

## SOUNDING BOARD

## Appropriate Use of Artificial Nutrition and Hydration — Fundamental Principles and Recommendations

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For two decades, clinicians have been guided by an agreement about the appropriate use of artificial nutrition and hydration (ANH). In general, ANH has been seen as a medical treatment that patients or their surrogates may accept or refuse on the basis of the same considerations that guide all other treatment decisions: the potential benefits, risks, and discomfort of the treatment and the religious and cultural beliefs of the patients or surrogates. Although this agreement has never been universal, it is well established among ethicists,<sup>1</sup> clinicians,<sup>2-5</sup> and the courts. For instance, the 1990 Supreme Court decision in the well-known case of Nancy Cruzan specifically stated that the administration of ANH without consent is an intrusion on personal liberty.<sup>6-11</sup>

However, this agreement has faced recent challenges to its legitimacy. For instance, even though the cases of Terri Schiavo<sup>12</sup> and Robert Wendland<sup>13</sup> were complicated by disagreements among family members, the cases also involved public questioning of the premise that decisions about ANH should be made in the same way in which decisions about other treatments are made. Similarly, a recent papal statement that strongly discourages the withdrawal of ANH from patients in a permanent vegetative state will have a profound effect on decisions about ANH if it is accepted into Catholic doctrine.<sup>14,15</sup> Several states have made the withdrawal of ANH more difficult than the withdrawal of other forms of life-sustaining treatment.<sup>16</sup>

Clinicians also face substantial obstacles that prevent them from applying sound, ethical reasoning when discussing ANH with patients and families. For instance, patients and families are often not fully informed of the relevant risks and potential benefits of ANH.<sup>17</sup> In addition, financial incentives and regulatory concerns promote the use of ANH in a manner that may be inconsistent with medical evidence and with the preferences of patients and their families.<sup>18,19</sup> Finally, preferences about ANH may not be honored

after a patient is moved from one care setting to another.<sup>20</sup>

It is not possible to prevent all disagreements about the use of ANH. But it is possible, and indeed it is essential, to clarify the principles that should underlie decisions about ANH and to ensure that these principles guide decisions in clinical practice. Therefore, in this article we examine the ethical principles that have guided the appropriate use of ANH during the past 20 years and recommend steps to promote clinical practices that are more consistent with these principles.

### CLINICAL DECISIONS AND MEDICAL EVIDENCE

ANH is usually administered enterally through a nasogastric tube or a gastrostomy or jejunostomy tube that is placed with fluoroscopic or endoscopic guidance. ANH may also be administered parenterally through peripheral or central venous access. Hydration alone can also be provided by subcutaneous infusion.

ANH may improve survival among patients who are in a permanent vegetative state. These patients may live for 10 years or more with ANH but will die within weeks without nutritional support.<sup>21</sup> Parenteral ANH can also prolong the lives of patients with extreme short-bowel syndrome,<sup>22</sup> and tube feeding can improve the survival and quality of life of patients with bulbar amyotrophic lateral sclerosis.<sup>23,24</sup> Finally, ANH may improve the survival of patients in the acute phase of a stroke or head injury<sup>25,26</sup> and among patients receiving short-term critical care,<sup>27</sup> and it may improve the nutritional status of patients with advanced cancer who are undergoing intensive radiation therapy<sup>28,29</sup> or who have proximal obstruction of the bowel.<sup>30</sup>

There is less evidence of benefit when ANH is used for other indications. For instance, some studies suggest that ANH improves the survival rate among patients receiving chemotherapy,<sup>31</sup>

but other studies do not support this finding.<sup>32,33</sup> Studies of the effect of ANH on complication rates after cancer surgery have also produced conflicting results.<sup>34,35</sup> The bulk of the available evidence suggests that ANH does not improve the survival rate among patients with dementia.<sup>19,36-39</sup>

ANH is associated with considerable risks. For instance, patients with advanced dementia who receive ANH through a gastrostomy tube are likely to be physically restrained and are at increased risk of aspiration pneumonia, diarrhea, gastrointestinal discomfort, and problems associated with feeding-tube removal by the patient.<sup>36,40-42</sup> In addition, when a patient's renal function declines in the last days of life, ANH may cause choking due to increased oral and pulmonary secretions, dyspnea due to pulmonary edema, and abdominal discomfort due to ascites.

#### ETHICAL PRINCIPLES FOR DECISION MAKING

Because ANH is associated with uncertain benefits and substantial risks, it is essential to ensure that decisions about its use are consistent with the patient's medical condition, prognosis, and goals for care. Therefore, decisions about ANH require careful consideration of its risks and potential benefits.

Decisions about the use of ANH should be made in the same way in which decisions about other medical treatment are made. Many people believe that nutrition must always be offered, just as pain management, shelter, and basic personal care must be. This view is deeply rooted in cultural and religious beliefs.<sup>43</sup> It is often expressed with the use of the word "starvation"<sup>14,43-45</sup> to describe the condition of a patient who does not receive ANH. Patients, families, and physicians are entitled to hold these beliefs, which are not easily set aside. However, to help patients and families make decisions about ANH, physicians should present the contrary view by emphasizing three key points.

First, physicians should emphasize that ANH is not a basic intervention that can be administered by anyone, as food is. ANH is a medical therapy administered for a medical indication (e.g., dysphagia) with the use of devices that are placed by trained personnel using technical procedures. ANH therefore has more in common with other surgical and medical procedures that require technical expertise than with measures such as sim-

ple feeding. Second, physicians should explain that unlike the provision of food or other forms of comfort (such as warmth or shelter), the procedures required for ANH and the subsequent administration of ANH are associated with uncertain benefits and considerable risks and discomfort.<sup>35,36</sup> These factors need to be considered carefully before ANH is initiated. Finally, physicians should clarify that the goal of ANH is not to increase the patient's comfort. In fact, during the administration of high-quality palliative care, symptoms of hunger or thirst generally resolve in a short time or can be managed effectively (e.g., mouth dryness can be alleviated with ice chips) without the provision of ANH.<sup>46-48</sup> Throughout the comprehensive informed-consent process for patients and families, physicians should explain the potential benefits of ANH for a patient, as well as its risks and discomfort and all relevant alternatives, just as they would for other health care decisions.<sup>8,49</sup>

After this discussion, patients and families may remain convinced that ANH differs from other treatments. Beliefs about food and the associations concerning food are deep-seated, and in some cohorts and communities they are linked to historical or personal experiences with starvation (e.g., during the Holocaust or the Great Depression). Patients and families may decide to accept or refuse ANH on the basis of these beliefs. When physicians have beliefs about ANH<sup>50</sup> that prevent them from supporting the decision-making process of a patient and his or her family in an unbiased way, they should consider transferring the patient's care to another physician. Hospitals and health care facilities should support physicians in doing so.

#### WITHHOLDING OR WITHDRAWAL OF TREATMENT

Many people believe it is more acceptable to withhold a treatment than to withdraw it,<sup>51-53</sup> and one cannot discount the emotional burden that families in particular may feel when they believe that the withdrawal of treatment will allow a patient to die. This distinction is not supported, however, by currently accepted ethical and legal reasoning.<sup>1,49,54-57</sup> In fact, a more cogent argument can usually be made for the withdrawal of ANH after it has been administered for a trial period if it has proved to be ineffective or if experience has provided more information about its risks and discomfort.

**EVIDENCE OF PATIENT PREFERENCE**

When a patient lacks the capacity to make decisions, a single surrogate (usually defined in a state law according to a hierarchy) should make choices on that patient's behalf on the basis of available evidence of the patient's preferences and values.<sup>58</sup> These decisions may be based on previous statements (either oral or written) by the patient or on a surrogate's knowledge of the patient. This standard of surrogate decision making has been widely supported in the law<sup>7,57-59</sup> and among ethicists.<sup>49,60</sup> In some states, however, a patient's advance directive must include a statement that the patient would not want ANH.<sup>16,57</sup> This higher standard of evidence is inappropriate for two reasons.

First, decisions about ANH should not be held to a higher standard of evidence, because the balance of risks and potential benefits is, in most situations, no different for ANH than for many other medical treatments. For many patients, such as those with dementia, the balance may favor other interventions over ANH. Therefore, it is illogical to require a higher level of evidence in order to withhold or withdraw ANH than would be required for other medical treatments or procedures that offer a similar risk-benefit balance.

Second, a higher standard that requires specific evidence of a patient's preferences regarding ANH is not realistic. Although in its decision in the Cruzan case, the Supreme Court upheld the constitutionality of requiring clear and convincing evidence of a patient's preferences,<sup>8</sup> any higher standard has proved to be very difficult to satisfy. Despite moderate increases in the prevalence of advance directives as a result of the Patient Self-Determination Act, most adults have not executed a written advance directive,<sup>61-63</sup> and even those who have may not have specified their preferences about ANH. Therefore, a higher evidentiary standard makes it harder for surrogates to make decisions that reflect a patient's goals and preferences. Furthermore, a higher standard is illogical because it would permit certain restraints on liberty — the imposition of ANH without consent — whereas impositions of other treatments are prohibited.

**LACK OF ADVANCE DIRECTIVE**

Although surrogates should make decisions on the basis of a patient's preferences, sometimes an advance directive is not available. In this situation, the patient cannot be assumed to want ANH. Indeed, there are a variety of reasons why patients

do not complete advance directives, including cultural concerns, lack of information, and reluctance to initiate discussions about advance directives.<sup>64-66</sup> When a patient's preferences are unknown, surrogates must consider how a reasonable person with a cultural background, life experience, and worldview similar to the patient's would weigh the risks and potential benefits of ANH. This "reasonable person" standard often may be easier to apply than the related "best interest" standard, which requires surrogates to consider the difficult philosophical question of whether a decision that could result in death is in a patient's best interest.

Although only a minority of states explicitly permit the reasonable-person standard,<sup>57</sup> reasonable people often choose to forgo life-sustaining treatment if its discomfort outweighs its benefits<sup>67-69</sup> or if those people perceive a health condition to be worse than death.<sup>68,70</sup> The balance of risks and potential benefits for ANH may be less favorable than the balance for other treatments that surrogates refuse on a patient's behalf. Therefore, states that allow surrogates to make other health care decisions on the basis of a reasonable-person standard also should permit this standard for decisions about ANH.

**PROVISION OF PALLIATIVE CARE**

Patients who forgo ANH may experience hunger or thirst. Although hunger typically resolves after several days, thirst may persist.<sup>46</sup> Other symptoms attributable to the withholding or withdrawal of ANH include dry mouth, confusion and delirium, and diminished alertness.<sup>46</sup> Some of these symptoms (in particular, altered mental status) are part of dying and may occur during any progressive illness.<sup>71</sup>

When ANH is withheld or withdrawn, physicians should reassure patients and families that most of the resulting discomfort can be managed effectively.<sup>2-4,72</sup> Altered mental status can often be prevented by environmental modifications (such as reducing noise at night and placing orientation cues in patients' rooms), and delirium can be treated pharmacologically.<sup>71</sup> Thirst and mouth dryness can be alleviated with ice chips, a mouth rinse, or moistened swabs.<sup>46</sup> Evidence suggests that these and other interventions can help ensure a comfortable death.<sup>48</sup> All patients who forgo ANH should be offered comprehensive palliative care, including hospice.<sup>3,73</sup> A comprehensive palliative care or hospice plan should address physical and psychological symptoms and should

include emotional and spiritual support as well as bereavement support for the family after the patient's death.<sup>72</sup>

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#### OBSTACLES TO ETHICAL DECISION MAKING

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Despite general agreement about these ethical principles, their application to decisions about ANH at the bedside may encounter numerous obstacles. We propose the following five recommendations to help ensure that patients and their families retain the right to make decisions about ANH and that these decisions are supported at the bedside by health care providers, by the law, and by the health care system.

First, given the inadequacies in the typical informed-consent process for ANH,<sup>17</sup> all clinicians need to be better able to engage patients and families in meaningful discussions. Medical educators should better prepare clinicians to engage in these and other difficult end-of-life discussions by emphasizing both the ethical principles that underlie decisions about ANH and effective communication techniques. Reimbursement for physicians will also need to be increased proportionally, because effective, comprehensive discussions about ANH are time-consuming.<sup>17</sup> It will be important to ensure that physicians and other clinicians have access to thorough nutritional assessments for the patient and to effective decision aids.<sup>74</sup>

Second, decision making about ANH in nursing homes should be shielded from financial and regulatory pressures. Although the loss of the ability to eat is an expected part of dementia, one third of cognitively impaired nursing-home residents have a feeding tube.<sup>75</sup> Nursing homes should not be reimbursed at a higher rate for residents who are receiving ANH than for those not receiving ANH,<sup>76</sup> since providing ANH costs less than feeding by hand.<sup>18,77</sup> In addition, staff and surveyors should be informed that nursing homes should not be cited when a patient loses weight after a decision to forgo ANH.<sup>78</sup> Finally, publicly reported data on weight loss, which are available on the Centers for Medicare and Medicaid Services Web site,<sup>79</sup> should exclude data for residents whose weight loss is the result of a choice to forgo ANH.

Third, state laws should allow the same standard of evidence of a patient's preferences for decisions about ANH as they do for other deci-

sions. These laws should allow families to make reasoned and caring decisions on the patient's behalf if they are based on knowledge of the patient's values and preferences. If a patient's preferences are unknown, surrogates should be allowed to make decisions, in close collaboration with the patient's health care providers, that are guided by thoughtful judgments about what a reasonable person would choose. The Uniform Health-Care Decisions Act achieves most of these aims in a clear and thoughtful way and should be adopted by state legislatures.<sup>80</sup>

Fourth, attorneys, physicians, and other health care providers should encourage and help patients to complete advance directives and to include preferences about ANH. Because decisions about ANH are often complicated by disagreements among family members, advance directives should also identify a decision maker. More generally, state laws should specify a hierarchy of decision makers to reduce the possibility of ambiguity and conflict among family members.

Fifth, health care facilities should ensure that preferences are respected in all health care settings. Problems with information transfer between institutions can affect all patients and are particularly common when nursing-home residents are transferred to a short-term care setting.<sup>20</sup> Nursing homes and hospitals should develop effective documentation strategies, such as Physician Orders for Life-Sustaining Treatment forms, which ensure that a patient's preferences are clearly documented and readily available to guide the patient's care.<sup>81,82</sup>

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#### CONCLUSIONS

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Patients and families should be allowed to make decisions about ANH in an informed-consent process that is guided by well-established principles. Moreover, the right of the patients and their families to make independent decisions about ANH and other medical treatment should be defended against legal, financial, and administrative challenges at the bedside. A variety of stakeholders — including organizations of medical professionals, legal associations, and other health care organizations — will be needed to ensure this defense. Through advocacy activities, disease-based organizations can also help guarantee that all patients who forgo ANH receive high-quality, compassionate care near the end of life.<sup>83</sup>

But efforts by individual organizations will

not be enough. In order to ensure that patients' preferences are respected and that obstacles to high-quality care are removed, these organizations will need to work together closely. Moreover, they will need to form partnerships with legislators, payers, and regulatory agencies to promote the five recommendations. More generally, efforts to facilitate decisions about ANH that are compassionate, ethically sound, and clinically reasonable need to be part of a larger agenda to improve care for all patients with serious illness.

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