Seeking equilibrium in decision making: The balance between clinical judgment and patient goals

LINDSEY MOSES, IRA J. KODNER, MD, FACS, DOUGLAS BROWN, PHD, BRIAN NUSSENBAUM, MD, FACS AND JENNIFER YU, MD
PUBLISHED JULY 1, 2016 • Bulletin of the American College of Surgeons

As a cornerstone of the surgeon-patient relationship, shared decision making is a critical factor in determining whether a patient should undergo an elective procedure. The decision as to whether an operation is appropriate should be made based on the surgeon's understanding of the risks and benefits of surgery and the patient's goals and quality of life. In some instances, however, patients may request a procedure in which the surgeon believes the risks would outweigh any potential benefit based on the patient's history and current health status. Such cases present an ethical dilemma for the surgeon.

This article describes a case in which the surgeon believes a conservative approach to care is best based on the patient's history and previous postoperative complications; however, the patient wants to pursue a more aggressive approach in order to improve her quality of life. Details of the patient's history and health status are described, and four possible means of resolving the predicament are discussed.

The case

A young mother with two children presents with an enlarging neck mass. She is diagnosed as having bilateral vocal fold paralysis and a squamous cell carcinoma with invasion into the larynx. She undergoes treatment with a total laryngectomy and a partial pharyngectomy with pectoralis flap reconstruction followed by adjuvant radiation therapy. The patient has a complete oncologic response but suffers from pharyngoesophageal stenosis as a complication of her treatment. She undergoes esophageal dilation, which improves her swallowing. However, one month later, she develops chondro-radionecrosis of the trachea that requires hyperbaric oxygen therapy to heal. Over the course of the next year, she undergoes several more esophageal dilations and becomes pregnant with her third child. Due to the risk of anesthesia required for dilation, the patient agrees to have a Dobhoff tube in place during the second half of her pregnancy to maintain a patent esophageal lumen.

In the three years following her initial treatment, the patient undergoes more than 20 esophageal dilations as well as multiple stent placements. Following her last dilation, she suffers a pharyngeal perforation leading to abscess formation and a pharyngocutaneous fistula. With appropriate treatment (including another round of hyperbaric oxygen therapy), the fistula tract ultimately closes and the infection resolves. However, the patient now has a complete pharyngoesophageal stricture. She suffers from severe dysphagia and is unable to even take sips of water.

Throughout the course of treatment, the patient and her surgeon discuss a range of options, including conservative management (observation), repeated esophageal dilations, retrograde dilation through a percutaneous gastrostomy tract, and surgical intervention (performing an open pharyngectomy with free flap reconstruction). The patient initially opts for management with regular dilations. However, once she develops a complete pharyngoesophageal stricture, the only options remaining are to continue with conservative therapy or to conduct a radical operation with considerable risks—particularly related to the significant soft tissue toxicity from the radiation therapy—and possible death or prolonged disability.

The patient, with a strong and persistent desire to swallow again, repeatedly asks that the surgeon perform the open operation. The surgeon, after weighing carefully the risks and benefits of the operation indicated for quality of life measures, recommends that they pursue other options.

The ethical dilemma

The patient is requesting an operation that the surgeon offered as an option but that he would not recommend. After repeated conversations, the patient and surgeon are unable to agree on a plan of care. The patient in this case has been through years of treatment for esophageal stenosis, and her quality of life has diminished to a point where she is willing to risk severe, disabling complications in exchange for the chance to swallow again.

The surgeon is sympathetic to her perspective but believes the operation has only a low to moderate chance of success while carrying a significant risk of complications. The surgeon is faced with having to make a recommendation based on his experience and his judgment with regard to which approach will offer the greatest benefit to the patient.

To continue with conservative management would be a safe approach but would not address the patient's poor quality of life. Moving forward with the operation would place the patient, who is currently doing well from a clinical perspective, in a situation where possible outcomes range from improved quality of life to severe disability or death. How can the surgeon honor this patient's wishes while upholding his professional obligations to do what he believes is best and to avoid causing unnecessary harm?

Four possible options

Possible solutions to this ethical dilemma and a review of the pros and cons of each approach are as follows:

- Perform the operation at the patient's request
- Explain the reasons for not operating at this time but continue to provide care for the patient
- Seek the opinions of colleagues and patient family members
- Do not perform the operation and refer the patient to another physician

Option 1: Perform the operation at the patient's request

Respect for patient autonomy—an established ethical responsibility in medicine—honors the patient's right to make decisions that are consistent with his or her personal goals and values. Autonomy in medicine applies to both patients and physicians; that is to say, patients may choose or decline specific treatments or interventions, and physicians are free to act on their best judgment, advising a course of treatment that will yield the greatest medical benefit.[1] A distinction must be made between the concepts of autonomy and independence. Although patients have a right to and are encouraged to make decisions about their treatment plans, those choices should be based on clinical input from their physicians and on the needs and concerns of family and other caregivers.[2] In turn, the physician has a responsibility to offer recommendations and ensure that the patient can synthesize the information independently and arrive at an informed decision. Physicians have an obligation to share their unique knowledge and experiences to help their patients make truly informed autonomous decisions, regardless of whether they are in line with the physician's recommendations.

In this case, several factors have contributed to the patient's desire to have the operation. Given that she is aware of the significant risk of postoperative complications (including death) that could follow, the fact that she repeatedly has asked for the operation provides insight into her suffering. Her goal is clearly to achieve an improved quality of life, but what if the operation is unsuccessful? It can be challenging for patients to grasp potential outcomes that they have not experienced and to compare an unknown future to their known present.[2] The possibility that her quality of life might worsen following the surgery is likely difficult for the patient to imagine. Therefore, the physician is responsible for providing an accurate explanation of the full range of perioperative risks so that the patient can make an informed decision.[2]

Patients also may have unrealistic expectations about the potential outcomes of a procedure and place unquestioning faith in their surgeons.[3,4] When this patient first presented, she was an otherwise healthy young mother. Through her surgeon's thoughtful exam and workup, she was diagnosed with cancer and underwent a treatment that dramatically changed her life. She lost her voice and, over time, her ability to eat, but ultimately she was cancer-free. Given these experiences, the patient may have become more focused on the possibility of success than the potential of the operation failing and worsening her condition.

The patient in this case has been informed of the risks and benefits of surgery and is an adult who is capable of making her own health care decisions. She has engaged in a thorough discussion of those risks and benefits with her surgeon, listened to the surgeon's recommendations, and has requested an operation to restore her swallowing function. Since her initial presentation, the patient has actively participated in her own care, following up regularly to receive treatment for the esophageal stenosis and wound healing issues that resulted as complications of her cancer treatment. She went to

great lengths for several years to preserve her swallowing abilities and clearly demonstrated that she was committed and willing to bear the treatments necessary to regain the ability to swallow. The surgeon engaged the patient in multiple discussions about the risks involved and the potential consequences of the operation. She nonetheless made the autonomous decision to proceed. Although he may disagree with this course of action, a surgeon who views patient autonomy as a priority would support her decision.

Option 2: Explain the reasons for not operating at this time but continue to provide care for the patient

Commitment to beneficence and nonmaleficence are key factors that guide physicians as they make recommendations to their patients. Attempts to determine the risk-benefit ratio of a particular treatment or intervention followed by discussion of the patient's goals and values usually leads to agreement on a treatment plan.[1]

In this patient's initial operation, the agreed-upon goal was to cure the patient of cancer. To achieve that objective, the patient underwent a major operation and received adjuvant radiation therapy; unfortunately, she subsequently developed complications related to her treatment. These complications are fairly common for this course of treatment; in fact, pharyngoesophageal stenosis occurs in up to 20 percent of patients who undergo radiation therapy for laryngeal cancers, with 5 percent of these patients developing a severe or complete stenosis.[5] These risks were discussed in the development of the patient's initial treatment plan. At that time, the surgeon and patient agreed that the risks of treatment were justifiable because of the potential benefit of curing the patient's cancer.

Several years later, the patient and surgeon now must decide whether to proceed with a second operation, this time to restore the patient's ability to swallow. Their discussion must again take into account the risk-benefit ratio. The desired benefits of treatment have changed and now are focused on improving the patient's quality of life. The operation is not medically essential because the patient can receive all necessary nutrition through a gastronomy tube and has maintained a healthy weight.

However, her quality of life has been significantly compromised as she cannot swallow even small amounts of water for comfort. The surgeon believes the intervention that the patient has selected, which would involve a total pharyngectomy and free flap reconstruction, is extremely risky because of the soft tissue toxicity the patient experienced as a result of prior radiation treatments and as evidenced by her poor wound healing abilities and dense soft tissue fibrosis.

The surgeon explained to the patient that the risks of this procedure are great and could include death if complications related to the neck vasculature developed or prolonged disability from wound healing issues (including a second potential pharyngocutaneous fistula). In the surgeon's estimation, the risks of a second operation outweigh the potential benefit.

Because he has known and treated the patient for many years, the surgeon undoubtedly feels a great deal of responsibility for the suffering she has experienced and a duty to help her achieve a better quality of life. In an interview study of 10 Norwegian surgeons in 2005, many agreed, "…it is more difficult to withhold treatment the younger the patients are because the emotional feelings surrounding the decisions are experienced as more difficult."[4] The surgeons in the study were referring to withholding treatment in a life-threatening situation when the outcome is unpredictable.

The same sentiment can be applied to the surgeon in this case. He is struggling with the choice to undertake an elective operation with an unpredictable outcome, knowing that if the procedure goes poorly, the patient would have to endure unnecessary suffering and spend a great deal of time away from her family. The patient's status as a mother with three young children puts an even greater amount of pressure on the surgeon to deliver a positive outcome should he operate. The surgeon in this case is a compassionate and caring physician who has invested a great deal of time and effort in treating this patient. However, his belief that the operation has a low to moderate chance of success based on the complexity of the operation and the patient's history, coupled with the fact that she has young children at home and thus much to lose if complications arise, ultimately leads the surgeon to argue against the operation. The surgeon clearly has what he believes are the best interests of the patient and her family in mind, and prioritizing beneficence and nonmaleficence in this case would lead him to decline to perform the operation but continue to offer care to the patient.

Option 3: Seek the opinions of colleagues and patient family members

This case illustrates an ideal physician-patient relationship built on the foundation of mutual trust, understanding, and respect. However, it may be the very nature of this relationship that has caused the surgeon to feel so torn in choosing a course of action. If a colleague had sought his advice on this same case, the surgeon's relationship with the patient would not cloud his ability to assess the situation objectively. Does he feel more compelled to operate because he regards this patient as someone to whom he has devoted many years and is willing to go further to help, or does his knowledge of the patient's family and the impact that potential complications would have on them sway his judgment?

Surgeons commonly seek the advice of colleagues to learn from the experiences of others, to gain a new perspective on a situation, or to gain support and validation.[6,7] Guidance often is sought at formal meetings, such as at multidisciplinary tumor board conferences where experts discuss many aspects of patient management, including whether to pursue more or less radical surgery.[7] Because patients with head and neck cancer frequently are at increased risk of treatment-related morbidity, tumor boards are an excellent forum in which to assess difficult cases.[8] These meetings also allow for a discussion of treatment options without taking into account personal factors that may influence the situation, leading to a more objective evaluation based on medical facts.[7]

The surgeon in this case is struggling with a difficult choice. He must confront many competing factors, including his sense of personal responsibility. Other surgeons who are detached from the patient may strongly oppose the operation based strictly on the medical facts presented. Discussing the case with colleagues may offer the surgeon not only different points of view, but also the support needed to endure such a challenging situation.

In addition to seeking impartial medical opinions, the surgeon might consider a discussion with the patient's family. This conversation might help to clarify the patient's goals and whether her family would be able to cope with potential complications. Conversations with family members and close friends of the patient may clarify how the issues she faces affect her daily life and those around her. The commitment of family members to support the patient's wishes or their concerns about moving forward with such a risky operation could have a major impact on the patient's decision to continue conservative management or to opt for surgical intervention. When the best course of action is unclear, additional points of view can help to illuminate what is most important to the patient and better define the context in which the decision must be made.

If an agreed-upon treatment plan still cannot be reached, it would be reasonable to bring this case to an ethics committee for further review. An ethics consultant may offer additional perspectives derived from a comprehensive review of the case and help engage the patient and physician in shared decision making.

Option 4: Do not perform the operation and refer the patient to another physician

The decision to undergo an elective operation is always in the patient's hands. Implicit in that decision is an agreement between the patient and surgeon that the operation chosen has the potential to benefit the patient and is a medically reasonable course of action.[9] If a surgeon believes that the operation will be harmful to the patient or cannot be medically justified, he or she has the right to refuse to perform the operation on the grounds of a professional and moral obligation to do no harm.

The surgeon in this case is asked to perform a major elective operation intended to improve the patient's quality of life. Although the surgeon has the right to refuse the request, several factors add to the complexity of the situation, including the fact that the patient's esophageal stenosis occurred as a complication of prior treatment for her cancer. The surgeon treated her stenosis for several years with esophageal dilations, but unfortunately, it progressed to a point where major surgery is the only option for potentially restoring the patient's ability to swallow. Given that the patient's stenosis has worsened and the surgeon no longer feels that repeated interventions will provide her any additional benefit, it would be reasonable for him to refuse to perform another operation.

Just as a physician has the right to refuse to perform an operation, patients have the right to seek care elsewhere and to look for a physician with whom they can develop a mutually agreeable treatment plan. The surgeon in this case has diligently treated the patient's cancer and the complications that arose from the operation and radiation treatment, but he has now exhausted all of the options that he believes are justifiable. If the patient feels that she wants additional

treatment and would like to find another surgeon who would be willing to proceed with an operation, it would be acceptable for the surgeon to refer the patient to another specialist and turn over the case to that individual.

Bottom line

Surgery has the potential to improve a patient's quality of life and to rid a patient of cancer; it also can take away a patient's ability to eat or speak and change the patient's physical appearance forever. Each time a patient undergoes an operation, all of the possible outcomes must be considered and weighed against other treatment options. It is impossible to predict the outcome of every operation, so recommendations must be grounded in data and experience. Physicians use data and other objective measures to justify their advice, but for each individual patient, the only outcome that matters is the one he or she experiences.

The patient in this case poses an ethical challenge to the surgeon because every course of action has the potential to result in harm. If the surgeon chooses to operate as the patient requests, she may suffer more than she already has and her family will suffer if she dies or has a painful and protracted postoperative course. However, if the surgeon refuses to operate or offer another intervention, the patient will face a lifetime of severe dysphagia and discomfort, which may ultimately cause her more harm psychologically and place an enormous burden on her family. The surgeon's argument against operating is based on the medical facts of the case. His professional experience, as well as the patient's history of poor wound healing and a previous pharyngocutaneous fistula, inform his recommendation not to operate. He is upholding his professional responsibility to provide a complete overview of the possible outcomes of surgery and the estimated likelihood of success given his past experience and the patient's history.[10] However, the decision to continue conservative management or pursue aggressive treatment ultimately belongs to the patient.

References

1. Jonsen AR, Siegler M, Winslade WJ. *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine.* 7th ed. New York: McGraw-Hill; 2010.

2. Elwyn G, Frosch D, Thomson R, et al. Shared decision making: A model for clinical practice. *J Gen Intern Med*. 2012;27(10):1361-1367.

3. Nabonzny MJ, Kruser JM, Stefens NM, et al. Patient-reported limitations to surgical buy-in: A qualitative study of patients facing high-risk surgery. *Ann Surg*. January 2016 [e-pub ahead of print].

4. Torjuul K, Nordam A, Sorlie V. Action ethical dilemmas in surgery: An interview study of practicing surgeons. *BMC Med Ethics*. 2005;6:E7.

5. Gavriel H, Chowdhury AT, Duong C, Spillane J, Sizeland A. Poor functional performance following bidirectional dilatation of severe post radiation oesophageal stricture. *Acta Otolaryngol*. 2015;135(6): 629-634.

6. Torjuul K, Nordam A, Sorlie V. Ethical challenges in surgery as narrated by practicing surgeons. *BMC Med Ethics*. 2005;6:E2.

7. Pillay B, Wootten AC, Crowe H, et al. The impact of multidisciplinary team meetings on patient assessment, management and outcomes in oncology settings: A systematic review of the literature. *Cancer Treat Rev.* 2015;42(1):56-72.

8. Wheless SA, McKinney KA, Zanation AM. A prospective study of the clinical impact of a multidisciplinary head and neck tumor board. *Otolaryngol Head Neck Surg*. 2010;143(5):650-654.

9. Schwarze ML, Bradley CT, Brasel KJ. Surgical "buy-in": The contractual relationship between surgeons and patients that influences decisions regarding life-supporting therapy. *Crit Care Med*. 2010;38(3):843-848.

10. Quill TE, Brody H. Physician recommendations and patient autonomy: Finding a balance between physician power and patient choice. *Ann Intern Med*. 1996;125(9):763-769.