sensitizer, cisplatin remains the first-line agent in most cases (see Table 2[30]).

In certain clinical circumstances, patients with more aggressive oropharyngeal cancers (that is, stage III or IV oropharyngeal squamous cell carcinoma or symptomatic primary lesions) may be treated with induction chemotherapy (high doses of chemotherapy before either a surgical or radiation-based approach is initiated). Induction chemotherapy is usually given for two to four cycles, and the standard regimen is a combination of docetaxel (Docefrez, Taxotere), cisplatin, and fluorouracil (Adrucil). However, since scant data show improvement with this more aggressive approach in patients with advanced head and neck cancer, the use of induction chemotherapy remains controversial.[30]

Multidisciplinary care. Because of the effects of radiation therapy on the oral cavity and salivary glands, all patients scheduled to receive radiation therapy for oropharyngeal cancer should be evaluated by a dentist prior to treatment and instructed in routine dental care during and following treatment to prevent dental caries due to dry mouth and decalcification of the teeth.[31] Dental trays containing fluoride or a toothpaste with a high fluoride content may be prescribed.

Since a majority of patients receiving radiation therapy develop mucositis with severe dysphagia, consideration must be given to patients' pretreatment nutritional status. Underweight patients or those who lost a significant amount of weight as a result of symptoms caused by the tumor should be referred to a nutritionist and evaluated for a percutaneous endoscopic gastrostomy tube to avoid further deterioration. Following treatment, swallowing therapy is important to prevent loss of that function.

Before beginning cisplatin therapy, patients should be referred to an audiologist for evaluation. Physical and occupational therapy may be necessary to help patients overcome postoperative weakness of the spinal accessory nerve following neck dissection, or to improve range of motion after radiation therapy. Social workers may be called upon to assist patients and caregivers in accessing financial resources or to help alleviate their anxiety as a result of the cancer diagnosis and fear of the unknown.

Before beginning all cancer treatment, patients and their caregivers should be made aware of potential adverse effects of treatment. Since there is an enormous amount of information for patients and caregivers to process and absorb, such information should be regularly revisited throughout the treatment process. Nurses caring for patients with oropharyngeal cancer play an integral role in providing pertinent information, answering questions, and helping patients manage treatment-related sequelae.

Table 2. Chemotherapy Drugs Used to Treat Oropharyngeal Cancer[30]

Drug	Classification	Adverse Effects
Cisplatin	Alkylating agent	Nephrotoxic, ototoxic, peripheral neuropathy
Carboplatin	Alkylating agent	Nausea and vomiting, peripheral neuropathy
Fluorouracil (Adrucil)	Antimetabolite	Mucositis, diarrhea, sensitivity to sunlight
Cetuximab (Erbitux)	Monoclonal antibody	Rash
Paclitaxel	Plant alkaloid, taxane	Arthralgia, myalgia, sensitivity to sunlight
Docetaxel (Docefrez, Taxotere)	Plant alkaloid, taxane	Mucositis, peripheral neuropathy

LATE AND LONG-TERM EFFECTS OF TREATMENT

After treatment for head and neck cancer, patients continue to face major challenges as they experience a wide range of late and long-term treatment-related effects. Research has demonstrated that the six-to-12-month period following treatment for head and neck cancer is the most crucial for delivering assistance and rehabilitative care.[32] Approximately 40% to 50% of patients treated for head and neck cancer experience both acute and persistent toxicity due to multimodal treatment.[29]

The National Cancer Institute's Symptom Management and Quality of Life Steering Committee has identified 10 core symptoms patients experience and two health-related quality of life domains that are negatively affected following head and neck cancer treatment. The 10 core symptoms are[29]:

- difficulty swallowing
- oral pain
- changes to the skin
- xerostomia
- dental health problems
- trismus
- taste changes
- excessive mucous or thick saliva
- shoulder dysfunction
- voice changes or hoarseness

The two health-related quality-of-life domains are the social and the functional domains.[29] Although survivors of oropharyngeal cancer may experience a wide range of treatment-related effects, the discussion that follows addresses the most frequent effects for which nurses can provide guidance or referral to appropriate therapy.

DYSPHAGIA

Dysphagia, or difficulty swallowing, is common after head and neck cancer therapy. It can be an acute problem or it may become a chronic problem, diminishing quality of life and potentially causing nutritional problems, dehydration, and even aspiration pneumonia. Three months following head and neck cancer treatment, patients may experience an 18% decline in swallowing proficiency.[33] Depending on the patient's age and disease stage, swallowing function may continue to decline, with one study reporting a clinically significant deterioration in 24% of patients between six months and five years following treatment.[34] In a study of 167 patients who underwent either chemoradiotherapy or radiotherapy for head and neck cancer, 48% identified swallowing as a major concern following treatment. The prevalence of this problem is likely because patients frequently score their dysphagia as worse than their health care provider has determined.[33]

Swallowing is a complex mechanism that requires many muscles and nerves working together to move food from the mouth (oral phase) to the pharynx (pharyngeal phase) to the esophagus (esophageal phase), and ultimately to the stomach. Dysphagia following head and neck cancer treatment is usually related to the first two phases of swallowing—namely, the oral phase, especially if dry mouth is an issue, and the pharyngeal phase. Patients with early-stage disease who are treated with TORS initially experience dysphagia and odynophagia (painful swallowing). At six and 12 months, however, patients' swallowing ability is usually significantly better following TORS than it is following chemoradiation, and TORS normally results in shorter gastrostomy duration than chemoradiation (three months versus six months).[35]

The degree of dry mouth a patient experiences is directly related to the cumulative dose of radiation received.

Various radiographic studies are available to evaluate swallowing, but the modified barium swallow is the test most often used.[36] This is a radiologic evaluation conducted by a speech and swallowing therapist who assesses the patient's ability to swallow various foods of different consistencies. Patients scheduled to undergo treatment for oropharyngeal cancer should be evaluated by a speech and swallowing therapist before beginning treatment. Research has demonstrated that prophylactic swallowing therapy improves post-treatment outcomes and may prevent or reduce dysphagia.[37] These patients should continue to be seen regularly by the swallowing therapist during treatment to ensure that they continue to practice swallowing exercises even if they are unable to take their nutrition orally. Performing swallowing exercises throughout head and neck cancer treatment is associated with improved pharyngeal transit, and the benefits are maximized with regular practice.[38] Nurses can be instrumental in promoting patient adherence to performing swallowing exercises simply by asking regularly if patients are performing them. If patients are not doing so, are reporting increased difficulty swallowing, or are reporting coughing with swallowing, initiate a referral to a swallowing therapist.

XEROSTOMIA

Xerostomia, or dry mouth, is an effect of radiation on the secretory cells of salivary glands. Radiation causes these cells to atrophy, diminishing the amount of saliva produced and changing its consistency.[39] The degree of xerostomia is directly related to the cumulative dose of radiation received. Radiation doses as low as 25 Gy can impair salivary gland

function.[39] Intensity-modulated radiation therapy can reduce the extent of xerostomia patients experience. Once salivary gland atrophy occurs, there is no way to reverse the process. Xerostomia can disrupt the normal oral mucosa because of the lack of salivary lubrication, increase the number of dental caries, cause dysphagia and nutritional problems with changes in taste, and disturb the normal sleep cycle (since patients frequently wake because of oral dryness).[40] Instruct patients to practice meticulous oral hygiene to prevent dental caries and demineralization and to use a prescribed fluoride treatment—either a toothpaste or a gel applied to dental trays—twice daily.[41] Encourage quarterly dental cleanings to help patients prevent osteoradionecrosis, which occurs in about 5% of patients.

Xerostomia in these patients can be made worse by other medications, including diuretics, antihypertensive medications, or antianxiety or antidepressant drugs.[41] Be sure to obtain a complete medication profile of patients who have been treated for head and neck cancer because their dosages may need to be adjusted—especially if the xerostomia is severe and diminishing quality of life. Patients with a history of head and neck cancer should avoid smoking to prevent secondary tumors, but also because smoking can exacerbate oral dryness. Discuss the importance of not smoking and provide any smokers with a smoking cessation referral.

In managing xerostomia, patients should carry a bottle of water with them at all times to keep the mouth moist, but use of commercial salivary substitutes can be helpful as well. Many such products are made in a viscous gel form and used to coat the tissues of the mouth to maintain lubrication. Instruct patients to avoid sugar-laden and caffeinated beverages, as these can reduce saliva production further.[41] Encourage patients to use a humidifier, especially in the bedroom, to avoid severe nighttime xerostomia due to mouth breathing. The physiologic stimulation of chewing sugar-free gum or sucking on sugar-free candies may also provide some relief.

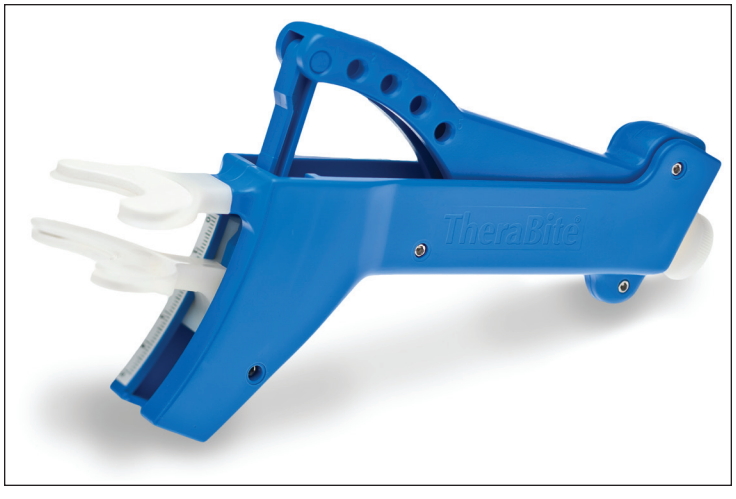

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Figure 4. The Therabite Jaw Motion Rehabilitation System

TRISMUS

Trismus, the inability to open the mouth fully, is a common complication of both radiation therapy and surgery for head and neck cancer.[42] It most often occurs one to nine months following radiation therapy and can cause nutritional problems, speech difficulty, oral hygiene issues, and limited oral evaluation by health care providers. Up to 38% of patients treated for head and neck cancer develop trismus following treatment.[42]

A normal mouth opening is three finger widths, or approximately 47 mm, when measured from the anterior top to the anterior bottom incisors.[43] Nurses can assess patients for trismus by asking them to try to insert three fingers between their central incisors. If the patient is unable to meet this standard, treatment for trismus should begin, as the condition usually worsens with time. There are a range of treatment options available, but research has shown that the use of a mobile mandibular device, such as the Therabite Jaw Motion Rehabilitation System (Atos Medical Inc, West Allis, WI) (see Figure 4), significantly improves maximum incisal opening by about 13 mm compared with stacked tongue depressors or manual jaw stretching exercises.[44] In addition, the use of the Jaw Dynasplint System (Dynasplint Systems, Inc., Severna Park, MD) (see Figure 5) in a multimodality treatment regimen that included physical therapy, botulinum toxin injections, and pain medications improved interincisal openings by 11 mm.[42] Nurses should teach patients with head and neck cancer about the potential for trismus during the pretreatment phase, so they can practice jaw opening with facial muscle massage during and following treatment. Appropriate patient education materials with evidence-based recommendations should be developed and provided to patients so they can practice appropriate mandibular exercises and facial massage at home. Any patient experiencing trismus should be referred to a physical therapist so as to avoid worsening the condition.

FIBROSIS OF THE NECK AND SHOULDER

Neck and shoulder fibrosis, a typically late complication of radiation therapy and neck dissection, occurs in approximately 20% of treated patients.[45] It results from a buildup of collagen and other materials within the connective tissue, and can decrease elasticity, limit the neck's range of motion, and cause considerable pain and neuropathy.[46] Affected patients experience diminished quality of life, with a reduced ability to carry out activities of daily living because of limited

range of motion in the arm, neck, and shoulder.[47] They also tend to lose muscle strength and may develop edema of the neck or arm.[48] To prevent postoperative morbidity and possibly limited function resulting from radiotherapy, patients scheduled for selective neck dissection require preoperative teaching that includes shoulder and neck exercises. With assistance from rehabilitation medicine, nurses can develop educational materials and provide them to patients. Fibrosis cannot be reversed once it occurs, but rehabilitation therapy can relieve some of the symptoms. Patients scheduled for neck dissection should have an evaluation with a physical therapist to reduce the complications caused by this treatment.

DEPRESSION AND ANXIETY

It has been frequently noted in the medical literature that patients with head and neck cancer experience significant depression and anxiety, most notably at the time of diagnosis and during treatment; but these symptoms can continue for years following treatment.[49] In one study, the emotional needs of patients with head and neck cancer outweighed those of trauma victims by almost 10%.[50]

Following completion of head and neck cancer treatment, patients have described the sensation of being in a "black hole" of depression, of being alone and with no relief in sight.[51] Among patients with head and neck cancer, depression rates can reach 43% before treatment and 44% afterward, whereas overall rates of depression among all oncology patients vary from 20% to 30%.[52] Participation in psychoeducational support groups can be valuable for patients with head and neck cancer, but antidepressant medication may also be required.

The NCCN has published an algorithm, based on the recommendations of the American Society of Clinical Oncology, for screening cancer survivors for depression and anxiety.[53] Following recommended screening practices is particularly important when caring for patients with head and neck cancer. Assessment for depression should be performed at every clinical encounter using a reliable screening tool,[53] such as the NCCN's Distress Thermometer, which is available online at www.nccn.org/patients/resources/life_with_cancer/pdf/nccn_distress_thermometer.pdf. Appropriate interventions should be initiated with a proper referral for psychiatric counseling and management when necessary.

MR. ATKINS REVISITED

After undergoing radiation and chemotherapy, Mr. Atkins experienced severe mucositis and tinnitus. After treatment, he was left feeling isolated and apathetic. His partner, Ms. Weir, who was initially supportive, had become more emotionally distant. Mr. Atkins often spent his days in bed, and he continued to experience left ear pain and throat pain with thick, tenacious saliva that made him feel nauseated and further reduced his poor appetite.

Photo courtesy of Dynasplint Systems, Inc.

Figure 5. The Jaw Dynasplint System

Mr. Atkins's posttreatment scans indicated that the left neck nodes identified at diagnosis remained suspicious for malignancy; he required a left modified neck dissection. Within three months after surgery, Mr. Atkins had stopped performing the neck exercises the nurse had taught him before surgery. As a result, he was having difficulty raising his left arm and experienced occasional pain in his left shoulder and upper back.

Fearful that the shoulder pain meant his cancer had returned, Mr. Atkins reported for a follow-up with the ENT sooner than his scheduled appointment. After a thorough examination and flexible laryngoscopy procedure, the ENT reassured Mr. Atkins that there was no evidence of disease and recommended physical therapy for the shoulder pain. Mr. Atkins was also instructed to resume his neck exercises to prevent worsening of the pain. Although he left the physician's office relieved that the cancer had not returned, Mr. Atkins worried that he would never feel normal again, be able to swallow without difficulty, and feel free of his cancer diagnosis.

He returned to work eight months after completing treatment. Initially he had difficulty working a full day because of exhaustion; but after several weeks, his energy returned. At 10 months following treatment, Mr. Atkins learned of a head and neck cancer support group and began to attend monthly. The patients in

this group helped alleviate the anxiety he felt before medical appointments and radiologic examinations, putting it in perspective as a normal temporary reaction they referred to as "scanxiety."

He still had dry mouth but had adapted by using the nurse's suggested techniques, such as always having a bottle of water available to moisten his mouth and throat. Although he was able to eat soft, moist foods with gravies or sauces to make swallowing easier, he still missed his favorite meal, surf and turf, because he had difficulty swallowing steak. He continued doing his neck exercises regularly and experienced only occasional neck, shoulder, or upper back pain.

Although Mr. Atkins continued to experience posttreatment sequelae, he had developed strategies for dealing with them. He started to feel more like his "old self"—what his friends in the support group called his "new normal." He continued to monitor his diet and, ultimately, returned to his pretreatment exercise level, which he believed helped him endure his posttreatment struggles. He knew he'd have bouts of anxiety until he passed the "five-year-disease-free" goal, but the support he received from friends and health care providers helped him develop a game plan for achieving that goal.

NURSING IMPLICATIONS

Nurses must assess and monitor head and neck cancer survivors for late and long-term effects of treatment at every medical visit. Integral evaluations include

- observing oral mucosa.
- assessing nutritional status.
- monitoring weight and oral hygiene.
- assessing swallowing.
- monitoring for trismus.
- checking for shoulder dysfunction.
- screening for depression and anxiety.

Before, during, and after head and neck cancer treatment, nurses can teach or reinforce trismus and neck exercises. A regular review of medications is important to help patients avoid exacerbating adverse effects such as xerostomia and dysphagia related to dry mouth.

Patients can be periodically assessed for smoking and use of other tobacco products. When appropriate, they can be referred to a smoking cessation program, nutritionist, physical therapist, or speech and swallowing therapist.

Because HPV is a sexually transmitted disease, a diagnosis of HPV-related head and neck cancer can have distressing and confusing consequences for patients and their partners. It may also produce discomfort in health care professionals who lack confidence in discussing sexual matters with patients. Nurses should remind patients that the majority of sexually active adults in this country have been exposed to HPV; it is not a sign of promiscuity. It is imperative to approach this disease in a nonjudgmental manner and to relieve patients' distress by providing appropriate patient teaching and disease-related information. Patients in exclusive, established sexual relationships should receive reassurance that they need not make any changes in their sexual behavior.

Finally, patients should be informed of support groups or organizations such as Support for People with Oral and Head and Neck Cancer (www.spohnc.org), where they can obtain valuable information about dealing with treatment-related effects and access monthly newsletters with articles written by physicians and other health care practitioners who treat patients with head and neck cancers.

Patients with head and neck cancer undergo complex treatment regimens and experience an extensive array of resultant complications that pose challenges for all health care practitioners involved in their care. As the incidence of HPV-related oropharyngeal cancer is on the rise worldwide, it is incumbent upon every health care practitioner to become familiar with this type of head and neck cancer, the patients it affects, the treatments they receive, and their posttreatment struggles. ▼

For three additional continuing nursing education activities on oral cancer, go to www.nursingcenter.com/ce.

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