Ethical Issues in Palliative Care

To Feed or Not to Feed? A Case Report and Ethical Analysis of Withholding Food and Drink in a Patient With Advanced Dementia

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Abstract

It is well established that competent patients have the right to refuse artificial nutrition and hydration. There is less clarity regarding withholding nutrition in patients who lack decision-making capacity but who are still physically able to eat and drink. This case highlights the ethical dilemma of withholding food and drink in a patient with advanced dementia. J Pain Symptom Manage 2015;50:887—890.

Key Words

Advanced dementia, Alzheimer's disease, voluntarily stopping eating and drinking, VSED

Introduction

As the population ages, Alzheimer disease will create a growing population of patients who are ultimately unable to make their own medical decisions. Alzheimer disease is the fifth leading cause of death in people older than 65 years. The number of people living with dementia worldwide is estimated at 35.6 million, and this number is expected to double by 2030 and more than triple by 2050.[1] As people gain more personal experience with end-stage dementia, some patients may want to forgo treatments as their dementia progresses. This was illustrated in a recent article in *The New York Times*, in which Mr. Mendalie says that if he develops advanced dementia, he would want to forgo "ordinary means of nutrition and hydration."[2] Patients are encouraged to participate in advance care planning, but the health care system is not set up to support some decisions that people may wish for themselves, such as withholding food and drink via ordinary means (i.e., oral intake) in end-stage dementia.

Case Description

Mr. A was an 80-year-old man with Alzheimer disease. He had been living in a nursing home for four years. Mr. A had the equivalent of Functional Assessment Staging of Alzheimer Disease Tool 7B, being able to communicate his basic needs with one- to three-word responses, requiring full assistance with activities of daily living and being bedbound from lower extremity contractures.[3] But three months ago, he had new-onset hemiplegia and worsening aphasia. He was presumed to have had a stroke, but a diagnostic workup was not pursued. Mr. A was alert but not verbal, appeared to no longer recognize his daughter, and developed dysphagia that required a modified diet and slow hand-feeding. As a result of this clinical change, Mr. A was admitted to hospice.

At Mr. A's hospice interdisciplinary team meeting, his nurse and social worker raised the concern that Mr. A's daughter, his appointed health care agent, had given instructions to the nursing home staff to withhold food and drink from her father. Given the stroke and severity of Mr. A's dementia, he could no longer verbally communicate his needs but he willingly opened his mouth and ate food when offered. It was not possible to assess whether he would oppose not receiving food. Mr. A's hospice nurse and social worker, and nursing home staff, were not comfortable with the request to withhold food. Therefore, a family meeting was held with Mr. A's daughter, his hospice

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nurse, social worker, chaplain, hospice medical director, and the nursing home director.

Mr. A's daughter felt that she had waited a reasonable amount of time since the presumed stroke to determine that her father had not recovered to an acceptable quality of life. She advocated that her father would not want any medical intervention to prolong his life and viewed fully assisted hand-feeding as a life-prolonging intervention. Mr. A's daughter relayed conversations that she had with her father about other family members who had died in similar situations. She felt conflicted because her intention was not to hasten her father's death, but she felt that she would be honoring his wishes by withholding food and drink. She felt frustrated with medical providers who would not allow her to uphold her father's wishes and made her feel deplorable as if she was not acting in his best interest.

Mr. A's Living Will, completed nearly a decade earlier, enumerated that he did not want medical interventions, such as resuscitation, artificial feeding tubes, and did want to "withhold or withdraw life-sustaining treatment that serves only to prolong the process of my dying if [he] should have a terminal condition or a state of permanent unconsciousness." Mr. A also had clearly elected his daughter as his surrogate. The Living Will did not explicitly state to stop hand-feeding him.

The nursing home staff was concerned about causing Mr. A discomfort by "starving him," especially because they believed that he was expressing a desire to eat and drink. All medical providers were unsettled that fulfilling Mr. A's daughter's request possibly meant condoning neglect and endangering a vulnerable older adult.

Ethical Analysis

Is It Ethically Justifiable for a Surrogate to Refuse Food and Drink on the Patient's Behalf?

It is well established that competent patients have the right to refuse any medical or surgical interventions, including artificial nutrition and hydration, even if doing so will hasten death.[4] Because patients have the right to forgo life-sustaining treatment, it has been argued that competent patients with a terminal or incurable illness can choose to voluntarily stop eating and drinking (VSED). Physicians cannot overrule a competent patient's decision to refuse treatment. A "competent" patient with a terminal illness has the right to VSED.

Mr. A was not competent and he had an advance directive (AD) that did not explicitly anticipate his current state and problem. Even if it had, there are valid ethical questions about the gaps between what effects Mr. A thought dementia would have on him in the future and what actually transpired as the disease progressed. Some would suggest that for a person to make an informed decision, they must have a genuine understanding of the experience.[5] In Mr. A's case, he had experience with this disease and its outcome in his family members. It is plausible he knew insofar as anyone could comprehend and communicated his views and wishes to his daughter and elected her as his surrogate to carry them out. Menzel and Chandler-Cramer[6] propose a framework by which patients could elect VSED by ADs. However, at this time, there is no system in place by which a patient's AD or surrogate can refuse food and drink on behalf of the patient in the U.S.

There are medical and ethical mandates to provide food. The American College of Physicians' End-of-Life Care Consensus Panel maintains that "food and drink must not be withheld from incompetent persons who are willing and able to eat."[7] The right to food is also protected by the Universal Declaration of Human Rights Article 25, adopted by the General Assembly of the United Nations.[8] A surrogate can choose to forgo medical procedures on the patient's behalf, but because hand-feeding is not a medical procedure, failure to offer food to an incompetent patient could be viewed as neglect. There is currently no generally accepted mechanism by which a surrogate can refuse "oral" food and drink on behalf of an incompetent patient in the U.S. Legal frameworks for advance care planning vary across different countries, and the authors are unaware of countries where surrogates can legally refuse oral food and drink on behalf of incompetent patients.

Is It Ethically Justifiable for Caregivers to Withhold Food and Drink From the Patient?

Withdrawing or withholding any medical intervention or life-prolonging measure can be done on the basis of net beneficence (doing good for the patient).[4] Other important ethical principles involved in answering this question pertain to justice (Mr. A should be treated fairly and equally) and autonomy (Mr. A should be able to make his own decision). Autonomy is discussed subsequently. In addition, nonprinciple-based approaches, such as virtue ethics and narrative ethics, can provide additional frameworks to answer this question. It is beyond the scope of this discussion to review these, but they are very well presented elsewhere.[9]

Applying net beneficence in the case of VSED would mean that the benefits of withholding food and drink outweigh the risks associated with continuing to offer food and drink. Mr. A shows no signs of distress when offered food. His daughter is, however, upset that her