The management and treatment of neck lymph node metastasis from squamous cell carcinoma of an oral cavity cancer has gradually evolved over the last several decades. Sentinel lymph node biopsy of neck lymph nodes in patients presenting without obvious lymph node metastasis may represent the latest step in this evolution. The most important prognostic factor in squamous cell carcinoma of the head and neck is the status of the cervical lymph nodes. The chance for cure decreases significantly when the cancer has spread to neck lymph nodes. In contrast, in patients in whom the cancer has not spread to the cervical lymph nodes, the cure rate for head and neck squamous cell cancer is quite good.

For patients who present with no obvious evidence of neck lymph node metastasis, the management of the neck can be problematic. Even for small cancers of the oral cavity, the risk for unsuspected, microscopic, occult metastasis to the neck lymph nodes is significant. It is logical to assume that early diagnosis and treatment of the occult metastasis would result in improved cure rates and disease control.

Over the past several decades there has been a gradual change in the management of this problem. Initially, a strategy of observation was employed. Following surgical removal of the cancer at the primary site, the neck was kept under close observation. The patient who developed cervical lymph node metastasis was treated with radical neck dissection and/or radiation therapy. This strategy of observation was eventually replaced by a more proactive approach employing either routine neck dissection or radiation therapy. Both of these approaches were flawed. They required unnecessary treatment with potentially significant morbidity for the majority of patients. In response to this problem, the concept of a selective neck dissection for staging developed. In this approach, a selective, partial neck dissection is performed at the time the primary cancer is removed. The neck dissection removes the lymph nodes which are at greatest risk to harbor occult metastasis. For the oral cavity, this procedure is the supraomohyoid neck dissection. At many institutions, a supraomohyoid neck dissection for patients who present with no obvious lymph node metastasis has become the standard of care. The supraomohyoid neck dissection consists of the en bloc removal of nodal regions I, II, and III. The procedure is performed on both sides of the neck for patients with cancers of the midline, tongue and floor of the mouth.

Patients in whom pathologic review of the neck specimen shows lymph node metastasis are candidates for a course of adjuvant radiotherapy. Despite the wide acceptance of this strategy of treatment, there remain some concerns. Even though supraomohyoid neck dissection is associated with a lower risk of morbidity than radical neck or modified radical neck dissection, it still proves to be an unnecessary procedure in most patients (those who have no nodal metastasis). In addition, supraomohyoid neck dissection can occasionally miss some cases of occult lymph node metastasis; specifically, those cases in which the lymph node metastasis are outside the area of the neck which is removed by the supraomohyoid neck dissection.

It appears that sentinel lymph node biopsy is the next step in the evolution of the management of patients who present with no obvious neck lymph node metastasis. The technique of sentinel lymph node biopsy requires the injection of a small amount of radioactive tracer material and/or temporary blue dye at the site of the primary cancer in the oral cavity. This material is then picked up by the adjacent lymphatic vessels and travels to the closest draining lymph node. This lymph node is called the sentinel lymph node. If there has been any early microscopic metastasis to lymph nodes it most likely will be present in this sentinel lymph node. Following the injection of the dye or tracer, the patient is brought to the operating room and undergoes surgical removal of the primary cancer in the oral cavity. At the same time, during the same surgery, a radioactive sensor probe is used to identify the location of the sentinel lymph node in the neck. A small incision can then be made at the site of this lymph node and the lymph node removed. This lymph node is then sent to the pathologist for analysis to determine whether or not it harbors microscopic, occult cancer. If on pathologic review there is no evidence of cancer within the lymph node, this implies that the cancer probably has not spread to the cervical lymph nodes and that cervical lymph node biopsy of neck lymph nodes in patients presenting without obvious neck lymph node metastasis is an unnecessary procedure in most patients. In contrast, in patients in whom the cancer has not spread to the cervical lymph nodes, the cure rate for head and neck squamous cell cancer is quite good.
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COMING IN MARCH 2005
“The Challenge of Eating When Your Treatment Involves Chemotherapy and Radiation”
Mary Ellyn Witt, RN, MS, AOCN & Allison Dekker, RN, BSN, OCN

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that no further treatment is indicated (other than observation). If microscopic disease is identified in the sentinel lymph node, then the patient can be offered either neck dissection with radiotherapy or radiotherapy alone.

The technique of sentinel lymph node biopsy may eliminate some of the concerns surrounding selective, staging neck dissections. It has the potential to identify early neck metastasis and yet, avoid unnecessary treatment in many patients. Potentially, the procedure involves less risk of side effects and complications than neck dissection.

The question of whether or not sentinel lymph node biopsy is a legitimate replacement for selective, staging neck dissection is as yet unanswered. Sentinel lymph node biopsy has been proven to be a useful and accurate method for lymph node staging for other cancers including melanoma of the skin and breast cancer. It is reasonable to assume that sentinel lymph node biopsy would also prove to be useful and accurate in the management of squamous cell carcinoma of the oral cavity. Current efforts are ongoing in the United States and Europe to determine whether or not this is true.

The appropriate way to answer this question is to perform sentinel lymph node biopsy and selective, staging neck dissection in patients presenting with no obvious neck metastasis. The results of the sentinel lymph node biopsy can then be compared to the neck dissection specimen to determine the accuracy and correlation of the two methods. It may be that sentinel lymph node biopsy is more accurate than selective, staging neck dissection. A single lymph node can be subjected to a more intensive pathologic examination than an entire neck dissection specimen. On the other hand, it may prove that sentinel lymph node biopsy is less accurate than staging neck dissection. This would be the case, if it is shown that there are a significant number of cases in which an identified sentinel lymph node does not harbor occult disease, but that disease is present in non-sentinel lymph nodes within the next neck dissection specimen.

The European head and neck community has embraced the concept of sentinel lymph node biopsy in the management of oral cavity cancer. Many now advocate the procedure as a stand alone alternative to selective, staging neck dissection. The early results suggest that sentinel lymph node biopsy is more accurate than selective, staging neck dissection. Therefore, it is a valid replacement and improvement over selective, staging neck dissection.

In the United States, preliminary studies have indicated that no further treatment is indicated (other than observation). If microscopic disease is identified in the sentinel lymph node, then the patient can be offered either neck dissection with radiotherapy or radiotherapy alone.

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Climbing Out of the Black Hole: 
Coping with Depression Following Cancer Treatment

Janet McKiernan, RN, BSN, OCN; Christine M. Shea, MSSW, LMSW; 
Jill Solan, RN, MS, ANP, OCN; and Page Tolbert, LCSW

Don is a tall, handsome, robust-looking man in his mid-50's, with closely cropped grayed hair. He is a familiar figure at a monthly support group for people with head and neck cancers. An active and dynamic member of this group, Don always encourages new members, praising them for how far they have come since their treatment and assuring them that they are likely to continue improving. That is why it was a surprise to everyone when Don admitted that he was still struggling to emerge from “the black hole.” “What is that?” asked other members, as well as the nurse and social worker who facilitate the group. Don explained, “I was a tough guy going through the treatment – real macho,” says Don, shaking his head with wry amusement at the memory. When the treatment ended, however, instead of feeling better, he found that he had lost interest in life. It was not even he who noticed, but his wife, Roxanne. “He just was not doing the things he used to enjoy,” she says. “Nothing seemed to matter to him.”

What Don and Roxanne did not know at that time was that Don was clinically depressed. Of course, they certainly were not expecting to encounter this emotional hurdle. After all, he had made it through the treatment in good spirits, had regained most of his functioning, and looked more fit and healthy than most people who had never had cancer. Nonetheless, the overwhelming and life-changing experience of having a cancer diagnosis had taken its toll. Don was no longer sure who he was. Always the caretaker people could depend on, he now felt lost and confused and even his health care team that they are ‘lucky to be alive,’ and that they should be ‘thankful for every day.’ Many patients would like to feel this way, and try hard to do so in an effort to reduce the stress of the loving family members and friends. Additionally, patients often fear being labeled or judged to be crazy or abnormal because of their depressive symptoms, although they often experience relief after sharing their feelings with a medical professional. In truth, the experience of cancer entails many real losses – the loss of one’s health, one’s energy, one’s sense of control over life, and even the sense of the world being a safe place – and loss can lead to depression. This is simply the way human beings are constructed, and it is not a question of attitude or ‘fault.’

Unfortunately, patients with head and neck cancer may be at increased risk for depression, and the experience of depression as a result of a diagnosis of or treatment for head and neck cancer is not uncommon. The issues that confront patients with head and neck cancer are unique due to the role that the head and face plays in everyday expression and communication. In one study, for example, nearly 30% of participants were experiencing possible depression during treatment (de Leew et al, 2001). Distress regarding appearance or disfigurement or becoming dependent on medications that may be used to relieve other symptoms such as insomnia, poor appetite, and even their health care team that they are important that you bring this to the attention of your health care provider. In fact, patients with head and neck cancers may have special reason to seek out treatment for depression: If they attempt to ‘treat’ their uncomfortable feelings by taking comfort in the use of tobacco or alcohol, they are at greater risk for developing another cancer. The types of treatment generally utilized to treat depression include psychotherapy, pharmacotherapy which involves the use of antidepressant medication, or a combination of the two. In psychotherapy, coping strategies are explored in order to enable patients to confront such problems as changes in health and lifestyle, changes in financial status, an uncertain future, and concerns about disfigurement or becoming dependent on others. Pharmacotherapy involves the use of one or more antidepressant medications for the purpose of relieving the symptoms of depression, although there are also medications that may be used to relieve other symptoms such as insomnia, poor appetite, fatigue, restlessness or lack of interest in usual activities. Antidepressants have demonstrated an efficacy rate of approximately 80% in alleviating patients’ symptoms of depression.
A TIME FOR SHARING...CAREGIVER PERSPECTIVE

The summer of 2003 was great. I had retired two years earlier and was very comfortable with my new life. My husband, Bill, had already retired. We have no kids, nor pets, so we had few constraints. We were traveling a lot. When we were home, I could get up each morning and decide what I wanted to do that day. I had total freedom. This was a big change from when I was working, in a very demanding and stressful job.

As the summer progressed, we were gearing up for a much anticipated trip to Botswana in September. In the meantime, we spent time on our boat and I was gardening a lot. Our only concern was a small lump under Bill’s jaw, which he had noticed in June. He went through two rounds of antibiotics, but that did not clear it up. He then went to Ear, Nose and Throat specialist, who suspected a thyroid problem. Bill had a number of tests, but there was no diagnosis. Finally, toward the end of August, he insisted on a biopsy. We were leaving for Africa in three weeks and we wanted to resolve this. Just before Labor Day, we finally got an answer. It was some sort of cancer. Bill then went to an Ear, Nose and Throat surgeon, who readily determined the type, from a CT scan done earlier in the summer. Bill had Nasopharyngeal Cancer, Stage II B.

We did all the things that a family with a cancer diagnosis does. We started doing as much research as we could. We found doctors for radiation and chemo (Bill did not actually need surgery). He had a stomach tube and a port put in. We canceled all our plans, including the trip to Botswana. We actually thought that with all of our newly freed up time, we would catch up on sorting a huge backlog of slides from previous trips. That shows how naive we were at first. We had no comprehension of the cancer tsunami that was about to engulf us. And, at the time, I did not realize that I was going to lose my freedom. Ever since the diagnosis, cancer has controlled our lives. I was about to learn some really hard lessons.

It took all of September to get the radiation treatments mapped and ready to go (an agonizing wait). On the 30th, Bill finally began treatment. He would end up with 33 photon radiation treatments, followed by 10 electron treatments and then two sessions of brachytherapy. He had chemo every three weeks. He finished December 5th. We then had 6 weeks off, and began another 3 rounds of chemo, one week on, three weeks off. He finally finished all treatments on March 19, 2004.

And what did I do during all those months? Well, I continued to do most of the things that I had always done. Then, as Bill got sicker, I did most of the things that he used to do. I also became his scheduler. By the spring of 2004, he would have 10 doctors. I kept a master list of all of them, with addresses, phone and fax numbers and the names of all the nurses and assistants and what each of them was responsible for. I carried this list with me at all times (and used it frequently). I went to all of his doctor appointments with him right from the beginning. Later, I started taking him to all of his treatments as well. I became a connoisseur of doctor waiting rooms. I started rating them based on availability of parking, comfort of seats, good reading lights, the cleanliness of bathrooms and whether there was loud TV blaring away.

Another role I took on was to be the communicator. As Bill got sicker, he went off the air, so to speak. So I was the one that dealt with all our family and friends. This became a daunting task. I could not remember who I had told what. I was just too overwhelmed. I literally could not keep in touch with everyone by phone. Quite early on, I started sending out email bulletins, which eventually went to about 80 people. I tried to get them out every time we passed some sort of milestone. I found that I could only compose them on “good” days. Now, realistically, there were no good days. There were, however, some really awful days. So days that weren’t too terrible to realize that you are helpless. It was like trying to fix his pain. I couldn’t do it. This is lesson #2. It is terrible to realize that you are helpless.

As Bill’s pain increased, we began our search for the perfect painkiller. Unfortunately, we never found one. Strong morphine-based medications made Bill even sicker. We eventually went through quite a few different medications. We even went to a pain doctor, who ironically prescribed oral medications. This was at the point when Bill’s mouth was a landmine full of sores! There were days when I went to the pharmacy five times (taking prescriptions, picking them up). I found that I cried every time I went. I was desperate for the pharmacists to give me something that would make Bill feel better, a magic bullet that unfortunately never did materialize. Lesson #1 was that our oh-so-modern medicine cannot always “fix” problems.

I also tried to keep Bill’s spirits up, but this was indeed daunting. When we got into the six week break in treatments, Bill’s health began to improve a bit. I decided that we should try to get out of the house at least once every day. Many days, the most we could manage was to pile into the car and drive to one of the nearby beaches. It was the dead of winter and very cold, but we could manage was to pile into the car and drive to one of the nearby beaches. It was the dead of winter and very cold, but we

Evenings were a tough time. Every night, while Bill was taking a shower and getting ready for bed, I would throw a Lean Cuisine in the microwave and wolf it down. Bill was very sensitive to food smells, so I always had the kitchen exhaust fan on full force. My one concession to normalcy was that I would light candles for myself. After dinner, I would go upstairs, kiss him good night and tuck him in at about 8 PM. Then I was alone for the evening. Usually, I was exhausted. I really wanted to just sit and watch TV. But I found that I needed to use...
that evening time to keep up with my desk work. I had also started to write a diary. It helped me to process what was going on. But it was yet another thing that took up my time. When I finally went to bed, I would slip into the pitch dark bedroom and stop by the bed, to listen for Bill’s breathing. Luckily, he did keep right on breathing through this whole ordeal.

This was also a very lonely and difficult time for me. Bill is my best friend, my buddy. But now he was terribly sick. He would come home from treatments and crawl onto the couch and sleep. When he was awake, he was cranky, and miserable with the pain and frustration. All of this was understandable, but it was still disconcerting. He was not my beloved husband of 27 years. I missed him. But what was far worse was that Bill went through a great deal of pain. And I had to watch him.

Early on, I became obsessed with what Bill ate. Looking back, I think that I wanted to find a way that I could help. I started reading all about foods that had special properties, that would strengthen his immune system, that would provide certain enzymes, or have certain properties. I was keen that Bill eat as well as he could. Ha! Within two weeks of beginning treatment, due to an early case of Thrush, Bill was already using his stomach tube and we were down to Boost Plus. Then when he finally began to eat again, he wanted only those foods that tasted OK. Since his taste buds had altered significantly, this was a very short list of food. Here was yet another lesson. I had to let go. He would eat what he could eat.

We both suffered from mental lapses. For instance, the first time that we went to see the ENT surgeon, who is about an hour away, Bill drove. By the next time we went to see him, Bill was already getting sick from his treatments and an early case of Thrush. So I drove. Neither of us could remember the right exit on the expressway and we got lost. This is a good example of what we would eventually refer to M3T (more muzzy minded thinking). It was indeed uncomfortable to forget things and get easily confused, but it would happen to us a lot. It was also frightening. We were in a life and death situation. We had to make critical decisions. As Bill got sicker, more of the decisions fell on my shoulders. There were days when I was terrified to have to make a determination, because I knew that I was not always thinking clearly. Bill had always been my sounding board, but now he was not “there” to consult with and lean on.

I did of course talk to people while this was going on. Marie is a dear friend from college. Fortuitously for us, she is an ENT surgeon. Unfortuitously, she is now living on an Indian reservation in Colorado, so she was not always easy to get to. I called her whenever we were confused about treatments or when I was really scared. The poor woman got these awful phone messages, with me crying and trying to talk at the same time. Another stalwart was our friend Amy, a seven-year cancer survivor. She called every few days and touched base with me. Whatever we were going through, she had been there already. It was always a great relief to talk with her. No fear was too stupid to share. And she was enormously practical. A third key person was my friend Eileen, who lives nearby. She has an extremely busy schedule, but she made it a point to make sure that we took regular walks. The exercise was good; the talking was critical. I must have just talked about her ear off, but she never complained. One day when I was really on the edge, I told Bill that I was going to the pharmacy and went to Eileen’s instead. She answered her door and I literally threw myself into her arms and just sobbed.

Bill leaned on me. I leaned on almost no one (my fault). With very few exceptions, when things got tough, I was the one that held everything together. How did I fare? Well, I lost sleep. I lost weight. I developed a host of new medical problems myself. On any given day, if someone said something remotely sympathetic, I could easily start to ooze tears. Here was lesson #3. If you try to keep all of the burden squarely on your own shoulders, the weight becomes staggering. If you can shift some of it to family and friends (who are usually eager to help), your load gets lighter.

When Bill’s treatments finally ended in the spring of 2004, it was an huge milestone for us. We were so elated. It was OVER! But of course, it was not over. Bill had months of healing to get through. He had various side effects, like neuropathy in fingers and toes, which frustrated him considerably. His salvia and sense of taste were shot. He tired very easily. Both of us had fits of depression. Little things set us off. One night, we were cooking dinner and had the exhaust fan on. We forgot to turn it off before we sat down to eat. All of a sudden, the noise just grabbed me and took me back to the dark nights of eating alone. Also, when people talk about cancer or when we read about it, it triggers anxiety. For instance, a friend works in a lab at a hospital. She was explaining to me how she could identify certain types of cancer cells, back to the primary type of cancer even though she might be looking at cells from a secondary cancer that occurred years later. Her casual anecdote terrified me. The cancer is always there, waiting around the corner, ready to ambush even your best days.

So I was chauffeur and cheerleader. Chief financial officer and PR executive. Researcher and shopper. It was a lot to do, but I considered myself to be fortunate. Because I was retired, I did have the time to dedicate to wearing all my many hats. I cannot imagine trying to do everything that I did AND try to hold down a job and/or manage a family of children, but I know that many people do have to juggle these additional demands.

We have worked at reclaiming our lives. Several years ago, we had signed up for a trip to go to the North Pole by ship; it was scheduled for August of 2004. If we took the trip, it would be only 4 months after the end of Bill’s chemo. We asked our doctors if he could go. They thought we were crazy, but did not have any real medical reason to say no. I consulted my list server (a.k.a. chat room) of head and neck cancer patients. Some thought we should cancel; others urged us to go for it. At the time that we had to send in the final payment, Bill was still taking nourishment only through his PEG. We were not sure at that point if he would even be eating by August. For us, this was more than just taking a trip. It had become a metaphor for beating cancer. We decided to risk it and go. The trip worked out just fine. Bill did get tired easily, but he was eating real food. While on the ship, I wrote this poem.

Keep Hope
Cancer stalked us last winter
It aimed to take one away
But we fought it, doggedly
It brought us to our knees
But we harbored hope and more
A leap of faith, I told a friend
We would go north, to the Pole

Our fight raged on, to the spring
In the end, we held our ground

SHARING continued on page 6
Long Term Care Insurance for Special Risks - Cancer Survivors
By Vivian P. Gallo, CLU, CSA

Don’t ASSUME – we all know what that caveat means. It’s especially true when it comes to long term care insurance for cancer survivors and others with serious health histories. Many conditions make individuals ineligible to purchase coverage, but far too many people learn this when it’s too late — after a diagnosis has been made.

While it’s true that people with a history of cancer are frequently ineligible for life or LTD coverage, that’s not always the case with long term care insurance. The BIGGEST PROBLEM for cancer survivors is that they assume they’re no longer insurable and never even inquire!

What is unique about LTcI is that it is still a relatively new product, and actuaries haven’t amassed enough historical claims data to enable them to reliably determine what risks to accept and which to turn away. Although early LTcI dates back 30 years, the nursing home coverage provided in those early policies has little to do with comprehensive long term care of today. Assisted Living Facilities and Continuum Care Retirement Communities have emerged over the last decade, with admission criteria and treatment methods that vary widely, depending upon the state and licensing requirements.

So why should this matter? Because insurers have come to realize that the factors that lead people to make use of their long term care insurance and the duration of those claims differ significantly from those associated with other insurance products.

For cancer survivors, it generally takes only a few questions to determine if they can be considered for LTcI:
• What is the stage and site of the cancer?
• Were radiation or chemotherapy required? If so, for how long?
• How much time has elapsed since the end of treatment?
• Have there been any recurrences or evidence of metastases?

While many cancer survivors haven’t been properly informed and therefore simply assume they are uninsurable, here’s an inquiry from one who did ask: “I am a cancer survivor, I have had a kidney removed and I don’t know if I am insurable. Can I be considered for long term care insurance?”

The answer was yes, based on the following:
• It was a Stage I cancer;
• There was no radiation or chemotherapy required;
• The surgery occurred 48 months ago; and
• The only care provided was semiannual follow-up visits.

With some carriers, coverage could even be considered after 12 or 24 months, as a “standard risk,” with no additional premium charges. This client was unique, not just because she survived cancer, but because she was willing to call and ask that first crucial question—the one that allowed her to decide if she wished to put the process in motion.

A major problem the long term care insurance industry faces today is DENIAL, the assumption many people make that “it won’t happen to me!” One advantage cancer survivors have is the knowledge of what can happen, because it already has happened! As survivors, they’re more apt to be realists, and they deserve to be fully informed about their options where long term care is concerned.

Not everyone is eligible for LTcI, of course, but only those who are willing to take the first step by asking the question will find out!

While cancer isn’t the only serious medical condition that needs to be explored, it is one that too many people make erroneous assumptions about! How will things change for cancer survivors in terms of future coverage eligibility? The answer lies in future claims statistics.

What is interesting about long term care insurance is that there is still a lot to be learned about many conditions, how they will impact future claims, and how insurers will respond to those findings. People eligible for LTcI coverage today may not be eligible tomorrow.

For cancer survivors, then, what the insurance industry doesn’t know today may actually work in their favor!

Editor’s Note: Vivian P. Gallo is a CLU (Chartered Life Underwriter) and Certified Senior Advisor (CSA), specializing in long-term care insurance. She is licensed in NY, NJ, CT and GA. For additional information about long term care insurance, you may contact her at 1.888.232.1233 or ChoiceforLTCI@aol.com

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DEPRESSION continued from page 3
(Valente & Saunders, 1997). Your health care provider is equipped to connect you with a mental health professional who will discuss your treatment options. If you try a medication that doesn’t seem to work for you or one that causes unpleasant side effects, there may be a more appropriate medication for you. The side effects associated with these medications continue to improve; most patients can find one that they are comfortable with.

The treatment of depression in oncology patients has demonstrated considerable improvement in a patient’s sense of control over uncertainty about their disease, enhancement in quality of life, and has also been found to be beneficial in decreasing overall feelings of distress. When Roxanne helped Don to realize that he might be suffering from a clinical depression, he told his doctor about his feelings. He began a course of anti-depressant medication, and after several weeks of treatment Don’s feelings of depression improved. Of course, there is no medication that can erase all feelings of sadness or anxiety, and Don admits he continues to struggle with his mood. He also says he feels better than he did at one time, and he tries to support other patients, urging them to get help in climbing out of ‘the black hole.’

Editor’s Note: Janet McKiernan, RN, BSN, OCN; Christine M. Shea, MSSW, LMSW; Jill Solan, RN, MS, ANP, OCN; and Page Tolbert, LCSW are members of the Head and Neck Psychosocial Care Team at Memorial Sloan Kettering Cancer Center in New York, NY.

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