

## Living in a patient centric universe

Dennis H Kraus, MD

As I approached the gauntlet of the presidential address of the American Head and Neck Society, I wanted to identify an issue which represented a core value for me. As I considered topics, I not only weighed my upbringing, but my educational exposure. I am a graduate of the combined degree BA MD program of the University of Rochester. The medical school is the first post Flexner report institution, which sought major changes in the medical education curriculum in the United States, and was heavily influenced by both the report, and its major benefactor, George Eastman. The school purports to be the US home of the biopsychosocial model, and it is this influence which impacted on a majority of its graduates, and became the central theme of my presidential address.

I considered the dichotomy of two active patients in my practice. The first is a 54 year old Hispanic female who presented with a failure to diagnose T4 base of tongue cancer. She underwent an emergent tracheostomy for airway obstruction, followed by laryngectomy, resection of the base of tongue, pectoralis flap reconstruction and postoperative chemoradiation therapy. She has limited social support, multiple substance abuse, and limited health care access. She suffers from chronic pain and isolation. The second patient is a 72 year old man with a T4 oral cavity cancer. He suffered from chronic depression and was socially isolated in spite of having a doting spouse. His disease was long ignored, but had a relatively indolent course. He abused tobacco and alcohol and had access to health care and ample social support. He underwent segmental mandibulectomy, near total glossectomy, free flap reconstruction and post operative chemoradiation. He had several episodes of aspiration pneumonia.

There are a number of similarities and differences in these two patients which are readily evident. However, none of these comparisons could have prepared me for the diversity in response I received from each of these patients. The first patient sent me an expletive laden hand written note, telling me "I was worthless, and had been of no help to her". The second patient presented me with a plaque which stated "Start by doing what's necessary, Then do what's possible, And suddenly you are doing what's impossible – St. Francis of Assisi". It is easy as a physician to be alarmed by the first patient, or become over elated with the second, but to me there two central issues. How do we address the individual needs of our patients and assure a positive experience for each and every patient? And how do we help the patient successfully navigate the existential crisis engendered by the new diagnosis of head and neck cancer. To me, this is providing the environment to be successful in a patient centric universe.

The patient's perception of their care is created by the quality of the care, outcome of their treatment, the interaction and empathy displayed by the physician and health care team, and to a large degree the patient's world view. Although there are many shared values between the head and neck surgeon and patient, there are significant differences which can create challenges in priorities and impact upon both patient decision making and conflict between the patient, their family and the health care team. I will present two additional vignettes that illustrates this challenge. When reviewing the NCCN guidelines for advanced cancer of the oropharynx, options include concurrent systemic therapy, surgery for the primary and neck followed by risk adjusted adjuvant therapy, induction chemotherapy followed by radiation or chemoradiation, or multimodality therapy.<sup>1</sup> This led one of my patients to quote Frederick Nietzsche "Nothing is true, all is permitted".

An additional example is the maturing status of organ preservation in the setting of advanced larynx cancer. The VA larynx organ preservation study showed equivalent survival when comparing laryngectomy and chemoradiation with approximately two thirds of patients preserving their larynx.<sup>2</sup> Studies by McNeil<sup>3</sup> and Laccourreie<sup>3,4</sup> identified the willingness of patients to trade off reduced cure of their cancer in return for improved quality of life in the form of larynx preservation. Yet this trade off has resulted in a reduced survival for larynx cancer patients in the US during the last 20 years.<sup>5</sup> It is this dilemma which underscores the need for patient selection, patient education, access to multidisciplinary consultation and counseling, and the vital need for dialogue and understanding between the patient and the health care team.

A recent survey performed by Cancercare.org queried 3,000 patients representing a diverse group of cancer patients.<sup>6</sup> The goal of the survey was to define the engagement of the cancer patient, barriers to engagement with care providers, characterize financial, emotional, social and quality of life issues to patients and family, and develop strategies to promote access and engagement. There were 6 principle domains: understanding the diagnosis of cancer; treatment planning; communication with the health care team; financial and insurance issues; symptoms, side effects and quality of life; and survivorship. The authors conclude the results reflect the experience, perceptions and opinions of a significant proportion of patients diagnosed with cancer in the US. It is fair to characterize the survey as showing challenges abound! Only 70-90% of patients report understanding their conversation with different members of the health care team, with younger patients having less of an understanding. Approximately 90% of patients state they trust their physician's decisions regarding care and yet only 50-70% always take their cancer medication. Patient navigators are only available to 23% of patients and yet 94% describe them as being invaluable. Addressing distress by the care team is alarmingly low with end of life concerns being addressed in less than 20% of patients. Patients report less than 50% of the time being able to understand out of pocket expenses, reduced activities in 50% or more of the time, and greater than 40% of patients failing to have healthcare proxy, living will or end of life directives. It led the architect of the study, Ms. Ellen Sonet, to conclude "clearly, it takes a village to cope with cancer".

A significant component of patient care is the health care team and specifically the physician. A recent survey at the Mayo Clinic revealed a 50% incidence of burn out overall in their staff with some variation between specialties.<sup>7</sup> The perception of invincibility leads to isolation, lack of support, lack of autonomy, bureaucracy, fatigue and depression. This convergence of factors leads to the risk of burn out and suicide. How can we as physicians meet the emotional needs of our patients, if we can't achieve balance and happiness in our own lives?

In 2013, the Institute of Medicine published the seminal report "Delivering High Quality Cancer Care".<sup>8</sup> The central tenet is "engaged patients are at the center of the framework" for high quality cancer care. I emphatically agree. We as head and neck surgeons must collaborate with all members of the health care team to deliver the highest quality care. In closing, be kind and compassionate to your patients, help them to understand their disease, assist them in making treatment choices and return them to the best quality of life you are able. This will be the ultimate manifestation of living in a patient centric universe.

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