The Role of Tube Feeding and Total Parenteral Nutrition in Advanced Illness

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Consumption of food and drink is a fundamental part of North American culture. "All-you-can-eat" diners and lavish Thanksgiving turkey dinners are as American as Mom and apple pie. Eating and drinking is a valued social activity; we derive our strength from eating, and for many, the ability to eat and drink symbolizes life itself. The development of artificial nutrition has allowed us to feed patients who cannot eat and to continue to feed patients who are dying. It is no wonder that withholding food or withdrawal of artificial feeding may be seen as tantamount to assisted suicide or euthanasia by patients, families, and health professionals.[1] Because placement of a feeding gastrostomy or jejunostomy often falls to the surgeon, the role of tube feeding and total parenteral nutrition (TPN) in advanced illness is an appropriate subject for our review. Two case scenarios help focus the issues at stake.

Case scenario 1

OS was a 67-year-old man who was admitted for management of a partial small bowel obstruction from metastatic gastric cancer. His performance status and advanced stage of disease precluded chemotherapy, and palliative care was offered. Although he was partially obstructed, he was able to keep down small amounts of liquid without vomiting. As he began to tire and weaken, he demanded that he be placed on TPN in order to keep up his strength.

Resolution

A thorough discussion with this articulate and intelligent man revealed that he had a clear understanding of his prognosis. Once he understood that nutrition would not alter his life expectancy or improve the quality of his remaining life, he withdrew his request for TPN. "I just wanted to make sure someone will continue to look after me."

Case scenario 2

Pastor L was 91-year-old man who was admitted to the hospital from a nursing home demented, dehydrated, and unable to swallow. His medical care team hoped that his dementia would improve with hydration and enhanced nutrition, and a percutaneous feeding jejunostomy was placed. Unfortunately, the feeding tube was inadvertently placed through the ileocecal valve, causing severe diarrhea, and parenteral nutrition was started. Neither hydration nor hyperalimentation improved his sensorium.

Resolution

Careful review of his medical history and MRI scans of the brain disclosed generalized atherosclerosis and many small strokes to both sides of his brain. Atherosclerotic pseudobulbar palsy was the irreversible reason for his inability to swallow and eat. Because his living will stated, "If I am physically or mentally impaired and there is no prospect for recovery I do not wish to have my dying prolonged by artificial nutrition or ventilation," the parenteral nutrition was stopped. He died shortly thereafter.

DISCUSSION

In 1656, Wren administered the first parenteral feeding of intravenous nutrients (wine, opium, and oleic acid) to animals. Bernard injected egg whites, milk, and cane sugar solutions subcutaneously into animals in 1840. Biedl and Krause administered glucose intravenously to humans for the first time in 1896. Catabolic responses were documented after operative stress, large bone fracture, and battle injury in the wake of the First World War, but not until 1962 was Wretlind able to achieve positive nitrogen balance with intravenous nutrition. In 1967, Dudrick was able to support normal growth and development in puppies and achieved the same goal in

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an infant the next year. Enthusiasm for total parenteral nutrition blossomed in the 1970s and has grown into a multibillion-dollar industry.[2]

In the context of terminal illness, two goals are potentially served by enhanced nutrition: to sustain life and to alleviate suffering related to thirst and hunger. The critical questions are, "Does artificial nutrition prolong life?" and if not, "Does it improve the quality of life until death?" Conversely, the question can be asked, "Does artificial nutrition prolong the dying process?" There is no evidence that parenteral nutrition has had a significant impact on clinical outcomes;[3] in addition, in the natural course of dying, patients develop a reduced sense of thirst and hunger.

As patients progress toward the terminal phase of their illnesses, they may lose their appetite, lose weight, and become profoundly weak and tired, finding even the most basic activities difficult. These are manifestations of the cachexia syndrome. Seen most markedly in cancer patients, especially those with lung and upper gastrointestinal cancers, it is also seen in advanced heart failure, COPD, liver and kidney failure, and AIDS. The degree of cachexia correlates poorly with the severity of illness or the burden of disease.

Cachexia is a catabolic metabolic process that actively breaks down skeletal muscle, fat, and carbohydrates despite reduced nutritional intake. Resting energy expenditure rates may, in fact, increase despite relative inactivity. Metabolic studies have suggested a number of responsible factors, including elevated cytokine, neurotransmitter, and acute phase protein levels, tumor or disease products, and hormonal changes, but its exact mechanism is still poorly understood.[4] What is clear is that cachexia is a chronic and profound metabolic change that cannot be reversed with the simple addition of shortterm nutritional supplementation. Energy expenditure in starvation, on the other hand, is reduced by rising blood ketone levels, which signal tissues to minimize glucose use, reduce basal energy levels, and curtail muscle protein breakdown. In contrast to cachexia, nutritional support can reverse the catabolic changes of starvation.

There is little evidence of benefit for artificial nutritional support in the context of cachexia. Two randomized trials examined the role of oral nutritional supplementation in patients with advanced cancer undergoing chemotherapy.[5,6] Despite a significant increase in nutritional intake in the study group compared with the control group, no difference was found in body weight, quality of life, or survival. A number of randomized trials of parenteral nutrition in advanced cancer patients have demonstrated no improvement in nutritional status or survival.[7,8] Studies of perioperative parenteral nutrition in cancer patients have also been disappointing. Although the most malnourished patients may have improved survival, most patients do not benefit, and may develop increased complications from the central venous access required.[9-11] Improvement in quality of life has not been adequately studied.[12] But terminally ill patients do not report suffering from hunger or thirst as they progress toward death.[13]

Nonetheless, cachexia-induced weight loss, lack of appetite, and weakness cause a great deal of distress for patients and their families. The patient may be seen as "giving up." Patients and their caregivers may believe that the patient would regain health and vitality if only he or she could eat more. Because enteral and parenteral nutrition is readily available, artificial nutrition is often the next step anticipated in the patient's medical care. It is rarely indicated.

A request for artificial nutrition should prompt a thorough assessment of the patient's condition. The diagnosis of cachexia is made by clinical history, which includes a history of substantial weight loss, and a physical examination demonstrating muscle wasting. Decreased serum albumin and elevated C-reactive protein, an acute phase protein, may reflect the severity of the condition.[14] More recently, a protein excreted in the urine of cachexic patients that induces cachexia in mice has been discovered, offering promise as a diagnostic tool.[15] Successful treatment of the underlying disease or tumor may reverse the cachexia syndrome, and this issue should be explored and abandoned if futile so that the patient, family, and health care professionals are clear on this issue.

Reversible causes of reduced food intake should be treated. These include inadequately treated pain, nausea, obstruction, an inability to swallow, malabsorption, gastroparesis from autonomic dysfunction (common in advanced malignancy), and clinical depression. Nausea is extremely common, and may be exacerbated by medication or treatment side effects. A more thorough approach to the diagnosis and management of anorexia and cachexia is beyond the scope of this article but has been well described.[12,16,17]

The patient's goals of care should be articulated and

understood. This may be the first time such a discussion has taken place. A family meeting is often helpful to allow the patient and family to shift the goals of care from unrealistic expectations of cure to the provision of comfort. The risks and benefits of artificial nutrition should be clearly explained in the context of the individual's terminal illness and prognosis. All forms of artificial nutrition have the potential of complications, and involve expense and energy in order to be delivered safely.

Options other than artificial nutrition may satisfy the patient's goals of care. Aggressive medical management of patients with malignant bowel obstruction may allow removal of the nasogastric tube, and small amounts of favorite foods presented tastefully may preserve the pleasure of eating.[18] Lifting dietary restrictions may provide welcome relief. Instead of sharing meals, families and caregivers can share stories and memories. Patients with progressive dementia may be successfully managed by continued oral feeding, letting the natural course of the disease define the extent and duration of feeding.[19]

Occasionally, the decision to begin artificial nutrition is appropriate for the individual patient with terminal illness. Patients with amyotrophic lateral sclerosis, a motor neuron disease, lose the ability to eat early in the course of their illness. Depending on the patient's values and preferences, artificial nutrition will prolong life and enhance quality of life by reducing episodes of aspiration and choking. Patients with obstructing tumors may live to attend an important personal event by the provision of artificial nutrition. It is helpful to agree a priori to periodically reassess the need for artificial nutrition by setting well-defined endpoints and making provisions to stop when these goals are no longer being met.

The situation is more difficult if patients are unable to articulate their goals. Has an advance directive been prepared that states the patient's preference in this situation? Has a surrogate decision maker (power of attorney for health care) been identified who can clearly speak to the patient's wishes with respect to artificial nutrition? A family meeting in this situation is essential.

Beneficence, nonmaleficence, justice, and autonomy remain the important ethical principles that guide decision making at the end of life. Physicians are called to mitigate suffering and to do what is good and helpful (beneficence). We are bound by a sacred oath to first do no harm (nonmaleficence). Justice examines an action from the perspective of society as a counterpoint to the individualistic perspective of autonomy. We respect the patient's autonomy or right to self-determination when we apply an advanced directive, as in the second case scenario. Such a document provides patients with the opportunity to express their own values and preferences. Unfortunately, vague nomenclature and changing circumstances may make advanced directives difficult to apply and limit their usefulness in practice.[20] The issue of medical futility brings these concepts together, where a potential treatment, because of individual circumstances, may be of no real benefit, and if it were performed anyway could expend valuable resources that might have been used for the benefit of others. Futile treatments violate the ethical principles of justice, beneficence, and nonmaleficence. Parenteral or enteral feeding at the end of life often qualifies as futile.

Several legal decisions have supported the right of competent patients to refuse treatment, including artificial nutrition.[21,22] For mentally incompetent patients, the situation is more variable. Individual states may override requests to stop artificial nutrition or other treatment when the patient's wishes have not been clearly expressed before becoming incompetent. So the importance of an advanced directive (with fairly explicit instructions regarding specific interventions such as feeding tubes, etc) or the naming of a healthcare proxy (durable power of attorney for healthcare) is underscored.

What does a request for artificial nutrition really mean? Both case scenarios identify common issues that arise during the care of those with advanced illness. The request may reflect a lack of clear understanding and acceptance about the true prognosis and nature of the illness among the patient, loved ones, and the team of providers. Such requests may also reflect a need "to do something" for the patient simply because it can be done, rather than because of any measurable benefit or relief of suffering. Perhaps most importantly, the request is an opportunity to explore patients' fears, anxieties, and goals of care, and to reassure the patient that he or she will not be abandoned as the goals of care shift from cure to palliation. An important part of such discussion with the terminally ill and their families is to help them understand the normal physiologic changes that precede death. Knowledge of what to expect and the realization that a gradual loss of interest in food is a normal part of the dying process can help to alleviate much anxiety and restore a crucial sense of control.

In summary, the provision of artificial nutrition must

be individualized to each patient and should be viewed as part of an overall care plan designed to maximize the dying patient's comfort and to respect his or her wishes. It is usually possible to reach a resolution that is satisfactory to all involved as long as realistic goals of care are set. This process may be time consuming, but ultimately may be extremely rewarding for patients, their families, and their surgeons.

Appendix

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Invited Commentary

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The specific indications for providing nutrition by the enteral or intravenous routes are not well defined, and