The Standard of Caring: Why Do We Still Use Feeding Tubes in Patients With Advanced Dementia?

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A consensus among geriatricians, ethicists, and neurologists supports a palliative approach to the care of individuals with late-stage dementia. But ten years after the publication of the first large study demonstrating the lack of efficacy of percutaneous endoscopic gastrostomy (PEG) tubes in prolonging life for patients with advanced dementia, and seven years after the appearance of two articles in major medical journals arguing that tube feeding should no longer be the standard of care for individuals with advanced dementia, gastrostomy tubes remain commonplace in this population. One overlooked reason that many families and physicians continue to opt for artificial nutrition is that the case for feeding tubes is a moral one and not a scientific one. What may be at issue for families is how best to demonstrate caring, and caring is not readily amenable to empirical study. A better approach to family members who want feeding tubes for the demented is to acknowledge the symbolic value of nutrition for them and to seek an alternative means of satisfying the need to feed. (J Am Med Dir Assoc 2008; 9: 364–367)

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Factors Promoting Tube-Feeding

According to the most recent statistics available, the rate of feeding tube use among patients with advanced dementia living in nursing homes varies widely from state to state, ranging from a low of 7% in Maine to a high of 40% in Mississippi. It has fallen somewhat from the national average of 34% reported in 2003, although the decline is not found in minority populations. A large literature has developed that seeks to explain the barriers to change. Several articles address patient factors: religion, socioeconomic status, or site of residence of the person with dementia. Other articles...
address institutional and regulatory factors, finding that nursing homes with in-house speech therapists have higher PEG use.12 Still other articles have identified state statutes that limit the ability of health care proxies to authorize withholding of artificial nutrition as a potential contributor to prevailing practice.13 Finally, some investigators have examined the role of economic factors—the way PEG treatment is paid for—in the hope of explaining the dramatic regional variability in the use of feeding tubes in advanced dementia.14 Their conclusion is that states whose Medicaid programs provide markedly greater reimbursement to nursing homes for the care of tube-fed residents than hand-fed residents have higher rates of tube feeding. But all these factors, while clearly a crucial part of the story, do not fully account for the rate of PEG use in individuals with advanced dementia.

Another possible explanation for the continued use of PEGs is that the data that form the case against feeding tubes are not sufficiently compelling. The landmark 1997 article analyzing survival in 1386 nursing home residents with advanced dementia and feeding difficulties was an observational study, not a randomized trial. If our intuition tells us that feeding tubes ought to prolong life, even in individuals who are in the final stage of dementia, then surely we should demand rigorous proof, not merely a statistical analysis of government-mandated nursing home data.

But perhaps one overlooked reason that many loving families and caring physicians continue to opt for artificial nutrition is that the case for feeding tubes is a moral one and not a scientific one. Clinical experience suggests that family members who express concern about "starving" their relatives to death may not be asking for more data. They may not be interested in the relative merits of randomized versus observational studies. They are unlikely to be persuaded by claims that feeding tubes not only fail to prolong life but also are ineffective in preventing aspiration pneumonia or pressure ulcers.6 These medical outcomes, which can be scientifically measured, are of interest to physicians; it is not at all clear that they are important to families. From this perspective, families will derive little reassurance from a new, better designed study or a multipronged intervention that simultaneously addresses each of the factors that have a small but statistically significant effect on PEG usage.15 What may be at issue for families is how best to demonstrate caring, and caring is not readily amenable to empirical study.16

**WHAT MATTERS TO PATIENTS AND FAMILIES NEAR THE END OF LIFE**

What matters to patients near the end of life is not uniformly the same as what physicians identify as important. Patients want their symptoms to be controlled, they wish to remain in control, they are concerned about being a burden to their loved ones, and, what is most readily extrapolated to an individual with dementia, they wish to be treated respectfully.17 Cognitively intact dying patients are able to articulate that their dignity is upheld when health care providers affirm their personhood.18 Family members echo these concerns and often express disappointment with nursing home care precisely because they find that their relatives are not treated with respect.19

Determining how best to show respect to an individual with advanced dementia is difficult since patients cannot speak for themselves. Few studies have specifically addressed how families believe their demented relatives should be cared for. Specialists in Alzheimer's disease who recognize the importance of trying to enhance the well-being of people with dementia have focused principally on individuals with mild to moderate disease.20

**FEEDING TUBES AS CARING**

Quantitative analysis can provide some help in determining a standard of caring. Investigators have designed instruments to measure pain in advanced dementia21 as well as scales to assess multiple dimensions of suffering.22 These tools can in principle help ascertain whether patients with advanced dementia suffer in the absence of artificial nutrition and hydration. One study of nursing home residents with severe cognitive impairment and pneumonia found that symptoms of discomfort diminished as death approached, even in the absence of artificial nutrition, but the study was small, uncontrolled, and restricted to individuals with pneumonia.23 But studies purporting to measure suffering with and without a feeding tube are likely to be helpful to families only if they clearly show that withholding nutrition increases suffering. If tube feeding is not necessary to prevent suffering—as extrapolation from patients dying of cancer suggests—it could nonetheless demonstrate caring and preserve dignity.

Feeding has symbolic significance in our culture. For many families, arguing that the loss of the ability to swallow or of interest in food is part of the dying process is an insufficient reason for withdrawing or withholding artificial nutrition. Stating that the appropriate goal of care for the individual with advanced dementia is comfort rather than life-prolongation also misses the point: the family's goal in many instances is precisely to maximize comfort. The question is how best to achieve their goal, how to demonstrate caring, respect, and love. It is this question that cannot readily be answered by scientific studies.

The standard of caring is defined by social and cultural norms. In 21st century America, we assume that individuals with advanced dementia should be kept warm and clean, even though we have no data that demonstrate conclusively that people with profound cognitive impairment experience being cold as uncomfortable or are bothered by being unkempt or dirty. We take it for granted that those with dementia should be kept clothed and insist on covering individuals who repeatedly remove their clothes. We argue that an elderly person should remain dressed to preserve his dignity, even though patients with dementia often disrobe, presumably with no loss of dignity. When we claim to be showing respect for the person, we mean that being dressed is of symbolic significance.

Most families show their love for their demented relative—or for the person she once was—through physical affection: hugs, kisses, caresses. We do not expect the medical profession to perform studies purporting to show that Alzheimer's patients are, say, less susceptible to upper respiratory infections if they are hugged 3 times a day than if they are not. More-
over, if a carefully conducted study definitively demonstrated that hugging has no effect on the immune system, no daughter would stop hugging her demented mother.

Beyond these accepted norms—maintaining warmth and cleanliness and showing affection—the standard of caring is in flux. For some families, administering antibiotics in the setting of an infection is a sign of respect for it involves treating the person with Alzheimer’s disease exactly as she would be treated if she did not have dementia. For others, pneumonia is truly the old man’s friend, and combating it with medication is a burdensome way of prolonging a period of intolerable suffering. For some families, providing nutrition is an essential element of caring, even if it can only be administered artificially, via a gastrostomy tube. For others, use of a feeding tube in a person in the final stage of Alzheimer’s disease is a burdensome technological intervention with little medical benefit.

Until we achieve a broader consensus on what constitutes the appropriate way to care for patients with dementia—and in a pluralistic society whose members have differing values and beliefs, such a consensus may never be achieved—some families (and physicians) will continue to advocate feeding this group. Ideally, an agreed upon standard of care will be developed, perhaps using the consensus conference approach successfully employed by the National Institutes of Health to evaluate a variety of types of treatment. Once a standard of care is adopted, implementation will require the Centers for Medicare and Medicaid Services to reimburse treatments only if they meet that standard. Surely tube feeding would not be regarded as “reasonable and necessary,” the statutory basis for Medicare coverage, if it were rejected by a consensus conference defining appropriate care for individuals with advanced dementia.

Until such a standard of care is established, and until reimbursement is tied to conformity with that standard, as already is the case for a procedure such as pacemaker insertion, we will need to find satisfactory ways to respond when a family requests a technical intervention that medical professionals regard as unjustified. Physicians typically argue that medical interventions should have measurable medical benefit. Tube feeding, as one commentator put it, has nothing to do with apple pie and motherhood. Tube feeding should be assessed physiologically, not culturally.25 But is it true that we can so neatly separate the physiologic from the cultural, the technical from the symbolic? Rejecting tube feeding on the grounds that it does not work is just the latest instance of physicians attempting to invoke futility in place of moral argument. What we learned with the first generation of futility disputes is that physicians typically try to invoke futility in order to unilaterally refuse medical interventions they believed to be inappropriate: they hope to substitute a technical argument for a moral one, asserting the interventions were ineffective.26,27 In the best-known futility case, physicians attempted to remove the respirator from 88-year-old Helga Wanglie, who was in a persistent vegetative state, on the grounds that it was nonbeneficial. In fact, Wanglie’s respirator was not “physiologically futile”; the problem was that Mrs. Wanglie’s husband disagreed with her physicians about whether the goal of treatment—maintaining her life in a persistent vegetative state—was reasonable.28

A MORAL RESPONSE TO THE FEEDING DILEMMA

A better approach to family members who want feeding tubes for the demented is to acknowledge the symbolic value of nutrition for them and to seek an alternative means of satisfying the need to feed. Hand feeding is one strategy, and when the individual with dementia will eat if fed—albeit typically only very slowly, then this is the approach of choice. It is very labor-intensive and difficult to implement in the nursing home, where many individuals with advanced dementia live, but with a modified reimbursement system for nursing home care, it may be feasible. For those individuals who cannot be hand fed, either because they will not allow it or because their swallowing dysfunction is so profound, physicians will need to offer something else that meets the family’s psychological need. We will need to create Ensure lollipops, for those who can use them, or sublingual high-calorie drops, for those who cannot swallow. This approach responds to the symbolic need for nutrition without subjecting an uncompromising, frail individual near the end of life to an invasive technological procedure. It redefines palliative care for the individual with advanced dementia in a way that acknowledges that the trajectory toward death is different from that of the typical cancer patient or heart failure patient. It recognizes that determining the most humane form of care is extremely difficult in those who, precisely because they are demented, cannot describe their experience. And it accepts that good palliative care goes beyond the needs of the patient to encompass the concerns of the family.

REFERENCES