Healthline VOLUME 20

Coram®* Continuing Education Program

Nutrition Support at End of Life

As technology evolves and enables patients to enjoy longer lives, ethical issues arise throughout the patient care continuum. At end of life, these issues can include decision-making related to the delivery of nutrition support. Impacting this decision-making are factors such as limited resources, equitable access, quality of life and who defines it, patient autonomy, and informed consent, all of which must be addressed at a time when care goals include maintaining moral and ethical balance and preserving patient dignity.

At the end of this program, the reader will be able to:

1. Describe the hierarchy of ethical principles relevant to healthcare;
2. Identify factors that can affect continuing or discontinuing nutrition support care at end of life; and
3. Explain the need for informed consent for the patient and/or family regarding nutrition support at end of life.

Background

Nutrition support in the form of parenteral (intravenous) or enteral (tube feeding) nutrition may be considered for patients when their usual oral diet cannot be tolerated. Surrounding the use of nutrition support in patients at end of life are issues concerning initiating, withholding, and withdrawing sustenance. According to the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.), nutrition support therapy is considered a medical therapy. Withholding or withdrawing nutrition support therapy often involves considerations different from those associated with other life-sustaining therapies, in part because of associated emotions, religious beliefs, and patient wishes regarding acceptable interventions. Incorporating nutrition support therapy in a patient care plan involves understanding the medical indications for, as well as the benefits and burdens of, nutrition support, and applying this intervention in a moral, ethical, and legal manner that is satisfactory to patients, families, and caregivers.[1] Ultimately, when deciding if or how to incorporate nutrition support in the end-of-life care plan, it is paramount that the patient's decision is made after he or she has been educated on the therapy's potential benefits and burdens.

> From a legal perspective, there is no distinction between withdrawing or withholding nutrition care.[2] However, there may be strongly perceived differences to patients, families and healthcare providers.

Ethical Principles Involved

A hierarchy of ethical principles comes into play in support of informed decision-making for patients.

Nonmaleficence is the principle of "do no harm." Healthcare providers are obligated: 1) not to inflict evil or harm upon patients, and 2) to prevent evil or harm when possible. This principle is frequently considered in decisions concerning initiation or discontinuation of nutrition support.

Beneficence is the principle by which healthcare professionals actively do good. Since the ultimate goal of any medical intervention should be improvement of the patient's prognosis, comfort, well-being, and/or general state of health, beneficence surrounding nutrition support takes into consideration anticipated benefits and the recognition of potential burdens. See "Benefits and Burdens of Nutrition Support for All Patients" below.

The Principle of Autonomy

Autonomy is a primary principle of healthcare ethics; it prioritizes the competent patient's right to make his or her own treatment decisions. According to this principle, individuals have the right to request or refuse nutrition and hydration as a component of their medical treatment. In order to make informed and reasonable decisions regarding these issues, patients must be given an honest assessment of their condition, prognosis, and the benefits and burdens of proposed treatments.

Autonomy is important because only the patient can define his or her own quality of life, and they should have the key voice in deciding if and how to sustain that life. The definition of "ordinary" versus "extraordinary" support will vary among patients and families. For example, enteral feeding may be considered ordinary care to one patient, while another views it as "the beginning of the end" and therefore a treatment to be avoided. Clear and thorough explanations from healthcare providers regarding the benefits and burdens of treatment are essential to helping patients and caregivers make these critical decisions.

When individuals opt to forgo any type of nutrition and hydration, perhaps despite medical evidence of benefit, ethical deliberation ensues and must address clinical, ethical, and legal factors.[3] (This must also occur when individuals lack decision-making capacity and others must decide how to proceed.) Arguments can be made both for and against the provision of nutrition support, but the informed patient must always have the strongest say. It is a primary healthcare team responsibility to ensure that the patient clearly understands his or her right to make and exercise treatment decisions throughout the continuum of care.

Decision-making

There are numerous ways in which a patient and family can help ensure that decision-making reflects their desires and beliefs. Communication should be initiated when the patient is competent and can make his or her wishes known to friends, family and healthcare providers. Missing this important early step can result in family conflict; different family members can perceive the patient's intentions in different ways since they are also influenced by their own fears, beliefs, and knowledge. The result may be that the patient receives medical treatments that go against his or her wishes.

One way to communicate wishes effectively is for the patient to complete a Living Will or Durable Power of Attorney, which are each referred to as an Advanced Directive. These legal documents specify which medical treatments the patient does and does not want to undergo, and who should make decisions on their behalf in the event that the patient is unable to do so. Some examples of issues that can be addressed in an Advanced Directive include:

- Withdrawing/withholding care
- Delineation of the meaning of palliative care
- Identification of a surrogate to help make patient-preferred decisions in case the patient is not able to make a decision

Of course, all therapies should be initiated with the understanding that benefit versus burden will be reevaluated periodically, including any psychosocial impact on the family.

Benefits and Burdens of Nutrition Support for All Patients

Healthcare team members must deliver medically appropriate treatment using evidence-based medicine, and inform the patient and family of the benefits and risks or burdens associated with that therapy for that particular patient. Let us consider potential and anticipated benefits and burdens of nutrition support.

> The patient's best interests should always be at the center of healthcare decisions. Patient-centered care is defined as care that is respectful of the individual person and responsive to his or her preferences, needs, and values, and care that ensures that patient values guide all decisions.[4]

Global Benefits of Nutrition Support

As stated above, the ultimate goal of any medical intervention should be improvement in the patient's prognosis, comfort, well-being, and/or general state of health. For many patients, nutrition support, including oral nutritional supplements, enteral tube feeding, and parenteral nutrition, is an important component of their care management, positively impacting clinical outcomes, resource utilization, including hospital length of stay, and total cost of care. Adequate nutrition supports a patient's healing and recovery, can help prevent complications such as infections or decubiti, and helps support immune

> It is the position of the **Academy of Nutrition and Dietetics** that individuals have the right to request or refuse nutrition and hydration as medical treatment…When individuals choose to forgo any type of nutrition and hydration (natural or artificial), or when individuals lack decision-making capacity and others must decide whether or not to provide artificial nutrition and hydration, registered dietitians have a professional role in the ethical deliberation around those decisions.[3]

system function. By preventing complications of malnutrition, it can also promote such potential benefits as: longer length of life; restored systemic functions, including improved wound healing and response to therapy; relief from pain and suffering; and improved quality of life. For other patients, however, the burdens of nutritional support therapy may outweigh the benefits and/or go against the patient's wishes.

Enteral Feeding—Administration and Burdens

Depending on the patient's level of awareness and/or anticipated length of therapy, there are several different options for the provision of enteral feedings. Most often, a nasogastric (NG) tube, or either a gastrostomy tube (G-tube) or jejunostomy tube (J-tube), is used. For a conscious patient for whom nutrition support is either urgent or anticipated to be short-term, an NG tube, which is placed through the nasal passages into the stomach, may be the best choice. Placement of an NG tube can be uncomfortable for the patient, particularly if the nasal passages are not adequately anesthetized and/or the patient is not clear on their responsibilities to help versus fight the insertion.

If longer-term enteral nutrition (EN) is anticipated, it is typically provided via a G-tube or J-tube. These accesses, however, carry the burden of surgical placement.

Enteral feedings, regardless of type of tube placement, can also cause distension, nausea, and diarrhea. Additional risks/burdens may include vomiting, aspiration, and subsequent pneumonia, particularly in patients with reduced oral and pharyngeal sensation. Dysphagia, delayed gastric emptying, and reflux due to supine position can also negatively impact patient comfort. All of these risks can be reduced with proper patient and/or caregiver education and ongoing patient monitoring. A registered dietitian is a valuable resource in such cases, and can recommend appropriate formulas to help improve tolerance, troubleshoot access device and pump issues, and assist in reducing therapy-related symptoms.

Complications of Enteral Feeding In Dementia Population

Up to a third of nursing home patients with advanced dementia have a feeding tube.[5] Those with advanced dementia often develop dysphagia and experience changes in appetite. Apraxia (difficulty coordinating movements) may make it too difficult for a patient to feed him- or herself. Because of these disease-related changes, and the concerns and emotional burden often associated with watching a family member not effectively eating, relatives may request EN, voicing concern that the patient may starve. Clinicians, aware that in some cases the risks outweigh the burdens, may nonetheless feel pressured by institutional, societal, or even legal directives to intervene.

Compounding the difficulty of decision-making is a lack of firm evidence supporting the use of EN in these situations. It is not clear whether EN is effective in prolonging survival, improving quality of life, or decreasing the risk of pressure sores. In fact, enteral feeding may actually increase the risk of developing pneumonia, due to inhaling small quantities of the feed, and may even increase the risk death.[6]

Complications of Parenteral Feeding

Factors that may negatively impact the patient experience with parenteral nutrition (PN) include the development of therapy-related complications. Central line

Table 1

Questions to Ask When Considering the Use of Nutrition Support
• What is the level of risk for potential medical and metabolic complications for each available nutrition alternative?
• Will the administration of EN or PN at home or in a healthcare facility be contraindicated because of staffing, monitoring ability, or financial constraints?
• Is it more humane for the patient to stop the aggressive provision of nutrition?
• Is death imminent—within hours or days?
• Is the enteral patient at risk for aspiration, diarrhea, or vomiting that may lead to further complications?
• Is the PN patient at risk for fluid overload, infection, or metabolic alterations?
• Has the competent patient expressed an informed preference not to receive aggressive nutrition support that would not improve quality of life, or is the intervention perceived by the patient to be undignified, degrading, or physically or emotionally unacceptable?

infections, or other catheter-related complications, are of particular concern in an already compromised patient. Fluid overload, ascites, peripheral edema, pulmonary edema, hyperglycemia, and thrombosis are other potential complications, the development of which can create significant and lasting patient burden. Minimizing the risk of such complications requires committed, skilled nursing assessment, teaching and monitoring. Perceived burdens may include the numerous patient or caregiver responsibilities associated with therapy administration.

Misconceptions About Nutrition Support Therapy at End of Life

Patients and their families often carry misconceptions regarding the impact of either providing or withdrawing nutrition support and hydration at the end of life. These misunderstandings must be resolved to ensure that informed consent is uncompromised.

For example, patients and family members often question whether, at the end of life, the withdrawal of artificial nutrition and hydration will lead to a long and painful death. In fact, the situation is likely to be the opposite. Patients near death are seldom hungry. If patients do feel hunger, small amounts of food will usually satisfy them.[7] Symptoms such as nausea, vomiting, abdominal pain, incontinence, congestion, and shortness of breath are often diminished when artificial nutrition and hydration are discontinued, increasing the patient's comfort.[8]

Starvation and dehydration affecting the metabolism: elevated levels of ketones produce a mild sense of euphoria, and the sense of hunger is actually eliminated. Importantly, too, the body produces endorphins, a natural pain reliever, in response to a lack of food. This effect is lost if patients take in food.[8] In another example, pneumonia patients cough less and experience decreased shortness of breath when their fluid intake is decreased.[10] In fact, for these patients, providing nutrition support during this time can actually decrease quality of life by increasing secretions and urine output and preventing the numbing effect of dehydration.

There are also burdens, however, with withholding hydration. Dry mouth is a burden associated with a lack of intake, but can be managed with oral hygiene that includes ice chips, lip and mouth lubrication, and mouth swabs. In addition, while endogenous endorphin production increases and provides additional opiate-like pain relief, it also contributes to confusion, lethargy, and hypernatremia.

Role of the Healthcare Team

According to The Joint Commission (TJC), the patient has the right to participate in decisions regarding his or her care, including the right to refuse treatment such as nutrition support. Patients must be informed by healthcare practitioners of the risks, benefits, and burdens of nutrition support. And advance directives should be made available to address the patients' preferences, goals, and values. Each TJC-accredited healthcare facility must have a system in place to meet these standards.

If a patient's condition is virtually certain to be irreversible, the healthcare team will need to establish guidelines regarding if and when to stop nutrition support. Healthcare team members must set patient-centered goals that respect the unique values and the personal decision of the patient. Within the extent allowed by the law, the family should share in decision-making when the patient's preference is not stated. The healthcare team should discuss with the family the issues of ethics, values, and/or religious guidelines as needed.

The dietitian should provide education about nutrition and hydration issues and options. He or she should also help the patient and family understand the administration of the therapy itself and the responsibilities they can expect to face once at home.

The clinician should work with the medical team to: review the benefits and burdens of each therapy and ensure that the family is well-informed; serve as a patient advocate; and participate in navigation of the legal and ethical issues regarding nutrition support feeding.

Table 2

The Role of the Healthcare Team
• Establish guidelines
• Educate patient and family members on oral, enteral, parenteral nutrition
• Communicate with patients and their families
• Participate in ethics committee
• Enforce policy for advance directives

Other Consideration: Religious Concerns

While developing overall guidelines for nutrition support at end of life, it is valuable to consult with religious or spiritual leaders to incorporate interventions that are appropriate

based on the religious tenets. One specific issue that may be affected by religion is advance directives. Because medical conditions are highly variable and unpredictable, and because the directives are written in advance, and have changed subsequent to the original directive, some may argue that advanced directives not be honored.

The patient and family also often find value in consulting with religious leaders as they are making decisions about their own end-of-life care. They may not be aware of their religion's stance on ethical issues, and even if they are aware of the specific teachings, they may not adhere to the same philosophy. It is important for healthcare providers to confirm what the patient believes and wants before assuming that they wish to follow their religious doctrine.

Conclusion

Decisions surrounding whether and how to incorporate nutrition support therapy into a patient care plan at end of life can be challenging for patients, families, and healthcare providers. On the part of the healthcare team, it involves understanding the medical indications of the particular therapy, understanding the associated benefits and burdens, and applying these interventions in an ethical and legal way. It also involves helping patients make the decisions that are right for them, or, when the patient is not able to make decisions, helping families voice what the patient would have wanted. Overall, managing nutrition support decisions at end of life focuses on avoiding harm, doing good, and supporting patient autonomy based on informed consent and the patient's perception of benefit versus burden and ordinary versus extraordinary care. ♦

Do not use the information in this article to diagnose or treat a health problem or disease without consulting a qualified physician. Patients should consult their physician before starting any course of treatment or supplementation, particularly if they are currently under medical care, and should never disregard medical advice or delay in seeking it because of something set forth in this publication.

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Self-Assessment Quiz: Nutrition Support at End of Life

LEARNING GOAL

To have a basic understanding of:

1) the key principles that must be addressed around nutrition support and the end of life; and 2) the benefits and burdens of nutrition support in the last phases of life.

LEARNING OBJECTIVES

At the end of this program, the reader will be able to:

1. Describe the hierarchy of ethical principles relevant to healthcare;
2. Identify factors that can affect continuing or discontinuing nutrition support care at end of life; and
3. Explain the need for informed consent for the patient and/or family regarding nutrition support at end of life.

SELF-ASSESSMENT QUESTIONS

In the Quiz Answers section on the next page, fill in the correct answer for each question. To obtain two (2.0) contact hours toward CE credit, the passing score is 100%. Return your Self-Assesment Quiz to Coram via email or fax. See the next page for details on how to return to your quiz. Please allow approximately seven days to process your test and receive your certificate upon achieving a passing score.

1. **According to the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.), nutrition support therapy is considered a medical therapy.**
   a. True
   b. False

2. **In legal interpretations, there is no distinction between withdrawing or withholding nutrition care.**
   a. True
   b. False

3. **Ultimately, when deciding if or how to incorporate nutrition support in the end-of-life care plan, it is paramount that the patient's decision be made after:**
   a. Understanding the clinical indication for nutrition therapy
   b. Having had education on the therapy's potential benefits and burdens
   c. A and B

4. **The following statements are true about the ethical principle of autonomy EXCEPT:**
   a. Autonomy prioritizes the competent patient's right to make his or her own treatment decisions.
   b. Autonomy cannot be considered with the incompetent patient.
   c. According to this principle, individuals have the right to request or refuse nutrition and hydration as a component of their medical treatment.
   d. An autonomous decision requires that the patient be given an honest assessment.

5. **Outside resources such as clergy may be consulted in order to help determine the patient's quality of life.**
   a. True
   b. False

6. **Potential benefits of nutrition support include:**
   a. Positively impacted clinical outcomes
   b. Improved immune system function
   c. Decreased risk of complications
   d. All of the above
   e. B and C

7. **Potential burdens of enteral feeding include:**
   a. Discomfort during NG-tube placement
   b. Surgical placement of a J-tube or G-tube
   c. Abdominal distension
   d. Pneumonia
   e. A and B
   f. All of the above

8. **Potential burdens of parenteral feeding include all of the following EXCEPT:**
   a. Decreased risk of central line infection
   b. Fluid overload
   c. Therapy cost
   d. Patient and caregiver responsibilities

9. **Which of the following statement(s) is (are) true regarding withholding nutrition support at end of life:**
   a. The body produces endorphins, a natural pain reliever
   b. The sense of hunger is eliminated
   c. Patients feel a mild sense of euphoria
   d. B and C
   e. All of the above

10. **According to The Joint Commission (TJC), advance directives should be made available to address the patient's preferences, goals and values.**
    a. True
    b. False

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QUIZ ANSWERS

Fill in the key below with the correct answers to receive 2.0 Continuing Education credits.**

1. (a) (b)
2. (a) (b)
3. (a) (b) (c)
4. (a) (b) (c) (d)
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7. (a) (b) (c) (d) (e) (f)
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9. (a) (b) (c) (d) (e)
10. (a) (b)

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