

Artificial Nutrition and Hydration

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A 49-year-old male came into the cardiac care unit with an inferior wall myocardial infarction, and shortly thereafter coded. Resuscitation attempts succeeded; however, over the course of a few days he went into multisystem failure. On a respirator, receiving multiple medications to support life, and unable to eat anything by mouth or to tolerate tube feedings, the nursing staff were concerned with his nutritional status. An ongoing debate occurred between the physicians and nurses, with the physicians maintaining that he was not “viable enough” for total parenteral nutrition (TPN) but if his condition were to stabilize he would be a candidate. The nurses argued that without adequate nutrition the patient would never stabilize and heal; they felt that he was being starved to death. The intense emotional response of the nurses led the physicians to rethink their approach to care. After 10 days without food and still in multisystem failure, the patient was started on TPN. Regardless, he died several days later.

Artificial nutrition and hydration (ANH) are medical treatments and imply any form of nutrient intake by an individual beyond assisted oral feeding (American Academy of Hospice and Palliative Medicine, 2006; Geppert, Andrews, and Druyan, 2010). They may be further defined as nutritional and fluid support of an invasive nature requiring placement of a tube into the gastrointestinal tract (enteral tube feedings), or parenteral via the intravenous (central-TPN or peripheral PPN) routes. On occasion, fluids may be administered via subcutaneous (hypodermoclysis) or rectal means.

Food and water are basic human needs, without which we will die. Food and water also symbolize caring and nurturing. To withdraw or withhold food and/or fluids in someone who is at the end of life and is no longer able to spontaneously eat and drink symbolizes for some abandonment and neglect. Because the provision of food and water is so basic to human survival, the role of artificial hydration and nutrition at the end of life remains controversial

for many families and clinicians and is frequently fraught with emotions (Diekema, Botkin, and Committee on Bioethics, American Academy of Pediatrics, 2009; Gillick and Volandes, 2008). This is especially the case when a family is struggling to accept that death of a loved one is near, and that ANH will neither prolong life or, for the vast majority, improve comfort.

Although an individual position on artificial nutrition and hydration may be based on religious or moral beliefs, it may also be influenced by misunderstanding of the medical aspects of ANH (Arenella, 2005; Schaffner, Kedziera, and Coyle, 2010). There may be the mistaken perception that forgoing ANH leads to a painful death due to starvation. In addition, there may be a failure to recognize the potential complications and discomfort associated with ANH. The experience of expert hospice and palliative care clinicians, as well as some small studies, indicate that the majority of patients at the end of life do not experience lasting hunger or thirst and that those that do can have their symptoms relieved by meticulous oral care or ingestion of small amounts of fluid (Palecek et al., 2010; Sullivan, 1993).

The provision of food and fluid, in whatever form, is viewed by some religious traditions as ordinary care and obligatory. However, “withdrawing” and “withholding” may be viewed very differently within these religions (Gillick, 2001; Gupta and Mukherjee, 2010). In addition, how the question is framed within the circumstances of the particular patient, including their level of suffering, may also influence the response given. It is important that a belief of a particular religious tradition is not assumed by the clinician or even the family. The framing of the question, with all of the subtleties involved, may influence the answer. The question as posed earlier in the disease process about ANH may have led to one response, but when the patient is close to death, a reframed question about ANH may result in a different answer. The clinician may need to guide the family on how to frame the question or ask permission to ask the question themselves.

As life draws to an end and the body is closing down, it is a natural process that the person will gradually decrease food and fluid intake and eventually stop eating and drinking. This is the usual scenario for someone who dies at home under hospice care. For someone who dies in an acute care setting or long-term care facility, without hospice care, continuing artificial nutrition or hydration is much more common (Teno et al., 2009). In such settings this may be the norm, reflecting an institutional standard of care without careful thought and consideration to the benefits and burdens for a particular individual. However, as hospice and palliative care have begun to move into

long-term care facilities, these norms are changing (Lopez, Amella, Strumpf, Teno, and Mitchell, 2010; Teno, Mitchell, Kuo, et al., 2011; Teno, Mitchell, Skinner, et al., 2009).

When advising a patient or surrogate about whether or not to initiate, withhold, or withdraw ANH, it is necessary to have a basic understanding not only of the patient's medical situation, but also of his or her culture, religious beliefs, and traditions, including those concerning nutrition and hydration at the end of life. For example, to a Holocaust survivor, the suggestion that food or fluid be withheld or withdrawn at the end of life may be unthinkable. With this knowledge as a foundation, appropriate information, care, and support can be provided.

It is generally accepted that individuals have a right to voluntarily stop eating and drinking at the end of life. In the United States, the Patient Self-Determination Act (1990) specifies that individuals have the right to refuse any medical treatment, including artificial nutrition and hydration. Withholding and withdrawing such interventions are considered ethically and legally to be the same. Even so, it is not unusual for a clinician to say that it "feels" different to withdraw versus withhold ANH. Some religious and cultural norms also may not accept this ethical and legal position and, as previously noted, consider the provision of food and fluids as ordinary and obligatory care. This reflects a stance that a fundamental difference exists between medical technologies and sustenance technologies that supply nutrition and hydration. The argument is that technologies that supply artificial nutrition and hydration are nonmedical means of maintaining life, unlike optional forms of life-sustaining technologies such as respirators and dialysis machines (Beauchamp and Childress, 2001).

Although every state in the US allows individuals to refuse artificial nutrition and hydration through the use of an advance directive such as a living will or durable power of attorney, state laws vary as to what must be done to make a person's wishes known (Gillick, 2006). Because the provision of food and water is so fundamental to human survival, some state statutes maintain separate and higher legal standards for ANH as compared to other life-sustaining treatments. In some states individuals are required to state specifically whether or not they would want ANH at the end of life. When there is uncertainty or conflict, ANH will usually be continued.

From a strictly medical viewpoint there are indicators and contra-indicators for the provision of artificial nutrition and/or hydration to patients at the end of life (Casarett, Kapo, and Caplan, 2005; National Hospice and Palliative

Care Organization, 2010). An example of a situation where ANH might be of benefit is a patient with a partial gastric outlet obstruction associated with newly diagnosed inoperable gastric cancer, who vomits when attempting to eat or drink, and is complaining of thirst and hunger. Nutrition and hydration may improve these symptoms. Another possible medical indicator for a trial of artificial hydration is in a patient with acute delirium associated with dehydration that may be reversed by rehydration (Bruera et al., 2005).

In contrast, a patient who is dying from end-stage pulmonary, cardiac, or renal disease with normal intestinal function would not benefit from ANH. For the majority of similar patients at the end of life, the burden and risk of ANH far outweigh any potential benefit. Such burdens include fluid overload, edema, ascites, infection, nausea, vomiting, diarrhea, aspiration and pulmonary congestion, among other things (Arenella, 2005; Cervo, Bryan, and Farber, 2006; Ersek, 2010).

CASE STUDY

Mrs. J is an 85-year-old woman with advanced dementia and Stage IV non-small cell lung cancer (NSCLC), being cared for at home. Her daughter was distressed that her mother was no longer able to eat and drink “sufficient quantities to sustain life.” Feeding her had become a battle—she spat out her food, turned her head away, and struck out whenever attempts were made to feed her. The daughter asked about placement of a feeding tube so that her mother could be fed “passively” without the “stress” of attempted oral feeding. She expressed that this seemed such a “minor procedure” with the potential for great benefit to her mother. The daughter described her mother as a fiercely independent woman whose husband (her father) had died shortly after her birth. She had never remarried and had worked two minimum wage jobs to support her daughter, as well as attending evening classes in a community college. She was described as a woman who rarely asked for help for herself but had always extended a helping hand to others. The Catholic Church was reported as a place of comfort for her.

This elderly and much-loved woman did not have advance directives and had become increasingly withdrawn and uncommunicative over the past decade. Earlier conversations between the daughter and her mother did not reflect what she would want if she was no longer able to eat and drink independently, although she had expressed throughout her life a dread of being dependent on others. Independence and self-sufficiency were fundamental values for her and ones on which she prided herself. This daughter cared deeply for her

mother, acknowledging the sacrifices her mother had made so that she could have a good education and opportunities in life that she herself never had. When Mrs. J was no longer able to care for herself her daughter had taken her into her own home, and had recently taken a leave of absence from work to care for her. Her husband and children were supportive.

ANALYSIS

Clinical ethics are grounded in the narratives of individual patients and their families in the setting of cultural and ethical norms. It is about stories and people, lives interrupted, and suffering. It is difficult if not impossible to apply ethical principles hypothetically; they need to be validated by context on a case-by-case basis. Similar to the medical model, a diagnosis cannot be established until the narrative—the context—is understood. Clinical ethics are not primarily grounded in the medical and science issues. Although those aspects are an extremely important part of the equation, what inevitably comes to the fore, especially when there is conflict or disagreement, are social, legal, religious, and cultural concerns. Many of the concerns, as with the issue of withholding or withdrawing ANH, are emotionally loaded. The ability to acknowledge these emotions, validate them, and then step back to systematically facilitate the conversation, is part of the clinical analysis. Some of these important concerns might be: what would this person want; what is possible; what is consistent with their goals and values and how they have lived their life; and what constitutes good medical care (Gillick, 2006; Gillick and Volandes, 2008).

Tensions may exist between ethical principles, depending on the lens through which the situation is being viewed. For example, beneficence versus maleficence—will withholding or withdrawing ANH in someone close to death prolong or hasten death; increase suffering or prevent unnecessary burden? Intent is a critical aspect in any ethical equation. Sometimes intent may be clouded in the setting of an exhausted family, exhausted clinicians, clumsy communication, and misunderstandings around culture and religious beliefs. Stepping back and again focusing on the individual patient and what that person would want will frequently reground the decision-making process.

The ethical question raised by this case is whether the provision of ANH for Mrs. J, who no longer has capacity to make the decision for herself, reflects her previously expressed goals and values, and whether any benefits of the intervention are disproportionate to the risks. The analysis of the case is grounded in the following: the medical context and goals of care (beneficence,

nonmaleficence); her narrative (respect for autonomy with the right to choose); the legal decision maker (who gets to decide); and justice. Each area reflects respect for Mrs. J's dignity and personhood. Within this framework, a series of questions will be posed for the clinician to consider regarding the appropriateness of ANH as a medical intervention in this situation.

The first question is what burdens and benefits is Mrs. J likely to incur?

Mrs. J has Stage 4 NSCLC superimposed on advanced dementia. There are no available medical interventions that will reverse her advanced lung cancer or her end-stage dementia. Artificial nutrition and hydration will not reverse her medical condition and will not prevent aspiration. While in some situations ANH can extend life and improve the person's quality of life, in Mrs. J's situation, ANH may impose significant burden on her dying process with a disproportionate burden-over-benefit ratio. ANH requires the placement of an enteral feeding tube or the use of intravenous access. Depending on the enteral feeding approach selected, associated risks include displacement, bleeding, infection, and burdens such as discomfort, need for repositioning, or replacement.

Studies in people with advanced dementia indicate that ANH does not prolong life, improve function, prevent aspiration, or reduce pressure sores (Cervo et al., 2006; Finucane, Christmas, and Travis, 1999; Kuo, Rhodes, Mitchell, Mor, and Teno, 2009; Meier, Ahronheim, Morris, Baskin-Lyons, and Morrison, 2001). The evidence suggests there is the potential for a decreased quality of life and quality of dying by providing AHN, through increased pulmonary symptoms associated with aspiration, volume overload, pulmonary edema, and dyspnea. In addition there may be gastrointestinal symptoms such as nausea, bloating, and diarrhea. Two ethical principles are appropriate to include in this discussion of benefit versus harm—nonmaleficence and beneficence.

Nonmaleficence: This principle states the obligation not to inflict harm on others. At the end of life, in the discussions around ANH, the distinction between hastening death or killing and letting die come to the fore. Based on the life story of Mrs. J, her medical condition and closeness to death, to initiate ANH is likely to cause her harm without benefit, and therefore cannot be justified. Provision of ANH in this case would be extraordinary and disproportionate to the real burdens it would impose. Invasive procedures such as gastrostomy feeding tube placement are not passive in nature; they are uncomfortable procedures and require the administration of anesthesia,

which comes with another set of risks (Arenella, 2005). Tube feedings in and of themselves come with other significant risks for harm such as the possibility of aspiration and fluid overload. There is no obligation, in fact there is quite the reverse, to provide a medical intervention to a patient where there is a disproportionate risk to benefit ratio.

Beneficence: This principle states the obligation to remove harm and to do or promote good. Beneficence implies positive acts. In Mrs. J's case, these acts included offering food but not forcing it, meticulous mouth care, treatment of pain and other symptoms, support for the daughter and family, and sensitive care of Mrs. J as a respected and loved member of the family. It was important that Mrs. J's daughter felt comfortable expressing her unease about not providing ANH for her mother, despite recognition that her mother was dying and the understanding of the harm, rather than benefit, that would likely result from such an intervention. She was encouraged to discuss the situation with her Catholic priest and felt reassured that her decision was supported and was the right one. The medical context does not support recommending ANH for Mrs. J (Ersek, 2003; Good, Cavenagh, Mather, and Ravenscroft, 2008; Kuo et al., 2009; Sorrell, 2010). It is medically contraindicated and there is no obligation for a clinician to provide nonbeneficial medical interventions.

The second question is how much weight should Mrs. J's goals and values be given in advising about the benefit and burden of ANH?

Here the principle of autonomy, recognized through the narrative of Mrs. J, comes into play.

Autonomy: Respect for autonomy recognizes the right of the individual to decide for him or herself according to beliefs, values, and a life plan. The principle of autonomy insists that the rights of those who have lost capacity should have their previously expressed wishes honored. The use of advance directives is encouraged to protect the choice of an individual who has lost decision-making capacity. Mrs. J was determined to lack decision-making capacity. She was unable to understand information and to appreciate her situation. She could not express or communicate a preference or choice. Her advanced dementia and Stage IV lung cancer were irreversible and she was terminally ill. She had not completed an advance directive. However, her previously expressed values, and the way she had lived life, reflected core values of independence and self-sufficiency. There was adequate evidence that she would have found the balance of risks versus potential benefits of ANH as unacceptable.

The third question is who is the decision maker for Mrs. J?

Because Mrs. J has not left an advance directive, is a widow, and has only one child, that child (her daughter) is her legal surrogate and has the authority to make decisions on her mother's behalf. The daughter's role as surrogate is to give voice to and represent what her mother would want in these circumstances, as best as she is able. This role reflects respect for her mother's autonomy. If, however, her mother's narrative did not reflect goals and values applicable to ANH, then the "best interest" standard would apply. Although Mrs. J had not discussed her specific wishes regarding care at the end of life, including the use of ANH, she had expressed a dread of being dependent. The daughter, respecting her mother's Roman Catholic faith, and struggling with whether providing ANH to her mother was basic care rather than a medical intervention, sought the advice of her priest. Based on information about her mother's specific medical situation and terminal state, and after an analysis of her particular case, the daughter was comfortable that withholding ANH was consistent with Catholic views. The daughter was encouraged to offer her mother food, feed her if she accepted the food, but not to try and force her to eat.

Justice: In its simplest form, justice deals with the concept of fairness, especially in the way people are treated or decisions are made. More broadly, *distributive justice* refers to fair, equitable, and appropriate distribution of societal resources. This broader consideration of justice was not considered in Mrs. J's case. For Mrs. J, the concept of fairness implied not imposing the burden of ANH without the likelihood of any benefit to her. It also implied her right to receive respectful, compassionate, attentive, and skilled physical, psychosocial and spiritual care, and for her family to be supported. If considering broader terms of justice, whether or not actions are just from both individual and collective standpoints would be considered.

DECISION

Mrs. J's daughter, supported by her husband and children, decided that it would be in her mother's best interest not to request that ANH be started. Initially this decision was difficult, but through a series of discussions and family meetings, she was able to recognize that her role as surrogate was to represent the wishes of her mother. The daughter recognized that medically the treatment would not make a difference to the course of her mother's disease. More important, she understood that her mother would not have wished to be artificially fed and hydrated. The possible negative impact on the quality of life

that her mother continued to experience through the loving care she received from her family also entered into her decision-making equation.

AFTERWORD

Mrs. J continued to be slowly and painstakingly fed by spoon. Sometimes she accepted the food and at other times did not. When she did not eat, her daughter felt frustrated and distressed. Her basic instinct and self-talk was “she must eat or she will die; I am not a good daughter if my mother will not accept the food that I offer.” Ongoing reassurance from the home hospice team, supported by factual information about ANH, provided the necessary reinforcement that her mother’s inability to eat and drink and her refusal of food and water reflected the natural progression of her disease. Mrs. J died at home under family and hospice care approximately eight weeks after the initial discussion of providing artificial nutrition and hydration was raised.

CONCLUSION

Two fundamental questions are raised in this case. The first is whether the provision of artificial nutrition and/or hydration is a medical treatment. The second and related question is in what situations should artificial nutrition and/or hydration be offered? The commonly held medical view in this society is that these are medical treatments. It is acknowledged, however, that there are strong spiritual, emotional, ethical, cultural, and social overtones in relation to the provision of food and water to someone who is totally dependent on another at the end of life. Compassionate and skillful communication around these issues is, therefore, essential. With this as a caveat, decisions about ANH at the end of life should be made in the same way as any other medical decisions at the end of life, on a case-by-case basis.

The medical indications for a trial of artificial nutrition and/or hydration at the end of life have been reviewed earlier. For the vast majority of dying patients evidence shows that burden and risks of ANH at the end of life far outweigh any likely benefit. Early communication between patients, families, and the health care providers about the benefits and burdens of ANH at the end of life is important. Such discussions will help clarify the patient context, including culture and spirituality, often expressed through values, beliefs, goals, and aspirations. These conversations can be especially difficult if held for the first time when a family is struggling to accept that death of a loved one is near, and that ANH will neither prolong life nor improve comfort. One lesson learned through this particular case—where the patient’s loss of decisional capacity was progressive and expected—was

that conversations and guidance in completing an advance directive would in all likelihood have been helpful in reassuring her daughter that the decision regarding ANH was indeed her mother's decision, as well as a medical one.

Organizations such as the American Academy of Hospice and Palliative Medicine (2006), the Hospice and Palliative Nurses Association (2003), and the National Hospice and Palliative Care Organization (2010), among others, have developed and published position statements on ANH at the end of life. These tools can be very valuable in helping to guide the clinician, both in framing the issues and holding the conversation.

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education in nursing; and a pilot intervention study to promote completion of advance directives with older adults in the community.

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