Title: Treatment Trials - The Need for an End-of-life Policy

Author: Mary Ellen Wurzbach

"A good death does honor to a whole life"[1]

Petrarch (1348)

Introduction

Twenty years ago tube feeding of residents of nursing homes was commonplace. The discussion of the place of artificial nutrition and hydration in health care had not yet taken place. Because of concerns about the ethical value of technology in caring for patients all "tubes" came under scrutiny.

At this time withholding and/or withdrawing artificial nutrition and hydration (feeding tubes) was first discussed. Nutrition and hydration were seen at that time as essential to life and the care of patients. The question arose, however, whether tube feedings were medical care or ordinary life saving measures. Several cases of persons in "persistent vegetative states" (a term not previously used) piqued the conscience of the country.[2] The case of Nancy Cruzan was argued all the way to the United States Supreme Court, where the decision was made that a proxy decision-maker must provide "clear and convincing" evidence of what the incompetent person would have wanted before a feeding tube could be withdrawn. At this same time the Hastings Center came to the conclusion that there was no moral difference between withholding or withdrawing a feeding tube; that "trials" of a tube feeding were morally permissible; and that although no moral difference existed, there was still a psychological difference between withholding or withdrawing artificial nutrition and hydration - that psychological difference

being the belief that withholding was merely allowing the person to die, whereas withdrawing the tube was actually "killing" the person.[3]

The Context

In 1989 my great aunt, who had lived a healthy 93 years, fell and broke her leg. She had a cast applied and was sent to a nursing home. The stress was too much, and she had a stroke. She was moved to the hospital, but she could no longer communicate nor did she seem to understand communication, despite being able to push food away. She gradually became weaker and weaker and was near death. At that point, the social worker for the hospital decided that if the hospital was not actively treating her she had to be moved to a nursing home. Her doctor, and the entire family, wanted her to just peacefully pass away in the hospital.

The social worker found a nursing home, but the nursing home insisted that she had to have a nasogastric tube because all of their residents had to have fluids provided. Despite my objections, a nasogastric tube was placed and she was moved to the nursing home, where she was barely conscious for weeks on fluids but not nutrition. At one point nutrition via feeding tube was added at the order of the Nursing Home Administrator, leaving my aunt semi-aware of both her pain and possibly her predicament. I was in the process of becoming her guardian and trying to stop the tube feedings with a court order when she died, six months after being admitted to the nursing home.

Two decades later my uncle, an elderly man and the nephew of my great aunt, had a similar experience. He had been in a nursing home for seven years after being hit by a car while crossing the street in his hometown. He was sent to the hospital several times with a fever, continued vomiting and was unresponsive. Tests were done to determine whether he had a urinary tract infection or pneumonia and it was found that he had pneumonia, probably

secondary to an inability to swallow. In the hospital he was sent for a swallowing test, which he failed, so the hospital totally restricted his oral nutritional and fluid intake, keeping him on intravenous fluids. In the hospital he recognized me, but could not respond. Because he looked as though he was dying, I refused the gastrostomy tube.

After the gastrostomy tube was refused he was sent back to the nursing home. The doctor had taken him off all medications, but left one minor tranquilizer and morphine as needed. Suddenly, he was wide-awake and looked frightened and anxious, but could not speak or answer questions. I talked with the nursing home personnel and hospice and he was finally put back on a minor tranquilizer routinely rather than as needed and he relaxed. He died peacefully within a week. During that week food and liquids were offered to him but he refused all but a few bites.

This second episode had several striking aspects. First, most of the doctors and nurses refused to give any advice; they indicated that they were just there to support my decisions. This is what I call the "influence taboo",[4] the belief of doctors and nurses that they ought not influence the health care decision of the patient or family, still a strongly held belief after two decades.

The second aspect of the situation that was striking was that there seemed to be as much uncertainty and certainty about withholding or withdrawing a gastrostomy tube today as there was about withholding or withdrawing a nasogastric tube twenty years ago. The staff (both at the nursing home and in the hospital) was more amenable to the idea of withholding today than years ago, but still believed that if a gastrostomy tube were inserted it would not be removed until death.

Withholding or Withdrawing a Gastrostomy Tube - A Special Case

Withholding and withdrawing a feeding tube is a special case of the general case of restricting treatment. The process of withholding a feeding tube (these days a gastrostomy tube) is different than withholding or withdrawing a ventilator, dialysis, or antibiotics. With feeding tubes the decision-maker has the time to change his/her mind and/or to become uncertain about the decision. Despite this uncertainty and/or change of mind there may be a point beyond which there is no return. The process is not necessarily cruel or more cruel than removing any other treatment, but by the time the person dies, the decision maker has had to watch the results of the decision and the resident has had to experience a slow although seemingly not painful death.

There is also a difference in the psychological effect of refusing a feeding tube on another's behalf because, despite the belief that it is not "killing" the person, James Rachels may be right in that there is not much difference between this refusal and euthanasia.[5]

When the family is told that the tube will stay in until death the decision becomes an all-or-nothing decision. If one has witnessed other relatives dying after having been on tube feeding for many years in persistent vegetative states, there is pressure to withhold the tube to prevent this outcome.

Meanwhile, all information is not available to the proxy and different agencies (the hospital and the nursing home) are making decisions that impact the final decision, such as making the elder NPO if he/she fails a swallowing test, without consultation with the proxy. While more time is necessary for thinking and consultation, the resident or patient is in the process of being moved between facilities because a hospital can no longer provide care to the person who, from their perspective, has no more acute needs.

The process has not changed in that the decision-maker is alone with the decision and, although considered the true decision maker, miscellaneous decisions made by the health care team tacitly direct the decision. Each seemingly minor decision that is made by the hospital or nursing home leads to another decision by the guardian, who often never knows who made the original decision, why that decision was made, or how the elder for whom the decision was made feels about the decision. Decision-making time afforded the surrogate seems insufficient and decisions made, effect change quickly. No one in the hospital or nursing home knows or is able to spend a great deal of time considering the alternatives - the expectation is that the guardian knows the person better than they do.

Treatment Trials - Why?

All of the drawbacks of immediate, constrained decision-making could be changed by one simple policy shift: seeing tube feeding the way in which the Hastings Center, decades ago, professed it was - a possible trial to allow for time to be given to the decision about whether a permanent removal would be performed. More time ought to be given to the decision that ends another's life, yet the health care system is not organized to consider alternative decisions and a lack of time and moral uncertainty or moral certainty drive the decisions that are made.

Arguments For and Against Treatment Trials from an Individual Perspective.

The primary argument for treatment trials is the need for time in which to make a decision. Time to consider possible outcomes, gather information, consult with health care practitioners, and to consult with the patient/resident if possible. There is also the wish to err on the side of life, reduce moral uncertainty and regret for the proxy, and base a decision on the gathered physiological, psychological and ethical information. Finally, there is the argument that

the Hastings Center also proposed so many years ago - that there is no ethical difference between withholding and/or withdrawing.[3]

The primary argument advanced by those who are opposed to treatment trials is that removing a gastrostomy tube is "killing" the resident. In addition, psychologically, withdrawing might be more difficult than withholding. Finally, the courts could get involved if there is a disagreement and this may lead to more people being maintained on "tubes" if circumstances evolve like they did in the Terry Schaivo case, where the family of Terry Schaivo disagreed with the husband's decision to withdraw nutrition and hydration from his wife, resulting in great public disagreement about how persons in a persistent vegetative state (PVS) ought to be treated. This may also prolong the decision-making process and make it more difficult for the family, proxy, and the resident.

Arguments For and Against Treatment Trials from a Community Perspective

The primary communal argument in support of treatment trials is that the community has an interest in preserving life and an interest in ethical decision-making related to the prolongation or diminution of life. As the community ages, many baby boomers will be decision-makers for elderly parents and will also become the patient/resident. There is an enormous problem looming on the horizon as the new millennium progresses, given the numbers of persons who may become incompetent without making their wishes known. Court costs for the courts to decide every case of withholding artificial nutrition and hydration could be enormous. Finally, the community wants sound, ethical decisions made about withdrawing and withholding.

The primary argument in opposition to treatment trials is that it is never permissible for a community to condone the "killing" of a resident or patient. A large portion of the community sees artificial nutrition and hydration as life saving and the community believes that it must

protect the vulnerable who are unable to speak for themselves, as is evidenced by the Terry Schiavo case.

Benefits of Treatment Trials for the Individual

The primary benefit of treatment trials for the individual is that of allowing the surrogate more time to gather information from others, to determine what the possible outcomes might be, to try to communicate with the incompetent person, and to err on the side of life while protecting both the resident and the proxy from the regrets associated with a precipitous judgment.

In the case of my aunt, she would not have been given the artificial nutrition and hydration, which caused her to live in anguish for many months. Once there had been a trial, the tube could have been removed. More recently, my uncle may have lived longer had I known that a treatment trial was possible. There would have been an error on the side of life and yet when life was seen as too burdensome for him the tube feeding could have been removed. A decision would need to be made on an individual basis about when to remove the tube, but there would be time to decide about the appropriate timing and the appropriate decision.

Benefits of Treatment Trials for the Community

Currently, there is an epidemic of elders in nursing homes with swallowing difficulties, Alzheimer's, and other maladies, which cause diminished decision-making capacity and initiate the discussion of whether to insert a gastrostomy tube. Concomitant with this is an overriding belief among health care practitioners that once a tube is inserted it will remain until the death of the resident.[4,6] This issue will become a major concern in the near future, given the sheer numbers of baby boomers becoming elderly and the number of times this decision must be made. The cost alone of arbitrating every decision of withholding or withdrawing would be enormous, not to mention the human cost in time and emotional energy necessary to make each of these

decisions. Treatment trials would allow each individual's position within the human community to be maintained until a final decision could be made about whether to withhold or withdraw artificial nutrition and hydration.

Conclusion

Treatment trials of gastrostomy tubes for elders with swallowing difficulties, Alzheimer's, atypical dementia and other chronic conditions which lead to the decision about whether to withhold or withdraw artificial nutrition and hydration will improve the choices for incompetent residents without violating their rights. These rights may be the right to choose, the right to life, or the right to be free of unwanted treatment. For each elder the decision may be different but the hope is that each treatment trial would lead to decisions that more closely approximate the wishes of the elder, unlike the present system of haphazard decision-making based on limited information and the choices of a DPOA-HC or guardian suddenly called into service but minimally aware of the resident's wishes.

In order to protect the autonomy of our soon-to-be large population of future elders, we must consider our long-term care and end-of-life policies now before we are overwhelmed by a plethora of choices. The need for frank discussion with family members and proxy documentation are essential, as is the communication of health care practitioners with residents and patients about these critical choices. The Hastings Center provided leadership years ago by advocating for treatment trials. It is now time for the social and cultural changes that will make this possible.

References

1. Petrarch. In: *The Macmillan Book of Proverbs, Maxims, & Famous Phrases*. New York: The Macmillan Company, 1948.

2. Cranford, R. The persistent vegetative state: The medical reality. *The Hastings Center Report.* 1988; 18: 27-32.

3. The Hastings Center. *Guidelines for the Termination of Life-sustaining Treatments and the Care of the Dying*. Briarcliff, NY: The Hastings Center, 1987.

4. M.E. Wurzbach, "Long-term Care Nurses' Ethical Convictions About Tube Feeding". *Western Journal of Nursing Research* 18 (1996): 63-76.

5. Rachels, J. Active and passive euthanasia. *New England Journal of Medicine.* 1975; 292: 78-80.

6. M.E. Wurzbach Treatment Trials: The Need for an End-of-life Policy. Unpublished manuscript (2008).