Caring for Patients With Dysphagia: Some Ethical Considerations

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What is spoken of as a ‘clinical picture’ is not just a photograph of a man sick in bed; it is an impressionistic painting of the patient surrounded by his home, his work, his relations, his friends, his joys, sorrows, hopes, and fears. (Peabody, 1927)

Decisions are not made in a void. They always occur in the context of relationships. Medical decisions are no exception; and the relationships that affect them are among the most interesting and complex. This article addresses two areas of ethical concern that arise in the care of patients with dysphagia. The first focuses on the process of decision-making and is captured by the concept of informed consent. The second touches upon the issue of withholding or withdrawing food and fluids from patients who cannot feed themselves. Through a discussion of some of the ethical principles and virtues that guide good decision-making, we will begin to explore those qualities that build good medical relationships.

As a physician, I like to believe I have a patient’s best interests in mind when considering a sensitive issue like limiting oral intake in someone at risk for aspiration. As a pulmonologist, I have a practical interest in protecting the person’s lungs. However, that practical interest must be balanced by the patient’s desire to maintain speech and swallowing function. Multiple medical conditions can lead to varying degrees of dysphagia and dysarthria. Frequently these impairments are the expected consequences of therapeutic interventions such as surgery or radiation. Occasionally a patient and physician are faced with therapeutic options, each of which is attended by different expected consequences. For example, a therapeutic total laryngectomy avoids the aspiration problem but requires an artificial larynx, whereas a supraglottic laryngectomy can preserve speech but leaves the risk of choking. It is the physician’s duty to advise which therapies are the “best” from a medical standpoint (for example, for controlling a malignancy). However, it is the patient’s prerogative to choose from among those reasonable options offered.

This ethical premise of the patient’s right to self-determination is embodied in the doctrine of informed consent, a concept grounded in the ethical principles of nonmaleficence, beneficence, and autonomy (Beauchamp & Childress, 1989) and the ethical virtues of integrity, compassion, and prudence (Pellegrino & Thomasma, 1993). The principle of nonmaleficence states that we should “do no harm.” This ancient principle, well-described in Hippocratic writings, acknowledges that our interventions bear potential harms as well as benefits. The principle of beneficence states that we are to do good; we strive to promote the health and well-being of our patients. And, based on the principle of autonomy—from the Greek, meaning “self governing”—we heed the desires of individuals concerning their self-determination. When their desires are not explicitly known, we do our best to keep their best interests at heart, weighing the benefits and burdens of proposed courses of action. Furthermore, we try to do this prudently, with integrity and compassion. Through prudence, one engages practical wisdom, one’s powers of intellectual and moral discernment. Having integrity, a person not only possesses moral character, but also recognizes the integrity, or “wholeness” of others and the potential for “dis-integration” during illness. Finally, the compassionate person “suffers together” with the patient, trying to understand—intellectually
and emotionally—the patient’s experience.

The legal expression of the informed consent doctrine was articulated in the words of Justice Cardozo in 1914: “Every human being of adult years and sound mind has a right to determine what shall be done with his body....” (Cardozo, 1986). This concept has been further elucidated in other cases, including the 1957 Salgo case, in which it was stated that physicians were obligated to reveal “any facts which are necessary to form the basis of an intelligent consent by the patient to proposed treatment” (Faden & Beauchamp, 1986). A clinician guided by these ethical and legal principles recognizes that one cannot compel a patient to believe something, but that one can “choos[e] instead to invite, to persuade, to educate, and to reason ...” (Mouw, 1987).

The practical implications of caring for patients in such a manner are both straightforward and ambitious. They include the need to be as knowledgeable as possible about treatment alternatives; to increase our knowledge about treatment outcomes (including such “nonmedical” outcomes as psychological impact and “quality of life”); and to provide multiple avenues for educating patients (including literature, audio and visual aids, and the use of patient volunteers and support groups). How does the patient feel about preserving the ability to eat over the ability to speak? Does he want to try to master special swallowing techniques that still leave him at risk for aspiration? Can his pulmonary status withstand episodic aspirations? Does the patient who is advised to refrain from eating or drinking fully understand the possible consequences of aspiration (including: acute airway obstruction, acute pneumonia, chronic lipoid pneumonia, fibrosis, and bronchiectasis)?

All of these considerations presume that the patient is competent and capable of making decisions. Other processes of decision-making ensue when patients are unable to make decisions for themselves. The processes include guardianship, surrogate decision-making, and advanced directives but a full discussion of these ethical and legal concepts is beyond the scope of this article. So far, we have looked at medical decision-making in terms of a patient choosing among alternative treatments. Implicit in the notion of informed consent is also the notion of informed refusal—patients (or their surrogates) may refuse treatments, even life-saving treatments. Some of the most difficult decisions we make involve the withholding or withdrawal of life-sustaining treatments. Decisions concerning the cessation of food and fluids are among the most poignant.

Not uncommonly, the situation arises in which a patient’s life is dependent on some form of medical intervention. This may range from a person in a persistent vegetative state whose only “medical” dependency is a feeding tube, to a severely ill patient in an intensive care unit dependent on mechanical ventilation, artificial feeding, dialysis, and medications. If a patient has clear wishes concerning the withholding or withdrawal of such treatments, it is generally considered acceptable to comply with those wishes. However, when no such wishes are known, decisions must be made based on the best interests of the patient and the balancing of the benefits and burdens associated with diagnostic and therapeutic interventions. Does the “burden” of feeding ever outweigh the “benefit” of receiving nutrition?

Part of the answer to this question hinges on whether artificial feeding is considered a medical treatment or not. This is a controversial issue: is the provision of food and fluids a “medical treatment” or a basic human need? In general, the courts have decided that artificial feeding (e.g., through a feeding tube or intravenous line) is a medical treatment. For example, in Barber v. Superior Court, a 1983 California case involving the cessation of intravenous fluids and hydration to a man who had suffered severe brain damage, the court decided:

Medical procedures to provide nutrition and hydration are more similar to other medical procedures than to typical human ways of providing nutrition and hydration. Their benefits and burdens ought to be evaluated in the same manner as any other medical procedure (Raffin, 1994).

Likewise, in 1986, a California court established the right of a competent patient to refuse food and water in the case of Bouvia v. Superior Court. And, in Massachusetts, the case of Brophy v. New England Sinai Hospital supported the cessation of nutrition and hydration to a man in a persistent vegetative state (Raffin, 1994).

However, many people believe that the provision of food and fluids is part of basic human caring and is not a “treatment” per se. In 1986, the New Jersey Catholic Conference submitted an amicus curiae brief stating its stance on this issue:

The conference maintains that nutrition and hydration, being basic to human life, are aspects of normal care, which are not excessively burdensome, that should always be provided to a patient. Nutrition and hydration are clearly distin-
gued from medical treatment ....Medical treatment is therapeutic; nutrition and hydration are not, because they will not cure any disease (Walter & Shannon, 1990).

Also, in the 1990 case of Nancy Cruzan, a woman in a persistent vegetative state, a Missouri court ruled that the continuation of tube feedings, was “not heroically invasive” because the “invasion took place when the gastrostomy tube was inserted.” The U.S. Supreme Court ruled on the Cruzan case, but it was over a states’ rights issue and not this question on the nature of artificial feedings. Nevertheless, in his opinion, Chief Justice William Rehnquist wrote: “For purposes of this case, we assume that the United States Constitution would grant a competent person a constitutionally protected right to refuse life saving hydration and nutrition” (Raffin, 1994). The central issue of the Supreme Court case was that individual states have the right to determine how much evidence they require to demonstrate that an incompetent patient would desire the withdrawal of life-sustaining treatment. Later that year, further evidence accumulated that Nancy Cruzan would not want to live in the manner in which she had been sustained; food and fluids were withdrawn; and she died.

The Cruzan case brought to national attention the agonizing controversies that surround decisions regarding the cessation of life-sustaining treatments. It also set into motion a national movement to increase the use of advanced directives, documents designed to clarify what sorts of treatment a person would or would not want to receive if he were incapable of speaking for himself. The Cruzan case, and others like it, demonstrate the tensions that can arise as we try to minimize burdens, maximize caring, and facilitate autonomous decision-making for our patients.

This brings us back to a discussion of the ethical principles and virtues which guide medical relationships. Tempered by nonmaleficence, we try to avoid inflicting harm. Prompted by beneficence, we try to provide compassionate caring. And, respecting autonomy, we seek to restore patients’ integrated self-determination. Decision-making guided by these principles and virtues is characterized by clear communication of relevant facts and values; an empathic balancing of the benefits and burdens of proposed treatments; and sincere respect for each other’s differing convictions. This is how we should care for our patients with dysphagia.

References


Note. I have mentioned only “natural” virtues: see I Corinthians for reference to the “theological” virtues (faith, hope, love).