Palliative Care for Patients With Head and Neck Cancer
“"I Would Like a Quick Return to a Normal Lifestyle"

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THE PATIENT’S STORY
Mr K is a 57-year-old financial analyst with a long history of precancerous and cancerous oral lesions. Although his medical history includes hypertension, diabetes mellitus, and HIV infection (well controlled with antiretroviral treatments), he has no risk factors for oral cancer, specifically no tobacco use or significant alcohol intake. In 1997, he developed a tongue lesion that demonstrated dysplasia. It was treated with topical steroids, and then both laser and surgical excision. The lesion recurred in 1999 and a biopsy revealed superficially invasive well-differentiated squamous cell carcinoma. He underwent wide resection with all margins clear of carcinoma, but with residual dysplasia at the edges.

He was followed up closely and in April 2006 began experiencing worsening tongue pain. Biopsy at this time showed recurrence of his squamous cell carcinoma. He was then referred to Dr U, who performed a right partial glossectomy and ipsilateral neck dissection. Pathology from the tongue specimen showed carcinoma extending to the lateral margin. At this point, mandibular resection and reconstruction with a free fibula flap was undertaken. Intraoperative frozen section margins did not show evidence of cancer, but on final pathological examination, however, there was extensive involvement of the mandible to the lateral margin. Mr K was taken back to the operating room for a third resection and reconstruction with a second free fibula flap. After the operation, he underwent radiation therapy to the neck. Currently, 3 months after completion of radiation therapy, he appears to be free of disease.

During his operations and radiation therapy, Mr K lost nearly 20 pounds. He remains dependent on liquid artificial hydration and nutrition, delivered through a gastrostomy tube. He has difficulty controlling his oral secretions. His speech is intelligible but significantly different from his former pat-
increasing evidence in the last several years of an epidemiologic is usual for the patients with oral cancer. which seemed to be much harder on him than the surgery, which all the sequelae that go along with surgery, primarily radiation, I know have been very taxing on him emotionally. He’s suffered patient has gone through that. He’s had multiple operations, which one of the primary problems for patients with oral cancer is high recurrence rate.... This patient has gone through that. He’s had multiple operations, which I know have been very taxing on him emotionally. He’s suffered all the sequelae that go along with surgery, primarily radiation, which seemed to be much harder on him than the surgery, which is usual for the patients with oral cancer.

Palliative Care for Patients With Head and Neck Cancer

Palliative care is interdisciplinary care that provides support for the physical, emotional, and psychological suffering2 of patients with any advanced illness, regardless of age, diagnosis, or life expectancy. The goal is to prevent and relieve suffering and to improve quality of life for people facing severe, complex illness. It differs from traditional hospice or end-of-life care in that patients who receive palliative care can also continue to receive curative or life-prolonging treatments. This distinction is particularly important in the case of patients with head and neck cancers because these patients often have a relapsing course that is marked by periods of freedom from disease and symptoms, interspersed with bouts of serious illness, debility, and numerous physical and psychological symptoms including pain, dysphagia, weight loss, disfigurement, depression, and xerostomia. Suggestions for treatment of symptoms discussed herein come from a comprehensive search of both PubMed and the Cochrane Review databases.

Epidemiology of Head and Neck Cancer

An estimated 30,000 people are diagnosed with head and neck cancers annually in the United States, and approximately 7500 individuals die of these cancers annually.2,3 The phrase “head and neck cancer” refers to a diverse group of diseases that include primary malignancies of the oral cavity, oropharynx, larynx, sinuses, and skull base. These malignancies primarily affect men (with a ratio of nearly 2:1) and are strongly associated with cigarette smoking and alcohol consumption.4,5 There has been increasing evidence in the last several years of an epidemiologic link between human papillomavirus and head and neck cancers, even in the absence of cigarette smoking or alcohol consumption.6,7

Although treatment options for head and neck cancer have evolved rapidly over the last 30 years, prognosis for patients with locally advanced disease still remains poor.10,11 Five-year survival rates for patients with head and neck cancer (all types and stages combined) is 59%.3 The mainstay of current therapies involves a combination of surgery, radiation, and chemotherapy; the sequence and timing of these interventions depends on both origin of the malignancy as well as its stage.10 Although these treatment modalities have increased the disease-free interval for patients with head and neck cancers, cure rates have not dramatically changed over the last 50 years. In other words, while the cure rates have not improved, patients are living longer with quiescent, subclinical disease.12 (A comprehensive outline of interventions and survival rates based on cancer type and stage is available elsewhere.13) As patients live longer with the consequences of the disease and its treatment, primary care physicians need to be familiar with the common adverse effects and ways to alleviate them.

Physical Symptoms in Patients With Head and Neck Cancer

Pain

Mr K: Radiation included rather unpleasant side effects. It’s painful and I got burns around my chin and neck. I had pain medication, and I put topical solutions on the areas of skin that were affected. I also had ulcers on my lips and yeast infections in my mouth. There was also bleeding in my mouth.

Although all patients with cancer may experience pain, individuals with head and neck cancer often have etiologies and pathophysiological mechanisms for pain that differ from other malignancies. Pain in the mouth or neck may be a presenting symptom,9 and it also may be a marker of recurrence. Pain re-
Sialorrhea and Xerostomia

Problems with controlling and producing saliva are troublesome treatment complications of head and neck tumors. Indeed, Mr K reported drooling postoperatively due to the loss of the normal architecture of his mouth caused by a resection of a portion of his mandible. Even though these hypersecretory symptoms can sometimes be addressed solely by swallowing and speech techniques taught by a speech pathologist, patients may benefit from pharmacological treatment with anticholinergic medications (eg, glycopyrrolate, hyoscyamine) to dry secretions.

In older adults, caution is warranted in using these medications as the tumor itself can be nociceptive, related to destruction of tissue such as the tongue or jaw, as well as neurogenic, related to tumor damaging or traveling along nerves. Although a discussion of treatment modalities for nociceptive vs neuropathic pain is beyond the scope of this article, distinguishing between the 2 is vital because they are treated with different medications and dosing intervals. Nociceptive pain is treated with opioid medications, whereas neuropathic pain is often treated with anticonvulsants, tricyclic antidepressants, local anesthetics, and other medications. Principles for treating pain among patients with head and neck malignancies are similar to that of other cancers, but patients may be unable to take certain formulations of medications due to difficulty swallowing. Therefore, transdermal preparations for patients on a stable dose of opioids (eg, fentanyl patches) or liquids that enable easier dosing via gastrostomy tubes (eg, liquid morphine) may offer better options. Although medications used commonly to treat neuropathic pain do not come in liquid preparations, consultation with a pharmacist is beneficial to determine which classes of medication can be crushed and either mixed with food or given via gastrostomy tube. Dermatitis and soft tissue damage of the face or neck are often seen in patients who receive radiation therapy. These symptoms begin 2 to 3 weeks after initiation of radiation treatment and can be quite severe. Usually beginning with erythema, the field exposed to radiation may become edematous and eventually blister, ulcerate, and slough. Acute radiation-induced changes begin to heal about 2 weeks after the cessation of treatment. Patients whose scalp is included in the field of radiation should be instructed to wash gently and use mild shampoos to help prevent skin reactions.

Topical agents such as low-potency steroid creams, topical acid-containing creams (such as hyaluronic or ascorbic acid), and aloe vera have been studied for both the prevention and treatment of acute radiation-induced skin reactions, but a systematic review found no benefit from these agents. As such, clinical experience suggests that initial use of a plain, nonscented, lanolin-free hydrophilic cream may be helpful for patients with skin discomfort due to radiation, but these creams should be discontinued if skin breakdown occurs. Itching resulting from radiation may be treated with low-potency topical steroids, but caution is warranted because these agents may lead to skin thinning if used for a prolonged period. Severe pain resulting from radiation may be managed with systemic opioids if necessary. Long-term complications can occur within 2 to 4 months after completion of treatment and include changes in skin texture, fibrosis, and atrophy of soft tissues. Chronic pain in the radiation field can occur but is not common. Skin changes may be more severe if chemotherapy is added to the treatment regimen.

### Table. Common Symptoms Encountered in Patients With Head and Neck Cancer and Suggested Treatments

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Treatment</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>Opioids</td>
<td>May need to be given via alternate route (eg, transdermal fentanyl patches, morphine elixir via gastrostomy tube)</td>
</tr>
<tr>
<td>Mucositis</td>
<td>Allopurinol mouthwash</td>
<td>Evidence supporting use of these agents is weak</td>
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<tr>
<td></td>
<td>Granulocyte-macrophage colony-stimulating factor immunoglobulins</td>
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<tr>
<td></td>
<td>Human placental extract</td>
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<tr>
<td>Dysphagia</td>
<td>Consultation with speech and language pathologist</td>
<td>Degree of dysphagia depends on origin of tumor and types of treatments. May be transient or permanent, may be severe and lead to dehydration or malnutrition</td>
</tr>
<tr>
<td></td>
<td>Artificial hydration and nutrition</td>
<td></td>
</tr>
<tr>
<td>Xerostomia</td>
<td>Frequent intake of water, ice chips</td>
<td>Based on common practice, evidence is weak; should be left to patient preference within boundaries of what is deemed medically indicated (eg, avoid water if significant aspiration risk). Pilocarpine has multiple adverse effects, which may limit its use, particularly in elderly patients</td>
</tr>
<tr>
<td></td>
<td>Use of sugarless candy or gum</td>
<td></td>
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<tr>
<td></td>
<td>Artificial saliva, pilocarpine (starting dose 2.5 mg enterally 3 times daily)</td>
<td></td>
</tr>
<tr>
<td>Change in speech</td>
<td>Consultation with speech and language pathologist</td>
<td>Many patients can relearn speech so this symptom does not always interfere with long-term function, but speech may not return to baseline patterns</td>
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<tr>
<td></td>
<td>Adaptive devices (eg, amplifier)</td>
<td></td>
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<tr>
<td>Decreased quality of life</td>
<td>Supportive treatments, including counseling and psychotherapy</td>
<td>In many patients, quality of life will return to baseline level over the long term</td>
</tr>
<tr>
<td>Depression</td>
<td>Emotional support</td>
<td>May be transient or prolonged; if patients are treated with antidepressants, adverse effects and interactions with other medications should be considered when selecting the medications</td>
</tr>
<tr>
<td></td>
<td>Referral to psychotherapy, counseling</td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td>Emotional support</td>
<td>Anxiolytics can be associated with fatigue, delirium</td>
</tr>
<tr>
<td></td>
<td>Referral to psychotherapy, counseling</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Antianxiety</td>
<td></td>
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*Consultation with speech and language pathologist is useful for many of these conditions as well.*
due to their multifaceted adverse effects profile (eg, orthostasis, constipation, urinary retention) and their propensity to induce delirium.21

As Dr U mentioned, xerostomia is also a complication of these malignancies, particularly in patients who undergo radiation therapy. The addition of chemotherapy to radiotherapy further increases the likelihood of developing xerostomia.34 Saliva is necessary for speech and eating, and it also serves to clean the mouth and reduce cavities. As such, the loss of saliva production can lead to difficulty eating and swallowing, trouble with speech, development of dental caries, and decreased quality of life.19 Because the radiation therapy destroys the glands that make saliva, higher doses are associated with more severe changes, which may be irreversible.25 Commonly used palliation for xerostomia includes drinking water frequently to keep the mouth lubricated, use of ice chips, and artificial saliva, which combines water with lubricants.18 Sucking on sugarless candy or chewing gum can also stimulate salivary flow.18 Pilocarpine, started at a dose of 2.5 mg by mouth 3 times daily that can be titrated up to 10 mg 3 times a day, is a parasympathomimetic compound that has been shown to improve patients’ symptoms to a certain extent,19,20 but its adverse effect profile (eg, sweating, rhinorrhea, urinary frequency) may limit its use.36

**Mucositis**

Mucositis is an inflammation of the mucosal membranes lining the gastrointestinal tract and frequently affects the mouth and pharynx of patients with head and neck cancer who undergo radiation therapy.17 As with xerostomia, the prevalence increases with the addition of chemotherapy.34 Mucositis can be extremely painful and result in the inability to eat, swallow, or speak. The discomfort can be so significant that it interrupts treatment plans.38 This condition can occur in either the mouth or pharynx and typically begins about 10 to 14 days after the commencement of radiation treatment (which is the length of time needed for the oral mucosa to regenerate, a process impeded by radiotherapy).23 The condition usually begins to abate 4 to 6 weeks after the completion of radiation.27 Clinically, the mucosal tissue may appear white and patchy at first and then may progress to erythema and, at times, ulcer formation. Mucositis can be exacerbated by superinfection by either *Candida* or oral bacterial flora. Numerous agents have been used in attempts to either prevent, reduce the severity of, or treat mucositis.15,39,46 These range from nonpharmacological treatments such as the use of ice chips, honey, and mucosal oral hygiene to local treatments (eg, topical lidocaine, sucralfate, “magic mouthwash” — a combination of drugs that varies by institution but often contains viscous lidocaine, diphenhydramine, and aluminum hydroxide41) to systemic treatments (eg, etoposide, granulocyte-macrophage colony-stimulating factor [GM-CSF]). Unfortunately, the data to support the use of many of these agents come from poorly designed studies whose results are often equivocal. In a recent comprehensive meta-analysis of agents to prevent or reduce the severity of mucositis, the Cochrane Collaboration determined that only 2 interventions showed promise in patients with head and neck cancer: amifostine (a free radical scavenger dosed at 200 mg/m2 and given intravenously before radiation treatment42-44) and hydrolytic enzymes.40 In terms of treating mucositis, a different meta-analysis by the same group showed that 4 agents were statistically beneficial for the treatment of mucositis: allopurinol mouthwash, GM-CSF, immunoglobulins, and human placental extract.13 However, in both prevention and treatment trials, the effect size for these agents is quite small and problems with study design often make these conclusions unreliable.15,40 Systemic opioids (given orally, intravenously, or transdermally) effectively treat the pain of mucositis13 and should be used aggressively if local treatments do not result in desired pain relief. Patients with severe mucositis need to be closely monitored to prevent malnutrition or dehydration and may require hospitalization if severe pain or dehydration requires intravenous medications or fluids.

**Dysphagia and Odynophagia**

Difficulties with swallowing are almost universal symptoms for patients with head and neck cancer and may stem from the primary tumor or develop as a sequelae of surgery or radiation. Swallowing difficulties can take the form of either dysphagia or odynophagia. Artificial hydration and nutrition, most often delivered through a gastrostomy tube, is commonly used in patients as a temporary mechanism to ensure adequate nutrition and hydration during the healing process.12 Unlike patients with other forms of advanced disease for whom data demonstrate that artificial hydration and nutrition is not beneficial and may even be harmful,14-17 there is less controversy about the benefit of artificial hydration and nutrition in this population. Mr K’s concerns about his inability to travel while using gastric feeding are common. Delivering larger quantities of artificial hydration and nutrition in a short period of time at regular intervals (bolus feeding) can help liberate these patients from the use of a pump and the need to be attached to external encumbrances. Consultation with a nutritionist is essential to ensure that patients receive adequate intake of calories, protein, and water. In those patients with advanced disease who require large-scale resections or permanent tracheostomy, the need for artificial nutrition may be lifelong. In addition to addressing swallowing difficulties, artificial nutrition may be needed to supplement caloric intake for patients who experience severe anorexia due to alterations in smell or taste. Systemic opioids may also be effective for those patients with severe pain that restricts their ability to swallow.

**Difficulties With Speech**

Depending on the nature of a patient’s cancer and the surgical procedures necessary to treat it, changes in speech may be transient or permanent. Alterations to the lips, tongue, teeth, hard or soft palate, and larynx can all result in different patterns of speech or voice disorders.23 In the case of Mr K, although his voice will never return to its preoperative character and quality, he is able to speak without the use of an assistive device.
For patients with more advanced disease or who require laryngeal resection, amplifying devices or alternate speaking techniques (eg, tracheoesophageal speech) must be used. Close collaboration with speech and language pathologists who specialize in the care of patients with head and neck malignancies should begin early in the course of a patient’s treatment.

Psychological Symptoms in Patients With Head and Neck Cancer

Dr U: One of the primary problems for patients with oral cancer is the high recurrence rate. This patient has gone through that. He’s had multiple operations, which I know have been very taxing on him emotionally. . . . Having said that, he has been surprisingly good at getting back to normal life. . . . His partner has been extremely supportive and helped him through therapy and the difficult decisions. . . . I think that the support he has gotten from his partner has improved his quality of life.

Mr K: Having cancer can be very depressing. I can’t say that I had severe depression, but I did have some intermittent bouts of depression. . . . While it is comforting that the cancer has been removed and the radiation will try to prevent the return, I would like a quick return to a normal lifestyle. I would very much like to eat real food again and converse as normally as possible.

Body Image and Functional Outcomes

Although physical symptoms must be considered in the care of patients with head and neck malignancies, the constellation of these symptoms and their impact on patients’ body image and overall quality of life are equally important to consider. Mr K sums up well the frustrations experienced by this group of patients. Although cure is possible for many, patients encounter numerous setbacks while undergoing the procedures and healing necessary along the road to recovery. Changes in body appearance—and body image—are almost universal. Since the 1980s, when surgeons began to consider aesthetics and function as well as treatment, reconstructive procedures have improved dramatically, due in part to collaboration between otolaryngologists and plastic surgeons. Patients who undergo surgery by a skilled surgical team may be left with little to no outward physical changes. The introduction of microvascular-free tissue transfer, a technique that transfers skin, muscle, bone, or all 3 from one part of the body to the neck for reconstruction of the tongue, jaw, and face, provided surgeons with the means to improve a patient’s quality of life by improving both functional and cosmetic outcomes. More recently, the application of robotic surgery and endoscopic techniques allows the resection of tumors without the deforming facial incision used previously. These new techniques have been developed in the past several decades, but few data on their impact on patients’ quality of life and functional outcomes are available. However, pending such data, patients should be encouraged to seek out medical centers that practice such procedures to maintain cosmetics and function.

Quality of Life and Depression

Because patients see themselves every day in the mirror and the face is a key element in the way we express ourselves to the outside world, even small alterations in visage can have a large adverse impact on patients’ body image and self-esteem. Likewise, because of difficulties with swallowing and nutrition as well as the cachexia that is associated with cancer, these patients may lose a great deal of weight. Due to these changes in appearance and the impact that both the malignancy and its treatments have on physical functioning and self-image, patients with head and neck cancer may experience a significantly worsened quality of life. Long-term studies of these patients, however, show that after a period of 12 to 36 months, self-rated quality of life may return to baseline in more than 50% of patients. A patient’s best achievable quality of life is dependent on factors such as current pathology, stage at diagnosis, and surgical or medical interventions. In spite of this eventual return to satisfaction with their quality of life, the period from diagnosis to full recovery may be marked by symptoms of frustration, hopelessness, and depression. Studies have shown that 20% to 50% of patients with head and neck cancers may have moderate to severe depression at some point after diagnosis. Whether these symptoms are a true episode of major depression or an adjustment reaction with depressive features, the use of antidepressant medications often helps patients with head and neck cancers. Choice of specific medications (eg, selective serotonin reuptake inhibitors [SSRIs] vs norepinephrine and dopamine reuptake inhibitors) should be guided by patients’ other physical symptoms and the medication’s adverse effect profile. For example, patients with weight loss may benefit from the tetracyclic antidepressant mirtazapine, which has been shown to cause weight gain in some patients, and patients with xerostomia should not receive tricyclic antidepressants due to their anticholinergic properties.

Anxiety

In addition to depression, the high recurrence rate of head and neck cancers may result in a constant sense of anxiety relating to concerns about relapse. Mr K has lived with his cancer for over a decade, a not-uncommon scenario for patients with head and neck malignancies. The anxiety caused by this uncertainty can be particularly pervasive, affecting patients and their families in multiple areas of function. Psychotherapy and support groups may be beneficial to patients with head and neck malignancies and their families. If this anxiety impairs function or quality of life, treatment of anxiety with medications such as benzodiazepines or SSRIs may be indicated. By asking patients about their concern of recurrence, clinicians can begin a discussion that allows patients to talk about their fears while at the same time offering therapeutic options. To begin such a conversation, a clinician may say, “Do you worry that every pain or discomfort means that the cancer is back?” or “Some patients find that speaking with other individuals with head and neck cancer can be helpful. Would you like me to provide you information on support groups?”
Guilt and Self-blame
For decades the epidemiological links between head and neck cancers and both tobacco and alcohol consumption have been well established4-6 and are thought to be mediated through the creation of oncogenes and ultimately tumor formation.61 Although some patients may blame themselves and feel they caused their own illness,62 patients may also feel guilt about the toll that the illness takes on their family and caregivers. Eating is a major social, cultural, and religious ritual in society, and patients with head and neck cancer often cannot participate in this activity. Even going out to dinner can become an impossible task, and patients may often be concerned about the impact this has on their family. Likewise, facial disfigurement—even if only temporary—may make it emotionally difficult for patients to leave the house, which can change the dynamic between patients and their loved ones. Feelings of guilt and self-blame in patients with head and neck cancer are therefore not only related to their own role in their illness but also to the belief that they are to blame for the impact the illness has on the quality of life of their loved ones. Physicians can assist patients with these feelings by encouraging them to talk about them with their loved ones, and even facilitating these conversations. For example, if a patient is accompanied to an office visit with a caregiver, the clinician can ask both of them, “What role has the illness taken on your relationship?” or even more directly, “Are you finding it difficult to eat out in public? How are you handling the changes imposed by the cancer on your social life or religious practices?”

Interdisciplinary and Supportive Services for Patients With Head and Neck Cancer

D8 U: The other thing that I have found helpful is using staff like the speech, physical, and occupational therapists. The surgeon simply cannot do all of those jobs and does not have the expertise to do those jobs. So I try to get [all of these disciplines] involved very early.

Mr K: [Oral communication] is a significant issue . . . I manage a group of employees and some of my employees are not relocated with me, so I have to talk to them by phone. Some of this is alleviated by modern communication and I can communicate with them by e-mail, for example. I am going to a speech and swallowing therapist. She’s given me certain exercises for my mouth, tongue, head, and neck. She gave me exercises to read aloud. I’m supposed to focus on pronouncing words and emphasizing certain syllables. She actually records video of my swallowing technique. I’m not sure what the device is called, but she runs a tube through my nose and down into my throat and records a video of how the swallowing looks. By studying that, she can then give me pointers as to how to improve my swallowing.

One of the fundamental principles of palliative care is that it is practiced within an interdisciplinary team, pooling the expertise of physicians, nurses, social workers, and chaplains to provide the best quality of care for patients and their families.1 For patients with head and neck cancer, this approach is key, but many other disciplines must be included to ensure optimal treatment and recovery for these patients.13,63,64 Although there is evidence that multidisciplinary palliative care teams improve outcomes for patients,65,66 no studies to date have examined their advantages in patients with head and neck cancers. In addition to otolaryngologist–head and neck surgeons and oncologists and radiation oncologists completing treatment, several other professionals play important roles. Dentists may create prostheses for the teeth or jaw if these are resected. Speech and language pathologists provide voice rehabilitation, including acoustic assistive devices, and teach patients modified swallowing techniques. They also work with families in meal preparation and in helping them to understand the effects of the disease and treatment. Physical therapists and occupational therapists help patients adapt to reconstructive procedures involving the use of flaps. Clinical social workers can help coordinate care across settings, nutritionists help assist patients obtain adequate nutrition and hydration, and ophthalmologists or neurosurgeons may be involved depending on the location of the cancer.

Early and regular contact between these members of the team is essential to ensure optimal care for patients with these malignancies. At our medical center, weekly meetings of the Multidisciplinary Program for Treatment of Diseases of the Head and Neck include otolaryngologists, oncologists, radiation oncologists, speech pathologists, social workers, and palliative care clinicians who discuss each patient who is to be admitted to the hospital to clarify the treatment plan and determine which services an individual patient will need. The palliative care nurse practitioners follow up ambulatory patients in the head and neck clinic to assess symptoms and help coordinate care. This approach to care improves patient satisfaction and ensures safe and efficient transitions across care settings, a key quality indicator for the health care of patients with complex disease.64,67,68 In addition, integrating palliative care into the care plan at an earlier point in the course of the patient’s disease process may help to reinforce, for both patients and clinicians, the idea that palliative care is not the same as end-of-life care.69,70 (For more information about staffing or sustaining a successful palliative care program, including solutions to common administrative and financial difficulties, go to http://www.capc.org.)

The team approach to care begins prior to surgery when a nutritionist and speech therapist provide patients with a series of pretreatment exercises that may improve swallowing and speech following surgery. Preoperative integrated care may also help patients develop expectations and reduce feelings of anxiety and helplessness.16

The interdisciplinary team also provides support for patients and their families, as well as promotes self-care and relieving stress and burnout among clinicians caring for these patients with serious illness.71 Studies have shown that caring for patients with serious illness takes a toll on the health of caregivers,12,74 and the high recurrence rate, along with high symptom burden and physical changes caused by head and neck cancer and its treatments, create serial challenges for caregivers.75,76

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Care of the Dying Patient With Head and Neck Cancer

Because of the unique nature of malignancies of the head and neck, special consideration must be given to end-of-life care for these patients. As with all cancer patients, predicting when an individual is near the end of life can be difficult. Signs include being bed-bound, semicomatose, only able to take sips of fluid, and an inability to take oral medications or tolerate artificial hydration and nutrition.77 At this point, clear communication with patients (when possible) and families is important so they understand that the patient has begun to enter the last phase of life. Referral to an inpatient palliative care unit or home hospice program should be considered to ensure excellent management of symptoms and to provide the needed emotional and psychological support.78 Although artificial hydration and nutrition plays a role for patients earlier in the course of their disease, it may become burdensome near the end of life and lead to edema, nausea and vomiting, and pulmonary congestion. Thus, it may make patients more uncomfortable and serve to only prolong the dying process.79-81 As such, families should be educated about how this once beneficial treatment may now be a source of suffering and stopping it should be considered.

Another management issue for many patients with advanced head and neck cancer is the “carotid blowout” syndrome—a process by which the cancer erodes into the carotid artery (or other great vessel in the neck) leading to exsanguination. This process may take place gradually, with occult blood loss into the surrounding tissues, or with rapid, massive blood loss from the neck. Although the prevalence of this dreaded complication is much rarer than in the past due to palliative surgical techniques,82 it can be frightening to both patients and their families. Patients with impending blowout should be managed in an inpatient setting, especially if children are present in the home. However, caregivers who understand the nature of this complication and wish to have the patient remain at home, as a practical issue, should keep dark towels (red or black) near the patient’s bedside to absorb the significant amount of blood that may be lost.

CONCLUSION

Palliative care is essential to the care of patients with head and neck cancer. These patients have unique physical symptoms and emotional needs relating to both the disease and its treatments. Including palliative care clinicians on the treating interdisciplinary team is a key element to improve care for patients with head and neck cancers, as well as for their family caregivers. As Mr K expressed, returning to a normal lifestyle is a goal patients and their families strive for and requires the expertise of a range of specialists to resume their lifestyle as much as possible. Ensuring that these patients—and their families—receive comprehensive support services can increase the likelihood that patients will be able to complete life-sustaining treatments and thus obtain the best possible outcomes and quality of life.

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Other Sources: For a list of relevant Web sites, see the article on the JAMA Web site at http://www.jama.com.


Web Resources for Palliative Care for Patients With Head and Neck Cancer

CENTER TO ADVANCE PALLIATIVE CARE
http://www.capc.org

The Center to Advance Palliative Care (CAPC) provides health care professionals with the tools, training, and technical assistance necessary to start and sustain successful palliative care programs in hospitals and other health care settings. Web resources include solutions to common administrative and financial difficulties encountered when creating and developing palliative care programs. A national organization, CAPC is dedicated to increasing the availability of quality palliative care services for people facing serious illness.

GET PALLIATIVE CARE
http://www.getpalliativecare.org

This Web site for patients and families explains palliative care and how it differs from end-of-life care and hospice. Particularly useful in the case of patients with head and neck malignancies, the site emphasizes the importance of supportive care along the road to recovery.

NATIONAL CANCER INSTITUTE PAGE FOR INFORMATION ABOUT HEAD AND NECK CANCER

Maintained by the National Cancer Institute, this page provides information about head and neck cancers, including information about diagnosis, treatment, and clinical trials.

NATIONAL COMPREHENSIVE CANCER NETWORK
http://www.nccn.org

This Web site provides guidelines for treatment of malignancies using the consensus process of national experts and review of relevant evidence from clinical trials. Specific information relating to malignancies of the head and neck can be found at http://www.nccn.org/professionals/physician_gls/PDF/head-and-neck.pdf

ORAL CANCER FOUNDATION
http://www.oralcancerfoundation.org

A national public service, this nonprofit entity is designed for prevention, education, research, advocacy, and support activities. It provides a patient-survivor forum that is open to the public where those currently fighting oral cancer can gain insights and support. This was founded by an oral cancer survivor. This site is recommended by the National Comprehensive Cancer Network and is supported by numerous pharmaceutical companies, including Bristol-Myers Squibb, Johnson & Johnson, Abbott, Introgen, and Colgate-Palmolive.

SUPPORT FOR PEOPLE WITH ORAL AND HEAD AND NECK CANCER
http://www.spohnc.org

This Web site for patients was created by a patient with head and neck cancer. It includes general information, information about treatments, and links to support groups across the country. This site is recommended by the National Comprehensive Cancer Network and is supported by numerous pharmaceutical companies, including ALIGN, AstraZeneca, Bristol-Myers Squibb, ImClone, Laclede, and Sanofi-Aventis.