Meeting Needs of Cancer Survivors

By Joe Munch

Thanks to new treatments and early detection, many types of cancer can be cured or managed, and more cancer patients are surviving than in the past. These long-term survivors have unique health care needs that are just beginning to be understood.

The term “cancer survivors” now includes cancer patients from the moment of their diagnosis to the end of life. As of 2007 (the last year for which data are available), there were 11.7 million cancer survivors in the United States. Nearly 65% of these survivors—regardless of whether they had been cured of their cancers—had lived with a cancer diagnosis for at least 5 years. These numbers are expected to go up as cancer detection methods and therapies improve. The boom in the cancer survivor population is giving rise to unanticipated new challenges.

“This is new territory,” said Lonzetta L. Newman, M.D., an associate professor in the Department of Clinical Cancer Prevention at The University of Texas MD Anderson Cancer Center. As cancer professionals explore this new territory, new concerns are coming to the forefront, but with those concerns come new opportunities to improve care.

Clinicians at MD Anderson have developed clinical practice algorithms for cancer survivors. “There are four domains of care in cancer survivorship—disease surveillance, risk reduction and screening for second cancers, late effects monitoring and management, and assessment for psychosocial..."
Meeting Needs of Cancer Survivors
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functioning,” said Fran Zandstra, executive director of cancer survivorship at MD Anderson. “The algorithms of care for each of these are individualized to each patient’s disease and treatments.”

Expanding the focus
One potential hazard of providing care for cancer survivors who no longer receive active treatment for their cancer is the tendency to focus on the patient’s cancer instead of appraising his or her overall well-being.

“Historically, patients were more likely to die from their cancer than survive it, so why worry about anything other than treating the disease? Now that patients are surviving, we have to think about the other things that went by the wayside before,” said Therese Bevers, M.D., a professor in the Department of Clinical Cancer Prevention. “As we care for our cancer survivors, we need to expand from being very focused on the cancer—though not forgetting it—to encompassing more of the wellness mindset.”

Focusing on the patient’s cancer, Dr. Bevers said, can overshadow other aspects of the patient’s health. Using breast cancer follow-up care as an example, she said, “Sometimes we get so focused on the patient’s cancer—making sure we’re doing the breast examination, doing the mammogram, checking for any symptoms of recurrence—that we forget all the other things that we would be thinking about if she hadn’t had breast cancer.”

To address the unique needs of survivors of different cancers, MD Anderson has clinics dedicated to the well-being of survivors of breast, colorectal, genitourinary, gynecologic, thyroid, and head and neck cancers; survivors of lymphomas, melanomas, and childhood cancers; and stem cell transplant recipients.

In the survivorship clinics, in addition to following up on any cancer-related concerns, clinicians screen patients for second primary malignancies and recommend strategies to reduce the risk of second primaries, look for any late effects of the disease or its treatments, and address any psychosocial effects stemming from the cancer diagnosis and treatment.

“It’s important to be aware of these issues and do whatever we can to address them,” Dr. Bevers said. “It would be horrible if a patient survived her breast cancer and then died of a colon cancer because we never thought to say, ‘Oh, by the way, you’re 50; you need a colonoscopy.’”

Watching for second primary cancers
An important issue facing cancer survivors is the risk of a second primary cancer. When considered together, second primary cancers account for about 10% of all cancers that occur. They are also a major cause of morbidity and death in cancer survivors.

Although not all risk factors for second cancers are well defined, clinicians in the survivorship clinics are able to monitor survivors with known risk factors. Some environmental, genetic, or treatment-related factors associated with the initial cancer may also give rise to a second primary cancer.

Second primary cancers can arise from the same lifestyle or environmental factors—such as smoking or working with carcinogenic materials—that contributed to the initial cancer. Obesity, for example, is a risk factor for many cancers, including breast cancer in postmenopausal women and cancers of the colon, kidney, uterus, pancreas, gallbladder, and esophagus.

Second primary cancers can also arise from the genetic condition that gave rise to the initial cancer. One such example is hereditary breast and ovarian cancer syndrome, which occurs in patients with mutations to BRCA genes. In the survivorship clinic, breast cancer survivors with such genetic dispositions are regularly screened for ovarian cancer with transvaginal ultrasonography and blood tests of CA-125 levels. If a cancer survivor does not wish to have more children or is postmenopausal, she may receive counseling about having her ovaries and fallopian tubes removed to reduce the risk of ovarian cancer.

Finally, second primary cancers can be related to the treatments used to eradicate the initial cancer. For example, tamoxifen given to treat breast cancer increases the patient’s risk of uterine cancer, and radiation therapy increases the patient’s risk of developing cancer in organs in or adjacent to the irradiated area. Clinicians in the survivorship clinics closely monitor such patients in an effort to detect potential new cancers in their earliest stages.

Not all second primary cancers are related to the patient’s initial cancer, however. The risk of a patient developing a second cancer because of age or other factors remains.

“Together, young girls who receive radiation therapy to the thorax for Hodgkin lymphoma have a very high risk of developing a second primary breast cancer,” Dr. Bevers said. “It was only as treatments for Hodgkin lym-
Thyroid Cancer Survivorship

Thyroid cancer presents a unique set of challenges to physicians providing care to survivors of the disease.

Thyroid cancer survivors face different long-term effects than survivors of most other cancer types because of the unique treatment strategy required for thyroid cancer.

“In thyroid cancer, our main tools are thyroidectomy, radioactive iodine treatment to eliminate residual disease, and in the vast majority of thyroid cancer patients—excluding those who have rare forms of the disease—thyroid-stimulating hormone suppression to guard against recurrent disease,” said Mouhammed Habra, M.D., an assistant professor in the Department of Endocrine Neoplasia and Hormonal Disorders.

Each therapy has its own potential long-term complications. Surgery can cause mobility and comfort issues in the shoulder and neck. Radioactive iodine can damage the salivary glands, leading to calculi in the salivary ducts, swelling, and/or severe xerostomia; its use has also evoked concerns about radiation-induced second primary cancers. Thyroid hormone suppression may cause an irregular heartbeat or reduce bone density.

“In the thyroid cancer survivorship clinic,” Dr. Habra said, “our goals include monitoring for disease recurrence and second primary cancers using surveillance studies such as ultrasonography; helping patients achieve normal thyroid hormone levels to reduce bone and cardiac issues; and addressing other issues stemming from treatment, such as dry mouth and voice and swallowing difficulties.”

At MD Anderson, the point at which thyroid cancer patients are transitioned to the survivorship phase of their care is determined using evidence-based clinical practice algorithms developed by a multidisciplinary team of clinicians. The way that care is managed depends on patients’ initial disease stage and the effectiveness of their cancer treatment. For example, patients who were initially diagnosed with T1 N0 M0 thyroid cancer may be transferred to the survivorship clinic if they have had no evidence of disease for 1 year; patients who were initially diagnosed with T2–4 N0–1 M0 or T1 N1 M0 disease may be transferred if they have had no evidence of disease for 3 years or if they have stable disease or minimal evidence of disease at 5 years. Patients who were initially diagnosed with metastatic disease remain under care in the thyroid cancer clinic rather than the survivorship clinic.

“In other cancers, they often talk about 5-year survival,” Dr. Habra said. “But the vast majority of thyroid cancer patients will live 20 years or more after treatment, so our approach to survivorship is a little different.”

FOR MORE INFORMATION

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Locally Advanced Squamous Cell Carcinoma of the Tonsil

Advances in surgical techniques may broaden treatment options for some patients

By Sunni Hosemann

Introduction

The treatment paradigm for squamous cell carcinomas of the palatine tonsil is evolving as a result of new radiation therapy and surgical techniques and, to a lesser extent, a shift in epidemiology.

This discussion is confined to tonsil cancers that are considered locally advanced—all but very small, confined lesions that would be considered stage I and very large or metastatic lesions that would be considered stage IVb or greater. Most patients with tonsil cancer present with these locally advanced, intermediate-stage cancers (stage II–IVA), and these patients’ treatment options are affected by anatomic considerations and complexities in staging that are unique to this disease. As with any type of cancer, individual patient characteristics are an important factor in treatment decisions, and the typical patient profile has changed in recent years.

Changing epidemiology: HPV

In the past three decades, a shift in epidemiology has occurred that can affect treatment considerations for oropharyngeal cancers, and those of the tonsil in particular. At one time, the classic patient presenting with tonsil cancer was an older patient who was a heavy user of alcohol or tobacco and often had comorbidities such as cardiopulmonary disease that could affect treatment decisions. But clinicians are now seeing younger, otherwise healthy patients with tonsil cancer without risk factors related to tobacco or alcohol use; in these cases, human papillomavirus (HPV) infection is the cause.

HPV has now replaced tobacco use as the leading cause of tonsil cancers. Chris Holsinger, M.D., an associate professor in the Department of Head and Neck Surgery at The University of Texas MD Anderson Cancer Center, estimates that 80% of the current population has been exposed to HPV. Of these people, only a minority will develop chronic infections, and some of these will develop a cancer. The latency period between time of infection with HPV and the emergence of a related cancer is unknown, and most experts anticipate a continued increase in the incidence of HPV-related cancers.

Fortunately, it appears that HPV-related tonsil cancers respond more favorably to treatment than do tobacco- or alcohol-related tonsil cancers. According to David Rosenthal, M.D., a professor in the Department of Radiation Oncology, studies have shown that patients whose oropharyngeal tumors tested positive for HPV had a longer overall survival than those whose tumors tested negative for the virus. While he noted that HPV status has not yet changed standard treatment recommendations, Dr. Rosenthal believes it will drive much of the research in this area.

Although HPV status does not necessarily affect treatment decisions, Dr. Holsinger said the younger age of patients with HPV-related cancers should be considered. “Chemoradiation therapy is effective, but it is associated with significant long-term toxicities,” he said. “Long-term toxicities were a lesser concern in the prototypical patient of the past who presented with this cancer at an advanced age but are a greater concern as we consider the younger population of patients presenting with this cancer.”

Anatomic factors

If tonsil cancer spreads locally, it often does so to the tongue, soft palate, or nasopharynx. Because of the tonsils’ proximity to lymphatics, tonsillar neoplasms often spread to lymph nodes in the neck and manifest as cystic masses.

The anatomic location of the tonsils is additionally important because of the delicate nature of the area. Vital functions such as swallowing and breathing as well as quality-of-life considerations such as speech and appearance may be threatened by the cancer itself and by its treatment.

Treatment strategies for tonsil cancers have evolved over time, in large part owing to a quest for treatment that is less disruptive to these functions. Until the 1990s, the standard treatment for these cancers was open dissection, often involving the mandible and often requiring at least a temporary tracheostomy tube and perhaps a gastrostomy tube as well. When radiation therapy was shown to achieve similar outcomes with less morbidity and less functional disruption, it became the preferred treatment. However, radiation therapy is not without side effects and may permanently affect swallowing function.
### SQUAMOUS CELL CARCINOMA OF THE TONSIL: Treatment Options

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### Staging

Stage II–IVa tonsil cancers are those classified as T1 N1–2 M0 or T2–4a N0–2 M0 using the American Joint Committee on Cancer staging system. About 80% of patients with locally advanced tonsil cancer present with T1–2 disease and 20% with T3–4a disease.

According to Dr. Holsinger, it is important to understand some of the nuances of the American Joint Committee on Cancer staging system for tonsil cancers when considering treatment options. Within a given stage, the clinical presentation of tonsil cancers varies widely, and thus appropriate treatment choices vary also. Therefore, stage is not a very helpful determinant of treatment choice.

As an example, Dr. Holsinger cited stage IVa disease, which includes large tumors with little or no lymph node involvement (T4a N0 and T3 N1) as well as smaller tumors with significant nodal involvement (T1 N2b and T2 N2a). At least some patients presenting with the smaller stage IVa tumors might be candidates for endoscopic surgery, as described below, while larger stage IVa tumors would preferentially be treated with radiation therapy and chemotherapy. The sequence in which these treatments are given varies and is determined on an individual basis.

### Treatment options

According to Merrill Kies, M.D., a professor in the Department of Thoracic/Head and Neck Medical Oncology, the optimal treatment sequence for a given patient with tonsil cancer should be determined by a very thorough pretreatment evaluation and a multidisciplinary consultation that includes medical, radiation, and surgical oncologists whose goal is to achieve cancer control with optimal functional outcomes. The decisions weighed for a given patient are whether transoral surgery is feasible and, if not, whether chemotherapy and radiation will be given concurrently or as induction chemotherapy followed by radiation therapy. The factors that determine the best approach include the size and location of the primary tumor, the patient’s performance status, and the extent of the disease.

#### Definitive chemoradiation

Radiation therapy with concurrent cisplatin-based chemotherapy is the standard initial treatment for patients with locoregionally advanced, nonmetastatic tonsil cancer who have larger primary tumors (T3–4). At MD Anderson, intensity-modulated radiation therapy or proton therapy is used. Because chemotherapy acts as a sensitizer for radiation, their concurrent use optimizes local disease control.

#### Surgery

Radiation with concurrent chemotherapy is the preferred definitive treatment for most patients with tonsil cancer because radiation therapy is associated with less morbidity, disfigurement, and loss of function than the older standard surgery—a transcervical partial pharyngectomy often including a partial mandibulectomy as well as a tracheostomy. For
most patients with tonsil cancer, the role of surgery is an adjuvant one for remaining or recurrent tumor when needed.

However, a new, minimally invasive surgery, transoral lateral oropharyngectomy (TLO), is now a primary treatment option for select patients. According to Dr. Holsinger, who is one of the pioneers of this approach, TLO has been shown to achieve rates of local control equivalent to those of radiation therapy for unilateral anterior T1–2 squamous cell carcinomas of the tonsil without posterior spread.

A related surgical advance has also made surgery possible for some patients in whom it was previously precluded by the proximity of the deep margin of the tonsil to the carotid artery. Dr. Holsinger described the technique, which is performed during TLO, as a maneuver that uses continual strong medial retraction of the specimen away from the parapharyngeal space to ensure the visualization and safety of the carotid artery. “Now we can get a wider and deeper mucosal margin without vascular injury,” he said.

These advances mean that more patients may now benefit from surgery than was previously possible. This is an important development because the younger population of patients with tonsil cancer has led to increased concern about long-term radiation sequelae.

Chemotherapy or radiation therapy may be given as adjuvants to TLO.

**Induction chemotherapy**

Although induction chemotherapy followed by radiation therapy or surgery is considered a treatment option for intermediate-stage tonsil cancer, its use is controversial.

A main goal of induction chemotherapy is to eradicate distant microscopic disease that would ultimately undermine the strategy of pursuing local treatments (surgery or radiation) with curative intent. For this reason, induction chemotherapy is often used to treat cancer types that are typically discovered at advanced stages, in which there is a greater risk for distant micrometastatic disease.

Tonsil cancer, however, produces noticeable symptoms that prompt most patients to seek medical attention before distant spread occurs. Despite the fact that its proximity to rich lymphatics often leads to tonsil cancer’s being detected after it has spread to lymph nodes in the neck, the immediate danger posed by tonsil cancer is more local and regional than distant.

Therefore, local control is a major driver of treatment decisions. “The natural history of the cancer is important,” Dr. Kies said. “For breast or lung cancers, the problem is distant disease, but for head and neck cancers it is more likely to be an uncontrolled primary tumor.” Further, he said that a decision to give systemic treatment first will delay local treatment and should be undertaken only with due consideration of the risk a growing tumor might pose to vital adjacent areas of the neck and their associated functions.

Another consideration related to this option is increased toxicity. Higher doses of drugs are used for induction chemotherapy than for chemoradiation therapy. “The resulting toxicity can be debilitating,” Dr. Kies said. He recommended that induction chemotherapy be reserved for patients with more advanced neck disease—involvement of multiple lymph nodes, retropharyngeal lymph nodes, or nodes lower in the neck—that might herald a risk for distant metastasis. He said that most studies currently investigating induction chemoradiation for tonsil cancers require that patients have N2b or N3 disease to enroll.

**Future directions**

According to Dr. Rosenthal, HPV is an independent prognostic factor whose value overrides other factors such as tumor size and lymph node status. “Since patients with HPV-related tumors have a better prognosis than those with tobacco-related tumors, we are now looking at ways to de-intensify treatment in these patients in order to address survivorship issues,” he said. “The question is: how can we get the same survival outcomes with better long-term function and fewer long-term side effects?”

According to Dr. Kies, the more favorable outcomes are not due just to the relatively better health of patients with HPV-related disease. “These cancers are generally more responsive to treatment, regardless of the modality used,” he said. “This may mean that less intensive treatments—with less risk of long-term effects—might be required, which would be particularly advantageous for patients in the 30–50-year age range.”

To those ends, studies are under way to identify the best initial treatments for patients presenting with this disease. One is a protocol headed by Dr. Kies in which patients are assigned to either chemoradiation therapy or induction chemotherapy based on likely patterns of failure—patients at high risk for distant disease are assigned to the latter arm. Studies such as this could further enable clinicians to identify which treatment strategy is best suited for each individual patient.

**References**


Sex After Cancer Treatment

Many cancer-related sexual problems can be solved

Cancer and its treatment can affect a patient’s sexuality, causing side effects that include problems with arousal and inability to achieve orgasm. Yet many survivors don't realize that help is available for dealing with these difficulties.

The most common sexual problems for cancer survivors are loss of desire and pleasure. Still, according to MD Anderson Cancer Center experts, most men and women can enjoy sex after cancer treatment even if their illness or treatment has created changes to their sex organs or required the removal of some organs in their pelvis.

Side effects in men

Men with cancer in their pelvic area are more likely than men with other cancers to have difficulty resuming sex after treatment. According to a recent report from the Mayo Clinic, sexual side effects for men are most common following treatment for bladder, colon, prostate, and rectal cancers.

Erectile dysfunction—an inability to achieve or maintain an erection—is the most frequent sexual side effect of cancer treatment in men. Other common problems include difficulty climaxing, weaker orgasms or orgasms without discharge of semen, loss of interest in sex, pain during sex, less energy, and feeling less attractive.

Finding a solution

If you are a cancer survivor with sexual difficulties, talking to your doctor is an important first step in getting help. Some people find they feel more comfortable when they write down their questions before their appointment.

Your physician may refer you to a specialist in sexual health, or he or she may recommend any of the various treatments available to counter sexual problems after cancer treatment.

For men who have erection problems after cancer treatment, options may include medicines, penile implants, or devices that can facilitate an erection. Often men find that it simply takes time after cancer treatment—often 1–2 years—to regain sexual function; however, many physicians advise against a conservative wait-and-see approach and recommend active sexual rehabilitation. Some studies indicate that active rehabilitation—which may include medications or injections that increase the flow of blood to the penis—may preserve function that might otherwise be lost over a year or two.

Women can use a water-based or silicone-based lubricant during sex or use a vaginal moisturizer to counter dryness or tightness in the vagina caused by cancer treatment. If the lubricants and moisturizers don’t help, another option is low-dose vaginal estrogen. For women who have had radiation therapy to the pelvic region, a vaginal dilator can reduce vaginal scarring or shrinking.

Several common emotional changes after cancer treatment can affect sexual function, including depression, anxiety, and changes in self-image. Counseling can help a cancer survivor deal with depression or anxiety that might be causing a loss of desire for sex.

You and your partner may have difficulty coping with cancer-related changes as a couple. Some couples lose intimacy altogether when side effects cause one partner to avoid even non-sexual affection for fear that it will lead to sex. Marital or couple therapy can help you talk more openly about these issues. Let your partner know what you’re feeling and how he or she can help you cope. Together you can find solutions to ease you back into a fulfilling sex life. Explore ways of being intimate, perhaps spending more time cuddling and caressing each other. Do some experimenting and pay attention to what works best.

Many people find talking with other cancer survivors helpful. This could mean joining a support group in your town or connecting with other cancer survivors online to see how they deal with problems similar to yours.

Above all, remember that despite your cancer or cancer treatment, you should be able to feel sexually satisfied. With time and patience and with advice from your doctors, you and your partner will once again be able to enjoy sexual activity.

—K. Snyck

FOR MORE INFORMATION
- Talk to your physician
- Visit www.mdanderson.org
- Call askMDAnderson at 877-632-6789
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Investigation is warranted or whether the assistance of other trained professionals is needed.”

While most patients are frank in their discussions of the symptoms they experience or the financial issues they are struggling with, many patients balk at talking about how their cancer diagnosis has affected their sexuality.

“Sexuality issues can increase stress within relationships,” Dr. Newman said. “But sexual health is a topic that patients are less forthcoming about unless you open the door.”

Opening that door, Dr. Newman said, involves broaching the subject gently and using the opportunity to educate patients.

“We let patients know that we’re asking these questions not to invade their privacy but to gain some knowledge about the long-term side effects of their therapies and to better meet their needs,” Dr. Newman said.

Improving communication with community physicians

To help ensure that patients get the well-rounded care they need, MD Anderson developed myMDAnderson.org, a secure Web site that includes patient health records and the Passport Plan for Health, an electronic tool provided to patients and their health care providers. This tool includes information about a patient’s cancer diagnosis and treatments received as well as forward-looking information such as potential late effects of those treatments and recommendations

for cancer screenings and preventive health measures. The passport provides a framework for community physicians to use when treating cancer survivors.

“The passport helps us coordinate our care with that of the patient’s primary care physician. It facilitates communication with the patients and with their outside physicians,” Dr. Newman said. “We don’t want patients to receive fragmented care or become lost to follow-up.”

By documenting what care is being done at MD Anderson and what is being done by outside physicians, the passport facilitates partnership between MD Anderson specialists and community physicians to address the full spectrum of patient care.

“The more our screening improves, the more our treatments improve, and the more we are able to reduce the mortality,” Dr. Bevers said, “the more we are going to learn about the issues facing cancer survivors and how to address them.”

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To learn more about the Passport Plan for Health, log on to https://my.mdanderson.org. The clinical practice algorithms mentioned in this article can be found at http://www.mdanderson.org/education-and-research/resources-for-professionals/clinical-tools-and-resources/practice-algorithms/index.html.