

# Artificial Hydration and Nutrition: A Practical Approach to Discussion and Decision-Making

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*It had been a difficult week. An 83-year-old long-term patient of mine had been admitted to the ICU with septic shock due to pneumonia. The prognosis looked grim. She had completed a living will and appointed a durable power of attorney for health care after many careful discussions in my office and at home. Despite her written wish not to be intubated or to be resuscitated in the event of a catastrophic illness, the family felt uncomfortable not “trying to do something.” After all, she had been living at home independently and had been very active up until this hospitalization. The patient had been intubated two weeks ago over a weekend while another physician was covering in the hope that her condition could be stabilized. Indeed, the patient had agreed to intubation “if it will help me get better.” It was now time to consider placement of a feeding tube and tracheotomy. But, given the patient’s condition and lack of progress, I was going to have to face this family and discuss end of life. In particular, the issue of artificial hydration and nutrition was sure to come up.*

This scenario is not uncommon in our current milieu of high technology in the hospital. Physicians frequently face complicated technological and ethical decisions that cannot be made in a vacuum – physicians need to be able to communicate this information to patients and their families in a time of crisis. It is important for each physician to understand the issues involved with life-threatening illness and end-of-life care because they are the trusted, physician-advisors to these patients and families. Ideally, an informed conversation regarding the types of decisions that may be faced in the hospital should take place prior to the time of hospitalization and crisis. Perhaps the most complex is that of artificial hydration and nutrition (AHN). In this article, a review of the pertinent issues regarding AHN in the literature will be presented and a framework for the physician to utilize in considering these issues which supports informed recommendations regarding the use of AHN in clinical practice will be provided.

When a patient is unable to maintain adequate nutrition

due to illness, the medical caregivers will necessarily look to technological means to provide the equivalent food and fluid. Many times caregivers initiate IV hydration and tube feeding while patients are hospitalized. This, however, should not be an automatic shift; the decision to provide this medical technology should be accompanied by a clear plan of care, taking into consideration the particular patient’s diagnosis, prognosis and realistic goals.

The assumption that all patients should have tube feeding has not been supported by scientific evidence.<sup>1,2,3,4,5</sup> Therefore, it is incumbent on the practitioner to determine whether the long-term provision of hydration and nutrition is not only supported by medical evidence but is also consistent with therapy goals. The prognosis for both survival and function associated with the patient’s illness should be clarified in the mind of the caregiver and communicated to the patient and family clearly so that informed decision-making is possible.

Withdrawal of AHN is not uncommon, nor is it immoral or illegal. In their article “Seven Legal Barriers to End-of-Life Care,” Meisel et al. discuss the facts regarding the legal issues surrounding end-of-life decisions. They point out that “many legal barriers to end-of-life care are more mythical than real.”<sup>6</sup> The American Medical Association (AMA) has issued a statement acknowledging that a physician can ethically withdraw all means of life-prolonging medical treatment, including food and water, from a patient in an irreversible coma. An excellent discussion of decision-making in the terminal patient can be found in the UNIPAC series.<sup>8</sup> The courts in many states and the U.S. Supreme Court have upheld this view and allowed the withdrawal of feeding tubes. Additionally, the American Academy of Hospice and Palliative Medicine clarifies that AHN are life-sustaining medical therapies with risks and benefits. The interventions comprising AHN may be indicated in the course of a terminal disease as a therapeutic trial directed toward well-defined, realistically set goals. AHN

may be withdrawn if the burden of therapy outweighs any benefit, or when the therapeutic goal shifts.<sup>7</sup>

Even with guidance and support, the decision to withdraw or withhold AHN at end of life may be a difficult decision for patients, families and health care staff. The patient's physical status, emotional and spiritual concerns, and prognosis may play a role in the decision to withhold or withdraw AHN.<sup>9,10</sup> When a decision is being made to withhold or withdraw any life-sustaining treatment, it should be based on:

1. Medical indications
2. Analysis of benefits vs. burdens
3. Determination of goals of treatment and quality of life based on patient wishes

Research provides us with evidence that not only do patients want to participate in their end-of-life decision-making, but they also overwhelmingly believe that their primary care physician should be the one to initiate the discussion. In 2005, Life Circle of South Dakota facilitated a survey of attitudes and knowledge about dying and end-of-life care in South Dakota. For this survey, a modified instrument from Life's End Institute was used. The survey was sent randomly to 10,204 South Dakota households.<sup>11</sup> Roughly 2,500 surveys (24.8 percent) were returned. The survey results indicated that 75 percent of those responding did not want artificial nutrition if they were dying and unable to eat. The results also revealed that 64 percent rejected artificial hydration if they were dying and unable to drink. Interestingly, the survey indicated that 88.8 percent of respondents felt "very comfortable" or "somewhat comfortable" talking about death. In contrast, only 6 percent indicated that they had discussed end-of-life care with their physicians. Thirty-nine percent said their physician should be the one to initiate end-of-life conversations, and 95 percent wanted honest answers from their physicians. This data supports that of other national studies about patient's wishes regarding end-of-life decisions.<sup>12,13</sup>

#### Medical Indications for AHN

The decision to initiate AHN in patients with advanced cancer or severe, life-threatening disease should be preceded by careful consideration of the goals of the patient and the evidence supporting this therapy.<sup>14</sup> The fact that medical technology is available does not mean that it is appropriate in every patient. The availability of PEG tubes

for enteral nutrition is an excellent example of how technology has been utilized without consideration of whether there is medical evidence that it is effective.<sup>2</sup> No studies demonstrate PEG tubes prevent aspiration, but PEG tubes are frequently placed with this reason as justification. Ethically and legally the decision to provide AHN is a medical decision. There is a tendency to allow cultural or emotional issues to influence the decision, leading to medically inappropriate actions.<sup>15,16</sup>

#### Burdens of AHN

1. Patient may require restraints to allow administration of AHN
2. Increased symptoms related to overhydration, or inability to tolerate feeding
3. Monitoring requirements, including laboratory draws
4. Increased caregiver responsibility, perhaps to the extent of changing the patient's location due to caregiver inability to perform necessary interventions
5. Risk of aspiration pneumonia, diabetes, diarrhea, gastrointestinal discomfort

#### Benefits of AHN

1. Dehydration-related delirium, myoclonus or seizures may respond to a trial of hydration<sup>17</sup>
2. A time trial may ease family anxiety and allow time to accept the ensuing loss of a loved one
3. Medically supplied nutrition may be indicated in specific situations:
  - a. Nonfunctional GI tract where death will occur due to malnutrition prior to the effects of the disease
  - b. Patients receiving curative therapy who temporarily are unable to maintain oral intake
  - c. A trial of nutrition is desired by the patient in whom nutrition may delay the loss of strength; in order to reach a specific goal (i.e., a family event)

Lack of hydration does not impose increased symptom burden in patients with terminal illness. Simple interventions such as moistening the lips, mouth care, and allowing sips of fluid and/or food have been demonstrated to relieve the symptoms of thirst and hunger.<sup>18</sup> Family and physician lack of understanding of the medical evidence regarding the benefits and burdens of artificial feeding may lead to

uninformed decision-making about the initiation of AHN. Personal feelings about the patient's weight loss and inanition, as well as the denial of the upcoming loss of a loved one can overshadow evidence-based decision-making. In particular, the weight loss associated with advanced cancer is expected due to decreased caloric intake as well as cancer mediated hypercatabolism.<sup>19</sup>

Use of parenteral nutrition (TPN) should be limited to those situations where it is medically indicated. Parenteral nutrition is not indicated in advanced cancer because it has not been demonstrated to benefit the patient.<sup>20</sup> There are a few exceptions to this:

1. Head and neck cancer patients undergoing radiation, who have weight loss due to inability to eat during treatment
2. Patients who have nonfunctional GI tract who are losing weight due to inability to eat, such as patients with proximal obstruction of the bowel due to carcinoma
3. Patients with extremely short gut syndrome or ALS may have improved survival and quality of life with AHN if initiated in a timely way<sup>14</sup>

In patients with dementia, the lack of medical evidence and misunderstanding of the risks and benefits often leads to the initiation of AHN. Not only does the initiation of AHN fail to delay the progression of the disease, but it also adds burden to the patient at end of life.<sup>1,2,3,4</sup> Guidelines that may be used in the process of decision-making include the Karnofsky Performance Scale Score or ECOG Performance Scale.<sup>19</sup> James Hallenbeck, MD, encourages a review of benefits vs. burden. In this editorial he notes the trend of gastroenterologists to act as technicians and place feeding tubes without consideration of the medical indications, benefits and burdens.<sup>15</sup>

Medical decisions should be preceded by clear prognostication. The importance of the physician evaluating the patient and effectively communicating the prognosis to the patient or surrogate decision-maker cannot be overstressed. There is evidence that accurate physician prognostication is sadly lacking in the current medical environment.

Nicholas Christakis, MD, demonstrated in a study of 504 patients in a hospice environment that "only 20 percent of the prognoses made by 365 physicians were correct" and that "63 percent were overestimates."<sup>21</sup>

Improved scientific tools for prognostication are becoming available as palliative care research has addressed the issue of improving communication in patients with severe, life-threatening disease. Prognostication will always be an inexact science. Physicians need to be more comfortable with assisting patients and families in the use of the information that is available to make informed decisions. The challenge is how to educate caregivers regarding the skills of prognostication and communication, particularly in our current medical culture where physician time is at a premium. Marks and Sachar illustrate the difficulty of achieving a change in physician behavior in their article in the *Annals of Internal Medicine*. An example of how difficult it is to disseminate new ideas about management of patients with common problems is illustrated by their evaluation of pain management. In this study, misinformation about the treatment of pain was frequent and led to the lack of adequate pain management in this population.<sup>22,23</sup> It has been demonstrated that understanding prognosis leads to the earlier application of symptom management, thereby decreasing suffering at the end of life.<sup>24</sup> Because patients and families have been shown to make decisions based on their survival probabilities, accurate prognostication could allow patients to make better decisions about treatment choices.<sup>25</sup> Rather than leading to loss of hope, truthful discussions about prognosis leads to improved patient and family communication. This allows the family to spend quality time with the patient and allows earlier application of palliative strategies. Palliative prognostic scoring can assist the physician in clarifying the survival of patients with life-threatening illness.<sup>26,27</sup> Physicians, therefore, should be aware of the prognostic features of a patient's illness and include this in the discussion of the plan of care early in the course of the disease.

### Ethical Aspects of AHN

End-of-life care, in general, and decisions regarding artificial hydration and nutrition specifically, can be fraught with moral, cultural and spiritual issues. Sometimes the underlying concern is not readily evident. It is important to remember to evaluate each patient, treatment and goals on their own merit, according to that patient's particular set of circumstances, but against the backdrop of appropriate and effective medical care (casuistry). Robert Veatch, professor of medical ethics at the Kennedy Institute for Ethics at Georgetown University, points out that physicians should

not make value judgments about the validity of the decisions that patients and their surrogates make. In reference to the case of prolonging life in terminally ill or unconscious patients, he makes the point that although he and many clinicians would make the decision not to prolong the life of such a patient, approximately “10 percent of the U.S. public concludes that it is worth preserving life even when it is permanently unconscious or will be both inevitably short and burdensome.” He further points out “health professionals and lay people who do see value in preserving such life are not objectively wrong. They are simply different.”<sup>28</sup> He further points out, however, that “although some patients value life prolongation [this] does not lead to the conclusion that they automatically have a right to the interventions at stake.” From a justice standpoint, some demanded treatments might be in the categories of treatments that health systems should not provide due to excessive cost and consumption of resources. Some might be demonstrated to be physiologically futile in producing the desired outcome, and beneficence would require physicians to unilaterally refuse to provide such treatments.” This tension between respect for autonomy and the physician’s call to prevent harm and promote good often lies at the crux of the ethical dilemmas health care providers struggle with when facing the question of whether to withhold or withdraw treatments. While we should be cautious about imposing our values on the patient or decision-maker, it is clearly our responsibility to offer care that is medically sound.

Surrogate decision-makers also have difficulty in separating their own interests from that of the patient. Veatch states that “No longer do we view with a degree of inevitability that we must all eventually die.”<sup>29</sup> In his discussion of the ethics of nutritional support at the end of life, he points out that “for many caregivers, separating the patient’s quality of life from their own interests can cause difficulties” in much the same way our beliefs as physicians can interfere with an honest conversation about end-of-life decisions. As a result of this muddling of interests, the patient may not receive adequate symptom control at the end of life or may have life-prolonging interventions that add to the burden of dying. For instance, many patients that are dying are encouraged to eat and drink by their family. It may become a point of contention, or even cause friction. In the natural course of the disease process, the patient is experiencing less

desire to eat, yet the family equates the provision of sustenance as a required and familiar form of nurturing. Carefully explaining the dynamics of the body’s natural rejection of food and redirecting families to mouth care, encouraging sips of water or ice chips can ease the tension and improve quality of life significantly.

The distraction of conflicts that occur can lead to a lack of attention to the patient’s spiritual and existential needs. These issues cause distress not only to the patient, but the family unit as well. Because despair at the end of life is not uncommon, it is especially important that conflicts are mediated and that the patient and loved ones’ psychosocial needs are attended to. “Awareness of events common to the dying process, the potential physical and psychosocial suffering ... and the end-of-life care practices associated with reducing that suffering can lead to ... being able to take a proactive rather than a reactive approach to end-of-life care.”<sup>30</sup>

This review is not complete without a discussion of the influence of religious beliefs on decisions regarding AHN. Religious and cultural values do influence decision-making when patients and families are considering AHN. A physician who is guiding patients and families through the decision-making process should not impose their own belief system on their patient. The decisions regarding end-of-life care, including AHN, should be based on the medical indications, with concurrent respect for the patient and family’s values and wishes. In advising families and patients it is important to consider their religious and cultural beliefs, possibly including their spiritual advisors in the conversation if desired. At the same time, assumptions about a particular religion or cultural background should be avoided. As previously discussed, any recommendation about treatment should be preceded with careful consideration of the medical indications and patient prognosis. Clear discussion of the goals of AHN and the expected outcome can lead to cohesive goals that everyone can accept and support. Many religions have guidance available for their congregants to use in negotiating these types of decisions. Physicians are encouraged to become familiar with the religious philosophies common to their locale. A palliative care team or hospital chaplaincy can frequently assist in these discussions to assure that valid information is available to everyone involved.<sup>31</sup>

The physician caring for a patient with a potentially life-limiting disease is faced with many difficult tasks. In the usual course of medicine, diagnosis, treatment planning, support for the patient and cure generally fall together. It can be challenging when “cure” is elusive. Our responsibility is to be aware of the patient’s prognosis, ethical issues and wishes. We guide patients through difficult times and advise them during difficult decisions. In his book *The Nature of Suffering and the Goals of Medicine*, Eric Cassell

states “It is the responsibility of physicians to care for the sick even with imperfect means in a sea of uncertainty. This is the source of their grace. Thus it has always been and thus it is now — the relief of suffering is the fundamental goal of medicine.”<sup>32</sup>

We need not fear addressing the issue of AHN; working to choose appropriate interventions represents the core of why we are physicians – to care for patients.

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