Globethics Repository



Doing the Right Thing

This page was generated automatically upon download from the Globethics Repository. More information on Globethics see https://www.globethics.net. Data and content policy of Globethics Repository see https://repository.globethics.net/pages/policy.

Item Type	Article
Authors	Pensiero, Cheryl
Publisher	University of Mississippi Medical Center
Rights	With permission of the license/copyright holder
Download date	2026-11-16 15:39:40
Link to Item	http://hdl.handle.net/20.500.12424/171783

Doing the Right Thing – Helping Families Decide Whether to Withhold Artificial Nutrition & Hydration in Alzheimer Disease

Cheryl Pensiero, RN, MS, NP-C
Cap57@columbia.edu
Assistant Professor of Nursing
Columbia University
New York, New York

Abstract

At the end of life, family members and clinicians face many decisions about medical care for patients with dementia, none more unsettling than that regarding artificial nutrition and hydration (ANH). Many families and clinicians fear withholding food and drink believing that it is cruel to do so. Health care providers need to acknowledge that artificial nutrition and hydration are part of medical treatment, often not effective in prolonging life, preventing aspiration or providing nourishment. In fact, adverse consequences can and do occur. Discussions with families should center on medical outcomes and weighing the benefits and burdens of this treatment.

Introduction

Families who watch their loved ones deteriorate during the course of Alzheimer's Dementia (AD) are faced with many painful decisions. No decision is more anguishing than that which relates to artificial nutrition and dehydration (ANH) (Post, 1995). AD is a progressive disease characterized by degenerative neurological defects, including memory loss, problems with reasoning and judgment, disorientation, difficulty in learning, loss of language skills, and a decline in the ability to perform routine tasks (Marcheco, Bertoli, Rojas, and Heredero 2003). When patients with advanced dementia start to have difficulty swallowing or lose interest in eating, the decision is often made to insert a feeding tube.

In the absence of a family member or advanced directives, the decision to insert a feeding tube in a patient unable to give consent is made by members of the medical staff. A study at a municipal hospital in New York City in which a majority of the patients did not have advance directives showed that all of the patients evaluated for feeding tubes received feeding tubes (Gillich 2000). Even when a family does have a health care proxy, the decision is often made to insert a feeding tube. This decision is most commonly based on the family's desire to do the right thing for the loved one, to prolong life, and to alleviate suffering.

The Patient's Story

MP, an 89 year-old Italian female, who had long been the highly functioning matriarch of her family, began to show signs of memory loss, severe changes in behavior, and difficulty in decision making. Responding to an advertisement in their local paper, her daughters took her to a memory loss program affiliated with a reputable psychiatric institution. There the patient was seen by a neurologist and psychiatrist. An MRI revealed diffuse atrophy of the brain without evidence of mass lesions or infarcts. The patient was

diagnosed with probable early AD, Aricept was started, and the patient was followed for AD by this memory loss program.

As part of their management plan for patients with dementia, the psychiatric institution encouraged all patients to establish advanced directives and appoint a durable power of attorney (DPOA). MP, together with her family, decided to appoint her eldest daughter, with whom she was residing, to be her health care proxy and DPOA.

As MP's AD progressed, the family was forced into a significant decision-making role. One weekend the family brought MP to the emergency department (ED) following several days of extremely poor oral intake and decreased urinary output. The ED physician recommended that a gastrostomy tube be inserted to treat MP's malnutrition and dehydration. MP's eldest daughter, her health care proxy, consented to this procedure convinced that it would alleviate MPs discomfort and prolong her life. MP's family is an observant Roman Catholic family. They attend Mass every week and on holy days of obligation, and they are active lay ministers in their parish. The decision to insert the feeding tube was perfectly in keeping with the family's moral and religious beliefs. According to one of MP's granddaughters, their belief in the sanctity of life would not allow them to withhold food and water from her grandmother believing that this would cause extreme suffering and ultimately her death. This option would have been morally unacceptable to them.

As time went on, MP's physical and mental condition continued to deteriorate. She had multiple hospitalizations with elevated temperatures, sepsis, pneumonia, and she developed a fistula. As her dementia increased, she attempted to pull out her feeding tube and had her wrists restrained. Although the family by now was beginning to question their decision to insert the feeding tube, they never seriously contemplated removing the tube. Instead, they faced the overwhelming challenges of each episode of MP's decline. Within seven months of the insertion of the tube, MP had expired.

Erroneous Assumptions

MP's family had relied on several assumptions when they made the decision to have the feeding tube inserted. The first assumption regarded the alleviation of MP's suffering. They assumed that her anorexia was equivalent to suffering. We do not know what kinds of feeling hunger causes in a patient with the progressive deterioration of AD. Information yielded from the hospice movement relates that patients with cancer who are lucid and can relate the sensations of thirst and hunger, remark that the sensations are transient and can be alleviated with ice chips and mouth swabs (Gillick 2000). In addition, dehydration can act as a natural sedative, especially in the elderly, because sodium and waste products accumulate in the blood causing stupor or coma (Gillick 1994).

In a 2003 study in the Cleveland Clinic Journal of Medicine, Jacqueline Slomka, PhD, RN, points out that tube feedings can potentially cause diarrhea, nausea, vomiting, esophageal perforation and infiltration of formula into the lung (Slomka 2003). In addition, the gastrostomy tube site can become infected, the tube can become clogged or dislodged, and many patients must be restrained to prevent them from pulling out the tube. Aspiration pneumonia can result from the reflux of gastric contents and aspiration of saliva (Gillich 2003). Intravenous fluids can also cause severe adverse reactions, such

as infection, phlebitis, electrolyte imbalance, and in the case of inadequate renal function, peripheral or pulmonary edema (Slomka 2003).

A second assumption her family made was that the feeding tube would prolong MP's life. In theory, tube feedings should provide adequate nutrition. However, there is no proven long-term benefit in weight gain or markers of nutrition when tube feeding of demented patients is compared with age-matched controls (Capozzi and Rhodes 2000). Although it is true that MP lived an additional seven months following insertion of the feeding tube, her quality of life was so poor that her family seriously reconsidered their decision, even in light of their religious beliefs. The Roman Catholic position remains favorable towards continuation of nutrition and hydration even if assisted medically. However, further investigation of this statement reveals that the benefit must outweigh the burden to the patient (Gillick 2003). Orthodox Judaism traditionally requires life above all else, but in recent years has begun to reject interventions that cause or prolong suffering (Gillick 2003).

Whose Decision is it?

Who should decide when ANH is appropriate in a patient with AD? In 1990 Congress passed the Patient Self-Determination Act giving individuals the right to make decisions about end-of-life care through the use of advance directives. Currently, only twenty-five percent of Americans have completed advance directives (Gould, Williams, Arnold, 2000). Demented patients by definition are unable to contribute to decisions about their medical care because of the inherent disease process of AD. Therefore, a surrogate is often called upon to make health-care decisions on behalf of the patient. If a formal surrogate through health care proxy is not noted, the next of kin is allowed to make decisions (Capozzi and Rhodes 2000).

The highly publicized Terry Schiavo case (March 2005) highlighted the complications that can arise when close family members are unable to come to a consensus regarding medical decisions for an incapacitated person. In the Schiavo case, the courts found that her husband, rather than the parents, had the legal right to make her medical decisions. The prolonged agony of the legal battle to remove a feeding tube that prolonged the life of a brain-damaged woman emphasized the desirability of appointing a health care proxy while one is still able to do so.

Even when the patient has made her wishes clear prior to the onset of advanced dementia, definitions of life-prolonging treatment can be subjective. The 1976 Karen Quinlan case brought attention to the distinction between euthanasia and allowing a patient, who was being kept alive by artificial means, to die. Though the Supreme Court allowed individual states to set standards for decision making for patients considered to be incompetent, it was clearly noted by a majority of the Court that artificial nutrition and hydration was a medical treatment that could be withheld and withdrawn. In 1983, a presidential commission on ethics found that artificial nutrition and hydration was not needed or justified in all cases. Additionally, the American Medical Association, supported by the American Academy of Neurology and the American Nurse's Association, published a statement that artificial nutrition and hydration is a "life-prolonging treatment" (Angus and Burakoff 2003).

Notwithstanding these guidelines, many families and clinicians fear withholding food and drink believing that it is cruel to do so. It is incumbent upon clinicians to

educate themselves regarding the clinical and ethical variables of ANH so that they may be better prepared to handle questions and concerns of families making these monumental decisions. The language chosen by clinicians might also influence the family's perceptions of what is taking place. Emphasis of the patient's quality of life and reduction of symptoms help the families to feel comfortable in that their loved ones' needs are not being neglected should they decide against ANH (Slomka 2003).

Medical decision-making also has a broader perspective. Jeremy Bentham and John Stuart Mills frame ethical questions on terms of the greatest good for the greatest number. This approach is promoted by encouraging medical decisions to represent the wishes of the patient, whether or not that patient is able to express himself. Immanuel Kant spoke of ethical actions as reflecting one's duty rather than one's personal inclination. This philosophical view provides additional guidance for medical decision-makers who should not let sentiment impede logic and thoughtfulness.

Conclusion

Health care providers need to acknowledge that artificial nutrition and hydration are part of medical treatment and are often not effective in prolonging life, preventing aspiration or providing nourishment. In fact, adverse consequences can and do occur. Once this acknowledgement occurs, discussions with families and surrogates can center on medical outcomes and weighing the benefits and burdens of this treatment. In the case of end-stage dementia, it is imperative to remember that AD is a fatal disease and the amount of suffering can be diminished.

References

Anus, F. and Burakoff, R. 2003. The Percutaneous Endoscopic Gastrostomy Tube: Medical and Ethical Issues in Placement. *The American Journal of Gastroenterology, Vol. 98*, No. 2.

Capozzi, J.D. and Rhodes, R. 2000. Ethics in Practice. *The Journal of Bone and Joint Surgery, Volume 82,* May 2000, pp 748-749.

Gillick, M. 1994. Robbed of Mind and Memory: The Demented Elderly. *Choosing Medical Care in Old Age.* Harvard University Press: Cambridge, Massachusetts.

Gillick, M. 2000. Rethinking the Role of Tube Feeding in Patients with advanced Dementia. *The New England Journal of Medicine,* Vol. 342, pp. 206-210.

Gould, S.D., Williams, B., Arnold, R. M. 2000. Conflicts regarding decisions to limit treatment: A different diagnosis. JAMA 283 (7) 909-914.

Marcheco, B., Bertoli, A.M., Rojas, I. and Heredero L. 2003. Attitudes and Knowledge about Presymptomatic Genetic Testing among Individuals at High Risk for Familial, Early-Onset Alzheimer's disease. *Genetic Testing, volume 7,* number 1. p 45-47.

Post, SG., The moral challenge of Alzheimer Disease. Baltimore: Johns Hopkins University Press, 1995.

Slomka, J. Withholding nutrition at the end of life: Clinical and ethical issues. *Cleveland Clinic Journal of Medicine,* Vol. 70, pp.548-552.