Speech-language pathologists who provide services to patients with degenerative neurologic disease are faced with a series of difficult challenges. By providing early intervention and frequent follow-ups, especially at critical points in the course of disease progression, speech-language pathologists are often able to maximize communicative efficiency as speech deteriorates. In this way, social isolation, often a consequence of dysarthria, and dehydration, a secondary complication of dysphagia, can be avoided. As a faculty member in an academic training program, I believe that our students are equipped to assess and develop treatment plans for dysarthria. However, they are much less well prepared in the area of medical ethics. They receive little training in the principles of medical ethics to assist patients and their families in making difficult decisions related to medical care in degenerative disease.

Much has been written, especially recently, in the area of medical ethics (Ahronheim, Moreno, & Zuckerman, 1994; Beauchamp & Childress, 1983; Elliott & Elliott, 1991; Englehardt, 1986; English, 1994; Gillon, 1994; Harron, Burnside, & Beauchamp, 1983; Jonsen, Siegler, & Winslade, 1992; Pellegrino, 1993). Principles of biomedical ethics are increasingly being taught in medical school curricula as a means of helping physicians and other health care professionals make critical decisions about patient care. Whereas much of the literature relates to moral and legal issues involved in the physician-patient relationship, basic principles related to biomedical ethics are applicable to the speech-language pathologist and other ancillary medical personnel who work closely over time with patients who have progressive neurologic disease. In fact, speech-language pathologists frequently find themselves playing a key role in facilitating communication related to complex issues of patient care and medical ethics.

In this article, I will briefly define some basic principles of medical ethics. Several cases will then be described to illustrate how these principles are pertinent in the practice of speech-language pathology. These cases represent difficult ethical problems that require moral decisions regarding maintenance and quality of life. Each of these cases will be followed by a list of questions for thought or discussion.

**Theories and Principles of Medical Ethics**

Beauchamp and Childress (1983) suggested an approach to moral reasoning in deliberation that is based on hierarchical levels that they call “levels of moral justification” (see Figure 1). The lowest or most concrete level of their hierarchy is judgment and actions. A judgment is a decision or conclusion about a particular action. For example, a physician tells the patient that the mean life span of a patient with ALS is 2.5 years. On a slightly more abstract level, rules state that certain actions may not be done because they are wrong, or conversely, certain actions should be done because they are right. For example, a moral rule would suggest that it is wrong to lie. Principles serve as the foundation for rules. They are more general and fundamental in nature. The top level of the hierarchy is that of theories, in which the systematic relationship of principles and rules are considered. Although it is beyond the scope of this article to describe ethical theories, a few examples of principles are given to better describe this approach to moral reasoning and decision making.
Two basic types of ethical theories are predominant (Beauchamp & Childress, 1983; Harron, Burnside, & Beauchamp, 1983). These are deontological theories (sometimes referred to as formalist theories) and utilitarian theories. In deontology, judgments and actions are either right or wrong. It is the features of the acts themselves, rather than the consequence of the act, that make them right or wrong. Therefore, certain rules (e.g., telling the truth) must always be followed, no matter what the consequences. Utilitarianism, on the other hand, posits the philosophy that “the end justifies the means.” The rules are based, to some degree, on the consequences of decisions or actions. Whereas these theories provide a philosophical foundation from which one approaches ethical dilemmas, the literature in medical ethics relies heavily on the use of ethical principles as a guide to moral decision making.

Authors vary with respect to what principles are most important, and in how those principles relate to each other. Several commonly discussed principles include autonomy, beneficence, nonmaleficence, and justice. In addition, three principles are important to the patient-professional relationship: veracity, confidentiality, and fidelity. Veracity, or truth telling, is a requirement for mutual trust. The patient expects the professional to be honest and the professional expects the patient to be truthful and open about concerns, attitudes, and information regarding his or her health and mental status. The role of truth-telling is a part of the definition of the principle of fidelity. Fidelity refers to being faithful to duties and obligations. Although both truth-telling and fidelity seem obviously to be at the heart of the professional-patient relationship, the complexity of many medical interactions makes implementation of these not so straightforward. This is especially evident when one considers the principle of confidentiality. This principle, that professionals may not reveal the confidences entrusted to them in the course of medical attention, has been stated in a variety of codes, including the Hippocratic Oath and the AMA Principles of Medical Ethics. The necessity to preserve fidelity (by telling the truth and maintaining confidentiality) sometimes comes in conflict with the duty to obey laws and be beneficent to all persons. A brief discussion of each of the major principles of autonomy, beneficence, nonmaleficence, and justice will help illustrate some of these ethical problems.

**Autonomy**

The principle of autonomy refers to the right of the individual to self-determination (Beauchamp & Childress, 1983). That is, individuals determine their own course of action and make decisions concerning their own fate. Respect for autonomy, a term also used to describe this principle (English, 1994) is based on the notion of individual liberty. A person’s autonomy refers to the individual’s self-contained ability to make decisions for himself or herself. In contrast, a person with little or no autonomy is dependent on others whether or not he or she is capable of deliberating or acting on his or her own.

Respect for autonomy is one of the most common principles involved in moral dilemmas that face speech-language pathologists who work with patients with degenerative neurologic disease. Although respect for autonomy is one of the fundamental obligations in medical management, it is dependent on the maintenance of the patient’s ability to communicate. Facilitating communication efficiency or providing some means of augmentative communication may allow the patient to retain personal autonomy and the ability to make personal choices about medical care. However, even when communication is maintained and facilitated, the principle of patient autonomy still presents difficult moral dilemmas. This is especially true when faced with the sometimes contrasting principle of beneficence.

**Beneficence and Nonmaleficence**

Autonomy and beneficence have been said to be the conflict at the roots of bioethics (Engelhardt, 1986). Beneficence refers to “doing good,” and implies that positive steps be taken to prevent harm, remove from harm, as well as contribute to another’s welfare. Beauchamp and Childress (1983) state that beneficence is a duty, distinct from kindness and charity, to help others further their legitimate interests. In medical practice, the principle refers to furthering the optimal health interests of the patient.
(English, 1994). Until somewhat recently, beneficence often took precedence over autonomy. The doctor, or health care professional “knew best” and the beneficent decision was made for the patient. In medical practice, it is common for autonomy to come in conflict with beneficence. For example, a patient with a progressive swallowing problem may be advised that a percutaneous endoscopic gastrostomy (PEG) is the most appropriate intervention at a particular time and is in fact necessary for adequate nutrition and hydration. The speech-language pathologist is employing the principle of “beneficence” in the recommendation. The patient may be unwilling to accept the recommendation and choose to continue oral nutrition. In this case, autonomy has taken precedence over beneficence.

Whereas the principle of beneficence includes acts to prevent harm or remove harmful conditions, the principle of maleficence refers to the noninfliction of harm on others. Beauchamp and Childress (1983) consider nonmaleficence to be distinct from beneficence because of the conviction that our duties not to injure someone are distinct from and more stringent than our duties to benefit others. Nonmaleficence encompasses both intentional harm as well as the risk of harm, and the line between them is not always clear. Using the example of the dysphagia patient described above, we see that the principles of autonomy may conflict with beneficence, but also that maleficence comes into play because of the risk of harm.

Justice

The principle of justice is most often explained in terms of “fairness.” In medical ethics, the discussion of justice usually focuses on the distribution of services under a particular moral vision. The focus is on the comparative treatment of individuals given limited resources. Consider the public school clinician who has responsibility for providing treatment to a child who has returned to school following a closed head injury. Both cognitive and motor speech disorders are present, yet prognosis for improvement is excellent. The principles of beneficence and nonmaleficence would dictate that she see the child daily on an individual basis. Given her large caseload, however, that would mean denying, or severely curtailing, services to others. This moral dilemma illustrates that ethical decisions are not easily made.

Respect for autonomy is one of the fundamental obligations in medical management. Maintenance of the ability to communicate is a necessity not only to indicate needs, but to preserve social contact. Further, such ability allows the patient to retain personal autonomy and the ability to make known personal choices about medical care.

Cases

Five cases are presented here to provide opportunities to apply knowledge of the basic principles of medical ethics to situations in which speech-language pathologists often find themselves. These cases might be presented in classrooms, seminaries, staff development meetings, and so forth, to allow students and clinicians an opportunity to think through situations from a slightly different perspective. Following each case is a series of questions to guide discussion. These questions are structured so that one always begins by reviewing the facts of the case. From the facts, one can list issues that pertain to the medical ethics principles described above. For example, in Case 1, listing the facts leads one to determine that the issues involved are the questions regarding the patient’s cognitive competency; the patient’s prior request for no feeding tube, and the current risks to his well-being. This leads to a discussion of the principles of autonomy, beneficence, and maleficence. The principle of autonomy alone would lead to the decision to continue as he has, living alone eating. The principle of beneficence (doing good and preventing harm) would dictate that any necessary steps be taken to prevent probable frequent aspiration. Some would even argue that allowing this patient oral nutrition greatly risks his well-being and, therefore, maleficence is an issue. In each case, it will be clear that these are indeed ethical “dilemmas” because these principles do not fall into a “hierarchy” in terms of their importance. Clinical decisions will often be made only after weighing the consequences of possible solutions. For example, patient autonomy might be preserved while reducing the risks to beneficence if a full-time caregiver would be available to assist feeding and minimize risks. An alternative decision might be that, in this case, beneficence and maleficence outweigh patient autonomy. There are no “right” answers.

Case 1. RL was a 76-year-old man with advanced Parkinson’s disease. He had a moderately severe dysarthria and a history of aspiration pneumonia and weight loss. On admission to the hospital, he denied episodes of choking or other difficulty with swallowing. He lived alone, and had a part-time assistant. Prior to admission, he signed an Advance Directive not to have a stomach tube placed at any stage in his disease. The primary physician felt that he was competent enough to make this decision. The speech-language pathologist, concerned about the recent precipi-
tous weight loss, along with the history of aspiration pneumonia, completed a bedside swallow evaluation. She found the patient had a great deal of difficulty swallowing both thin liquids and some solid food. Further, the patient appeared confused, and had difficulty following directions. This information was presented at rounds.

Questions
1. What are the facts?
2. What other information do you need?
3. How do the principles of autonomy, beneficence, and maleficence come into conflict?
4. How do the facts in this case help you resolve the conflict?
5. What options do you have?

Case 2. PH was a 43-year-old woman with a recent onset of ALS. Her first symptoms were hypernasality and slurring of speech. She had recently been forced to quit her retail job due to decreasing intelligibility. She was married and had an 11-year-old daughter. With multiple visits to the Neuromuscular Speech and Swallowing Disorders Clinic, it became apparent that speech was becoming more labored and more difficult to understand; she was losing weight and her respiratory status was declining rapidly. Although walking was becoming more difficult, she refused to use a wheelchair. In fact, on one clinic visit she arrived an hour late in a tearful and exhausted state having just walked a quarter of a mile from the parking lot. When questioned she indicated that she had not told the parking attendant of her problem and had not asked for parking for the disabled or a wheelchair and assistance because she “thought she could make it.” When she arrived she was so fatigued that she could not participate in the clinic visit. Her husband declined to attend any clinic visit. She indicated, “He thinks I’m faking it and if I were stronger I’d be fighting it.” Although she declined information about augmentative communication systems or alternative feeding procedures, she indicated she wished to live as long as possible because her daughter “needed her so much.” When questioned about these decisions, she indicated that if her husband viewed her as having a disability, “he’d put me in a nursing home.”

Questions
1. What are the facts?
2. Is there other information that you need?

Case 3. NL was a 52-year-old woman 2-months post diagnosis of ALS when she was referred to the outpatient Neuromuscular Speech and Swallowing Disorders Clinic. She had just retired from a job that she enjoyed that required extensive public speaking. She was accompanied to the first clinic visit by her sister who had just lost her husband to cancer. Although NL’s first symptoms were entirely bulbar, she was only mildly dysarthric and denied swallowing difficulty. Both NL and her sister indicated that they knew of the natural course of ALS but that they intended “not to give in to the disease.” NL returned to clinic every 2 months. By the third visit, speech, swallowing and respiratory status had all declined. She was also showing increasing evidence of lability. During the second and third clinic visits the PEG placement was discussed. It was explained that the procedure would facilitate nutrition and hydration as well as conserve her energy. She was told she could eat when she wished, and use the tube to provide needed additional calories and liquid. Also, the timing of the PEG placement was discussed, including the need to carefully monitor respiratory status because poor pulmonary function may prevent PEG placement. Each time the PEG was mentioned she said, “not now, maybe later, I’m not ready.” At the fourth visit (8 months post diagnosis) vital capacity had declined to just over one liter and NL was counseled that a decision about PEG needed to be made soon. Her sister became upset that the team had “waited too long” to ask NL to make a decision and that this wait put NL at some risk. In an hour long tearful meeting, in which NL used a portable typewriting system, NL told the team that she felt “railroaded into an early decision.”

Questions
1. What are the facts?
2. What are the issues?
3. Is there anything the team could or should have done to prevent this situation?
4. What are the principles involved in this case? How might the principles have guided the team in their decision making?

Case 4. TW was a 30-year-old single woman with a diagnosis of Huntington’s disease who was referred to the Neuromuscular Speech and Swallow-
ing Disorders Clinic for evaluation of swallowing difficulty by her family physician. The only information we had when we met her other than her diagnosis was the clinic nurses note that she weighed 94 pounds and was 58” tall. Explanation of her low body weight was clear when we met the patient. She exhibited severe chorea and was essentially in constant motion. The dietitian estimated that her calorie intake was approximately 1900 calories, but that her calorie needs were between 4,000 and 5,000 per day. Her swallow was characterized by lack of coordination, mild to moderate risk of aspiration and difficulty in transport of the food to her mouth. She indicated that eating was a time-consuming activity that she did not particularly enjoy. When alternative means of feeding were discussed, she firmly refused. When threats to health of malnutrition, dehydration, and aspiration were presented, she indicated that she “didn’t have much to live for anyway.”

Questions
1. How do the principles of autonomy and beneficence come into conflict here?
2. What is the role of the speech-language pathologist in this situation?
3. What are your options?
4. What would you tell Susan if you were her supervisor?

References

Additional Readings


