FROM THE EDITOR-IN-CHIEF

Cancer Pain in America: Missing the Target of Relieving Suffering

This is not my usual issue specific and highly researched editorial piece, and for that I apologize in advance. In the next issue of *Neuromodulation*, I will discuss the significant issues with respect to quality control, patient outcomes and cost effectiveness facing both device manufacturers and physician practitioners of neuromodulation. During the production time of the current issue, however, my beloved wife and the mother of my young son has been diagnosed with lung cancer. While a horrific experience for anyone forced to see their family member suffer, these past few months have personally involved me in the cancer care and pain management system more intimately than I would ever have imagined. It has given me tremendous insight into the terrible fear and suffering that our patients endure and just how poorly we as health care professionals may sometimes address these issues. Pain management in general and neuromodulation for pain in specific are highly technical specialties; unfortunately, technology alone is not the answer to the problems that face our patients. I am afraid that many of us have lost our way with respect to our roles as healers; as technicians we provide only a small amount of what our patients require.

My wife’s saga began in late June, when she began with an irritating cough. Despite anti-tussives and time, the cough did not resolve. Not one, but two courses of antibiotics for presumed bronchitis failed to alleviate her symptoms and on August 9th, 2013, a chest x-ray was obtained. With no radiologist readily available, I reviewed the films myself. Even a neurosurgeon could clearly identify the 4 cm right upper lobe lesion; I don’t know whether having to tell my wife the devastating news or holding back my fears was the harder task. Alas, I am a selfish man, and the concept of a life without my wife was unfathomable. Just viewing the x-ray, I felt an emptiness that I had never felt before. My wife had never smoked, had never been hospitalized, had no preexisting medical conditions and took no medications and yet we were faced with the possibility of her having lung cancer and I immediately feared her death. I could not imagine how devastating this fear would be to her.

I was amazed to find that our head of neuroradiology was the most empathic and caring physician that we encountered. He immediately invited me to bring my wife to the medical center, took care of all of the difficult insurance issues with obtaining a scan that had not yet been approved by our insurance company, and performed a chest CT scan. He was genuinely concerned, conveyed an air of warmth and competence; while the news was grave, his manner helped us to be comfortable that we were in the right place. The CT scan showed a large, enhancing lung lesion. He arranged for a PET scan to be performed the next working day and again dealt with the difficult insurance issues; unfortunately that scan again revealed that the lesion was hyper-metabolic and almost certainly a malignant tumor. We met the next day with a pulmonologist, underwent pulmonary function testing, and the following day met with the cardiothoracic surgeon. Video assisted thoracoscopic surgery was performed six days after the chest x-ray. A 4 cm adenocarcinoma was completely resected and no lymphatic spread was identified; my wife was diagnosed with Stage IB lung cancer.

As a physician intimately involved with pain management, I had now entered my comfort zone, or at least I thought. My wife was unarousable for nearly 12 hours after surgery and incoherent for several hours after that; she had been given large doses of sedatives and narcotics, despite being opioid naïve, to help minimize postoperative pain. She had terrible pruritus following opioid administration which was only mildly controlled with diphenhydramine. Most
significantly, she had severe pain, routinely rated as 9-10 out of 10 on a verbal analog pain scale for the next 5 days in the intensive care unit before her needs were attended to. No one identified that she had mixed nociceptive and neuropathic pain. No one noticed that she had incisional pain but that her primary pain was due to lung irritation from a mobile chest tube or that she had severe neuropathic pain of her breast and chest wall from a nerve injury at surgery. Rather, nurses entered and left the room, documenting her 9 out of 10 pain level as required then immediately leaving the room making no attempt to provide relief. Upon hearing my wife scream in pain when the nurse knocked over the pleurevac unit attached to the chest tube, the nurse said “Well, that’s different” and left the room. The surgeon and his team suggested that my wife’s pain threshold was very low, blaming her for her pain complaints. No one entertained the idea, nor accepted my suggestions to add non-narcotic analgesics or to consider anticonvulsants. They took chest x-rays, they checked vital signs, they adjusted the pleurevac unit; in fact they did everything except attend to her pain complaints.

It was a blessing that 5 days after surgery, we were revisited by the OR anesthesiologist. Within a few hours, a pain consult had been performed (by a nurse practitioner as the doctor was too busy) and an epidural catheter was placed. My wife immediately obtained 90% pain relief; a true blessing for both of us. Despite that, and over my objections, the nurse practitioner ordered and administered high dose long acting opioids; it was the next day before my wife returned to full consciousness. After a week, she was finally able to leave the intensive care unit and leave the hospital.

Unfortunately, my wife’s outpatient experience has similarly been inconsistent, at times lacking in both skill and empathy. A wonderful pulmonologist told us of his wife’s battle with lung cancer and her survival, despite recurrence and lung transplantation, going on 12 years. Her surgeon, however, told her that he knew nothing about her severe chest wall allodynia, hyperpathia and neuropathic pain; he told her “that’s your husband’s business” and refused to address the problem. Although a very kind woman, her medical oncologist did not inspire confidence nor decrease her fears when she mis-prescribed the chemotherapy, twice, argued with her pharmacist in front of my wife and failed to give her accurate prognostic information and pre-chemotherapy education.

My wife’s experience in the chemotherapy infusion center was equally problematic. As I am writing this, my wife has just completed her first day of chemotherapy. The nurse, who once was an empathic, caring health care provider, I am sure, after years has become hardened to the needs and requests of her patients. After being informed of my wife’s sole fear of multiple needle sticks, the nurse chose an unusual site for her intravenous line, poked her several times without success and finally had the line “blow”; the intravenous solution infiltrated into her soft tissues. When my wife complained of severe pain and swelling with the infusion, the nurse told her to wait five or ten minutes and that it would feel better. When the swelling and pain became worse, she was told that the line was functioning well; it was only after her physician arrived that the nurse agreed to place a proper line. Neither the nurse nor the physician asked about my wife’s physical or psychic pain; they never addressed her terrible fears of death and dying, her fears for her son of growing up without a mother or talked with her as a person rather than an object for their therapies.

It is with great horror that I admit that despite the facts that pain is the primary symptom of many cancers, that significant pain affects 50 percent of all cancer patients and 90% of patients with end stage disease, our field has made little overall impact on the care of cancer pain in America. It is with great honor, however, that I can state without hesitation that the community of interventional pain management physicians has caregivers who break the pattern I observed and have devoted themselves selflessly to the care, and not simply the treatment, of patients with cancer pain. These physicians have given me great hope for the future generation of cancer pain management physicians, as they have distinguished themselves by their empathy, pragmatism and devotion to patients with cancer pain.

Dr. Lisa Stearns founded the Center for Pain and Supportive Care in Phoenix, Arizona in 2007. After watching both of her grandmothers pass away from cancer, Dr. Stearns experienced first-hand that many chronic pain and cancer patients do not receive the proper care they need and often feel neglected throughout the treatment process. Dr. Stearns has made it her life’s work to improve patient’s quality of life and not just focus on immediate pain treatment.

While she is one of the world’s foremost experts in interventional therapy for cancer pain, Dr. Stearns is equally committed to educating patients and healthcare professionals about the most effective pain management and supportive care techniques. In her Phoenix practice, she set out to tackle what she saw as fragmented and
narrow care for patients with chronic pain. Dr. Stearns has diligently worked to create a diverse team of providers, including specialists in cancer-related pain, supportive care, interventional pain management, yoga rehabilitation, and medication management.

Dr. Stearns further founded the Valley Cancer Pain Foundation, a nonprofit organization dedicated solely to cancer pain research, to raise awareness and to educate families, patients and providers on integrating interventional pain treatments. She is also a co-founder and executive committee member of the Cancer Pain Clinical Research Consortium, as detailed below.

Dr. Allen W. Burton, former Professor and Chairman of the Department of Pain Medicine at the University of Texas MD Anderson Cancer Center, led the pain program there from 2000 to 2010. One of the largest cancer centers in the United States, MD Anderson had a tremendous need for cancer pain therapy; there Dr. Burton pioneered the comprehensive, multidisciplinary therapy of patients with chronic cancer pain. Not surprisingly, Dr. Burton has had personal exposure to cancer and its impact upon patients and their families. While his interest and commitment predated this, I can only imagine how it has fueled his dedication to competent, timely and empathic care.

Several years ago, I received a telephone call from a neurosurgeon with expertise in complex spinal surgery. Trained at Harvard and having served on the faculty of the University of California, San Francisco, Dr. Rosenberg was then in practice in Kansas City, Missouri. He had come to the realization that spinal surgery was not a panacea for patients with back pain and asked to visit our clinic to learn more about chronic pain therapy and neuromodulation. Never have I had a more dedicated student; Bill asked questions that made me rethink about how and why we do what we do in pain management.

Dr. Rosenberg then went back to Kansas City and founded the Center for Relief of Pain at the Research Medical Center. He rapidly became one of the region’s busiest neuromodulation physicians. Being a deeply religious man and sensing a great need for service, Dr. Rosenberg became more and more dedicated to patients with chronic cancer pain. He thus founded, with Lisa Stearns, the Cancer Pain Research Consortium (CPRC), with its mission to generate and promote interdisciplinary, patient-centered, evidence-based care for cancer-related pain and suffering. The CPRC is a multidisciplinary group of cancer pain providers—medical and radiation oncologists, anesthesiologists, physiatrists, neurosurgeons and others—from across North America, in both academic and private practices, who are dedicated to investigating and promoting the best treatment of cancer-related pain. On April 4-5, 2013, the CPRC held its inaugural meeting in Kansas City. As Dr. Rosenberg has emphasized, “compassionate and effective cancer pain care is a realistic goal, and the Consortium is going to make that a reality”.

I am certain that my personal experience is not unusual; it is only somewhat unusual for a pain management physician to have such an intimate and negative exposure to our pain management and cancer care system. Nor do I think that I am alone; several of my dear friends and fellow pain physicians have had their families suffer from cancer and cancer pain. And certainly I recognize that
my family and I have suffered little thus far and even less relative to the suffering of others. I know that others have lost and suffered much more than I have and even more than I might in the future. I am still very hopeful that my wife will survive and that we can watch our son grow to be a man and we can grow old together. But I am heartbroken as a physician who has practiced and preached the importance of caring over technology to see that many, if not most patients must suffer as we have. We all must commit to doing better. We must avoid complacency. We must learn to not simply be technicians; but to care for the patient, their bodies, their minds and their souls. We must learn from Drs. Stearns, Burton and Rosenberg. Cancer is a terrible foe; not only does it cause intense pain and physical suffering, but it attacks the spirit and erodes our hope. We, and our patients, have a long road ahead of us.

Robert M. Levy, MD, PhD
Editor-in-Chief