Patients with head and neck cancer face a number of challenges in terms of treatment, cure of their underlying malignant condition, and quality of survivorship. This presentation will focus on the patient perception of both the quality of care and the empathy and availability of the head and neck oncology team. It has become evident that the quality of survivorship plays a central role in the patient’s decision-making process. The process of decision making by the patient facing head and neck cancer and the impact on treatment choices will be explored. The ability of the patient and her or his support system to navigate through the increasingly complicated health care system will be considered, with an emphasis on strategies for success. Finally, the role of the head and neck surgeon, and the need for physician wellness in predicated successful patient outcomes will be considered. The ultimate goal of achieving optimal care, superior patient outcomes, and patient satisfaction is the true objective of the concept of living in a patient-centric universe.

As I approached the gauntlet of the presidential address of the American Head & Neck Society, I wanted to identify an issue that represented a core value for me. As I considered topics, I weighed not only my upbringing but my educational exposure. I am a graduate of the combined-degree program (BA/MD) at the University of Rochester, the first US medical school to open its doors after the landmark Flexner report of 1910. The Flexner report sought major changes in the US medical education curriculum, and the University of Rochester was heavily influenced by both this report and by a major benefactor, George Eastman. The school purports to be the US home of the biopsychosocial model. These influences shaped a majority of its graduates and became the central theme of my presidential address.

I considered the dichotomy of 2 patients. The first was a woman in her 50s with T4 base-of-the-tongue cancer who underwent an emergency tracheostomy for airway obstruction followed by laryngectomy, resection of the base of the tongue, pectoralis flap reconstruction, and postoperative chemoradiation therapy. She had limited social support, limited health care access, and a history of substance abuse. She also had chronic pain and isolation. The second patient was a 72-year-old man with T4 oral-cavity cancer, chronic depression, and social withdrawal despite being married. He also had a history of substance abuse (tobacco and alcohol) but had access to health care and available social support. He underwent segmental mandibulectomy, near total glossectomy, free-flap reconstruction, and postoperative chemoradiation. He had several episodes of aspiration pneumonia.

There are a number of readily apparent similarities and differences between these 2 patients, but none of these can explain their extremely contrasting opinions of the medical care they received. The first patient explicitly informed her treating physician that her care had been useless to her. The second patient presented his physician with a plaque that stated “Start by doing what’s necessary, then do what’s possible, and suddenly you are doing what’s impossible—St. Francis of Assisi.” Any physician might be unnerved by the reaction of the first patient or overly elated by that of the second. However, beneath these diametrically opposed patient reactions are 2 central questions: (1) How do we address the individual needs and assure a positive experience for each and every patient? (2) How do we help each patient successfully navigate the existential crisis engendered by a new diagnosis of head and neck cancer? To me, the answers to these questions provide the context of a patient-centric universe.

Patients’ perceptions of their care are created by the quality of the care, the outcome of their treatment, the empathy displayed by the physician and health care team during their interactions, and, to a large degree, each patient’s individual world view. And while there are likely many shared values between the head and neck surgeon and patient, the complexity of many treatment regimens can create challenges in priorities that influence patient decision making and create conflict between the patient, his or her family, and the health care team. For example, the National Comprehensive Cancer Network guidelines for advanced cancer of the oropharynx include the following options: concurrent systemic therapy, surgery for the primary and nodal basins followed by risk-adjusted adjuvant therapy, induction chemotherapy followed by irradiation or chemoradiation, or multimodality therapy. To quote Frederick Nietzsche, “Nothing is true, all is permitted.”

More complexity is introduced by the maturing status of organ preservation in the setting of advanced larynx cancer. The Veterans Affairs larynx organ preservation study showed equivalent survival between patients undergoing laryngectomy and chemoradiation and approximately two-thirds of those who underwent larynx-preservation therapy. Studies by McNeil et al and Laccourreye et al identified the willingness of patients to sacrifice reduced cure rates for their cancer to achieve improved quality of life through larynx preservation. But this trade-off has resulted in reduced survival for US patients with larynx cancer in the last 20 years.
It is this dilemma that 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 a diverse group of 3000 patients with cancer. The goals of the survey were to define the level of engagement of patients with their clinicians; to identify barriers to this engagement; to characterize financial, emotional, social, and quality-of-life issues of patients and their families; and to develop strategies to promote access and engagement. There were 6 principal domains evaluated: (1) understanding the diagnosis of cancer; (2) treatment planning; (3) communication with the health care team; (4) financial and insurance issues; (5) symptoms, adverse effects, and quality of life; and (6) survivorship. The authors conclude that their results reflect the true experiences, perceptions, and opinions of a substantial proportion of patients diagnosed with cancer in the United States, and if this is so, challenges abound.

The survey found that only 70% to 90% of patients report understanding their conversations with different members of the health care team, with younger patients having less of an understanding than older ones. Approximately 90% of patients stated that they trust their physician’s decisions regarding care, and yet only 50% to 70% always take their cancer medication. Patient navigators are available to only 23% of patients, and yet 94% of patients describe them as being invaluable. The ability of the care team to address patient distress is alarmingly low, with end-of-life concerns being addressed in less than 20% of patients. Patients report being able to understand out-of-pocket expenses less than 50% of the time; they understood instructions on reduced activities about 50% of the time; and they did not have a health care proxy, living will, or end-of-life directives more than 40% of the time. The findings led the architect of the study, Ellen Sonet, JD, MBA, to conclude “clearly, it takes a village to cope with cancer.”

An important component of patient care is the engagement and competence of health care team, especially the physician. However, a recent survey at the Mayo Clinic revealed a 50% incidence of burnout overall among staff physicians, with some variation between specialties. False perceptions of physician infallibility leads to isolation and lack of support; medical bureaucracy creates lack of autonomy leading to fatigue and depression. This convergence of factors leads to the risk of burnout and suicide. How can we as physicians meet the emotional needs of our patients if we cannot achieve balance and happiness in our own lives?

In 2013, the Institute of Medicine published the seminal report “Delivering High-Quality Cancer Care,” of which the central tenet that patient engagement in the treatment decisions is essential 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, I advise all of my colleagues to 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.