

History and Perspectives on Nutrition and Hydration at the End of Life

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The question of whether to provide artificial nutrition and hydration (ANH[†]) to a patient with terminal illness or at end of life has been debated over many years. Due to the nature of the question and the setting in which it presents, prospective trials are not feasible, and the health care professional is left to work with the patient and family to make decisions. This perspectives piece addresses the issue in a format designed to inform the reader as to the pertinent considerations around ANH. We briefly review significant historic, religious, ethical, and legal contributions to this discussion and physiologic underpinnings. We address the beliefs of patient, family, and health care providers surrounding this issue. Our goal is to provide a review of the considerations for health care providers as they address this issue with patients and families in the course of compassionate care.

HISTORY AND PERSPECTIVES ON NUTRITION AT END OF LIFE

“I am sorry, but you have failed your swallowing study. It is no longer safe for you to take food or fluids by mouth.” This medical diagnosis can cause great distress to patients and families. Eating and drinking fulfill a basic physiologic need, but are also associated with psychological, social, and symbolic significance [1]. These associations become especially important at the end-of-life or in comatose states. Those diagnosed with terminal or advanced chronic medical conditions are likely to decrease their oral consumption of nutrients and hydration, leading to cachexia-anorexia syndrome [1,2]. Anorexia and dehydration can both be very upsetting to patients and families both as signs of progressive disease

and failure of medical treatments. As attempts to improve those disease states, artificial nutrition and hydration (ANH) require ethical, legal, cultural, and emotional considerations, and have associated risks and benefits, some of which we will explore in this piece.

ANH are defined as a group of medical treatments provided to patients who cannot meet their daily requirements orally, with resultant malnutrition, electrolyte abnormalities, and/or metabolic derangements. The various modalities to deliver ANH include intravenous hydration and intravenous parenteral nutrition, nasogastric feeding, and placement of surgical feeding devices to deliver the required hydration and nourishment. Being medical treatments, the initiation, termination, and withholding of these modalities must be medically and ethically justified [2,3]. To better understand these justifications, we will

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[†]Abbreviations: ANH, artificial nutrition and hydration.

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briefly review the ethical considerations associated with ANH.

Prior to modern bioethics, religion played an important role in end-of-life decision making for many patients. Pope Pius XII addressed the Congress on Anesthesiology in 1957, concluding that using medical technology to prolong life was an extraordinary measure, which the Catholic Church viewed as idolatry [4]. He argued that the emphasis of medical care, according to the Catholic Church, should be to alleviate pain and suffering [4]. With the advent of early bioethics in the 1970s and advancements in medical technology, that emphasis shifted to patients' rights and autonomy [4]. As discussions progressed in the 1980s, some ethicists considered ANH to constitute life-sustaining treatment, and therefore basic and standard care, while others argued that these treatments constituted life-prolonging modalities at the end-of-life, and could be withheld and/or withdrawn [4]. Modern bioethics dictate that ANH should be considered within the framework of the four cornerstones, namely, beneficence, non-maleficence, autonomy, and justice.

To satisfy the principle of beneficence, ANH must benefit the patient [2]. The concept of non-maleficence, or "do no harm," requires a provider to consider the risks involved in the treatment. The principle of autonomy means taking into consideration the patient's wishes and decision regarding such any treatment, and therefore includes informed consent. Finally, justice should lead a provider to consider the accessibility and equality of the use of the treatment as applied to a group of patients with similar circumstances [2].

These principles of modern bioethics can be framed within the context of some relevant court cases. In 1976 the New Jersey Supreme Court ruled in favor of Ms. Karen Quinlan's parents, who sought to disconnect their daughter from a mechanical ventilator, as she remained in a persistent vegetative state after a cardiac arrest [5]. They ruled that a competent adult can make decisions about his/her own medical care, and that these rights should not be lost when a person becomes incompetent [5]. This topic was addressed nationally in the 1990 Supreme Court landmark case of *Cruzan vs. Director, Missouri Department of Health* [4,5]. Briefly, Ms. Nancy Cruzan, a 26-year-old woman involved in a motor vehicle collision was resuscitated after a cardiac arrest and remained in a persistent vegetative state [4,5]. Her parents appealed to the court to have her feeding tube removed, given her previously expressed wishes [4,5]. The Supreme Court decided that while competent adults can make decisions about their treatment options, including termination of, or withdrawal of life sustaining treatments, incompetent patients require a higher standard of evidence that included their previously stated wishes [4,5]. This case led to the passage of the Patient Self-Determination Act

and increased the public's awareness of living wills and advance directives. In 1990, the year the *Cruzan* case was decided, Ms. Theresa Marie "Terri" Schiavo sustained a cardiac arrest at the age of 27 that left her in a persistent vegetative state after her resuscitation. Several court cases ensued with religious groups and politicians becoming involved in the case, including the United States Congress [6]. Ultimately Ms. Schiavo's feeding tube was removed, and she died in 2005 [6]. This case led many people to re-examine the importance of living wills, health care proxies, and advance directives [6]. All of these cases demonstrate that decisions about the medical prolongation of life can be emotionally charged and culturally driven.

The practice of medical nutrition and hydration provokes both supportive and opposing views. Some ethicists would argue that the symptom of thirst should be addressed, because without it, the patient will experience confusion, restlessness, or neuromuscular weakness, thus decreasing the patient's quality of life. Others may argue that the terminally ill patient with declining renal function receiving artificial hydration will suffer from choking on increased secretions, pulmonary edema, and ascites [6]. In order to provide artificial nutrition and hydration, medical devices such as urinary catheters and surgically placed feeding tubes must be used. A patient with decreased mental capacity may try to remove these devices. Attempting to continue the therapy, caregivers may use restraints or sedation, resulting in decreased quality of life.

In patients with end stage cancer, metabolic alterations can cause anorexia, proteolysis, and lipolysis, leading to malnutrition. Side effects from these processes include muscle wasting, fatigue, and respiratory complications [7]. Even so, providing ANH has not been shown to improve life expectancy or quality of life.

In the setting of sparse evidence and the absence of formal prospective trials, the perspectives of patients, family and caregivers provide the basis for decisions regarding ANH. Strong opinions surrounding these decisions may be rooted in religious or historic beliefs, or in a prior (good or bad) personal experience of witnessing a loved one at end of life.

FAMILY BELIEFS

Families may believe that hydration decreases pain, replenishes the body, enhances effectiveness of medications and in general can make the patient feel better both mentally and physically. At the end of life, families may feel that they are responsible for maintaining their loved one's dignity, and continued hydration may contribute to their perception that this is being accomplished. In some cases, the family's insistence that the patient take nutri-

tion may cause conflict even before the implementation of ANH becomes the only option. Strong beliefs in the value of nutrition and hydration at the end of life may give the family some satisfaction that they are helping the patient. The patient's refusal to eat may exacerbate the family's feeling of helplessness. Families' perceptions of the importance of nutrition may also color their impression of the dedication of the healthcare team. If the family believes that the medical team is not placing enough importance on nutrition and hydration, this may translate into the perception that the health care team is negligent.

PATIENT BELIEFS

Patients at the end of life lose interest in eating, have fatigue, altered body image, and a decreased ability to digest. These are all highly correlated with psychological distress [1]. Patients may believe that if they are not able to take food and fluid orally, then ANH will, help them survive by preventing dehydration and increasing physical strength. They may also believe that a gastrostomy or a nasogastric tube can make their quality of life worse. If it is not something that will cure their illness, patients may decline ANH [8]. However, in many studies, the majority of patients and families would choose to implement ANH rather than go without [8,9]. Patients may also believe that ANH is a symbol of their families' love for them; an important part of their meticulous care for their health and well-being [8].

PROVIDER BELIEFS

Health care providers have a significant influence on patients and families regarding decisions about ANH at the end of life. This influence comes in the form of education and their own beliefs in the setting of a trusted caregiver relationship [8]. Physicians who do not frequently participate in the care of terminally ill patients are more likely to recommend ANH and consider it necessary care. Those clinicians who regularly care for terminal patients are more likely to consider ANH a form of active medical treatment and may be less inclined to recommend it [1]. In some cases, these physicians caring for patients at end of life may be accused by other physicians of performing euthanasia, or even murdering their patients [10].

CULTURAL BELIEFS

Cultural differences exist regarding the meaning of continuing nutrition at the end of life. In Western cultures, eating is paramount to survival, and the lack of nutrition accelerates death [1]. But in the Hindu tradition, decreasing oral consumption signifies mortality, but is not a cause of it [1]. The thinking is that at the end of life,

a person voluntarily stops eating to prepare for a dignified death [1]. In contrast, the Taiwanese cultural belief is that a person should not die hungry, as his/her soul will be restless, thus the preference is to provide ANH [1].

Because treating a patient with ANH can be charged with emotional, social, and symbolic significance, and decreased oral consumption by a patient can be anxiety provoking to all parties involved, providers must educate patients and their families about the risks and benefits involved with ANH. To frame this discussion, we have reviewed the four pillars of modern bioethics. To be considered medically ethical and justified, ANH must provide a benefit to the patient (*beneficence*), avoid harm (*non-maleficence*), be in accordance with the patient's wishes (*autonomy*), and avoid overutilization of resource for one patient with harm to others and be available to all patients in similar circumstances (*justice*). The possible benefits of feeding via ANH include improvement in the patient's quality of life and improved nutrition with decreased incidence of bedsores and other infections [2,11]. However, these treatment modalities are not without risk to the patient. ANH can lead to fluid overload and electrolyte/metabolic derangements, aspiration pneumonitis or pneumonia, and are associated with an increased risk of infection [2,11]. Moreover, the procedures involved with feeding device placement can themselves lead to increased morbidity and mortality [11,12]. Finally, while there is no evidence that withholding nourishment and hydration in terminal illness causes pain or suffering. Some clinicians would argue that it does not prolong life, but only prolongs the dying process [2].

CONCLUSION

As health care providers we are often tasked with helping educate and guide patients and their families about treatment options. While some consider hydration and nourishment as basic care, ANH are treatment modalities that must be medically and ethically justified. Discussions about end-of-life care, including the use of ANH, should begin early and prior to disease progression, to ensure the patient's understanding and that wishes are expressed and followed. A lack of legal documentation of a patient's wishes, or expressed viewpoint to a health care proxy, makes these decisions more difficult at the end-of-life, especially when disagreements arise amongst providers and/or family members.

Because most families suffer significant stress around this issue in the setting of their loved one's severe illness, it is beneficial to consider and discuss the families' feelings of helplessness. This discussion may allow clinicians to educate patients and families about our knowledge (and lack thereof) around ANH, provide emotional support and reassure them that symptom man-

agement is the primary concern.

Feelings about aspects of medical care such as nutrition and hydration are likely to aggravate the already large stress around a family member approaching death. There are many ways to think about these treatments and these can lead to increasing conflict at a time that is already likely to be causing suffering amongst all concerned. Utilizing the ethical principles mentioned above, clinicians should encourage open conversations with patients and families so that different beliefs can be reviewed and discussed. This would allow for the most informed decision, and one that is in line with the patient's wishes.

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