Medical and Ethical Aspects of Long-term Enteral Tube Feeding

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Clinicians frequently care for patients in whom long-term enteral tube feeding is being considered. The substantial increase in the use of endoscopically placed tubes for long-term feeding reflects the aging population, advances in medicine and technology, and inadequate advance care planning. Physicians should address advance care planning with all patients at the earliest opportunity. Prospective randomized trials measuring clinical outcomes in patients receiving long-term tube feeding are understandably limited. In addition, confusion regarding medical and ethical guidelines for long-term tube feeding often exists among clinicians, patients, and surrogate decision makers. Therefore, we discuss the physiology and clinical tolerance of limited oral nutritional intake, the prevalence of an indications for long-term tube feeding, the endoscopic procedures and their complications, the reported medical and quality-of-life outcomes, and the clinical importance of advance care planning. We present our multidisciplinary approach that combines medical, nutritional, and ethical principles for the care of these patients.


AD = advance directive; NSS = Nutrition Support Service; PAS = physician-assisted suicide; PEG = percutaneous endoscopic gastrostomy; PEJ = percutaneous endoscopic jejunostomy; QOL = quality of life

Recent national attention on the use of long-term enteral tube feeding has sparked intense interest in this treatment and in the importance of advance care planning. The escalation in use of long-term tube feeding results from the aging population, advances in medicine that extend life, technical innovations for enteral access, and requirements by many nursing homes for permanent tube feeding access for residents unable to swallow safely. Misperceptions persist among clinicians, patients, and family members regarding the clinical tolerance of limited nutrition and hydration in terminally ill patients, the risks and benefits of long-term tube feeding, and the ethical issues related to these treatments. In this article, we address the physiology and clinical tolerance of limited intake of nutrition and hydration. We review the prevalence of, indications for, and alternatives to long-term tube feeding, as well as its risks and benefits. Endoscopic enteral access procedures and their complications are highlighted because this information can help patients and surrogate decision makers with decisions related to use of long-term tube feeding. We discuss our approach by applying nutritional and ethical principles to case vignettes representing commonly encountered patient situations. The relationships and communication among patients, family members, and clinicians are key. Finally, we review the ethical issues related to these treatments and highlight the importance of advance care planning to best honor each person's health care values and goals, cultural perspectives, and spiritual beliefs.

The decision to choose artificial nutrition and to give up tasting and enjoying food with others is emotionally charged. Food carries a symbolic importance for patients and their families. Helping someone to eat can be an important nurturing act, and use of artificial nutrition limits this opportunity. Family members associate food with health and often relate more readily to nutritional issues than to other complex medical information. They report a sense of urgency and responsibility for initiating the patient's nutritional care and fear that lack of nutrition will lead to starvation.1

BIOLOGY OF ANOREXIA AND RESTRICTED NUTRITIONAL AND FLUID INTAKE

Many sick patients want to eat but are unable because of anorexia, nausea, altered smell or taste, dysphagia, and/or depression. Anorexia often accompanies illness, in part due to cytokine-mediated decrease in volitional food intake. In elderly patients, anorexia related to illness may be superimposed on what has been termed the anorexia of aging. This physiological decline in food intake is attributed to reduced physical activity and body composition changes characterized by relative increases in body fat and decreases in skeletal muscle. The Third National Health and Nutrition Examination Survey cross-sectional study of persons between 20 and 80 years of age found an average decrease in daily energy (caloric) intake of 5527 kJ (1321 kcal) in men and 2632 kJ (629 kcal) in women.2 Physicians often are asked what level of energy intake is adequate for elderly hospitalized patients; an average daily intake of 4184 to 5021 kJ (1000-1200 kcal) is generally sufficient short-term.

The consequences of fasting have been studied in persons fasting for therapeutic, religious, or political reasons.3,4
The key physiological adaptation to starvation is the shift of energy substrate from carbohydrate to fat. Initially, changes in hormones and substrates maintain glucose homeostasis to meet the brain’s requirement for glucose as a fuel while conserving protein stores. Starvation leads to a decrease in insulin and glucose serum concentrations and to an increase in glucagon levels. These changes stimulate release of free fatty acids and amino acids for metabolic functions and gluconeogenesis. The gluconeogenic response to starvation occurs at the expense of increased protein metabolism and is a temporary adaptive response. As fasting extends beyond a week, energy requirements are met by a shift to fat metabolism by most body organs and by increased ketone use by the brain.

Elevated ketone levels act as a signal to decrease amino acid metabolism and hepatic gluconeogenesis. The reduced use of amino acid substrate lessens the urea load to the kidneys, which decreases urinary volume to a level that can be met almost completely by the water produced through fat metabolism. Starvation leads to decreases in cortisol secretion and to the peripheral conversion of thyroxine to triiodothyronine, with a subsequent increase in metabolically inactive reverse-triiodothyronine. These changes lead to decreases in the metabolic rate and in the degree of proteolysis required to support the body’s energy requirements.

Insight regarding the timing of death due to lack of nutrition and hydration has been drawn from persons undergoing voluntary fasts, such as the Irish Republican hunger strikers. In these healthy young men who ingested only water, death occurred in approximately 60 days (mean, 61±2 days), in agreement with the estimated time that they would lose all their body fat but only one third of their lean tissue. Clinical experience suggests that ill persons can survive for approximately 2 weeks if completely deprived of food and water.

Understandably, patients and family members often are concerned about the potential for suffering due to limited intake of food and fluids. The increase in circulating ketones observed during prolonged periods of energy deprivation is associated with a significant reduction in appetite. Terminally ill patients achieve adequate hydration with much lower volumes than recommended for healthy persons. Clinicians experienced in the care of terminally ill patients report that conscious persons with advancing terminal illness generally do not experience hunger or thirst and that those who do are satisfied by small amounts of food or fluid or even with moistening of the mouth. A survey of hospice nurses found that voluntary dehydration by patients resulted in a peaceful death that typically occurred within 2 weeks of stopping food and fluid intake. Reports of human experiences with fasting for spiritual reasons document preservation of mental function and alertness without suffering. Physicians should reassure patients and family members that, for those with terminal illness, generally it is the underlying disease, rather than the lack of nutrition, that leads to death.

**LONG-TERM TUBE FEEDING**

**DEFINITION, INDICATIONS, AND FEEDING SITE**

Artificial nutrition includes parenteral (intravenous) nutrition and tube feeding (eg, nasoenteric, gastrostomy, and jejunostomy tubes). Tube feeding should be considered for patients with a functioning gastrointestinal tract who cannot or will not eat. Tube feeding has physiological advantages, has fewer complications, and is less costly than parenteral nutrition. Also, physicians, patients, and families perceive tube feeding as less invasive. A soft, small-diameter nasoenteric tube should be placed in patients who have a short-term (<4-6 weeks) requirement for tube feeding. Long-term access for tube feeding is recommended typically for patients needing tube feeding for 4 to 6 weeks or longer, as suggested by the American Gastroenterological Association. Tube feeding can be delivered into the stomach or small bowel. Gastric, rather than jejunal, feeding should be used when possible. Gastric delivery allows intermittent feeding 3 to 4 times daily, resulting in a more physiological hormone profile. An infusion pump is not required for gastric feeding. Jejunal feeding should be considered for patients with tube feeding-related aspiration, clinically important gastrointestinal mobility disorders producing intolerance of nasogastric feeding, gastroesophageal reflux, insufficient stomach from previous resection, or for those who require feeding distal to an obstruction. Jejunal feeding requires continuous infusion by pump, which may limit patient mobility. Jejunal administration of medications can pose issues for medications that are activated in the stomach or that are absorbed more proximally.

**PREVALENCE**

Permanent placement of feeding tubes can be done endoscopically, radiologically, or surgically. Percutaneous endoscopic gastrostomy (PEG) tube placement, introduced in 1980, has become the method of choice for administering long-term tube feeding. Placement of PEG tubes has increased substantially. Although exact numbers differ, approximately 61,000 PEG tubes were placed in 1988, and 121,000 were placed in 1995; 30% of patients receiving these PEG tubes had dementia. These numbers reflect only PEG tubes placed in hospitalized patients and do not include PEG tubes placed in outpatients or in Medicare beneficiaries who have health maintenance organization–based insurance plans. The estimates include...
the number of nasoenteric tubes or gastrostomies and jejunostomies that are surgically placed for long-term tube feeding.\textsuperscript{16,17}

**Endoscopic Procedures and Complications**

For the PEG procedure, conscious sedation is administered, and endoscopy is performed with the patient supine. The endoscope is passed, and the stomach is filled with air to keep the stomach near the abdominal wall. This is important to ensure that when the stomach wall is punctured, there is minimal opportunity for gastric contents to leak into the peritoneum. The endoscope light is directed anteriorly to produce a red glow (skin transillumination) that can be seen on the abdomen. This allows the gastroenterologist to rule out the presence of blood vessels or a loop of bowel in the path created for the PEG tube. When a suitable abdominal skin site is chosen, the area is coated with povidone-iodine 10\% solution (\textit{United States Pharmacopeia}), and a local anesthetic is administered. A needle is advanced through the skin, and aspiration of air into the syringe confirms passage of the needle into the stomach. Proper needle placement is also confirmed by the endoscopist. A skin incision of 0.5 to 1.0 cm is made over the selected site, and a trocar is passed through the incision into the stomach. Nylon thread is passed through the trocar into the stomach and grasped with a snare. The thread is then withdrawn along with the endoscope, through the mouth. The PEG tube, typically an 18F to 20F catheter made of silicone or polyurethane, is attached to the thread and pulled through the mouth into the stomach until it exits the abdominal wall. The internal retention bolster should be palpable through the abdominal wall to confirm proper placement. If correct placement is uncertain, the endoscope is reintroduced into the stomach for visual confirmation. PEG tubes are placed successfully approximately 98\% of the time.\textsuperscript{18} Tube feeding usually can be initiated 4 hours after uncomplicated procedures. Minor complications occur in approximately 10\% of patients and include pain and erythema around the PEG site, bumper-related abdominal wall ulcers, wound infections, peristomal leakage, and tube displacement.\textsuperscript{17,19} Major complications occur in approximately 3\% of patients and include hemorrhage, bowel perforation, fistula, aspiration, and buried bumper syndrome.\textsuperscript{18,20} Buried bumper syndrome results from tight apposition of the PEG tube external bumper against the abdominal skin, and this increased tension leads to erosion of the internal bolster into the abdominal wall. Thus, to minimize this risk, the PEG tube external bumper should be positioned to allow a space of 1 to 2 cm from the skin surface.\textsuperscript{20,21} Procedure-related mortality is extremely unusual; mortality within 24 hours of the procedure usually is related to underlying disease comorbidity.

Endoscopic jejunal access can be achieved by placement of a PEG tube with jejunal extension or by direct percutaneous endoscopic jejunoostomy (PEJ). PEG with the jejunal extension procedure is easier to perform, and because the jejunal (feeding) and gastric (decompression) ports are combined in a single tube, patients requiring gastric decompression do not need another tube to be placed for decompression. However, a major disadvantage is that this method does not permit a stable anchor within the small bowel and the tube is prone to migrate back into the stomach.\textsuperscript{22} To place a PEG tube with jejunal extension, a PEG site is created or the existing PEG tube is used. A jejunal extension tube, varying in diameter from 8.5F to 12F, is inserted through the PEG tube and advanced with endoscopic guidance over a guidewire into the small bowel.

Although randomized prospective data comparing these 2 methods (ie, PEG with a jejunal extension and direct PEJ) are not available, direct PEJ provides a more stable jejunal access and has a lower rate of endoscopic reintervention.\textsuperscript{23} For a direct PEJ procedure, a pediatric colonoscope or small-bore enteroscope is advanced into the jejunum. Once skin transillumination is achieved, the PEJ procedure is similar to the PEG procedure.\textsuperscript{24} Technical success rates range between 72\% and 88\%. Minor complications, such as peristomal infections, enteric ulcers, and leakage, occur in up to 20\% of patients. Complications requiring surgery occur in 2\% of patients and are related to bleeding, abdominal wall abscesses, and colon perforations. There have been case reports of mortality with direct PEJ (as with PEG) tube placement that were related to bleeding. A PEG tube may be placed at the same time for patients requiring gastric decompression. PEG and PEJ procedures should be avoided in patients with ascites. Ascites results in an inadequate seal between the stomach or small bowel and anterior abdominal wall, which could lead to peritonitis due to leakage of tube feeding formula into the peritoneal space.

**Outcomes**

Aspiration is common (25\%-40\%) in patients receiving tube feeding.\textsuperscript{25} The true incidence is difficult to ascertain because of differing definitions, poor detection methods, and varying levels of clinical recognition.\textsuperscript{25} Predicting the rate of progression of individual aspiration events to pneumonia is not possible. Major risk factors for aspiration include previously documented aspiration, decreased level of consciousness, neuromuscular disease, structural abnormalities of the upper digestive tract, endotracheal intubation, vomiting, persistently elevated gastric residual volume, and need for prolonged supine position.\textsuperscript{26} Studies that have evaluated the effect of gastric or jejunal tube feeding on aspiration pneumonia were small and underpowered.
Because feeding tubes do not prevent aspiration of contaminated oral secretions or regurgitated gastric contents, PEG or PEJ tubes should not be recommended solely to reduce the risk of aspiration.26,27 Nutritional, functional, laboratory, and health-status parameters were evaluated in 150 patients who received PEG tubes and were monitored in a community setting during a 14-month period. Patient groups included patients with stroke (42%), neurodegenerative disorders (35%), and cancer (13%). Mortality at 30 days was 22% and at 1 year, 50%. Among persons surviving 60 days or more, at least 70% had no significant improvement in nutritional (body mass index and triceps skinfold thickness), functional (activities of daily living and upper and lower body function), laboratory (albumin and total cholesterol level), or subjective health status (functional assessment scale) parameters compared with baseline assessment.28 However, there was no comparison group randomized to not receive a tube. Maintenance may be all that is possible with nutritional support in patients with underlying illness.

Quality of life (QOL) issues are key for patients receiving tube feeding. However, these studies are challenging and difficult to complete because many patients are unable to provide consent for participation or accurate information. In one study, 100 consecutive patients receiving long-term tube feeding by PEG tube or surgical gastrostomy were evaluated at the time of tube placement and 4 to 8 years later.29 Patients were divided by diagnoses into acute central nervous system disease, chronic illness, and gastrointestinal tract dysfunction. Follow-up information was provided by telephone call using a validated QOL instrument; if patients had died by follow-up, information was provided by a relative’s recall of patient status. There was no significant change in the patients’ QOL. This study did not include a control group and could not make definitive conclusions regarding outcomes for patients who received a PEG tube compared with those who did not.

The high mortality rate after PEG tube placement is due to the poor prognoses of patients’ underlying illnesses. A positive correlation between shorter median patient survival and a PEG tube was found when the Charlson comorbidity index (to predict long-term risk of death from comorbid disease) was 4 or greater.30 This was a small study that measured outcome by telephone interview or written survey, but it suggests that patients with multiple comorbid conditions may have decreased survival after tube placement. However, serious underlying illness may have prompted tube placement and may have contributed to the risk of death.

The number of studies reporting survival rates after PEG tube placement is limited compared with frequency of tube placement. In hospitalized patients aged 65 years or older who were receiving Medicare benefits and were discharged from the hospital in 1991, mortality was 24% at 30 days, 63% at 1 year, and 81% at 3 years.27 Prospective follow-up of 417 patients receiving long-term tube feeding showed mortality of 20% at 1 month, 58% at 1 year, and 75% at 5 years. Approximately 35% of persons in the survey had neurologic disease, 18% had gastrointestinal disease, 15% had head and neck cancer, and 13% had dementia.31

MULTIDISCIPLINARY APPROACH

A multidisciplinary collaborative approach provides the best care for patients and families and is consistent with Joint Commission on Accreditation of Healthcare Organizations standard of care for nutritional support. Services and/or disciplines involved may include the primary service, the Nutrition Support Service (NSS), the gastroenterologist placing the feeding tube, the dietitian and nursing staffs, and, when indicated, the occupational therapist, the speech therapist, and the Ethics Consultation Service. Because many people and services may be involved, effective communication is essential to provide a consistent care plan to patients and families. Patients and their surrogates should not be rushed in their decision-making process.

At the Mayo Clinic in Rochester, Minn, the primary service is responsible for managing the patient’s overall medical care. Its responsibilities include establishing the diagnosis, clarifying the prognosis, reviewing the advance directive (AD) (the written document that promotes the autonomy of patients who lack, but once had, decision-making capacity), discussing treatment options, and obtaining informed consent. The gastroenterologist reviews and obtains informed consent for the procedure. The NSS evaluates all patients being considered for PEG or PEJ tube placement (Table 1; Figures 1 and 2). The NSS physician and team members meet with the patient and family to discuss the risks and benefits of providing or withholding long-term tube feeding and to answer questions about nutrition therapy. If the patient and/or surrogate decision maker want to proceed with long-term tube feeding, the NSS develops the nutrition and metabolic monitoring program, provides tube and site care, reviews medications for drug-nutrient interactions, and coordinates education of patients and families in administration of tube feeding. Because people learn by different modes, the NSS provides individualized verbal, written, and “hands-on” practical education about the nutrition program, PEG or PEJ tube and site care, and the administration of tube feedings. This knowledge helps to empower patients and family members regarding tube feeding and to decrease their anxiety about its administration. Patients and/or caregivers must be able to demonstrate proficiency in all aspects of tube feeding.
use and administration. The NSS home enteral nutrition coordinator reviews insurance eligibility and coverage and works with the medical staff to complete the required insurance documentation. Medicare reimbursement for long-term tube feeding requires both anticipated tube feeding of at least 3 months and anatomical or functional abnormalities of the gastrointestinal tract that prevent adequate intake or absorption of food to maintain body weight. Examples include dysphagia, obstruction, or dysmotility. Medicare coverage is not provided for long-term tube feeding in patients with malnutrition due to depression-related anorexia. Private third-party insurers do not have the same Medicare requirements. The coordinator contacts the provider about needed supplies and equipment, provides recommendations for follow-up care, and offers tube and nutrition program troubleshooting information.

**Frequently Encountered Clinical and Ethical Issues**

The following case examples illustrate frequently encountered clinical and ethical questions related to long-term tube feeding.

**Illustrative Case 1.** A 95-year-old woman with mild dementia was hospitalized with progressive neuromuscular disease and dysphagia. She experienced a 10% unintentional weight loss during the prior 3 months and dehydration due to the inability to take food and water by mouth for 1 week. Videofluoroscopic swallow evaluation revealed aspiration of all consistencies of food and liquid. Tube feeding was recommended because permanent tube feeding was anticipated. The patient was alert and oriented to person, place, and time, could articulate the risks, benefits, and alternatives to tube feeding discussed with her, and wished to proceed with PEG. After the procedure, she expressed a desire to eat small amounts of food in addition to receiving tube feeding. Again, she could articulate the risks (eg, aspiration), benefits, and alternatives to eating small amounts of food and remained steadfast in her desire to eat.

The word *autonomy* is derived from the Greek words *autos* (“self”) and *nomos* (“rule”). The principle of respect for patient autonomy is the basis of informed consent. The elements of informed consent include information (eg, the illness, the proposed intervention, and the risks and benefits of and alternatives to the proposed intervention including doing nothing), understanding of the information, decision-making capacity, and voluntary agreement to the intervention.

Society and law assume that all adults are competent. *Competence* is a legal term, and only a court can declare a person incompetent. In contrast, clinicians determine whether a patient has intact medical decision-making capacity, which patients must have to be fully autonomous and participate in the informed consent process. Although no universally accepted tool for determining decision-making capacity exists, numerous groups, including the American Psychiatric Association, provide useful guidelines. Decision-making capacity includes the ability to evidence a choice (ie, to reach a decision and effectively communicate the decision), the ability to understand the nature of the decision, the ability to understand and appreciate the risks and consequences of the decision, and the ability to manipulate information rationally. Clinicians are obligated to protect patients with impaired decision-making capacity from inappropriate health care decisions.

The patient in the case example had mild dementia but had sufficient decision-making capacity for consenting to...
PEG tube placement and tube feeding. She understood and could articulate the indications, risks, and benefits of the procedure and voluntarily consented to it. Patients with impaired cognition may have sufficient decision-making capacity for specific health care decisions. The level of decision-making capacity should be in accordance with the risks and benefits of the decision to be made.\textsuperscript{32} For example, one should be absolutely certain that a patient who refuses a low-risk yet life-saving intervention has adequate decision-making capacity.

The patient in the case example expressed a desire to eat small amounts of food despite the risk of aspiration. It is ethically and legally permissible for patients with decision-making capacity to refuse unwanted medical interventions and to ignore recommendations of the clinician.\textsuperscript{37} A patient’s choice not to adhere to a clinician’s recommendations may be at odds with a clinician’s desire to “do good” or avoid harm.\textsuperscript{38} If the patient is sufficiently informed about the risks and benefits of acceptance (informed consent) or refusal (informed refusal) of a proposed intervention or treatment and refuses, the clinician should respect the patient’s decision.\textsuperscript{39} In the case example, the patient placed a high value on the experience of tasting even small amounts of food and on the social aspects of eating with others. The NSS discussed potential risks of eating with the patient, documented the discussion, and supported her decision by asking a dietitian and occupational therapist to work with her to develop the safest approach to eating small amounts of food. Regardless of the decisions made, clinicians should not abandon their patients.\textsuperscript{39} If the clinician conscientiously objects to a patient’s decision, the clinician should arrange to transfer care of the patient to another clinician.\textsuperscript{34}

**Illustrative Case 2.** An 84-year-old man with severe Alzheimer dementia was hospitalized with cough, dyspnea, weakness, and dehydration. He had been able to eat with assistance until 2 weeks before admission and experienced a 5% involuntary weight loss during the previous 2 months. Aspiration pneumonia was diagnosed. He lacked decision-making capacity and had no AD. The family recalled no conversations with the patient regarding artificial nutrition and requested PEG tube placement and long-term tube feeding.

An AD allows persons to express their future health care goals if they lose decision-making capacity.\textsuperscript{40} In general, there are 2 types of ADs: the living will and the durable power of attorney for health care. The living will allows persons to list interventions and other actions that should or

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**FIGURE 1. Decision algorithm for long-term tube feeding (TF).**
should not be taken in specific circumstances (eg, PEG procedure and long-term tube feeding). The durable power of attorney for health care identifies a surrogate decision maker who can make health care decisions if the patient no longer has decision-making capacity. Persons also may identify an alternate surrogate in case the first person designated is unavailable. Some states have a health care directive that combines the features of a living will and durable power of attorney.

Clinicians commonly care for patients with impaired decision-making capacity who have not completed an AD. Indeed, one study found that only 10% of decedents in the United States had completed an AD. When caring for a patient who lacks decision-making capacity and has not completed a durable power of attorney, clinicians must identify a surrogate decision maker. The ideal surrogate is someone who best understands the patient’s health care values and goals. In the United States, some states have hierarchies for surrogate decision making (eg, spouse, next of kin), whereas others do not. In these situations, clinicians should work with the patient’s family and health care team to determine the appropriate surrogate or surrogates. If the situation remains unresolved, an ethics consultation and if necessary a court proceeding may be required to identify the most appropriate surrogate decision maker for the patient.

Surrogates must be fully informed of the risks, benefits, and alternatives to a proposed procedure or treatment. Surrogates should base their decisions on the patient’s previously expressed values and goals (substituted judgment). However, as with the case example, patients often do not discuss their health care values and goals with their surrogate. In these situations, surrogates must make decisions based on what they regard as most appropriate for the patient’s clinical condition, QOL, and other factors (best interest of the patient). Notably, patients may regard designating a trusted surrogate as more important than trying to predetermine all the possible future medical issues and circumstances that may require a decision.

Because a common complication of the terminal phase of dementia is a considerable decrease in oral nutritional intake, the use of long-term tube feeding for patients with severe dementia is controversial. The number of persons with dementia is expected to increase substantially. Alzheimer disease is the most common type of dementia of aging. In 1990, approximately 4 million persons in the United States had Alzheimer disease, and this number has been projected to increase to 14 million by 2050. Therefore, clinicians need to be familiar with issues related to the use of long-term tube feeding for patients with dementia. No prospective randomized trials have been completed for

**FIGURE 2.** Decision algorithm for long-term enteral tube feeding (TF). PEG = percutaneous endoscopic gastrostomy; PEJ = percutaneous endoscopic jejunostomy.
LONG-TERM ENTERAL TUBE FEEDING

Clinicians need to be better informed about the risks and benefits of PEG feeding and about guiding ethical principles, such as respect for patient autonomy. Survey results of 416 general internal medicine and family medicine physicians underscore the discrepancy between physician response, clinical practice, and the reported literature for decisions related to use of tube feeding. In general, this group overestimated the efficacy of PEG feeding for persons with advanced dementia. A high percentage of physicians believed that PEG tubes reduce aspiration pneumonia (76%) and improve pressure ulcer healing (75%), survival (61%), nutritional status (94%), and functional status (27%) despite lack of support in the literature. The physician’s decision to place a PEG tube was influenced considerably by nutrition teams, speech therapists, nursing staff, and nursing home requests. In addition, one third reported that they would honor a family’s request to place a feeding tube even if the patient had previously stated his or her preference not to have a PEG tube placed. More than half responded that PEG tube use represents a standard of care in advanced dementia, yet three fourths of this group said they would not personally want a feeding tube if they had advanced dementia. This illustrates that it is far easier for physicians to decline intervention for themselves than to withhold treatment for patients who have not made their wishes known regarding artificial nutrition. Physicians have long been trained to err on the side of supporting life. Also, respondents underestimated 30-day mortality, which could influence the type (ie, nasoenteric tube vs gastrostomy or jejunostomy) of enteral access recommended by clinicians.

Surrogate decision makers listed the following reasons for choosing long-term tube feeding: improve nutrition (70%), increase patient comfort (22%), prolong life (18%), increase strength (14%), and help to overcome acute illness (10%). This information is discrepant with documented outcomes and highlights the need for surrogates to be better informed to help make sound decisions regarding long-term tube feeding. Also, patients need to communicate their desires to surrogates because many surrogates reported uncertainty in their recommendations about artificial nutrition. A telephone survey of surrogate decision makers for elderly patients residing in long-term care facilities found that only 57% of surrogates felt confident that the person would have wanted long-term tube feeding. Most of the patients had not completed ADs, and only 1 patient had specifically expressed wishes to the surrogate regarding long-term tube feeding. Approximately one half of surrogates believed they had received adequate support from the health care team in making the decision. Approximately one fourth of surrogates did not speak with or did not remember speaking with a physician about the decision. Most surrogates believed they understood the benefits

patients with dementia to compare survival, aspiration, nutritional status, or QOL for those receiving tube feeding vs oral nutrition. Such trials are unlikely because of ethical concerns.

A cohort study with 24-month follow-up using the National Repository of the Minimum Data Set resident assessments was completed for 1386 nursing home residents older than 65 years with severe cognitive impairment. Approximately 10% of residents underwent placement of a feeding tube. Factors independently associated with feeding tube placement included age younger than 87 years, aspiration, swallowing problems, pressure ulcer, stroke, less baseline impairment, lack of a do-not-resuscitate order, and absence of dementia. Clinical characteristics and survival were compared for residents fed by feeding tube or fed by oral nutrition for 24 months. Survival did not differ between these 2 groups, even after adjusting for independent risk factors for feeding tube placement. This was not a prospective randomized comparison, and residents receiving feeding tubes were likely more ill as judged by factors associated with feeding tube placement.

A cohort analysis of all PEG tube placements completed for 361 consecutive patients in 2 different hospitals reported increased mortality for patients with dementia. Patients were categorized into 4 groups (oropharyngeal cancer, acute stroke with dysphagia, dementia, and a miscellaneous group that included many diagnoses), and median follow-up was 110 days. Overall mortality was 28% at 1 month and 63% at 1 year. Patients with dementia had a mortality of 54% at 1 month and 90% at 1 year. However, this was a retrospective study, and information about comorbid conditions was not provided.

Pressure ulcers are associated with decreased survival in nursing home residents and are a commonly used quality indicator for long-term care facilities. Risk factors for the development of pressure ulcers include poor nutrition, skin pressure, and immobility. No prospective randomized trial addresses whether use of long-term tube feeding decreases the likelihood of pressure ulcer development or progression. Two longitudinal studies reported neither improvement of existing pressure sores nor protection from developing new pressure sores with feeding. However, both immobility and incontinence were associated with nonhealing ulcers, and some residents were incontinent, restrained, and/or immobilized. A 1-year retrospective study reported improved healing of pressure ulcers for 59 nursing home residents receiving PEG tube feedings compared with 50 patients with dysphagia or anorexia in whom PEG was refused or deemed inappropriate. In this study, there was no difference among groups in age, medical needs, or early survival, whereas late mortality was lower for patients with PEG tubes.
of tube feeding, but less than one half believed they understood the potential risks. Prevention of aspiration and prolongation of life were medical benefits cited most often as reasons for requesting long-term tube feeding.

In the case example, the health care team met with the patient’s family and spent time to discern and understand the family’s reasons for desiring PEG tube feeding. The family believed that feeding by PEG tube would eliminate the chance for aspiration and prolong the patient’s life. The family was informed about the risks, benefits, and alternatives to the PEG procedure and to long-term tube feeding. Subsequently, they decided that PEG tube feeding was not in the patient’s best interests and withdrew their request for its use. After consultation with a dietitian, the patient was dismissed home to receive assisted oral feeding of appropriate food consistencies.

**Illustrative Case 3.** An 80-year-old woman with breast cancer was hospitalized with acute abdominal pain diagnosed as partial large bowel obstruction due to metastatic disease. The oncologist had documented that metastatic disease had progressed to the lungs, and treatment goals were palliative. After conservative medical treatment for the obstruction, the patient was able to resume oral nutritional intake, but her average intake did not reach her estimated daily energy requirement. The patient and family believed that lack of artificial nutrition would cause suffering, and the NSS was asked to meet with them to review nutritional options.

Anorexia is common in patients with malignancy and occurs in 40% of persons at the time of diagnosis and in more than two thirds of patients with end-stage disease. Anorexia may result from altered taste and/or smell, early satiety, cytokines, and other factors. Cachexia is common in persons with cancer and is associated with more than 20% of cancer deaths. Weight loss is associated with a poor prognosis in patients with cancer. However, clinical trials using aggressive oral supplementation have not shown benefit. Tube feeding use is controversial for most terminally ill patients with cancer (as with our patient) in whom beneficial effects on outcome or QOL have not been shown. Despite the lack of proven survival benefit for most malignancies, artificial nutrition often is prescribed. Patients and family members need to be informed that use of artificial nutrition in these situations often fails to ameliorate or reverse weight loss or lead to beneficial outcome.

Studies suggest that nutritional support may be helpful for severely malnourished patients with cancer in certain perioperative settings, for patients receiving chemotherapy in the setting of hematopoietic stem cell transplantation, and for patients with head and neck cancer. Artificial nutrition often is recommended for patients receiving nonpalliative chemotherapy and radiotherapy to support those treatments.

Studies support tube feeding for patients with head and neck cancer in the perioperative period to decrease surgical complications and during radiotherapy to improve outcomes. In a retrospective study of 88 patients, 40% of whom received PEG tubes prophylactically, patients fed by PEG tube had less weight loss (3.1 vs 7.0 kg), no interruptions in cancer therapy (0% vs 18% of patients), and fewer hospitalizations for dehydration and malnutrition compared with patients who did not receive feeding by PEG.

In another study of 934 patients with head and neck cancer, tube placement was initiated for 212 patients who developed acute gastrointestinal radiotherapy toxicity. Tube feeding was more likely in individuals of advanced age, with higher radiotherapy dose, or during adjuvant chemotherapy. Feeding tubes were maintained for a mean duration of 3.8 months. Tube feeding was required for late gastrointestinal radiotherapy toxicity in only 2% of patients. In another study of 196 patients with head and neck cancer requiring chemoradiotherapy, tube feeding was required for 76% of patients immediately after treatment. However, only 77% of patients required tube feeding at 3 months and 8% of patients at 1 year. In this study, age older than 60 years and stage IV disease were predictive of prolonged tube feeding.

It may be that reduced nutritional intake, if not too severe, that occurs from anorexia of long-term illness (including many types of cancer) may have an extremely slow effect on nutritional status. The net effect may be that tube feeding may not have much efficacy in these patients. However, in patients with head and neck cancer, in whom oral nutritional intake often is severely limited for anatomical reasons (rather than the anorexia of illness) or during radiotherapy, when oral intake is severely limited but short-lived, the benefits of tube feeding on survival (and even sometimes on morbidity) are more apparent.

Feeding tube use had the most negative effect on QOL in 570 patients with head and neck cancer who responded by questionnaire with use of the Medical Outcomes Study 36-Item Short-Form Health Survey and the Head and Neck Quality of Life (QOL) instrument. Of the 13 items affecting QOL reported in this study, the most significant factors included feeding tube use, comorbid medical conditions, tracheostomy tube, chemotherapy, and neck dissection. However, the study was not randomized, and the negative perception also may have reflected concerns related to the underlying disease.

Accurately predicting life expectancy in terminally ill patients is challenging and imperfect. Physicians provide survival estimates by clinical experience and intuition and are typically optimistic in their estimates of patient survival. A study of 343 physicians found that for 468 termi-
nally ill patients admitted to outpatient hospice programs, only 20% of survival predictions accurately predicted the actual day of death; 63% of predictions were overly optimistic.63,64 Another study reported that when physicians estimated prognoses for patients who were terminally ill with cancer and were referred for hospice care, median observed survival was 24 days, formulated (eg, clinical experience and intuition) survival was 75 days, and survival communicated to patients was 90 days.65 These over-estimates could influence physician recommendation patterns regarding long-term tube feeding.

For patients with advanced cancer, data are accumulating to improve prognostic indicators of survival.66,67 Valuable indicators include performance status, dyspnea, dysphagia, weight loss, xerostomia, anorexia, and cognitive impairment. The effect of illness on QOL has received increasing recognition. Health-related QOL is a subjective and multidimensional appraisal of the effect of illness or related therapy that must be assessed from the patient’s viewpoint rather than from that of the family or caregiver (Table 2).68

What if a terminally ill patient lacks decision-making capacity, does not have an AD, and her children demand that “everything be done” including PEG and long-term tube feeding? Given the patient’s terminal illness, many clinicians would describe artificial nutrition and hydration as futile, nonbeneficial, and potentially harmful. Clinicians are not obligated to provide futile treatments, ie, treatments for which evidence shows no benefit from any perspective.69 However, futility is difficult to define.69,70 A useful guideline for determining futility occurs when there is an outcome goal, a proposed treatment aimed at achieving the goal, and virtual certainty that the treatment will not achieve the goal.71

Conflict can occur when the patient (or surrogate) and clinician have different treatment goals. For example, a surrogate may request PEG tube feeding for a patient because the goal is to keep the patient alive (for instance to attend an important family event). Intervention and treatment are necessary to achieve that goal. The clinician may regard the treatment as futile because of its potential risks and the likelihood that it will not restore the patient to health. In other words, what is futile to the clinician may be viewed as effective and necessary by the patient or surrogate. The Wanglie case72 illustrates this situation. The patient, an elderly woman with multiple comorbid illnesses who was in a persistent vegetative state, was dependent on life-sustaining treatments for more than 1 year. The medical institution claimed that life-sustaining treatments were futile to restore the patient to consciousness and desired to withdraw them. However, supporting the patient’s life in its current state was valuable to the family, and treatment was essential to achieve that goal. The medical institution sought guardianship of the patient, but the court refused. The court affirmed the rights of families or surrogates to make decisions about life-sustaining treatments when patients are not capable of doing so. The court declared that surrogates could not be impeached as decision makers as long as the surrogate is acting in accordance with the patient’s previously expressed wishes.73

If the goal is to restore good health to a patient with terminal illness, then artificial nutrition and hydration are futile, and the medical team is obligated to discuss the reasons that this treatment is futile with the patient and surrogate. However, if the goal is to respect the patient’s beliefs and values, provide a means to palliate symptoms, and sustain life to allow closure for the family, then treatment would not be considered futile.74 If conflicting views persist, an ethics consultation and ultimately transfer of medical care to another clinician or medical institution may be necessary.75 Information should be conveyed explicitly, accurately, and with empathy and compassion. After we met with the patient and her daughters, they stated they did not desire PEG tube feeding, and hospice planning was initiated.

Illustrative Case 4. A 72-year-old previously healthy woman was admitted to the hospital for elective mitral valve replacement surgery. Postoperatively, the patient was unconscious due to an intraoperative middle cerebral artery stroke. Examination was remarkable for a wetsounding voice, facial droop, and left-sided paralysis. Ten days later, the patient was alert and oriented. Dysarthria was present, and her left-sided paresis had improved slightly. Nasogastric tube feeding had been well tolerated for the past week. The NSS was asked if a PEG tube should be placed for long-term tube feeding before the patient was transferred to a nursing home.

Stroke is the leading cause of disability and the third-leading cause of death in adults. Dysphagia occurs in 27%
to 50% of patients after stroke, and both dysphagia and malnutrition are associated with poor outcome. Aspiration pneumonia, the most important early-onset complication in stroke-related dysphagia, reportedly occurs in 13% to 44% of patients. Independent risk factors that help identify persons most likely to have dysphagia include incomplete lip closure, a wet-sounding voice and cough after swallowing water, hypoglossal nerve dysfunction, and National Institutes of Health Stroke Scale score. Cough on swallowing is the most reliable symptom for aspiration, with sensitivity/specificity and positive/negative predictive values all greater than 70%.\(^7\)

Swallow evaluation at the patient’s bedside is a useful screening study for aspiration but does not detect silent aspiration and has variable sensitivity (42%-92%), specificity (59%-91%), and interoperator reliability. Although oxygen desaturation during swallowing improves the predictive value of bedside evaluations,\(^7\) the best assessment of aspiration risk is a videofluoroscopic barium swallow.\(^7\) The video swallow provides anatomical and functional information and clarifies the oral diet that is safe, if any.\(^7\)

Aspiration occurred in 25%, 29%, and 89% of patients with mild, moderate, and severe pharyngeal barium retention, respectively.\(^8\) The likelihood of developing pneumonia is related directly to the degree of swallowing dysfunction, including pooling of pharyngeal secretions, or radiographic penetration or aspiration.\(^7\) Tube feeding in patients with stroke does not eliminate the risk of aspiration pneumonia. Studies suggest that aspiration pneumonia is caused more commonly by the neurologic deficits that affect swallowing in patients with stroke than by aspiration related to tube feeding.\(^7\) Of note, pneumonia was diagnosed as early as the second or third day after stroke (median, 2 days; mean, 2.4 days; range, 0-9 days). Independent predictors for pneumonia include impaired level of consciousness and severe facial palsy.

Data suggest that allocation of tube feeding use in long-term care facilities is based on factors other than medical need. Nationwide, 18% of nursing home residents who were severely cognitively impaired had a feeding tube in 1999, based on the National Repository of the Minimum Data Set among 385,741 nursing home residents. Information about the type of feeding tube was not provided. A 10-fold difference in the states’ (plus the District of Columbia’s) rate of feeding tube use was reported, with the rate varying from 4% in Nebraska to 45% in the District of Columbia.\(^8\) Resident characteristics associated with greater likelihood of feeding tube use included younger age, nonwhite race, male sex, divorced marital status, lack of AD, recent decline in functional status, and no diagnosis of Alzheimer disease. Residents who lived in facilities that were for profit, were located in an urban area, had more than 100 beds, and lacked a special dementia care unit had a higher chance of having a feeding tube.\(^3\)

Many nursing homes require residents to have long-term enteral access rather than nasoenteric feeding tubes. Self-extubation of feeding tubes creates a problem because nursing homes do not have the capability to safely replace nasoenteric feeding tubes. Also, residents with nasoenteric tubes who are confused may require physical restraints to minimize the likelihood of inadvertent removal of feeding tubes. The potential for physical restraint has been shown to affect the decision of residents regarding feeding tube use. One third of 379 nursing home residents with intact medical decision-making capacity reported they would choose tube feeding if they could no longer eat because of impaired cognition.\(^4\) When these nursing home residents learned that physical restraints sometimes are required in such situations, one quarter changed from desiring to declining tube feeding. In addition, because of trends toward decreased hospital length of stay, clinicians often have insufficient time to determine whether long-term (PEG or PEJ) or short-term (nasoenteric) tube feeding would be most appropriate.

At the time of our discussion with the case patient, she had intact medical decision-making capacity and agreed to PEG if required. We recommended a clinical bedside swallow evaluation, which showed weak tongue control and delay in oral food transfer and pharyngeal swallow. The occupational therapist recommended a barium videofluoroscopic evaluation. On the basis of findings from the video swallow, the patient was advised to follow an oral dysphagia diet with thickened liquids under strict aspiration precautions (ie, avoiding oral intake when fatigued, assuming an upright posture during all oral intake, and avoiding lying down immediately after eating). Although the patient was able to consume adequate oral nutrition, she was unable to maintain hydration with thickened liquids and consented to PEG tube placement for hydration.

We recommend a swallow evaluation study before PEG or PEJ procedures for patients able to cooperate during the test to see if any oral intake is safe. A swallow evaluation is indicated even if the major source of nutrient intake is by nasoenteric tube feeding and even if the patient has consented already to PEG or PEJ. Also, Medicare coverage generally requires documentation of dysphagia.

Two randomized trials comparing PEG to nasogastric tube feeding suggest that PEG tube feeding was associated with improved nutrition (eg, weight and mid-arm circumference), fewer treatment failures, and decreased mortality.\(^5\) The main criticism of these 2 trials is the small number of patients. A multicenter trial compared outcomes of 321 patients with stroke-related dysphagia who were fed by PEG tube vs nasogastric tube: feeding by PEG tube was significantly associated with risk of death or poor outcome,
although it is likely that patients with PEG tubes were more ill.16,87

A retrospective assessment compared outcome and survival for patients who were fed by PEG tube after stroke (n=83) or other diseases (control group, n=115).88 Patients who had a stroke were older, had a similar (19%) 1-month mortality, and were more likely to have recovery of swallowing than were patients in the control group. Swallowing recovery occurred in 27% of patients after stroke, but most still required PEG tube feeding at 3 months. Compared with younger patients with stroke, those older than 74 years had increased 1-month mortality (26% vs 12%) and were less likely to regain swallowing (20% vs 31%). The percentage of patients with stroke who required tube feeding varied widely, from 8.5% to 44%.39 A retrospective study of 74 patients who entered nursing homes and required PEG tube feeding after acute stroke reported that 25% could resume oral nutrition and discontinue tube feeding by a median period of 4 months.90 Therefore, swallowing function should be assessed regularly for patients with clinical improvement to determine whether oral nutrition can be initiated. In our patient, neurologic function improved gradually, a swallow study was completed, and the patient was able to resume oral intake.

Illustrative Case 5. A 70-year-old man was hospitalized after a hemorrhagic stroke that resulted in dysphagia and severely impaired cognition. The patient did not have decision-making capacity and had not completed an AD. After exploring the patient’s previously expressed health care values and goals, the health care team and the patient’s family agreed to a 3-month trial of PEG feeding, and the patient was transferred to a nursing home. At 3 months, he had experienced no neurologic recovery, and the family requested removal of the PEG tube.

Both clinicians and patients believe that medical care near the end of life needs more emphasis.91 Patients list controlling pain, avoiding inappropriate prolongation of the dying process, and strengthening relationships with loved ones as key end-of-life goals.92 To achieve these goals, withholding and withdrawing of life-sustaining treatments perceived as burdensome are widely practiced.93 It is ethically and legally permissible for dying patients to refuse or request the withdrawal of unwanted life-sustaining treatments (eg, feeding tubes).32,94,95 It is permissible for patients to refuse previously consented treatments if the patient’s health care values and goals have changed.93 There is no ethical or legal difference between withholding or withdrawing life-sustaining treatments; therefore, treatments should not be withheld because of concern that they cannot be later withdrawn.94

Several court decisions in the United States have clarified a patient’s right to refuse or request the withdrawal of life-sustaining treatments, including artificial nutrition and hydration. In the 1976 Quinlan case,96 the New Jersey Supreme Court ruled that a competent person has the right to refuse unwanted life-sustaining treatments and that this right is not lost if the person becomes incompetent. In the 1990 Cruzan v Director case,97 the US Supreme Court affirmed the right of competent patients to refuse unwanted life-sustaining treatments, including artificial nutrition and hydration. In fact, the court made no distinction between artificial nutrition and hydration and other forms of life-sustaining treatments (eg, ventilator support). The Supreme Court also affirmed the rights of incompetent persons to refuse life-sustaining treatments through ADs and surrogate decision makers. However, for situations involving incompetent patients who never executed an AD, the court affirmed that states had the authority to require “clear and convincing evidence” that a patient would refuse artificial hydration and nutrition if the patient could speak for herself or himself.98,99 “Clear and convincing evidence” may include explicit written instructions (eg, an AD in which a person forbids the placement of a feeding tube). Although all 50 states and the District of Columbia have laws related to ADs, laws regarding surrogate decisions about life-sustaining treatments vary from state to state. For example, several states allow a surrogate to make decisions about artificial nutrition and hydration for a patient only if the patient specifically authorized the surrogate to do so. For incompetent patients who have not identified a surrogate through an AD, most states define a hierarchy of default surrogate decision makers. However, states typically restrict the authority of default surrogates. For example, Florida state law defines the default surrogate as the spouse and requires “clear and convincing” evidence that the patient would not have wanted artificial hydration and nutrition before honoring the surrogate’s request to withhold or withdraw this form of life-sustaining treatment.99

Honoring a patient’s request to refuse or to withdraw a life-sustaining treatment is not the same as physician-assisted suicide (PAS) or euthanasia. In PAS, a patient intentionally terminates his or her life by using a means provided by a clinician (eg, lethal prescription). In euthanasia, a clinician intentionally terminates a patient’s life (eg, lethal injection). In PAS and euthanasia, a new variable is introduced (eg, drug), and the intent is the patient’s death. In contrast, when a patient dies after a life-sustaining treatment is refused or withdrawn, the underlying disease is the cause of death. The intent is freedom from treatments perceived as burdensome.32,37,100-102 In the 1986 Bouvia v Superior Court case,103 the California Court of Appeals ruled that competent persons have the right to refuse life-sustaining treatments including artificial hydration and nutrition and that such a refusal is not suicide. In the 1997
Vacco v Quill case, the US Supreme Court reaffirmed that persons have a right to refuse unwanted life-sustaining treatments, that such a refusal is not suicidal, and that death after such refusal is not suicide, but rather is due to the underlying disease. Notably, no American court has found a clinician liable for wrongful death after honoring a patient’s or surrogate’s request to refuse or withdraw life-sustaining treatments.

Clinicians must be certain that patients who refuse or request the withdrawal of life-sustaining treatments (such as artificial nutrition and hydration) have adequate decision-making capacity and are informed of the consequences of their request. However, many patients lack decision-making capacity when decisions to withhold or withdraw life-sustaining treatments are made, highlighting the need for advance care planning. Clinicians should discuss end-of-life values, goals, and preferences regarding life-sustaining treatments, including artificial nutrition and hydration, with patients when they possess decision-making capacity. When possible, these discussions should occur when persons are not sick. Clinicians should encourage patients to discuss these values, goals, and preferences with their potential surrogates and to clarify the surrogate’s authority regarding life-sustaining treatments.

In the case example, the patient lacked decision-making capacity and did not have an AD. The health care team explored with the family the patient’s previously expressed health care values and goals and developed a plan that included a trial of tube feeding for a designated period to determine whether the patient would sustain a meaningful recovery from his stroke. The patient did not recover, tube feeding was withdrawn, and the patient died eventually of his neurologic condition.

Preventing and Addressing Ethical Dilemmas
The prima facie principles that characterize the ethical aspects of clinical medicine are respect for patient autonomy, beneficence, nonmaleficence, and justice. Respect for patient autonomy refers to the duty to respect persons and their rights of self-determination. Beneficence refers to the clinician’s duty to act for the good of the patient, whereas nonmaleficence refers to the duty to avoid harming the patient. Justice refers to the duty to treat patients fairly. When caring for patients for whom long-term tube feeding is being considered, clinicians may find these ethical principles at odds with each other. For example, respect for patient autonomy may conflict with the clinician’s desires to be beneficent and to avoid harm.

Effective communication among clinicians, patients, and surrogate decision makers may help prevent ethical dilemmas. Clinicians should take time to learn about the patient and the patient’s values, goals, and beliefs. The patient should be provided ample time to discuss and provide his or her concerns related to nutrition and hydration. When conveying medical information concerning benefits and risks of long-term tube feeding, clinicians should avoid using complex medical language and frequently should assess the patient’s comprehension. Conversely, ineffective communication among clinicians, patients, and surrogate decision makers may result in ethical dilemmas. Lack of training, perceived lack of time, fear of the patient’s emotional response, and general discomfort with these topics may result in clinicians avoiding these discussions. In fact, discussions about life-sustaining treatments between clinicians and patients are reportedly uncommon.

Despite good communication, clinicians may face ethical dilemmas related to long-term tube feeding that they cannot resolve. In these situations, an ethics consultation may be valuable. The Ethics Consultation Service at our institution uses the 4-topic case-based approach described by Jonsen et al. This approach (Table 3) reviews medical indications, patient preferences, QOL, and contextual (eg, financial, religious, cultural, and allocation of resources) issues of a given case and facilitates the exposition, organization, and analysis of the ethically relevant facts (ie, the facts related to the prima facie ethical principles). Answering the questions in Table 3 is a convenient approach to the 4 topics, and, reviewed together, the answers to the questions not only define the ethical problem but often suggest a solution.

Conclusions
The use of long-term tube feeding has increased substantially. Review of the literature highlights the need for improved education for physicians, patients, and surrogate decision makers about use of long-term tube feeding and its ethical implications. Clinicians should take an active role in recommending ADs to their patients. Patients should be encouraged to identify a surrogate decision maker and to make intentions clear to this person about use of long-term tube feeding. Although outcome data from prospective, randomized, controlled studies are limited, information from observational studies is useful. In general, PEG or PEJ feeding tube placement should not be considered unless the anticipated duration of tube feeding is at least 1 month. The technical procedures to secure enteral tube access are generally safe, but they are not risk free. A simple guideline to outline the appropriate use of long-term tube feeding does not exist because each person has a unique perspective about their QOL. As with other forms of medical interventions and treatments, the approach should be individualized. However, as discussed earlier, a
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TABLE 3. Four-Topic Approach to Identify Ethically Relevant Facts*

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<td></td>
<td>3. What are the goals of PEG/PEJ placement and long-term tube feeding?</td>
<td>4. What are the probabilities of success?</td>
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<td>5. What are the plans in case of therapeutic failure?</td>
<td>6. In sum, how can this patient benefit from medical and nursing care, and how can harm be avoided?</td>
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<tr>
<th>Patient preferences</th>
<th>1. Does the patient have decision-making capacity?</th>
<th>2. If the patient has decision-making capacity, what are his or her preferences for treatment?</th>
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<td>3. Has the patient been informed of the benefits and risks of PEG/PEJ placement and long-term tube feeding, understood this information, and given consent?</td>
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<td>4. If the patient lacks decision-making capacity, who is the appropriate surrogate?</td>
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<td>5. Has the patient expressed preferences about PEG/PEJ placement and long-term tube feeding previously (eg, advance directive)?</td>
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<td>6. Is the patient unwilling or unable to cooperate with treatment? If so, why?</td>
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<td>7. In sum, is the patient’s right to choose being respected to the extent possible in ethics and law?</td>
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<th>Quality of life</th>
<th>The principles of beneficence, nonmaleficence, and respect for patient autonomy</th>
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<tr>
<td>1. What are the prospects, with or without PEG/PEJ placement and long-term tube feeding, for a return to normal life?</td>
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<td>2. What physical, mental, and social deficits is the patient likely to experience if treatment succeeds?</td>
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<td>3. Are there biases that might prejudice the clinician’s evaluation of the patient’s quality of life?</td>
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<td>4. Is the patient’s present or future condition such that his or her continued life might be judged undesirable?</td>
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<td>5. Is there any plan and rationale to forgo treatment?</td>
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<td>6. Are there plans for comfort and palliative care?</td>
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<th>Contextual features</th>
<th>The principles of loyalty and fairness (justice)</th>
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<td>1. Are there family issues that may influence decisions related to PEG/PEJ placement and long-term tube feeding?</td>
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<td>2. Are there clinician issues that may influence treatment decisions?</td>
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<td>3. Are there financial and economic factors?</td>
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<td>4. Are there religious or cultural factors?</td>
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<td>5. Are there limits on confidentiality?</td>
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<td>6. Are there problems of allocation of resources?</td>
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<td>7. How does the law affect treatment decisions for PEG/PEJ placement and long-term tube feeding?</td>
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<td>8. Is clinical research or teaching involved?</td>
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<td>9. Is there any conflict of interest on the part of clinicians or the institution?</td>
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*PEG = percutaneous endoscopic gastrostomy; PEJ = percutaneous endoscopic jejunostomy.

Adapted from Jonsen et al.,111 with permission from McGraw-Hill.

systematic approach (Figures 1 and 2) can facilitate the decision-making process. Physicians should first determine whether the patient’s treatment goals are potentially curative, rehabilitative, or palliative. Next, to allow informed decision making, clinicians should clearly communicate with patients and surrogate decision makers about the patient’s diagnosis, prognosis, and potential outcomes from providing or withholding long-term tube feeding. For patients in the terminal stages of dementia, cancer, or other illnesses, current studies do not document improved outcome from long-term tube feeding use. It is unrealistic to expect artificial nutrition to favorably improve medical outcomes in these conditions; however, it is important to recognize that, in certain situations, patients and surrogate decision makers will choose long-term tube feeding to achieve personal goals, independent of medical outcome. If the potential medical outcome is curative or rehabilitative, the decision should rest on the patient’s wishes. Patients and surrogate decision makers should be given sufficient time and support for making informed decisions regarding long-term tube feeding use, and their decisions should be honored. Research is needed to improve the clinician’s ability to estimate the needed duration of artificial nutrition in order to select short-term vs long-term enteral access for feeding and to assess the effect of long-term tube feeding on QOL and medical outcome for differing medical conditions.

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