



Ethical Decision-Making in Dysphagia Management

Helen M. Sharp
University of Chicago

Leigh B. Genesen
Loyola University Medical Center, Chicago



Sharp



Genesen

Ethics historically refers to the analysis of moral duties and obligations that guide human behavior. In health care, ethics is applied both to professional behavior, guidelines for which have been described in various codes of ethics, and to clinical care decisions relating to difficult choices in patient management. Ethics in speech-language pathology have traditionally focused on professional concerns, such as certification, fee setting, advertising, allocation of resources, and research issues (ASHA Code of Ethics, 1994; Folkins, Gorga, Luschei, Vetter, & Watson, 1993; Pannbacker, Middleton, & Lass, 1994; Resnick, 1993). However, speech-language pathologists also face clinical ethical dilemmas. These dilemmas commonly involve management decisions for patients with communication and swallowing disorders (Groher, 1990; Segel & Smith, 1995; Serradura-Russell, 1992), yet a framework for resolution of such conflicts has not been adequately described.

Speech-language pathologists have established an important role in the assessment, diagnosis, and treatment of pediatric and adult patients with dysphagia. A recent survey of hospitals and extended care facilities revealed that greater than 50% of speech-language pathologists' caseloads involve the assessment or treatment of feeding and swallowing disorders (Logemann, 1994). Dysphagia evaluations are usually requested by a physician or medical team to determine the safety of patients' swallowing function and their ability to achieve adequate nutrition and hydration via oral feeding. The most common goal of intervention is to facilitate oral feeding using modifications in food texture, patient positioning, and/or the application of various swallow-

ing techniques. Some patients, however, are unable to achieve adequate oral intake or are considered to be at high risk for complications secondary to consistent aspiration. In these circumstances, speech-language pathologists, in conjunction with a physician or medical team, usually recommend an alternate means of nutritional support [e.g., nasogastric (NG) or gastrostomy tubes]. Most patients and their families agree to tube feedings in order to maintain nutrition and/or avoid the complications of aspiration, which may lead to pneumonia, respiratory distress, and sometimes death. This provision of artificially administered fluids and nutrition is usually consistent with both the medical and ethical standards of care. However, some patients and families legitimately refuse artificially administered nutritional support. Some reasons for refusing tube feedings include an unwillingness to forgo the pleasures of oral feeding, perceived discomfort associated with NG or surgically placed tubes, or concerns regarding prolonging suffering by sustaining life. In most cases, the use of a feeding tube is ethically justifiable or may even be obligatory, but as this paper will illustrate, there are cases when it may be optional or even inappropriate.

Ethical dilemmas may arise for speech-language pathologists involved in the clinical management of patients with dysphagia when the attempts to balance the obligation to benefit the patient (*beneficence*) against the obligation to minimize unnecessary harm (*nonmaleficence*) seem to conflict. The role of the speech-language pathologist in facilitating ethical decision-making while maintaining good clinical care may differ from the traditional rehabilitation model and demands consideration of an unfamiliar perspective on dysphagia management.

This paper describes an ethical decision-making model that can be applied by speech-language pathologists, as part of a health care team, to facilitate the resolution of clinical ethical dilemmas. Cases will be presented to illustrate the issues encountered when patients, families, or the medical care team choose nonstandard management options for patients with feeding or swallowing disorders.

Clinical Ethical Decision-Making Model

Ethical dilemmas may arise during the shared decision-making process between the caregiver and patient. Most often, these dilemmas occur because of uncertainty, lack of clarity, or conflict regarding the medical facts, goals of treatment, or different value systems

FIGURE 1. Clinical and ethical decision-making model adapted from Jonsen, Siegler, and Winslade (1992). The figure illustrates the four components of their decision-making model. Most clinical and ethical decisions can be made by balancing the medical indications with the preferences of the patient. These two features have the most weight in ethical decision-making and thus are depicted above external assessments of quality of life and other contextual features.

<p style="text-align: center;">Medical Indications</p> <p>medical history accurate diagnosis accurate prognosis treatment options</p>	<p style="text-align: center;">Patient Preferences</p> <p>personal history religious & personal values expressed preferences advance directives self assessment of quality of life ability to make & communicate decisions</p>
<p style="text-align: center;">Quality of Life</p> <p>external assessment of benefits and burdens subjective judgment who should decide when the patient cannot?</p>	<p style="text-align: center;">Contextual Features</p> <p>economic—insurance, availability, cost family preferences legal issues burdens on caregivers</p>

(Jonsen, Siegler, & Winslade, 1992). The use of a systematic framework for identifying and negotiating these differences can assist in resolving clinical ethical problems. Several models for ethical decision-making have been adopted in clinical medicine (Jonsen et al., 1992; Robbins, 1984; Smith, Churchill, & Frey, 1986; Thomasma, 1978). We will focus on one model that was designed for practical application to a variety of clinical situations encountered by members of medical care teams and is applicable to the practice of speech-language pathology. The model is summarized in Figure 1 and involves the examination of four aspects of clinical problems: medical indications, patient preferences, quality of life, and contextual features (Jonsen et al., 1992).

Medical Indications encompass the medical facts of the case, including certainty of diagnosis, prognosis, and the various medical management options available. Medical indications are considered to be the most critical aspect of good ethical decision-making in this model as in others, because without accurate facts all further discussions regarding goal-setting become meaningless. It is particularly important to differentiate potentially reversible from irreversible or even progressive swallowing dysfunction. For example, a patient with a swallowing disorder seen 4 days following a stroke might be expected to improve over time, whereas a patient with a permanent structural anomaly (see Case 1) might be considered to have an irreversible swallowing disorder. The ethically acceptable treatment options may be determined based on the potential reversibility of a disease or disorder.

Patient Preferences consider the patient's values, religious beliefs, and goals of treatment

and require an accurate understanding of the medical facts as presented by the physician or care team. Patients may express their wishes in conversation with their clinicians or they may elect to document their preferences in writing. Patients may also use formal statements of their preferences, known as *advance directives*. There are several types of written advance directives, but the two most commonly used are a Living Will and a Durable Power of Attorney for Health Care. A Living Will is a written request to forgo certain treatments in the event of a terminal and irreversible condition. A Durable Power of Attorney for Health Care allows a patient to name someone to make decisions on his or her behalf should he or she lose the capacity to make decisions. Determining a patient's preferences is critical to good ethical decision-making, based on the principle that patients have the moral right to make decisions which affect their care.

Quality of Life is perhaps the most difficult term to define because it is a subjective notion characterizing what makes one's life worth living. This broad definition encompasses such complex concepts as changing perspectives with experience, and the influence of psychosocial, cognitive, and religious or other spiritual influences. When a patient cannot express his or her wishes, identifying who should make quality of life judgments and what clinical decisions are justified by reference to a quality of life standard can be extremely difficult (Jonsen et al., 1992). Nevertheless, for dysphagic patients, quality of life considerations are often the source of questions that necessitate ethical analyses.

Contextual Features include a variety of issues that may or may not become important in a

particular case, including social factors, cultural differences, financial issues, legal considerations, institutional policies, family preferences, and the burdens of care on the care providers.

Medical indications and patient preferences are usually the basis on which medical and ethical decisions are made and therefore are considered to be of higher priority than quality of life and contextual features. In fact, when both medical indications and patient preferences are clear, ethical conflicts rarely arise, because a well informed, competent adult patient almost universally has the right to accept or refuse a proposed recommendation (President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1983). More often, in ethical conflicts, the medical diagnosis or prognosis and/or patient preferences are unclear or unknown. In these cases, quality of life and contextual features become critical in both defining and resolving the ethical conflict.

Application of the Decision-Making Model to Patients With Dysphagia

The following three cases are based on our experiences in a hospital setting. These cases illustrate many of the concepts of ethical decision-making that can be applied to other clinical settings.

Case 1

JW is a 35-year-old male with a self-inflicted gun shot wound to the neck. The injury resulted in cervical spine injury and quadraparesis with significant structural damage to the larynx and surrounding structures. The patient has a tracheostomy and intermittently requires mechanical ventilation. He is referred for assistance with communication and a swallowing evaluation secondary to multiple pneumonias. JW is successful in communicating using eye gaze or an electrolarynx, but he is unable to establish laryngeal voicing with the use of a Passy-Muir valve (a one-way valve, which permits airflow through the tracheostomy, but then closes on exhalation to force airflow upward through the larynx, thus allowing vocal function for speech). Laryngeal damage is found to be irreversible on assessments by otolaryngology. JW aspirates on all food consistencies during several clinical or "bedside" assessments of his swallowing. He has a tracheostomy, so the presence and extent of aspiration is easy to observe clinically. JW is difficult to transport and has poor sitting tolerance, so a gastrostomy tube is recommended without the benefit of a

videofluoroscopic study. JW refuses to consent to surgery and insists if he cannot eat by mouth he would prefer to die. JW and his family demonstrate an understanding of the risks of aspiration and the potential complications and state that they wish to continue with oral feedings.

Analysis of Case 1

The medical indications and patient preferences are clear in this case, but the patient's and team's goals of management are in conflict. Further, respect for JW's preferences may differ from the team members' personal and/or professional moral standards. A review of all treatment and nontreatment options is useful in order to consider the feasibility of JW's request:

1. Provide nutrition via gastrostomy tube with nothing by mouth.
2. Use a gastrostomy tube together with small amounts of relatively safe food consistencies taken orally.
3. Provide oral feeding with or without supplemental NG tube feedings as needed.

This case requires balancing the medical goals of life prolongation with the patient's expressed goal of maintaining oral feedings as an aspect of his quality of life. It is important to consider patient autonomy and decision-making capacity in order to determine the appropriate balance between the conflicting goals of the optimal medical treatment model and quality of life as assessed by the patient.

Autonomy refers to a patient's right to self-determination and maximization of independence in medical decision-making (Beauchamp & Childress, 1989). It has been well established that competent adult patients have the right to consent to or refuse any medical interventions, including life-sustaining treatments (President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1983). An adult patient's ability to consent to or refuse treatment rests on a clinical determination of his or her competence to make these decisions. *Mental competence* is a legal consideration, typically used by the courts with regard to level of function for all aspects of daily living, including financial management. Clinically, decision-making capacity is more often considered. *Decision-making capacity* refers to the patient's ability to make specific decisions regarding his or her own current or future medical care and can be determined clinically without involving the court system. The practical aspects of determining decision-making capacity may vary depending on the

nature of the question, the patient's tolerance to prolonged conversation, or the patient's ability to communicate. Jonsen and colleagues (1992) suggested the following criteria for establishing a patient's medical decision-making capacity: (a) the ability to understand and interpret the medical information being presented along with the options for treatment and consequences of each choice, (b) the ability to make and communicate a choice, and (c) the ability to use a rational thought process in considering personal values as they relate to the treatment options being presented.

In JW's case, decision-making capacity might be questioned because the injury was self-inflicted. The patient was receiving psychiatric care and medication for depression at the time of his evaluation. In this circumstance, the patient's psychiatrist should be consulted with regard to the patient's current status for medical decision-making and presence or absence of depression or suicidal ideation (Sullivan & Youngner, 1994). For patients who lack decision-making capacity, a process of surrogate decision-making is initiated by first determining the appropriate decision-maker(s). Issues regarding incompetent patients and surrogate decision-making will be illustrated by Cases 2 and 3.

If medical decision-making capacity is established, decisions to accept or refuse almost every aspect of medical care must be respected. However, some physicians may try to override a patient's refusal in a situation in which the risks of a treatment are extremely low and the potential benefits are considered to be very high (Jonsen et al., 1992). In this case, overriding the patient's refusal of feeding tube placement would be difficult to justify, based on the risks of surgery together with the uncertainty of achieving elimination of aspiration by using tube feedings. Aspiration has been reported in 10–58% of nursing home patients with gastrostomy tubes and in 47% of patients with NG tubes (Ciocon, Silverstone, Graver, & Foley, 1988; Cogen & Weinryb, 1989; Olivares, Segovia, & Revuelta, 1974; Patel & Thomas, 1990). The sources of aspiration with a feeding tube include: reflux, improper NG tube placement, or continued primary aspiration (e.g., the patient may aspirate his or her own saliva or other secretions). The data are based on studies of elderly patients and do not address the risks for younger persons requiring tube feedings or the possibility that at least some of the patients may have had aspiration related to continued oral feeding. However, the data do suggest that the risks for aspiration and subsequent complications are not eliminated through the introduction of feeding tubes.

Assuming that JW demonstrates decision-making capacity and an appropriate understand-

ing of the risks and benefits of all treatment choices, then his argument that eating is one of his only pleasures would probably be compelling, and with evident family support of his decision, should probably lead to the continuation of oral feedings. Patient preferences, in the case of a rational adult with decision-making capacity who is refusing an intervention, outweigh medical indications and the management preferences of the team, especially when the medical treatment options provide uncertain benefit.

The role of the speech-language pathologist in management of a patient known to aspirate is challenging because the goals of intervention may change from those of traditional dysphagia management, which maximize life prolongation, to the goals of palliation and maximization of quality of life, even at the risk of reducing potential life expectancy. Ideally, the speech-language pathologist, patient, family, and medical team will continue to work together to facilitate the safest possible oral feeding program. The speech-language pathologist may provide ongoing treatment services, diet modifications, and other recommendations. At a minimum, the speech-language pathologist should monitor the patient with the medical team. Many speech-language pathologists may feel uncomfortable feeding a patient who aspirates, and they may worry about legal liability. Although specific legal advice is beyond the scope of this paper, a clinician's discomfort may be reduced by consulting with a clinical ethicist and/or with risk management personnel. However, for some clinicians, encouraging oral feeding in a known aspirator may violate a personal moral conviction and prevent further involvement in a therapeutic relationship. In this case, the speech-language pathologist may elect to discharge the patient from his or her care, but has a continued responsibility to notify the patient and must attempt to identify another speech-language pathologist willing to provide treatment services. It may be appropriate to continue to counsel the patient and acknowledge his right to alter his decision in the future. Additional considerations with regard to medical management involve the entire medical team and include "do not resuscitate" status in the event of choking or respiratory failure and decisions regarding treatment or nontreatment of aspiration pneumonias.

Case 2

BJ is a 9-month-old infant referred for a feeding evaluation secondary to inadequate oral intake. He has a history of multiple pneumonias and gangliosidosis (Tay-Sachs disease), a metabolic disorder leading to rapid, progressive neurologic decline and death.

A clinical or “bedside” swallowing evaluation is inconclusive, and a videofluoroscopic study of his swallowing mechanism is requested. BJ is found to be a nonfunctional oral feeder, and the medical team recommends placement of a gastrostomy tube.

The infant’s mother is reported to have expressed a desire to take her baby home to “die with dignity,” and had previously refused alternate nutritional support via NG tube. Her stated goal is to reduce any pain and suffering associated with the baby’s imminent death.

Analysis of Case 2

Pediatric cases require a modified ethical analysis because the patient preferences cannot be established. In an effort to accommodate the mother’s goal of death with dignity and the medical team’s goal of maintaining nutritional support during the dying process, a review of the management options is necessary:

1. Gastrostomy tube with or without fundoplication (fundoplication is a procedure designed to reduce or eliminate reflux by tightening the lower esophageal sphincter).
2. NG tube feedings.
3. Intervention by an occupational therapist and/or speech-language pathologist to facilitate oral feedings.
4. No intervention and discharging the patient to the mother’s care with oral feedings as tolerated by the patient.

In this case, the patient has never had decision-making capacity. Therefore, a *surrogate decision-maker*, who can act on behalf of the patient, must be identified. Selection of an appropriate surrogate is usually uncomplicated and typically a legal surrogate is only necessary when conflicts arise between family members or care providers with equal interests in the patient’s well-being.

For children, parents are almost always considered the appropriate surrogates. In Case 2, the mother appears to be the logical surrogate, but it is beneficial to involve the patient’s father as well as additional supportive family members in the decision-making process. As surrogates, the parents play a particularly important role in decision-making for this infant because the diagnosis and dismal prognosis are certain. If the baby had a good chance to live and recover, it is possible that a parental decision not to provide fluids and nutrition may be overridden. Surrogate decision-making rights have tended to be more restrictive for children because the state maintains an interest in protecting children and

other vulnerable individuals (Holder, 1983; *In Re E.G.*, 1989; *In Re Green*, 1972; *In Re Sampson*, 1972). In the U.S., each state has developed specific statutes permitting the state to override parental decisions to refuse medical treatment when nontreatment will likely result in serious harm to the child, and the treatment is clearly beneficial (Holder, 1983).

Part of the resolution in managing BJ is acknowledging that he is imminently dying. As such, the goals for a dying patient often shift from the traditional medical goals of life prolongation to support during the dying process. Questions then arise as to the appropriate use of available medical technologies that might allow us to postpone this infant’s death (Cranford, 1991). In the face of parental refusal, forcing life prolongation in an infant who is terminally ill is most often inappropriate. However, many clinicians are uncomfortable with the notion of “starving patients to death.” Caregivers and medical professionals have historically provided artificially administered fluids and nutrition to most patients, in some cases including those with no hope of recovery (*In Re Requina*, 1986). The reasons for doing so are complex, but include a presumed obligation to provide food and water and the relative simplicity of doing so for patients who are unable to eat on their own (Callahan, 1983; Meilaender, 1984). The uneasiness of caregivers regarding withholding fluids and nutrition from patients most often stems from the assumption that “starving” is associated with pain and discomfort. In fact, reports of dying adults indicate that as long as good oral care is continued, the termination of nutrition and hydration appears to result in increased comfort when compared with those patients in whom hydration alone is maintained (McCann, Hall, & Groth-Juncker, 1994; Printz, 1988; Schmitz, 1991; Zerwekh, 1983). These reports, together with an understanding of the sedative and anaesthetic effects of dehydration, challenge the notion that maintenance of fluids and nutrition is always in the best interests of the dying patient (Dresser & Boisubin, 1985; Groher, 1990; Quill, 1989).

Artificially administered fluids and nutrition may be considered as would any life sustaining treatment such as ventilators or dialysis (Lynn & Childress, 1983). Considering artificial fluids and nutrition as medical treatment together with the data regarding patient comfort makes the decision to withhold or withdraw fluids and nutrition an ethically justifiable option in some cases.

The infant’s mother expressed her wish to avoid tube feedings so that BJ may die “with dignity.” For her, this request eliminates both gastrostomy and NG tube feedings. For this fragile infant, the burdens of feeding tube

placement are significant, with probable minimal benefits given the rapid, progressive decline associated with his disease. If the parents are able to state an understanding that the decision to forgo tube feedings may result in an earlier death, then in this circumstance of an infant who is imminently dying and who is perceived to be suffering, the parents' decision ought to be respected.

Case 3

AD is a 20-year-old male with Cornelia deLange syndrome, a congenital disorder delineated by severe mental retardation, short stature, growth failure, and a characteristic facial appearance (Jones, 1988). He was admitted to the hospital with pneumonia and dehydration and is referred for a feeding evaluation secondary to poor oral intake. AD demonstrates poor oral-motor control for bolus manipulation, including anterior leakage of liquids and habitual use of a backward head tilt to move thicker consistencies posteriorly to be swallowed. A weak, wet cough following 3 to 5 bolus presentations is observed.

A videofluoroscopic study shows severe oropharyngeal dysphagia including reverse pharyngeal peristalsis and multiple swallows (as many as 12) to clear less than one-half teaspoon volumes of puree. Minimal aspiration and subsequent clearance with cough or throat clear is observed with small volumes of puree, but consistent aspiration with an inconsistent cough response is seen with thin liquids.

AD is not considered to be a candidate for the introduction of dysphagia treatment techniques because he is unable to follow simple directions secondary to his mental retardation. AD has no means of formal communication; however, he is able to express pleasure through smiling and laughing. His foster care providers are aware of his food likes and dislikes.

AD was being fed exclusively orally prior to this admission. He is reported to self-feed at home for 1 to 2 hours per meal. Based on the summary of findings, it is suggested that he receive nutritional support via NG or gastrostomy tube and that small volumes of puree (50 cc or less) be provided during mealtimes for socialization and pleasure.

The team was notified that the placement of a feeding tube would alter the care requirements for the patient. For licensure purposes, the patient would be placed in a medical foster facility, rather than the foster home he had lived in for 8 years. AD's foster family resists feeding tube placement on learning of the change in his placement.

Discussion of Case 3

Patient preferences cannot be determined directly in this case. The medical indications for AD are complex, because the selection of a treatment plan could affect not only his medical status, but also his quality of life and other social or contextual features. Thus, an ethical analysis is indicated for decisions regarding treatment goals and recommendations. Options include:

1. Gastrostomy tube with or without fundoplication, nothing by mouth.
2. Gastrostomy tube feedings for nutritional support with small volumes of puree for pleasure.
3. NG tube feedings with or without oral feeding for pleasure.
4. Continued oral feedings.

Options (1), (2), and (3) would require that AD move to medical foster care and unfamiliar care providers, whereas option (4) would allow AD to remain in his current living situation.

AD is not able to participate in the decision-making process. Nevertheless, he has interests that ought to be considered. Identification of the appropriate surrogate is difficult in this case. Attempts to contact the patient's biological parents were unsuccessful. The insight contributed by the long-standing caregiver, who knows AD well and appears to be acting in his best interests, bears significant moral weight, but as a ward of the state, this patient was assigned a court appointed guardian who had no prior knowledge of him.

When the situation arises in which a patient is unable to express his wishes, and the legal surrogate has minimal knowledge of him, the medical team has a special obligation to consider the patient's interests in making treatment recommendations. This process of interpreting the patient's *best interests* is the method of moral reasoning used only when a patient is unable to participate in decision-making, and the surrogate decision-maker has no basis on which to interpret what the patient would have decided for himself. Deciding what is in a person's best interest requires an assessment of the person's overall welfare, the weighing of the benefits and burdens of each treatment option, and considerations of length and quality of life.

Quality of life assessments consider the patient's physical, social, and mental performance together with prognosis (Jonsen et al., 1992). In this case, it is critical to consider the patient's ability to experience pain and pleasure, but care must be taken to avoid bias

regarding one's own individual attitudes and interpretations of AD's situation. The medical team is responsible for interpreting the medical and social aspects of quality of life for each treatment option and making an appropriate recommendation for AD.

If the goal of treatment is life prolongation, it would best be met by the most aggressive intervention of gastrostomy tube placement with fundoplication. A permanent feeding tube seems optimal for the medical management of AD as he does not demonstrate the capacity for functional oral feeding and is not a candidate for dysphagia treatment. However, surgical placement of a gastrostomy tube has associated risks and discomfort, as have been discussed for Cases 1 and 2. An NG tube was used during the hospitalization and physical limb restraints were required in order to maintain it. Gastrostomy or NG tube use would require a significant change in living arrangements and care providers for AD, who has the capacity to recognize familiar surroundings. For this particular patient, the benefits of life prolongation appear to be outweighed by the burdens of restraints, pain, and discomfort together with a change in environment.

Similarly, the decision whether to allow or prohibit the provision of oral feedings for this patient requires consideration of the benefits of pleasure and socialization versus the burden of aspiration and probable pneumonia. In order to sustain nutritional intake, multiple small meals with lengthy mealtimes allowing for multiple swallows and delayed clearance will be required. AD's foster parent reported prehospitalization mealtimes of 1 to 2 hours and indicated the ability to provide similar care on discharge.

Although life prolongation could be achieved for this patient, the interpretation of quality of life considering the benefits and burdens of the treatment options would tend to favor the continuation of oral feeding with a return to the patient's foster family, understanding that the length of AD's life may be shortened. In this case, we support forgoing artificially administered fluids and nutrition and instead providing education regarding food textures, use of thickened liquids, pacing of bolus presentation, and positioning, which could contribute to the goal of life prolongation while allowing the benefits of a familiar environment with pleasurable feedings.

Discussion

The cases we have reported are illustrative of some of the ethical dilemmas commonly experienced in the clinical management of

patients with dysphagia. We specifically chose not to address a case in which a team might override a patient's or family's decision. We elected not to do so for three reasons: first, the purpose of this paper is to illustrate the importance of respecting a patient's preferences, even when we do not agree with their choices. Second, it is rarely the case that it is appropriate to override a patient's or family's wishes, in any area of health care. There are exceptionally few circumstances in which overriding a refusal of tube feedings might be appropriate. Finally, the topic of overriding patients' decisions is a complex one and involves an extensive legal literature. This subject could be the focus of future discussions in clinical ethics as applied to speech-language pathology.

The cases we chose illustrate extremely difficult issues and address questions with no easy answers. Our analyses are offered to demonstrate the process of ethical decision-making in the three specific cases described and are not meant as imperative resolutions. Each case is discussed in light of current ethical theory and practice. The reader should be aware that medical, ethical, and societal views regarding difficult choices surrounding death and dying are constantly evolving. Clearly, the alteration of circumstances, such as severity of dysphagia, certainty of prognosis, or the availability of family members could significantly change any conclusions and subsequent management of a patient.

Optimally, the care team, patient, and family will be able to resolve most dilemmas. However, some cases present troubling questions that may best be handled by a trained clinical ethicist. A clinical ethicist can make recommendations regarding the ethically justifiable and unjustifiable treatment options for a particular case, offer information regarding institutional policies and procedures, and facilitate conflict negotiation between patients, families, and/or care team members. An ethics consultant or committee should be able to enhance ethical analyses of these challenging issues.

The ongoing development and implementation of clinical ethics models adapted to the field of speech-language pathology should help promote optimal clinical care for people with communication disorders and dysphagia.

Acknowledgments

The authors gratefully acknowledge the assistance of Robert Orr, Sharon Fraser, and Gary Fraser of Loma Linda University Medical Center for their helpful suggestions during earlier drafts of this manuscript.

The MacLean Center for Clinical Medical Ethics

at the University of Chicago is supported by grants from the Dorothy J. MacLean Family, the Henry J. Kaiser Family Foundation, the Andrew W. Mellon Foundation, and the Pew Charitable Trusts.

References

- American Speech-Language-Hearing Association.** (1994, March). Code of ethics: Issues in ethics. *Asha*, 36(Suppl. 13), pp. 1–27.
- Beauchamp, T. L., & Childress, J. F.** (1989). *Principles of biomedical ethics*. New York: Oxford University Press.
- Callahan, D.** (1983). On feeding the dying. *Hastings Center Report*, 13(5), 22.
- Ciocon, J. O., Silverstone, F. A., Graver, L. M., & Foley, C. J.** (1988). Tube feedings in elderly patients. *Archives of Internal Medicine*, 148, 429–443.
- Cogen, R., & Weinryb, J.** (1989). Aspiration pneumonia in nursing home patients fed via gastrostomy tubes. *American Journal of Gastroenterology*, 84(12), 1509–1512.
- Cranford, R. E.** (1991). Neurologic syndromes and prolonged survival: When can artificial nutrition and hydration be forgone? *Law, Medicine & Health Care*, 19(1–2), 13–22.
- Dresser, R. S., & Boisubin, E. V.** (1985). Ethics, law, and nutritional support. *Archives of Internal Medicine*, 145, 122–124.
In Re E.G., a minor, 113 Ill.2d 98, 549 N.E.2d 322 (1989).
- Folkens, J. W., Gorga, M. P., Luschei, E. S., Vetter, D. K., & Watson, C. S.** (1993, April). The use of non-human animals in speech, language, and hearing research. *Asha*, pp. 57–65.
In Re Green, 292 A.2d 387 (S. Ct. Pa. 1972).
- Groher, M. E.** (1990). Ethical dilemmas in providing nutrition. *Dysphagia*, 5, 102–109.
- Holder, A. R.** (1983). Parents, courts, and refusal of treatment. *Journal of Pediatrics*, 103(4), 515–521.
- Jones, K. L.** (1988). *Smith's recognizable patterns of human malformation*. Philadelphia: Saunders.
- Jonsen, A. R., Siegler, M., & Winslade, W. J.** (1992). *Clinical ethics*. New York: McGraw-Hill.
- Logemann, J. A.** (1994). Evaluation and treatment of swallowing disorders. *American Journal of Speech-Language Pathology*, 3(3), 41–44.
- Lynn, J., & Childress, J. F.** (1983). Must patients always be given food and water? *Hastings Center Report*, 13(5), 17–21.
- McCann, R. M., Hall, W. J., & Groth-Juncker, A.** (1994). Comfort care for terminally ill patients: The appropriate use of nutrition and hydration. *Journal of the American Medical Association*, 272(16), 1263–1266.
- Meilaender, G.** (1984). On removing food and water: Against the stream. *Hastings Center Report*, 14(6), 11–13.
- Olivares, L., Segovia, A., & Revuelta, R.** (1974). Tube feeding and lethal aspiration in neurological patients: A review of 720 autopsy cases. *Stroke*, 5(5), 654–657.
- Pannbacker, M. H., Middleton, G. F., & Lass, N. J.** (1994). Ethics education for speech-language pathologists and audiologists. *Asha*, 36, 40–43.
- Patel, P. H., & Thomas, E.** (1990). Risk factors for pneumonia after percutaneous endoscopic gastrostomy. *Journal of Clinical Gastroenterology*, 12(4), 389–392.
- President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research.** (1983). Deciding to forgo life-sustaining treatment. Washington, DC: U.S. Government Printing Office.
- Printz, L. A.** (1988). Is withholding hydration a valid comfort measure in the terminally ill? *Geriatrics*, 43(11), 84–88.
- Quill, T. E.** (1989). Utilization of nasogastric feeding tubes in a group of chronically ill, elderly patients in a community hospital. *Archives of Internal Medicine*, 149, 1937–1941.
In Re Requina, 425, 517 A.2d 886 (NJ Superior Court 1986).
- Resnick, D. M.** (1993). *Professional ethics for audiologists and speech-language pathologists*. San Diego: Singular.
- Robbins, D. A.** (1984). The caregivers' personal concerns. In T. A. Rando (Ed.), *Grief, dying and death* (pp. 420–430). Champaign, IL: Research Press.
In Re Sampson, 29 N.Y.2d 900, 278 N.E.2d 918 (1972).
- Schmitz, P.** (1991). The process of dying with and without feeding and fluids by tube. *Law, Medicine & Health Care*, 19(1–2), 23–26.
- Segel, H. A., & Smith, M. L.** (1995). To feed or not to feed. *American Journal of Speech-Language Pathology*, 4(1), 11–14.
- Serradura-Russell, A.** (1992). Ethical dilemmas in dysphagia management and the right to a natural death. *Dysphagia*, 7, 102–105.
- Smith, H. L., Churchill, L. R., & Frey, J. J.** (1986). Teaching ethics. In W. C. McGaghie & J. J. Frey (Eds.), *Handbook for the academic physician* (pp. 358–372). New York: Springer-Verlag.
- Sullivan, M. D., & Youngner, S. J.** (1994). Depression, competence, and the right to refuse lifesaving medical treatment. *American Journal of Psychiatry*, 151(7), 971–978.
- Thomasma, D. C.** (1978). Training in medical ethics: An ethical workup. *Forum in Medicine*, 1, 33–36.
- Zerwekh, J. V.** (1983). The dehydration question. *Nursing*, 1, 47–51.

Received January 3, 1995
Accepted October 17, 1995

Contact author: Helen M. Sharp, MS, MacLean Center for Clinical Medical Ethics, University of Chicago, MC 6098, 5841 South Maryland Avenue, Chicago, IL 60637

Key Words: ethics, decision-making, dysphagia, swallowing disorders, speech-language pathology