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Withholding nutrition at the end of life: Clinical and ethical issues

ABSTRACT

Tube feeding in terminally ill patients has become routine. Indeed, many physicians question the ethics and legality of withdrawal of nutrition and hydration—even in patients whose prospects of recovery are bleak. To avoid unnecessary pain and suffering, patients, physicians, and family members need to discuss the patient's desires, carefully weigh the benefits and burdens of tube feeding, and examine their own beliefs and biases.

KEY POINTS

Withholding or withdrawing medically provided nutrition and hydration from patients is often disturbing for both physicians and family members.

Enteral and parenteral nutrition and hydration are medical treatments that can be withheld or withdrawn under appropriate medical and ethical circumstances.

Forgoing nutrition and hydration near the end of life leads to greater patient comfort in many instances.

The withholding or withdrawal of nutrition and hydration are distinct from physician-assisted suicide and euthanasia.

Focusing on the disease process rather than on starvation and dehydration as the cause of death may help the family and the physician provide optimal end-of-life care.

YOUR PATIENT, who had a massive myocardial infarction 3 months ago, has end-stage congestive heart failure, chronic renal insufficiency, and severe anoxic encephalopathy. He is in a nursing home and receives nutrition and hydration through a gastrostomy tube.

He has recurrent pneumonia, and you are about to start intravenous antibiotics and transfer him to a hospital. However, in your clinical judgment, he would not survive intensive care if his respiratory function were to deteriorate.

The patient's wife says, "My husband wouldn't want all this. He never wanted to be in a nursing home. Can't you just let him die in peace?" After further discussion, you agree that hospice care is medically and ethically appropriate. Your instructions to the hospice nurses include "do not resuscitate" and "comfort measures only" orders.

A nurse asks if nutrition should be withdrawn. You are uncomfortable with discontinuing a feeding tube, so you informally consult several of your colleagues. Some would stop the tube feeding, some would not, and some think the patient's wife should decide.

RELUCTANCE TO WITHHOLD NUTRITION

When a person cannot eat because he or she is ill, a clinical decision must be made about providing nutrition and hydration through intravenous hydration and a feeding tube or total parenteral nutrition. As in the clinical use of any medical device or treatment, this decision should be based on medical need and the burdens and benefits of the treatment.

Physicians generally do not have a problem with starting such treatment, but withholding or withdrawing it at the end of life



often is disturbing for both physicians and family members. Although physicians have become more skilled at medical-ethical decisions to withhold or withdraw treatments such as cardiopulmonary resuscitation, kidney dialysis, and mechanical ventilation, forgoing nutrition and hydration remains problematic.

Decisions to forgo nutrition and hydration are not always based on a careful weighing of the advantages and disadvantages. One study¹ showed that physicians were reluctant to stop nutrition and hydration even when the burdens of treatment outweighed the benefits. Another study^{2,3} demonstrated that physicians have biases about which treatments should be forgone at the end of life and are reluctant to withdraw nutrition and hydration.

This reluctance persists even though professional organizations have repeatedly stated that artificially provided nutrition and hydration are medical treatments that can be withheld or withdrawn under appropriate medical and ethical circumstances. For example, the American College of Physicians states in its ethics manual, “Artificial administration of nutrition and fluids is a life-prolonging treatment. As such, it is subject to the same principles for decisions as other treatments.”⁴

The American Medical Association (AMA) has stated that “Life-sustaining treatment may include, but is not limited to, mechanical ventilation, renal dialysis, chemotherapy, antibiotics, and artificial nutrition and hydration.”⁵ Recently, a consensus panel of the American College of Physicians and the American Society of Internal Medicine refuted the belief that forgoing nutrition and hydration at the end of life is illegal.⁶

Nevertheless, some physicians consider medically provided nutrition and hydration a basic human need, and they fear subjecting the patient to a painful death through starvation and dehydration.

The practice of evidence-based medicine requires that clinical decisions be made on the basis of clinical research.⁷ Recently, the routine use of feeding tubes in patients with severe dementia has been questioned because evidence of their effectiveness in achieving medical and social goals is lacking.⁸

A literature review by Finucane and col-

leagues⁹ showed that the usual reasons for tube feeding patients with dementia (ie, to improve survival and prevent aspiration pneumonia, malnutrition, pressure ulcers, and infection) are not supported by empirical data.

■ NOT THE SAME AS FOOD AND DRINK

Is withholding or withdrawing artificial nutrition and hydration the same as denying food and drink? Are nutrition and hydration basic care that is morally required by basic standards of human decency?

Certainly, like breathing and waste elimination, nutrition and hydration are basic human needs. However, discontinuing a ventilator or kidney dialysis somehow seems different than withdrawing a feeding tube, perhaps because of the tendency to attach meanings to images of various medical treatments.

These images may be dismissed as mere symbolism, but they are extremely important. For example, a red cross represents a humanitarian organization, but a cross burning on a lawn conjures a very different meaning.

Food and drink have many social meanings; most social gatherings, from a cup of coffee with a friend to a wedding reception, involve food and drink. Giving someone food and drink is equated with nurturing and caring. Over time, the image of nutrition and hydration has become conflated with the image of food and drink.

However, providing nutrition and hydration is not synonymous with feeding someone—or with eating. People eat in a socially normative way (ie, through the mouth) and with socially normative tools (eg, knives, forks, chopsticks). Medically provided nutrition and hydration is not socially normative. In fact, until fairly recently, the use of a feeding tube was called “forced feeding.”

The possibility that an alert, oriented person may need a feeding tube for nutrition (eg, in the case of abnormal esophageal motility) underscores the need to assess social burdens and benefits. For example, will medically provided nutrition and hydration enhance or decrease the patient’s ability to connect socially with others?

Often, a technology developed for a specific medical problem becomes widely and

The routine use of feeding tubes is being questioned

inappropriately used outside of the intended setting. For example, cardiopulmonary resuscitation (CPR) was originally developed to treat sudden, reversible cardiac arrest due to electrocution, drowning, or surgical anesthesia problems in otherwise healthy persons.¹⁰ Over the years, CPR became so widespread that it was attempted in nearly every patient who died. Empirical research in the 1980s eventually demonstrated that CPR was ineffective in many medical conditions, such as end-stage cancer or multiple organ failure.¹¹

Similarly, medically provided nutrition and hydration were developed for patients who for some, usually temporary, reason cannot eat and drink. However, feeding tubes became widely used in patients unlikely to recover (eg, who had a massive stroke or severe brain damage due to anoxia or head trauma).

Social forces, such as the growth of the nursing home industry in the 1960s and 1970s and improvement of technology in the 1980s, probably provided financial incentives and a moral imperative to maintain patients in these chronic, debilitated states. For example, the number of gastrostomies in hospitalized patients 65 years or older in the United States doubled from 1988 to 1995.¹²

In the lexicon of the clinical environment, medically provided nutrition and hydration became synonymous with “feeding,” a term with a heavy symbolic load.

■ TUBE FEEDING IS NOT INNOCUOUS

Medically provided nutrition and hydration is not necessarily innocuous. Potential side effects of tube feeding include diarrhea, nausea, vomiting, esophageal perforation, and infiltration of formula into the lung.⁹ An intravenous infusion can cause infection, phlebitis, and electrolyte imbalances. In a dying patient with inadequate or absent renal function, supplying intravenous fluids may precipitate peripheral or pulmonary edema and increase the need for suctioning.¹³

Decisions about nutrition and hydration should be based primarily on the potential burdens vs the potential benefits⁹ and the potential effects on the patient’s goals and outcomes. Goals of care may change during

the course of illness; the physician needs to negotiate goals and priorities of care with the patient or surrogate on a continuing basis.¹⁴

■ LEGAL CONSIDERATIONS

All states now have advance directive laws that enable patients to state their wishes about life-sustaining treatment before they become cognitively incapacitated. However, these laws may not address nutrition and hydration. Further, relatively few patients have executed an advance directive such as a living will or durable power of attorney for health care. Because laws vary from state to state, physicians need to become familiar with state laws and address legal concerns with hospital legal counsel.

The US Supreme Court, in its Nancy Cruzan decision,¹⁵ reiterated that nutrition and hydration are medical treatments and as such can be legally withheld or withdrawn under appropriate medical and ethical circumstances.

What are these ‘appropriate medical and ethical circumstances’?

The forgoing of life-supporting treatments, including nutrition and hydration, involves several considerations:

- **What is the patient’s medical prognosis?** Is the patient likely to recover with medical support, or will he or she die in spite of it?
- **If the patient has a chance of survival, will the quality of life be acceptable to him or her?** If the patient is unable to speak, his or her viewpoint must be surmised by the physician and the patient’s family.
- **Do the potential benefits of the treatment outweigh the potential discomforts, pain, and suffering?** Physicians, patients, and family members may differ in their assessment of burdens and benefits. Because the patient is the one to experience the effects of treatment, his or her viewpoint usually is accorded more weight in decision-making.
- **What are the patient’s wishes in regard to the use of life-sustaining treatment?** If the patient is unable to express his or her values, is a family member or patient-chosen proxy able to do so for the patient?

The use of a feeding tube used to be called “forced feeding”



■ DOES IT HURT TO STARVE?

Many people assume that death from starvation or dehydration is painful. However, numerous case reports demonstrate that forgoing nutrition and hydration near the end of life leads to greater patient comfort, while providing it may increase edema, secretions, and dyspnea.^{16,17} Ellershaw et al¹⁸ showed that dry mouth, thirst, and increased secretions in dying patients were unrelated to their level of hydration.

Patients dying without nutrition and hydration may be adequately hydrated but experience symptoms due to other factors, such as drug side effects¹⁸ or mouth-breathing.¹⁹ Another study of terminally ill cancer patients who declined food and drink showed that these patients generally did not experience hunger or thirst. Those who did needed only small amounts of food or liquid, while those who ate to please their families experienced nausea and abdominal discomfort.²⁰

Thirst and dry mouth can be alleviated through good nursing care (eg, offering ice chips; keeping the lips, nose, and eyes moist; providing good mouth care; using analgesia when appropriate).^{21,22} Anecdotal evidence has shown that ill persons often do not feel hungry. The effects of ketosis and the body's release of endogenous opioids during starvation are thought to block pain and discomfort.^{16,23}

■ IS IT 'KILLING'?

The forgoing of life-supporting therapy has been legally distinct from homicide since the 1976 Karen Ann Quinlan ruling,²⁴ in which the New Jersey Supreme Court allowed the withdrawal of a ventilator, which was expected to lead to the patient's death.

In the language of ethics, withholding and withdrawing life-sustaining treatment are morally distinct from physician-assisted suicide and euthanasia.²⁵ In physician-assisted suicide, a physician enables a patient to actively end his or her own life (eg, by writing a prescription for a large number of barbiturates); in the United States, this is legal only in Oregon. In euthanasia, a physician intentionally directly causes the patient's death (eg,

by injecting a bolus of potassium); euthanasia is illegal in the United States.

Physicians who are opposed to physician-assisted suicide and euthanasia are morally able to provide patients with adequate pain relief at the end of life through the "principle of double effect," in which providing the patient with adequate pain relief may unintentionally hasten the patient's death.²⁶

In forgoing a life-sustaining therapy such as nutrition and hydration, the patient's underlying disease causes death because the patient cannot live without the treatment.

Some may view these distinctions as semantics or symbolism, but as we noted earlier, the meanings we attach to things are very important. In a practical sense, if every discontinuation of life-supporting treatment were viewed as "killing," physicians would be reluctant to start potentially effective treatments and unwilling to stop ineffective ones.¹⁰

■ CAN FAMILY MEMBERS DECIDE?

Most patients and families do not have the medical knowledge and clinical experience to make medical decisions by themselves and therefore need the physician's guidance. In the case previously discussed, letting the patient's wife decide could be viewed as an abdication of physician responsibility because it assumes that the wife has knowledge and clinical experience equal to the physician's. However, the wife may be in the best position to know her husband's treatment preferences.

Together, the medical team and the family can consolidate their knowledge to set goals of care for the patient. Neither a loving family nor a caring physician wants to feel responsible for a patient's death. Shared decision-making means taking shared responsibility for decisions. Focusing on the disease process as the cause of death, as well as on realistic goals of comfort care, may help the family and the physician provide optimal end-of-life care.

■ PRINCIPLES FOR DECISION-MAKING

How should physicians handle situations such as the one described in the case at the beginning of this article?

Clinical judgment should take priority in decisions about tube feeding



- **Physicians need to further educate themselves** about the clinical burdens and benefits of feeding tubes and the symbolic power often attributed to this treatment. Journal articles and ethics textbooks are primary sources of information. The sharing of evidence-based knowledge with colleagues and students is important because physicians who are unclear about the clinical and ethical issues surrounding tube feeding are not able to effectively advise patients and families.

- **Clinical judgment should take priority** in decision-making. Specifically, what potential benefits or harm may result from this treatment, and how does it fit in with the overall goals of care?

- **Physicians and nurses need to consider their use of language** in speaking with patients and families. In patients with neurologic devastation and multiple medical problems, team members may view further aggressive treatment as futile. However, family members may interpret the word “futile” to mean that the physician does not think their loved one is worthy of care. Similarly, the term “withdrawal of care” may conjure concerns that the physician will stop caring and abandon their loved one.

In their program “Education for Physicians on End-of-Life Care,” the AMA recommends using language that emphasizes the goals of care (ie, “I will focus my efforts on treating your symptoms,” or “We will concentrate on improving the quality of your life.”)¹⁴

In the case of forgoing nutrition and hydration, the term “feeding tube” is misleading because the patient is not being fed in the normal social manner. A more descriptive and less emotionally laden term such as “gastric tube” or “stomach tube” could be used.²⁷

■ SUMMARY

The provision or discontinuation of nutrition and hydration at the end of life is a clinical decision that is complicated by the images associated with this technology. However, the process of decision-making is the same as that involved in the provision or discontinuation of any other kind of life-supporting treatment.

Basing their decisions on clinical evidence, physicians are beginning to reconsider routine tube feeding in patients with end-stage dementia.^{8,9} Such reconsideration may eventually lead to better care for all patients at the end of life.

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