Experiences of a Physician With Neck Cancer

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As a physician specializing in head and neck infections, I had extensive experience in otolaryngologic illnesses. However, when I was exposed to new, different, and challenging experiences as a patient with neck cancer, I had to deal with them as a patient and not as a physician. I was shaken to my core when I learned that I had hypopharyngeal cancer. I had to accept that I am not invincible and that life has an end. Despite the fact that the small cancer was surgically removed and I received local radiation, I was left with uncertainty about my prognosis because of the risks of cancer spread or recurrence.

I slowly recovered from the radiation side effects (altered taste, mucosal inflammation, reduced saliva, and hypothyroidism) and gradually began to believe that I was cured. However, after 20 months, a local recurrence was discovered.

Hoping to get rid of the tumor with minimal sequelae, I elected to accept the option of laser surgery. Unfortunately, my surgeons were unable to completely remove the cancer by laser on three separate attempts within three weeks. After each surgery, their initial message was optimistic. However, a few days later I received the bad news that residual cancer remained.

At that point, I was emotionally and physically drained and frustrated at my unending saga. My surgeons wanted to perform a laryngectomy, but I elected to receive the procedure at a different medical center that had greater experience with this type of cancer. An additional four weeks was needed for the surgery and postoperative recovery. The tumor was completely removed, and no local or systemic spread was found.

I had not appreciated how I would feel after the surgeries. The pain, weakness, feeling medicated, inability to eat or drink by mouth, complete dependency, staying connected to an IV line, needing humidified oxygenated air and constant suctioning to relieve sudden airway obstruction, having blood drawn almost daily, and being unable to talk were extraordinarily difficult to become used to. I realized for the first time why some patients elect to avoid heroic measures to prolong their lives when their prognosis is bad. This was a new realization for me because I have always believed in prolonging life as much as possible and practiced this principle as a physician.

Physician as Patient

As a physician, I not only wanted to be informed about my treatment, but I also needed detailed explanations and differential diagnoses. I also wanted to express my opinion and give my input. I was very aware of what was happening to me and was able to report to my caregivers useful input about my symptoms that helped them to address issues early. However, this became very difficult once I lost my voice and was forced to depend only on writing to communicate. I realized that some of my surgeons were impatient, rushing, and always in a hurry to finish rounds, especially when they had surgeries scheduled. I received the attention of the senior surgeons for only a few minutes daily. They rarely examined any part of my body except the incision and flap removal sites and listened to my lungs only when I asked them. The nurses also were inconsistent about listening to my lungs or doing a physical examination.

I prepared a written list of questions prior to rounds, but I rarely had a chance to write down a follow-up question or request further explanations. This was very frustrating because I anxiously waited to see the surgeons. I also encountered rude and abrasive physicians. Once I asked a resident to clean my obstructed tracheotomy tube. He grudgingly flushed it using tap water rather than sterile water, which was used by the nurses for this purpose. The tube he wanted to place back into my trachea was still dirty, and when I asked him to use the kit and brush the dirt out, he abrasively responded, “We call the shots here,” and left my room. I felt very humiliated, hurt, helpless, and angry after being treated in this fashion.

Despite all of these misgivings, I am most grateful to all the nurses and physicians who took care of me. Most of my caregivers were very compassionate, and I felt their genuine care.

Mistakes at All Levels

Although the care I received at all hospitals was overall very good, I realized that mistakes were being made at all levels. Fortunately, I was able to abort many, but not all. The first error was when my surgeons, using laser, mistakenly removed scar tissue instead of the tumor. The error was not discovered until a week later. This could have been prevented if frozen sections of the lesion, not just of the margins, had been
analyzed. I had to undergo an additional laser surgical procedure 10 days later to remove the tumor.

I also had experienced several hazardous situations because of nursing errors. On one occasion while I was in the surgical intensive care unit, I experienced airway obstruction and reached for the call button. However, I could not find the button as it had fallen to the floor. I tried to call the attention of the staff, but I was ignored until my wife happened to arrive about 10 minutes later. I was helpless in asking for assistance without a voice and was desperately in need of air while medical personnel passed me by.

Other errors by nurses and other caregivers included not cleaning their hands, not using gloves when indicated, taking an oral temperature without placing the thermometer in a plastic sheath, using an inappropriately sized blood pressure cuff, giving medications by mouth instead of nasogastric tube, delivering an incorrect medication dose, connecting a suction machine directly to the suction port in the wall without a bottle of water, forgetting to rinse away the hydrogen peroxide used for cleaning the tracheal breathing tube (causing severe irritation), forgetting to connect the call button, and forgetting to write down verbal orders.

The most serious error after my laryngectomy was feeding me by mouth a week too early. This continued for 16 hours, and only my persistent questioning brought the feeding to an end. The mistake happened because of miscommunication in verbal orders. I wonder what happens to patients who cannot recognize and prevent mistakes. Fortunately, despite those errors, I did not suffer any long-term consequences. However, I had to stay constantly vigilant, which was very exhausting.

**Finding a Voice**

Weeks of convalescence without being able to utter a word were frustrating. Like many laryngectomy recipients, I attempted to fashion a new “voice” by forcing air into a small prosthesis that connected my upper airway to my reconstructed throat, thus enabling it to vibrate, imitating the functions of vocal chords. Speaking became a physical challenge: I had to use my chest muscles and diaphragm to intensively force air into the prosthesis. Expressing emotions or altering the intensity of my speech was difficult. My lifestyle also changed: I avoided noisy restaurants, large gatherings, and many social situations.

I had to deal with the feelings of depression and hopelessness. Feeling depressed was strangely helpful when I initially faced the gloomy prospect of pending surgeries and the uncertain future. The feeling helped me to accept the potentially poor outcome. However, I did not feel immediate depression after the surgeries as I was determined to get better. The depression, however, returned after I was home and had to deal with new realities and limitations. The depression was enhanced by the hypothyroidism and postsurgical anemia I had developed.

I am very aware of the potential of cancer recurrence and spread. I feel apprehensive prior to each of my follow-up scans. I have slowly adjusted to my uncertain future. I feel that I did whatever was possible to have the cancer removed, even at the cost of radical surgery and its consequences. I appreciate the future that has been granted to me, enabling me to experience the joys of life such as the birth of my granddaughter and my children’s achievements. What helped me overcome the difficult times was my desire to set an example to my children that one should not give in to adversity and should do everything within one’s power to fight back.

I slowly was able to return to my previous routines. One of my greatest comebacks was to be able to lecture again with the help of a microphone. I realize that the quality of my voice will never be the same as before. However, I have discovered that I can find a new goal to my life that helps me, as well as others, by lecturing about my experiences and sharing them with other laryngectomy recipients and healthcare providers. In this arena, my present voice is an asset rather than a handicap.

**Writing as Therapy**

I embarked on writing a book that captured my story of facing cancer. I honestly and openly shared my fears, anxieties, frustrations, failures, and ultimate adaptation to life with continuous uncertainty about the future. Writing the book also was therapeutic, as it helped me turn a difficult and painful period into something positive that may benefit others.

I learned that much needs to be improved in patients’ postsurgical care. This includes thorough education of patients and their families about the medical and social implications of the procedures, greater personal attention to patients by the surgical team, implementing standard nursing techniques, and greater vigilance and better communication among staff to avoid medical errors. Surgeons and nurses in training should be educated about proper medical and psychological postsurgical care and the special needs of patients after major surgery, including laryngectomy.

I am telling my personal story in the hope that nurses and other healthcare providers will realize the difficulties and challenges faced by patients diagnosed with cancer and undergoing extensive surgeries. I hope that my story will encourage them to understand their patients and care for them diligently and compassionately.

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