The Paradox of Hydration in Advanced Terminal Illness

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"The thirsty scour the world for water, but water is also searching for the thirsty." Rumi[1]

Eighty-two-year-old John suffered from metastatic prostate cancer. He had developed lumbar vertebral metastasis with consequential lower extremity weakness. He lived alone and functioned independently, but recently had to depend on a walker for his new disability.

Early one morning, he fell. His family discovered him several hours later, and he was taken to the Emergency Room. John was awake, alert, and hemodynamically stable, but complained of severe neck and low back pain. His upper extremity strength was normal, but his lower extremity power was 3/5. He had poor rectal tone and was unable to void. A urinary catheter was placed.

Workup revealed an unstable C-2 fracture, and lumbar vertebral metastasis compressing the spinal canal. Neurosurgery placed him in a halo for C-spine stabilization. Metastatic involvement of C-2 was confirmed by bone scan.

Shortly after admission, John developed neck edema, aspirated, and required intubation and mechanical ventilation. Nutritional support was initiated with enteral feedings through a nasoduodenal feeding tube.

John frequently indicated that he had severe neck and back pain. Palliative radiation therapy was recommended, but could not be logistically accomplished because of his ventilatory support and halo devices. He required sedating doses of narcotics and anxiolytics to control his persistent pain. Finally, John was made comfortable on a regimen of transdermal narcotics and anxiolytics administered through his feeding tube. With aggressive pulmonary care and IV antibiotics, John improved sufficiently to be weaned from the ventilator and extubated.

He was again alert and communicated appropriately and quite clearly that he wished no further aggressive measures. He removed his feeding tube, was restrained, yet "escaped," and vigorously resisted the resident's attempts to insert another. He was unable to take an oral diet because of ongoing dysphagia from his halo positioning. IV fluids were continued until his cachectic arms precluded peripheral access. He refused to consent to central IV access. His frustrated doctors and fearful family pleaded with him to no avail. John persisted in his refusal of food and water. An ethics consult confirmed John's legal right to forgo both nutrition and hydration.

A hospice consult was obtained. His pain regimen was adjusted, and comfort care was instituted. The family was instructed in alternative measures to ease his discomfort. John gradually became oliguric; a week later he slipped into a coma; 2 days later he died peacefully with his family at his side.

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Historical perspective

The preceding narrative gives us a basis on which to discuss potential benefits and burdens of terminal dehydration, that is, withholding intravenous fluids or other forms of forced hydration. A more positive description of this practice is patient choice of limiting fluids to voluntary oral intake. Although we recognize that there are many overlapping physiologic and psychologic ties between eating and drinking, this article focuses primarily on hydration.

Less that a century ago, as death approached, the normal behavior of the dying individual was to gradually decrease, and then cease, oral intake of food and then water. Death from the underlying illness and coma overtook the individual as a natural course. Starvation and dehydration are as normal and natural a way to die as the reverse is a natural way of being born. Natural dehydration can be seen as a process of autoanesthesia.[2]

As medical science has advanced, our technologies have also evolved. Prolongation of life by ever-complicated means has become routine and, until recently, unquestioned in our 20th-century society.

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Traditionally, CPR, mechanical ventilation, and dialysis are thought of as "extraordinary" measures, and artificial nutrition and hydration are considered usual extensions of standard or "ordinary" care. In the surgical specialties, we are trained extensively in fluid resuscitation, with total parenteral nutrition being the ultimate symbol of hydration and nutrition. This may explain why the use of total parenteral nutrition in advanced illness is such a hot-button issue for surgeons and patients. It is ingrained in our very fiber to be aggressive in the maintenance of fluid and electrolyte balance, even though we all sardonically note the patient who "dies in perfect electrolyte balance."

Here the paradox occurs: nature's voluntary way of responding to impending death versus our scientific forced approach. It is no longer an issue of if we can provide "adequate" nutrition and hydration, but rather, if we should.

Benefits of terminal hydration

"You want water?! What are you talking about? You are up to your knees in a river!" Rumi[1]

As gradual organ dysfunction (renal, circulatory, or both) occurs near the end of life, fluid overload stresses the pulmonary system and increases patient discomfort. Terminal dehydration decreases total body water. This has many potential beneficial side effects. A synergy may occur between the physiology of terminal disease and withholding of nutrition and hydration. This process may facilitate a peaceful death.[3]

Dehydration may decrease brain swelling and reduce the discomfort of associated headaches and confusion. The combined effects of starvation and dehydration cause toxin buildup and body chemistry changes, which stimulate the production of natural endorphins. The resultant mild euphoria may also act as a natural anesthetic to the central nervous system, blunting pain and other noxious symptoms, reducing narcotic requirements. Basic mental function is generally preserved up to the last few days of life, when coma may occur.

There can be a reduction in cardiopulmonary problems, ie, decreased congestive heart failure and pulmonary edema.[4] With a decline in respiratory tract secretions, the patient will have less coughing, choking, and shortness of breath. The drowning, suffocating sensation may resolve. There may be a diminished need for repeated, unpleasant suctioning.

Gastrointestinal fluid production can fall, and so there will be a shrinking propensity to bloating, nausea, vomiting, aspiration, and diarrhea. The patient has less need to void and a reduction in urinary incontinence. This may obviate the need for a urinary catheter.

As dehydration progresses, there can be decreased peripheral edema and ascites, with increased comfort. Chronically or terminally ill patients many times lose peripheral IV access. Central access, whether short- or longterm, can be painful, and limit patient mobility. Mobility can also be restricted by restraints used to keep the invasive tubes and lines from inadvertent or purposeful removal by the patient. Removing IVs and tubes can permit discontinuance of restraints, allowing increased mobility, comfort, and dignity. Removal of IVs can be helpful by removing a technical distraction, allowing attention to be directed to other forms of support such as personal care or conversation. Not uncommonly, a physician and nurse will be seen making a beeline for the IV in a terminally ill patient when the emotional stakes are high and the relevance of IV fluids is low.

Burdens of terminal dehydration

"Parched lips are a message from the water." Rumi[1]

On the other side of the coin are the possible burdens of dehydration at the end of life. Medical consequences may include confusion, restlessness, and neuromuscular irritability. Adjustment of the narcotic and sedation regimen may ameliorate this problem. This is not a usual event. A common misconception about hospice care is that IV fluids are forbidden. This is not the case in practice or in Medicare hospice guidelines. Occasionally a patient with terminal illness will benefit by a brief trial of IV fluids to improve renal clearance when accumulation of opioid metabolites is a suspected reason for confusion or other forms of neuroexcitation. Other situations in hospice care where IV fluids may be recommended would be for the replacement of rapid fluid losses (diarrhea, overly aggressive drainage of ascites), resulting in distressing symptoms such as syncope and confusion.

The most common concern about forgoing forced hydration is thirst, a dry mouth and throat sensation, as the oral mucosa becomes parched, cracked, and painful. This can be alleviated with careful attention to local oral hygiene, not by forcing oral fluids. This is in contradistinction to the usual reference to thirst, ie, the requirement to drink a large amount of fluid to assuage the sensation. Thirst can be mitigated in terminally ill pa-

tients by small quantities of fluids, much less than that required to effect volume or osmotic receptors.[3]

The largest drawback to the withholding of fluids generally is not the physiologic consequences to the patient, but rather the multifactorial concerns of the family and healthcare providers. Most lay and nonhospice professionals have an aversion to allowing an individual to die by starvation and dehydration. They perceive this process to be an "awful death."[3]

Emotional and societal issues

There is historic symbolic value to food and drink, as representatives of nurture and caring. The innate psychologic link between oral sustenance and love begins in our infancy, when we are dependent on others for nourishment. In adulthood, we continue to perceive a connection between nutrition and emotional satisfaction. Eating and drinking together are longstanding social, communal customs, bonding our interpersonal relationships.[5]

Ethical and legal issues

The principle of autonomy is the basis for ethical and legal theory in the realm of end-of-life decision making. This concept establishes the right of the individual to make decisions about what interventions he or she wishes to undergo, or forgo.[6] There is legal consensus for end-of-life treatment limitation. Several landmark cases have established these precedents.

The United States Constitution's 14th Amendment liberty interest and the respect for bodily integrity, founded in ancient common law, permit a patient to refuse unwanted treatment, even if that refusal will result in his or her demise.[7-9] This principle pertains even in the absence of a life-threatening disease.

A legal myth reigned that withdrawing or withholding nutrition or hydration from a permanently unconscious or terminal patient was illegal. In reality, courts have upheld that withdrawing or withholding treatment can be justifiable. They have also refused to make a distinction between "extraordinary" and "ordinary" care. Nutrition and hydration withdrawal falls under this purview. This opinion was articulated in the Cruzan case in just the last decade.[7,10,11]

Not only are these rights endorsed by our justice system, but failure to honor these privileges may expose the physician to legal damages based on suffering, pain, and accumulated expenses of ongoing care.

Religious/cross-cultural issues

There is variability among religious groups about provision of artificial hydration. Some beliefs are unwaveringly prolife, claiming a moral mandate to preserve life at all cost, using all available technology, no matter what the prognosis. Other circles have concluded that the issue should no longer be extraordinary versus ordinary care, but rather burden versus benefit. These leaders have concluded that burdensome treatments are not obligatory in the eyes of their deity.[12] The public may lag behind in understanding, and not have a firm grasp of the current theologic theory. Clergy may be of assistance in the education and consolation of all involved.

Those of us with western European ancestry tend to be ethnocentric in addressing end-of-life issues (as well as many other life issues). We must remember that there are many diverse lifestyles and cultural approaches to the end of life. A recent focus group study done in Philadelphia examined attitudes of other communities, including African-American, Korean, Latino, Russian, and Cambodian. Although many of the participants did not have extensive knowledge of the mechanisms or potential complications of artificial hydration (or nutrition), they found the concept of this form of sustenance as "not real" food or water. Despite this bias, they still could not fathom withholding even this "fake" nourishment from their family member.[13] Other spiritual traditions validate the concept of fasting or voluntary denial of food and water to achieve a greater purpose. In the light of cultural differences, we may find assistance in community leaders or family elders in addressing these complex issues.

Summary

"You are looking at the waves but ignoring the Sea." Rumi[1]

An alternate view of traditional medical practice may allow us to understand that the rejection of food and drink at the end of life is natural, and that the technologic support of nutrition and hydration is artificial and unnatural. Perhaps it is not the inadequate nutrition and dehydration, but rather the artificial processes and elements that should cause us to cringe.[5]

Practical concepts exist. It may be difficult for family members and medical personnel to accept the patient's

choice to forgo food and water. Longstanding personal and cultural values may conflict with this decision. We must offer education and emotional support to both groups of caregivers (personal and professional).

The sensation of thirst can be powerful and uncomfortable. Excellent oral hygiene, including frequent swabing, will alleviate this symptom more readily than forcing unwanted fluids. A token glass of water, placed nearby, and easily available, may help alleviate the emotional angst of all involved by providing a cultural symbol of nurturance.

Careful attention to patient symptoms during the dying process will further produce a "good death." Adjustment of narcotics and antianxiety agents may improve patient comfort. Remember that an actual reduction of medications may be required as the final days and hours of life approach, in part because of decreased renal clearance.

A final gentle reminder: terminal dehydration is not swift. Death may not take place for several days to weeks. Occasionally unexpected but much welcomed consequences of forgoing forced hydration, such as marked reduction of massive edema or ascites, occur in longer term survivors. An average of 1 to 2 weeks may pass before the ultimate demise of the patient. Hospice can assist with valuable services to the patient and caregivers during this distressing time period.

In conclusion, terminal dehydration is a controversial topic, weighted heavily with historic symbolism, and strong religious, societal, and cultural conflicts. Of prime importance is the patient's legal right, the choice, to forgo hydration. It is a violation of autonomy, liberty, and dignity to force hydration on a competent patient who is unmistakably refusing.[14] It is our duty to respect and protect this decision, and to provide adequate care and comfort during the dying process.

Appendix

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REFERENCES

1. Freke T. Rumi wisdom: Daily teachings from the great Sufi master. New York: Sterling Publishing Company, Inc; 2000:34, 61, 81.
2. Karnes B. Gone from sight: The dying experience. (Pamphlet: Stilwell, KS). In: Webb M. The good death: The new american search to reshape the end of life. New York: Bantam Dell Publishing Group; 1997.
3. Byock IR. Patient refusal of nutrition and hydration: Walking the ever-finer line. Am J Hospice Palliative Care 1995;12:8–13.
4. Levetown M. Palliative care in the intensive care unit. New Horizons 1998;6:383–397.
5. Ahronheim JC, Gasner MR. The sloganism of starvation. Lancet 1990;335:278–279.
6. Walker RM. Ethical issues in end-of-life care. Cancer Control. 1999;6:162–167.
7. Emanuel LL, vonGunten CF, Ferris FD. Plenary two: legal issues. In: The education for physicians on end-of-life care (EPEC) curriculum, 1999.
8. Bartling v Superior Court, 163 Cal App3d 186, 209 Cal Rptr 220 (1984).
9. Bouvia v Superior Court, 170 CalApp3d 1127, 225 Cal Rptr 297 (1986).
10. Cruzan v Director of Missouri Department of Health, 109 SCt 3240 (1990).
11. Meisel A, Snyder L, Quill T. Seven legal barriers to end-of-life care: Myths, realities, and grains of truth. JAMA 2000;284:2495–2501.
12. Declaration on Euthanasia. Vatican Congregation for the Doctrine of Faith, June 26, 1980.
13. Phipps E, True G, Pomerantz S. Approaches to end-of-life care in culturally diverse communities. (Focus group study conducted in Philadelphia.) Results posted on www.lastacts.org web site 07/07/2000.
14. Miller FG, Meier DE. Voluntary death: A comparison of terminal dehydration and physician-assisted suicide. Ann Int Med 1998;128:559–562.

ADDITIONAL RESOURCES

1. Task Force on Ethics of the Society of Critical Care Medicine. Consensus report of the ethics of forgoing life-sustaining treatments in the critically ill. Crit Care Med 1990;18:1435–1439.
2. President's Commission for the Study of Ethical Problems in Medicine and Behavioral Research. Deciding to forgo life-sustaining treatment: A report on the ethical, medical and legal issues in treatment decisions. Washington, DC: US Government Printing Office; 1983.
3. Lynn J, ed. By no extraordinary means: The choice to forgo life-sustaining food and water. Indianapolis, IN: Indiana University Press; 1989.