The Role of Patients

Shared Decision-Making

Emily Beers, MD[a], Marci Lee Nilsen, PhD, RN[b], Jonas T. Johnson, MD[c,d,e,*]

KEYWORDS

- Shared decision-making • Autonomy • Bioethics • Patient-centered care
- Head and neck cancer • Physician-patient communication

KEY POINTS

- Treatment priorities between patients and clinicians may not be congruent.
- Most patients want to be offered choices.
- Treatment options need to be explained.
- Risks and benefits should be outlined and realistic.
- Clinical practice guidelines may facilitate these discussions.
- Decision aids, specifically patient education materials, support informed choices.
- Patient preferences vary.

INTRODUCTION

Most patients with squamous cell carcinoma of the head and neck present with advanced disease (stage III or IV).[1,2] They will face many decisions about their treatment, which can be very difficult for patients and their families. For many patients, the effects of their cancer and its treatment will persist for years and impact basic function of everyday life, such as swallowing, speech, and cosmesis. The Institute of Medicine now recognizes that shared decision-making (SDM) is a central component to patient-centered care and is essential to improving quality of care, especially in oncology.[3] Sharing in this process with patients helps ensure that they are educated and informed while incorporating their values and preferences into the decision process.

The authors have nothing to disclose.

[a] Section of Palliative Care, Department of Plastic Surgery, 3600 Forbes Avenue, Suite 405, Pittsburgh, PA 15213, USA; [b] Department of Acute and Tertiary Care, School of Nursing, University of Pittsburgh, 318A Victoria Building, 3500 Victoria Street, Pittsburgh, PA 15261, USA; [c] Department of Otolaryngology, University of Pittsburgh School of Medicine, Pittsburgh, PA, USA; [d] Department of Radiation Oncology, University of Pittsburgh School of Medicine, Pittsburgh, PA, USA; [e] Department of Oral and Maxillofacial Surgery, University of Pittsburgh School of Dental Medicine, Pittsburgh, PA, USA

* Corresponding author. Department of Oral and Maxillofacial Surgery, University of Pittsburgh School of Dental Medicine, Pittsburgh, PA.

E-mail address: johnsonjt@upmc.edu

Otolaryngol Clin N Am 50 (2017) 689–708
http://dx.doi.org/10.1016/j.otc.2017.03.006
oto.theclinics.com

EVOLUTION OF DECISION-MAKING MODELS

The American Medical Association's 1847 original *Code of Medical Ethics* advised doctors that "the obedience of a patient to the prescriptions of his physician should be prompt and implicit. The patient should never permit his own crude opinions as to their fitness to influence his attention to them."[4] This antique, authoritarian model of patients as passive recipients of doctor's orders is fortunately becoming a thing of the past. Despite that slow fade, however, the normative values of that paradigm that reigned for millennia have not entirely vanished. The increased emphasis on patient autonomy has in general been good; however, autonomy is itself a complex concept that has great bearing on the physician-patient relationship.

In the paternalistic extreme, the physician provided a plan that patients obeyed, removing agency from patients and giving all of the power to the physician. This model spanned from the time of Hippocrates to the 1970s. In that decade, massive culture shifts in America forever changed the roles of women, minorities, and society's view of authority. This change created a reactionary backlash to the paternalistic past on many fronts, and medical case law evolved in parallel. The 1972 case of *Canterbury v Spence* transformed our health culture by drastically changing standards for informed consent. Until that point, informed consent for a treatment included a discussion that met the standard of community disclosure, that is, whatever the most physicians in a community would say about such treatment. *Canterbury v Spence* detailed a patient who was advised to have a laminectomy for back pain; in his case the surgeon did not disclose the 1% risk of paralysis for fear that it would cause the patient to reject the beneficial treatment. When the patient suffered paralysis (either from surgery or a postoperative fall), the court ruled that the lack of disclosure was a failure on the physician's part. The court challenged the concept of *community standard* on grounds that it incentivizes physicians to protect themselves by limiting standard disclosure, which is not a practice aligned with patients' best interests.[5] In that ruling they noted "…the test for determining whether a particular peril must be divulged is its materiality to the patient's decision: all risks potentially affecting the decision must be unmasked."[6] This ruling resulted in legal codification of a physician's duty to fully inform, from which all current standards of informed consent have developed.

Bioethics also had a rapid evolution in that time, and the wave of antipaternalism caused some to advocate for a cultural reversal of power in the patient-physician dyad: in this version, patients dictated their preferences for treatment, and the physician's role was simply to execute a logical plan that honored those preferences. This version was the first stirring of patient-centered medicine, a model in which "the object of our studies is…therapy: not an isolated or specialized medical skill, but the doctor's whole professional activity regardless of whether he is a specialist or general practitioner."[7] As the pendulum swung from paternalism to physician as passive executor of medical possibility, the current standard has settled somewhere in the middle of those two margins.

In modern SDM, the physician provides the medical facts and treatment options, patients provide their values, and together they form a plan that best matches the facts to the values.[8] Although this model is far superior to either of the extremes, troubles remain with the way it is implemented. Firstly, this model presumes facts and values can remain completely separate. When physicians are giving facts, the data show that it is rare that they can provide these in completely value-neutral manner. In an analysis of 1057 audiotaped conversations of medical and surgical outpatients containing 3552 clinical decisions, only 9.0% of basic and 0.5% of complex decisions made met the criteria for informed decision-making.[9] That is, when we deliver information to patients