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Nutrition at the End of Life: It's Not What You Say, It's How You Say It

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Abstract
Purpose of Review The purpose of this review is to describe and appraise the available scientific evidence to guide the use of artificial nutrition and hydration at the end of life, with a focus on communicating with patients and families who are facing these decisions.
Recent Findings Research suggests artificial nutrition and hydration (ANH) may be burdensome at the end of life, yet disparities for its use in clinical practice persist. While no clear evidence supports the use of ANH for the majority of terminally ill patients, emerging data suggests that a subset of patients may derive some benefit.
Summary No clear criteria exist to ascertain the beginning of the dying phase, which can present challenges surrounding ANH. A better understanding of symptom burden and thoughtful communication between the clinician and patient can facilitate development of a medical plan of care, with or without ANH, that best meets the patient's goals of care.

Keywords Artificial nutrition and hydration · Enteral nutrition · Parenteral nutrition · Intravenous fluids · Nutrition support · End of life

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Introduction

The overall goal of artificial nutrition and hydration (ANH) is to optimize nutritional status and maintain fluid balance when the medical condition or behavior prevents adequate oral intake. For all patients, the biologic rationale of any intervention to improve the underlying medical condition needs to be considered. Furthermore, the benefits must be weighed against potential harms and filtered through patient's values, goals of care, quality of life, and financial resources. Decisions regarding ANH at the end of life may present a dilemma if two or more of the ethical principles (autonomy, beneficence, nonmaleficence, and justice) are in conflict. The objective of this review will be to (a) provide an overview of ANH, (b) describe the benefits and burdens of ANH, (c) describe challenges related to ANH at the end of life, (d) discuss withholding/withdrawing ANH at the end of life, and (e) discuss alternative approaches to ANH.

Artificial Nutrition and Hydration

ANH can be a life-sustaining medical intervention that allows an individual to receive nutrients and fluid when they are no longer able to take them orally. ANH can be provided via enteral nutrition (EN), parenteral nutrition (PN), and intravenous fluids (IVF). Each method carries benefits and risks that

need to be considered a priori to determine the best route of nutrition support to provide for the patient. The various types of artificial nutrition and hydration are briefly summarized below (Table 1).

EN delivers nutrients distal to the oral cavity when the patient is not able to meet their nutritional requirements orally [1]. For short-term enteral access (<4 weeks), a feeding tube can be inserted through the nose or mouth, with the tip of the feeding tube terminating within the stomach or small bowel. Long-term enteral access (>4 weeks) generally warrants a more permanent device such as a gastrostomy or jejunostomy tube, both of which can be placed using endoscopic, fluoroscopic, radiologic, or surgical techniques. Various methods are available for EN delivery, including continuous, intermittent, and bolus feeding options. The patient's medical condition, feeding tube tip location, and history of tolerance or intolerance to EN will determine the initial feeding method which can change as the patient's clinical status changes [2]. Benefits must be weighed against potential EN complications, including gastrointestinal issues (e.g., constipation, diarrhea, bloating, nausea, vomiting), pulmonary aspiration with or without pneumonia, drug-nutrient interaction, and clogged or dislodged feeding tubes. Despite these potential complications, EN is the preferred route of nutritional therapy in patients with a functional gastrointestinal tract.

ANH can be administered through the parenteral route when there is a contraindication for EN. PN confers a higher risk of complications compared to EN. Potential complications that need to be considered by the healthcare team include increased infection risk associated with intravenous access, stability and compatibility of the formulation, excess fluid accumulation, and metabolic alterations such as hyperglycemia, hyperlipidemia, azotemia, and electrolyte or acid-base imbalance [3]. For these reasons, frequent laboratory monitoring is often required to guide adjustments in PN dose, composition, and infusion schedule.

IVF alone can provide sufficient volume to prevent dehydration when a patient has incomplete or complete lack of oral hydration. For example, certain conditions such as dysphagia may require thickened liquids to prevent aspiration; however, thickened liquids may be less palatable and the diminished fluid intake can lead to dehydration. Excessive fluid loss can also accelerate the development of dehydration and a patient may not be able to maintain adequate fluid balance. Examples of these situations include chemotherapy-induced diarrhea, high ileostomy or colostomy output, and high-volume gastric fluid output. IVF administration predisposes the patient to less risk than PN, but does include the risk for bloodstream infection, and depending on the type of IV solution used, electrolyte imbalances.

Nutrition is viewed as a proactive and therapeutic strategy that may reduce disease severity, diminish complications, and favorably impact patient outcomes [4]. The success of ANH therapy, however, depends on the patient's clinical state and disease process. As it applies to end-of-life care, it is important to determine whether ANH has the ability to improve the underlying medical condition or contribute to symptom management. If the disease process is considered terminal, ANH becomes a "low yield" (i.e., palliative) therapy and the patient, family, and healthcare team must discuss how to proceed in the best interest of the patient.

Table 1 Types of artificial nutrition and hydration

Method	Potential benefits	Potential risks/burdens
Enteral nutrition	1. Sense of relief that nutritional needs are being met	1. Constipation, diarrhea, bloating, nausea, vomiting 2. Pulmonary aspiration 3. Clogged feeding tubes 4. Decreased mobility
Parenteral nutrition	1. Sense of relief that nutritional needs are being met 2. Symptom management for dysphagia, nausea/vomiting, and fatigue 3. Preserve functional status with slow-growing malignancy	1. Edema and ascites 2. Hyperglycemia, hyperlipidemia, azotemia, electrolyte, or acid-base imbalance 3. Bloodstream infection 4. Decreased mobility
Intravenous fluids	1. Alleviates thirst 2. Provides comfort and prevents uncomfortable symptoms such as confusion, agitation, delirium 3. Prevents neurotoxicity with high-dose narcotics	1. Frequent urination; urinary incontinence 2. Edema and ascites 3. Increased pulmonary secretions which may cause cough, choking, congestion 4. Bloodstream infection

Benefits Versus Burdens of ANH: a Quality of Life Discussion

When ANH is being considered, it is important to evaluate the potential risks and burdens to the patient and to provide therapy only when the benefits outweigh those burdens [5]. When the patient's or family's focus is to prevent death by starvation, a common misconception associated with forgoing ANH, the "big picture" may easily be overlooked. As in the case of advanced cancer diagnosis, for example, the dying process is not a direct consequence of nutrient deprivation, although a malnourished state may accompany the dying process [6]. Consideration of pathophysiologic changes associated with terminal illness, potential risks, and burdens associated with ANH itself, and also the potential discomfort associated with additional interventions required to execute and safely manage these therapies must all be considered. It is important that

the patient and family receive education on ANH at the end of life so that they can make informed decisions.

In the general population, starvation is the result of a prolonged period of fasting and is known to be accompanied by undesirable symptoms such as hunger, irritability, and weakness. Historically, research on the pathophysiology of patients with brain death, in a coma, or in a persistent vegetative state indicates that these patients do not experience thirst or hunger. This lack of hunger is due to absence of neuronal function in brain-dead patients and reduced cerebral metabolism in comatose and vegetative patients, similar to the reductions seen in general anesthesia [7]. Scientific findings also suggest that ketosis and dehydration are protective mechanisms against potentially painful symptoms of dying in conscious patients [8]. Ketones have anesthetic properties and some experts believe that fasting increases endorphin release [9]. Similarly, dehydration is accompanied by hyperosmolarity, azotemia, hypernatremia, and hypercalcemia which are associated with sedative properties. In a study of 32 patients admitted to hospice, 31 patients reported never experiencing hunger or experiencing hunger only initially, while 1 patient reported hunger until death. Regarding thirst, 11 patients reported never being thirsty, 9 reported thirst only initially, and 12 reported at least some thirst on the day of death that was managed with mouth moisture [10]. As more research emerges on the symptom burden at the end of life, however, providers may be better able to identify opportunities for symptom management. The symptom burden in cancer patients in their last days of life, for example, includes dyspnea, pain, drowsiness, confusion and delirium, nausea, vomiting, constipation, dry mouth, anorexia, dysphagia, anxiety or dysphoria, myoclonus, insomnia, and general weakness [11•]. Furthermore, artificial hydration may prevent the accumulation of opioid metabolites as well as other drugs, possibly resulting in the improvement or prevention of delirium [12]. A recent randomized controlled pilot study in 49 mild to moderately dehydrated terminally ill cancer patients found that hydration, compared with placebo, was associated with significant improvements in sedation and myoclonus, although no difference was observed for symptoms of fatigue, hallucinations, well-being, or perceived overall benefit [13•]. A subsequent large randomized controlled trial by Bruera did not find hydration to be superior to placebo in improving symptoms of dehydration such as hallucinations, myoclonus, fatigue, and sedation [14••]. Three trials exploring the perceptions and efficacy of ANH in advanced and end-stage cancers are currently underway [15].

To provide enteral nutrition, enteral access is required either via a nasoenteric (short-term) or enterostomy (long-term) device. If the patient is confused, disoriented, restless, agitated, or anxious, the likelihood that they will inadvertently pull their tube out is higher [16]. Parenteral nutrition and hydration require either peripheral (short-term) or central (long-term) intravenous access. Inadvertent manipulation of these access devices increases the patient's risk of infection and injury. To maintain patient safety, additional interventions such as nasal bridles and/or restraints may be required to prevent device manipulation. Unfortunately, these interventions may increase discomfort and limit patient mobility and independence. With the use of PN or continuous EN, the patient is more likely to be immobile during feeding while connected to the infusion pump. One study demonstrated an increased risk of developing new pressure ulcers because of decreased mobility following enterostomy tube placement [17]. Lastly, to safely manage ANH, routine monitoring of laboratory values may be required. With PN or IV dextrose, blood glucose monitoring via finger stick and/or regular phlebotomy may impair quality of life. An interview of advanced cancer patients and their families, however, revealed a sense of relief when nutritional needs were being met, which prevailed over the burden of limited mobility and reduced contact with family and friends [18].

Aside from the potential discomforts associated with placement and maintenance of access devices and laboratory monitoring, individual tolerance to ANH may vary considerably. Research has consistently demonstrated that enteral nutrition in terminally ill patients is associated with increased nausea, vomiting, diarrhea, and repeated aspiration pneumonia [19]. In some reports, PN has been used to treat nausea, vomiting, and fatigue rather than a non-functional gastrointestinal tract [20]. PN may be of benefit in patients with good functional status who suffer from an indolent malignancy and symptoms of starvation. In a prospective study of home PN patients with malignant gastrointestinal (GI) obstruction, those with a high functional score had longer survival than those with a lower functional score. However, patients with malignant GI obstruction had an increased rate of infection complications than those with non-malignant GI obstruction [21]. PN and IV hydration may also cause bladder distention, urinary frequency, bronchial secretions, dyspnea, pulmonary edema, and effusions or ascites [22]. Treatment or management of these symptoms may include additional medications, catheter placement, imaging studies, or invasive medical procedures. It is important that the clinician inform the patient of these potential benefits and burdens prior to initiation of PN.

Challenges to Nutrition at the End of Life

ANH has not been shown to prolong life in patients with terminal conditions. In many cases, increasing the amount of nutrients a patient receives will not change the overall trajectory of a terminal illness. Rather, the goal of nutritional interventions at the end of life should change from maintaining nutritional and functional status (e.g., weight, lean body mass, etc.) to ensuring the comfort and well-being of the patient. The transition to comfort measures may vary from patient to

patient depending on disease trajectory, treatment options, and individual values but is generally considered when therapeutic and prognostic treatment options are limited. Strong consensus suggests that prolonging life through artificial means should not prolong the dying process [5]. For many conditions, there are no clear criteria to differentiate when a patient progresses from a chronic disease to the dying phase. Additionally, estimating survival time remains a significant challenge when making recommendations or decisions regarding withholding or withdrawing ANH.

Even though estimating survival remains a significant challenge, the onset of eating difficulties in various conditions may indicate advanced disease. For example, the onset of eating difficulties is the hallmark of advanced dementia [23]. Anorexia is observed with advanced cancer, acquired immune deficiency syndrome (AIDS), advanced heart failure, and advanced chronic obstructive pulmonary disease. Dysphagia with swallowing may be another marker for terminal disease, especially head and neck cancer and neurologic conditions such as amyotrophic lateral sclerosis. These patients are often at risk for aspiration. Route and type of nutrition therapy may be the most common treatment decisions encountered for patients and surrogate decision-makers.

Withholding Versus Withdrawing: It's Not What You Say, It's How You say It

Withdrawing ANH is the action of discontinuing therapy for patients who have been receiving it. Commonly, patients or family members of patients with conditions such as amyotrophic lateral sclerosis (ALS), head and neck cancer, traumatic brain injury, or cerebrovascular accident will be faced with the decision to withdraw ANH, as it is a commonly used therapy in these populations. On the contrary, withholding ANH refers to non-action of not starting ANH for patients not previously receiving it. From scientific, legal, and ethical perspectives, there is no difference between the two terms. These two terms may have significant implications for patients and their families. Many consider "food" to be a necessity for life; the type, quality, quality, and frequency of food intake is personal with deep cultural and social roots. Although they are equivalent, the term "withdrawal" of ANH may be more emotionally difficult than "withholding" and could be perceived as abandonment, lack of caring, and/or purposeful starvation. Unfortunately, this may be the reason many healthcare providers shy away from raising this important issue with patients and family members. For the healthcare provider, it is important to recognize and differentiate emotions associated with food from nutrition support, the latter considered a form of medical therapy [24]. Additionally, the choice and phrasing of words used are critical when discussing withholding or withdrawing ANH. For example, ethics experts recommend using the term "forgoing ANH" as a more suitable choice of words, as opposed to terms such as "futile," which may pose confusion or be intimidating [8]. Furthermore, terms such as "medically inappropriate," "medically ineffective," or "low yield" to describe interventions may be received with less emotional distress [25, 26].

Alternative Approaches and Goal Setting

When developing a plan of care with a patient and their family members during terminal illness, it is important to display respect for the patient and incorporate the ethical principles of autonomy, beneficence, non-maleficence, and justice. In some instances, however, the clinician may be faced with an ethical dilemma when two or more of these principles are in conflict.

Despite the burdens that may be associated with ANH at the end of life, it is entirely possible that a patient or family member value their *quantity* of life over the quality. For example, a patient may wish for full medical cares, regardless of their own comfort, to live long enough to witness monumental life events, such as a marriage or the birth of a child or grandchild. In these circumstances, it is important to respect the patient's autonomy to make these informed decisions.

Religious beliefs, cultural beliefs, and general attitude regarding ANH should be taken into consideration during the decision-making process. Many clinicians have limited knowledge of the specific values and preferences within other cultures regarding end-of-life care and should make every effort to speak with the patient or the patient's family in order to understand their individual views, preferences, and values regarding ANH during this phase of life [5].

When the patient/family and healthcare team determine that ANH is not (or is no longer) consistent with the patient's goals of care, comfort feeding can be provided as a plan of care that specifically focuses on palliation and personal interaction. One benefit of comfort eating is the familiarity of food, which is especially important for patients with advanced dementia. Another benefit is the ability to stimulate the sense of taste, which is frequently listed as a subjective marker for quality of life. Comfort eating also increases the level of interaction, communication, and engagement between the patient and their family members or caretakers.

Time-limited trials are a widely accepted alternative to withholding or withdrawing ANH when there are logistical and emotional uncertainties surrounding this therapy [8]. With time-limited ANH trials, it is important to discuss expected short-term and long-term outcomes, and to reassess use of ANH therapy on a regular basis.

The advance directive remains the most useful tool to help family members and medical staff guide ANH. In a 2016 study of 99 elderly Japanese individuals, only 5% of patients wished to receive ANH during their end-of-life care. In fact,

up to 65% of respondents were against receiving ANH. Interestingly, however, only 27.6% of interviewed patients had discussed their views on ANH during end-of-life care with individuals who may someday become surrogate decision-makers [27].

Conclusions

Clinicians must learn effective communication skills and use them to initiate and maintain open and honest end-of-life care planning conversations with patients and family members. Doing so can help identify and address any fears or misconceptions the patient or family members may have regarding artificial nutrition and hydration (ANH). Being well educated on the benefits versus burdens of ANH in life-limiting illness will allow the clinician to educate patients and families, discuss alternative approaches to forgoing ANH all together, and establish a mutually agreed-upon plan of care. Patients should also be encouraged to establish advance directives and discuss their wishes with family members, as this ensures that their wishes are known and may help prevent ethical-legal conflicts at the end of life.

Compliance with Ethical Standards

Conflict of Interest Michelle Kozeniecki, Matthew Ewy, and Jayshil J. Patel declare they have no conflict of interest.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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- •• Of major importance

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