FEATURE ARTICLE

Hand Feeding: Moral Obligation or Elective Intervention?

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"Don't feed him, please. Bring the tray and set it in front of him. But if he doesn't eat don't help him. He would never want to live this way."

Increasingly those caring for institutionalized individuals with cognitive impairments are being asked not to hand feed residents who are capable of eating safely but whose brains fail to tell them to bring food and drink to their mouths. Behind these requests is usually a loving family member worn down by the relentless ravages of Alzheimer's disease or another dementia. Surprisingly, professional caregivers lack consensus about whether hand feeding is part of basic nursing care like paying attention to hygiene and helping with toileting or instead, an optional intervention, like ventilatory support, which may be foregone if a valid surrogate requests no hand feeding.

In a recent survey in a large hospice professional caregivers were split almost 50/50 when asked if they would honor a request not to hand feed. Those in favor of honoring these requests generally offer as a rationale, respecting the autonomous preference of a resident as communicated by a valid surrogate using the substituted judgment standard. In some instances an advance directive refusing medical nutrition and hydration in select circumstances was offered as proof that the resident would not want to be hand fed—although the directive did not address hand feeding. Several professional caregivers went so far as to say that they were amending their own advance directives to state that if they were ever in a similar situation they would NOT want to be hand fed. Those opposed to honoring requests not to hand feed were especially troubled when residents seemed to enjoy eating. They believe that if they honor these requests they are definitely causing death by failing to do something they are obligated to do. Further complicating the issue have been recommendations to families who want someone not to be hand fed to take the resident home where they can do as they please. Those who believe that everyone should be hand fed are then in the position of having to decide whether or not to report such a family to adult protective services. At issue is whether or not family caregivers have an obligation to feed these individuals and if failure to do

so is criminal neglect. While this article will address the specific concern about hand feeding, the underlying issue of what care is owed cognitively impaired individuals will serve as a backdrop. One family member recently opined, "Society is soon going to have to decide what to do about all the people we are warehousing."

First, a Clarification.

This article is not addressing the decision of whether or not to initiate tube feeding for persons with advanced dementia who can no longer swallow. The overwhelming medical consensus is that long-term tube feeding for individuals with advanced dementia offers no advantages and incurs a number of disadvantages.

The focus of this article is individuals with serious cognitive impairments who can swallow, but who need assistance with oral feedings, or hand feedings. At issue is whether hand feeding can be stopped at the request of a valid surrogate. While there are a few articles addressing voluntarily stopping eating and drinking (VSED) in the bioethics literature, there is very little written about assistance with oral feedings or hand feeding and we could find nothing in the nursing literature about whether or not nurses are obligated to hand feed patients who can eat, and who in many cases, enjoy eating when helped. The first mention of hand feeding in the bioethics literature that we could find occurs in Joanne Lynn's, *By No Extraordinary Means: The Choice to Forgo Life-Sustaining Food and Water* (1986).

The American Geriatrics Society (AGS) in its "Feeding Tubes in Advanced Dementia Position Statement" (2013) writes:

1. Percutaneous feeding tubes are not recommended for older adults with advanced dementia. Careful hand feeding should be offered; for persons with advanced dementia, hand feeding is at least as good as tube feeding for the outcomes of death, aspiration pneumonia, functional status and patient comfort. Tube feeding is associated with agitation, increased use of physical and chemical restraints, and worsening pressure ulcers.
2. Efforts to enhance oral feeding by altering the environment and creating patient-centered approaches to feeding should be part of usual care for older adults with advanced dementia.

While this is a clear endorsement of hand feeding for this population the statement does not address whether hand feeding is elective. The Alzheimer's Association statement, however, is adamant in urging that neglect in the area of hand feeding should not be tolerated.

> The Association asserts that it is ethically permissible to withhold nutrition and hydration artificially administered by vein or gastric tube when the person with Alzheimer's disease or dementia is in the end stages of the disease and is no longer able to receive food or water by mouth. The Association

> emphasizes that assisted oral feeding should be available to all persons with advanced Alzheimer's disease. **Neglect in this area should not be tolerated, and concerted efforts are called for to educate and support professional and family caregivers in techniques of assisted oral feeding [emphasis added]**.

The Case for Respecting Requests to Not Hand Feed

Cantor (2009) affirms that a surrogate acting on the previously documented wishes of a now-incompetent patient to reject all forms of nutrition and hydration in certain circumstances is appropriately using the substituted judgment standard of decision making to affirm the patient's autonomous choices. Absent prior instructions, the surrogate's decision "would likely be grounded on the conclusion that continued existence in a present highly debilitated state is inconsistent with the patient's best interests (in avoiding intolerable indignity as defined by widespread preferences of people fixing their own medical fates)". Tellingly, Cantor concludes his article noting that a competent patient's right to reject oral nutrition and hydration is revocable given a "change of mind" –a fact that raises many practical questions about a surrogate's permissible course of action:

> If an incompetent patient accepts hand feeding, is that a revocation of prior instructions? Can a surrogate decide that in order to respect the patient's prior considered decision no nutrition and hydration should be offered to the now-incompetent patient? What if a now-incompetent patient spontaneously requests a milkshake or even a drink of water? Can the surrogate—knowing that hydration may prolong the dying process—ignore the requests (relying on the patient's best interests) or even seek sedation as an alternative way to make the dying patient more comfortable? (p. 58).

Dr. Stanley Terman of Caring Advocates is an advocate for what he terms "natural dying." Natural dying, like natural child birth, does not depend on high tech medicine, and it requires even less skilled assistance for nature to take its course. When our brains can neither understand how to eat nor appreciate food, natural dying lets three things occur:

1. Cease manual assistance with oral feeding (as ultimately provided by skilled personnel),
2. Withhold/withdraw all life-sustaining treatment, and
3. Provide the best possible comfort care for a peaceful transition (http://caringadvocates.org/AD-PND.PO-PND.php)

Terman's stated mission is to "help competent individuals exercise the option of Voluntary Refusal of Food & Fluid which is legally available everywhere, which is peaceful if thirst is controlled, and which all competent patients can

use." His particular outreach is to those who fear that they will lose the ability to refuse food and fluid once dementia or a similar disorder deprives them of the ability to reason and communicate. Terman recommends that individuals who choose to die this way complete copies of his Natural Dying Advance Directive and Natural Dying Physician Order—both of which can be downloaded from his website. He also offers Natural Dying Living Will Cards/My Way Cards which present what it is like to live with advanced dementia. The My Way Cards are for "people who champion the right of self-determination." The Natural Dying Living Will Cards are for people "who want to follow the teaching of their religion or to be sure that their decisions are moral."

Terman's website includes "A Catholic View on the Natural Dying Living Will Cards," by Kevin McGovern, a priest and Catholic ethicist in Australia. McGovern identifies the sorts of circumstances in which hand/spoon feeding or other treatments will become extraordinary or disproportionate—without conflicting with Catholic teaching.

> The *Natural Dying — Living Will* cards therefore allow us to identify what we regard as the ordinary means of preserving life. They also allow us to identify the sorts of circumstances in which some treatments might become extraordinary or disproportionate, and therefore may be refused, withheld or withdrawn. … The cards detail various circumstances, which may occur as the dementia progresses. Many of these circumstances bring with them some extra burdens. At the same time, they render the patient more frail, and diminish their physical and moral resources. They also reduce the patient's capacity to strive for the spiritual purpose of life by knowing, loving and serving God, self and neighbor, and even their capacity just to enjoy life. These diminishments arguably reduce the benefits of ongoing, life-preserving treatment. … The *Natural Dying — Living Will* cards enable patients or their health care proxies to discern **if some treatments** in some circumstances have become an extraordinary or disproportionate means of preserving life (McGovern) [emphasis added].

Application of Catholic Teaching

McGovern's analysis appears to rest on first, categorizing hand feeding as a treatment, and then applying the ordinary (obligatory) extraordinary—disproportionately burdensome (morally optional) distinction. This approach seems flawed to us. In the church's *Declaration on Euthanasia* we see that euthanasia can result from an act or an omission intended to cause death. If hand feeding is not a treatment but rather a necessary act that obligates both family and professional caregivers, even the beneficent motive to free the patient from

a miserable life, thereby respecting intrinsic dignity, is unethical.

> Ultimately, the word *Euthanasia* is used in a more particular sense to mean "mercy killing," for the purpose of putting an end to extreme suffering, or having abnormal babies, the mentally ill or the incurably sick from the prolongation, perhaps for many years of a miserable life, which could impose too heavy a burden on their families or on society. It is, therefore, necessary to state clearly in what sense the word is used in the present document. By euthanasia is understood an action or an omission which of itself or by intention causes death, in order that all suffering may in this way be eliminated. Euthanasia's terms of reference, therefore, are to be found in the intention of the will and in the methods used (Sacred Congregation for the Doctrine of the Faith, 1980).

This teaching is echoed in the *Ethical and Religious Directives for Catholic Health Care Services*—both in the Introduction to the section on Care for the Seriously Ill and Dying and in Directive 58.

> The Church's teaching authority has addressed the moral issues concerning medically assisted nutrition and hydration. We are guided on this issue by Catholic teaching against euthanasia, which is "an action or an omission which of itself or by intention causes death, in order that all suffering may in this way be eliminated." While medically assisted nutrition and hydration are not morally obligatory in certain cases, these forms of basic care should in principle be provided to all patients who need them, including patients diagnosed as being in a "persistent vegetative state" (PVS), because even the most severely debilitated and helpless patient retains the full dignity of a human person and must receive ordinary and proportionate care.
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> 58. In principle, there is an obligation to provide patients with food and water, including medically assisted nutrition and hydration for those who cannot take food orally. This obligation extends to patients in chronic and presumably irreversible conditions (e.g., the "persistent vegetative state") who can reasonably be expected to live indefinitely if given such care. Medically assisted nutrition and hydration become morally optional when they cannot reasonably be expected to prolong life or when they would be "excessively burdensome for the patient or [would] cause significant physical discomfort, for example resulting from complications in the use of the means employed." For instance, as a patient draws close to inevitable death from an underlying progressive and fatal condition, certain measures to provide

> nutrition and hydration may become excessively burdensome and therefore not obligatory in light of their very limited ability to prolong life or provide comfort.

The Challenges of Caregiving

The first time we encountered the request from a wife to have the nursing home staff not hand feed her husband because "he wouldn't want to live like this," we were haunted by her statement that "society is going to have to decide what to do with all the folks we are warehousing today." The wife was seen as a caring person by the staff. She was, however, tired and wanting to "move on." What she raises is an important societal question perhaps best summed up by Leon Kass, in the book, *Taking Care: Ethical Caregiving in our Aging Society.*

> When thinking about caregiving, we have concerns about pension insecurity, rising costs of health care, shortages of available caregivers, and the insufficient number of good nursing homes. We have concerns about the potential neglect or abandonment of the elderly, and the possibility of welcoming euthanasia or assisted suicide as ways to "solve the problem" of lingering old age. Many of us face decisions about forgoing careers in order to act as caregivers, or spending less time with young children in order to care for aged parents, or using funds set aside for a daughter's college tuition in order to pay for a father's nursing home. **In short, we worry about whether we can afford to care, whether we will be willing and able to care, and what we must sacrifice in order to care for the elderly**. And many of us in the middle of life, thinking about growing older ourselves, fear the loss of our powers, the deprivations and loneliness that often accompany old age, and the prospect of being a burden on those we love most (The President's Council on Bioethics, 2005).

On a personal note, we recently had to pay $100/day ($200/day on weekends and holidays) to have a geriatric aide help our debilitated uncle eat breakfast and the evening meal. He was in an upscale skilled nursing facility following surgical repair of a hip fracture, and nursing leadership could not guarantee the extra attention and encouragement he needed to take in enough food and fluids to be hydrated and nourished. The experience forced us to reflect on the care being received by thousands of our frail elderly who lack knowledgeable family advocates or the financial resources to receive what should be basic care.

The staggering human and financial costs of caregiving are perhaps best captured in the following statistics. The Alzheimer's Association reports that over 5 million Americans are now living with Alzheimer's disease. One in three people aged 85 and older has the disease. In March, 2014, a report published in the medical journal of the American Academy of Neurology

listed Alzheimer's as the third leading cause of death, after heart disease and cancer (James et al, 2014). The personal costs of caring for someone with Alzheimer's disease can be devastating.

- In 2013, 15.5 million family and friends provided 17.7 billion hours of unpaid care to those with Alzheimer's and other dementias – care valued at $220.2 billion.
- Nearly 60 percent of Alzheimer's and dementia caregivers rate the emotional stress of caregiving as high or very high; more than one-third report symptoms of depression.
- Due to the physical and emotional toll of caregiving, Alzheimer's and dementia caregivers had $9.3 billion in additional health care costs of their own in 2013 (www.alz.org).

According to the Alzheimer's Association the growing Alzheimer's crisis is helping to bankrupt America.

- In 2014, the direct costs to American society of caring for those with Alzheimer's will total an estimated $214 billion, including $150 billion in costs to Medicare and Medicaid.
- Nearly one in every five dollars of Medicare spending is spent on people with Alzheimer's and other dementias.
- Average per-person Medicare spending for those with Alzheimer's and other dementias is three times higher than for those without these conditions.
- Average per-person Medicaid spending for seniors with Alzheimer's and other dementias is 19 times higher than average per-person Medicaid spending for all other seniors.
- Unless something is done, Alzheimer's will cost an estimated $1.2 trillion (in today's dollars) in 2050. Costs to Medicare and Medicaid will increase nearly 500 percent (www.alz.org).

Even if advances are made against the ravages of Alzheimer's and other dementias we face a growing number of frail elderly with increasing limitations, disabilities and dependencies. It was appropriate for Kass to query:

> ***How we care for the dependent elderly will test whether modern life has not only made things better for us but also made us better human beings, more willing to accept the obligations to care and more able to cope with the burdens of caregiving.*** Put simply, can a society that values self-reliance, personal freedom, and careerism reconcile itself to the realities of dependence, diminished autonomy, and responsibility for others? (The President's Council on Bioethics, 2005, p. 4).

Amour is a 2012 French-language film about the caregiving challenges an elderly couple face when the wife, Anne, suffers a

stroke, which paralyzes her on one side of her body. The film, which won the Palme d'Or award at the 2012 Cannes Film Festival and the Academy Award for Best Foreign Film at the 85th Academy Awards, painfully illustrates the difficulties involved as the husband, George, patiently helps to feed, bathe, toilet and move Anne—with very little help from neighbors and their one daughter. The ending for many is tragic. Overwhelmed by Anne's suffering, George picks up a pillow and smothers her. *Amour,* and the recent dismissal of charges against a Philadelphia nurse who allegedly handed her suffering father a bottle of liquid morphine to fulfill his death wish but who said she only handed him the medicine to alleviate his pain, exhort reflection on how we ought to respond to those who present with overwhelming suffering and related challenges for caregivers. Is hastened death the only or best response?

In striking contrast to *Amour* is Leo Tolstoy's short story, *The Death of Ivan Illich*. Tolstoy notes that in the third month of Illich's illness everyone, including Illich himself, was simply waiting for him to die, "to vacate his space. "All were aware that now other people's only interest in him "consisted in the question of how soon he would leave his place empty, free the living from the constraint of his presence, and be free himself from his sufferings" – all except Gerasim, the butler's assistant. As Tolstoy tells the story, Illich was becoming more uncomfortable and Gerasim, a simple young man from the village, was helping Illich with his basic needs. Illich asked Gerasim if caring for him was disagreeable. Gerasim replied: "Mercy why shouldn't I do it? It is a matter of you being sick." It was not whether what Gerasim did would prevent his dying or would be of "benefit" to Illich, but whether to support him, to meet his basic needs, to hold him was the natural human thing to do.

In my own experience as a young physician, I worked at a Franciscan mission in Zambia. There I met Vincent, a young man brought to the clinic from a distant village. Vincent had leprosy. We built him a house and provided for his basic needs. Soon other lepers joined this community. Not long after my return to the U.S., I learned from Father Joseph Scoma, a Franciscan priest from Italy, that there was concern on the part of some of the Americans and Europeans teaching at schools of the mission about having people with leprosy in the community. Father Joseph had told them: "Vincent is the reason we are here." Two years ago, I returned to the mission for a visit. Vincent had now been there 50 years. The settlement had grown to some 40 lepers. The persons with leprosy lived there with their families. Vincent was close to death and needed assistance with eating. The people in the community fed him and met his needs. He died naturally two weeks after my visit.

One final story. As a third year medical student on my surgical rotation I was assigned to a large ward at Chicago's Cook County Hospital where I was asked to help care for an elderly woman, Mary, with severe decubiti. The medical students were asked to help Mary meet her daily

needs and to provide "wound care." She changed little during those three months. What we did had little effect on the decubiti. If anything they worsened. I do think, however, that we affirmed her worth and inherent dignity. Mary taught us the meaning and value of our ability to be compassionately present to another and affirmed why many of us had chosen medicine.

When it comes to feeding and meeting other basic human needs, both at the beginning and at the end of life, the normal human response is to meet those needs. This may require the use of a cup, a spoon or even our fingers to provide basic sustenance. It is not something extraordinary, but something simple and ordinary. It is not something that should be medicalized. Families are floundering. What can we offer? Some Catholic nursing homes are training volunteers to assist with hand feedings. Few Catholic parishes are formally engaged in developing programs to assist family caregivers.

Conclusion

As a just and caring society, we need to explore new ways to meet the basic needs of all the members of our communities. Many aspects of our lives have become institutionalized and medicalized and are becoming more so. We need to seek out alternatives that involve family, friends, neighbors, members of our faith communities, and that are home or community based.

As Gospel communities committed to continuing the healing mission of Jesus, it is always appropriate to ask, "What would Jesus do?" Unfortunately there are no accounts in Scripture of Jesus hand feeding an individual with dementia. There are however, numerous accounts of Jesus reaching out to the outcasts of the day. It seems fitting to conclude with our church's call to each of us to find the "boundless kindness and charity needed to serve our vulnerable sisters and brothers."

> The norms contained in the Vatican's present *Declaration on Euthanasia*, are inspired by a profound desire to service people in accordance with the plan of the Creator. Life is a gift of God, and on the other hand death is unavoidable; it is necessary, therefore, that we, without in any way hastening the hour of death, should be able to accept it with full responsibility and dignity. It is true that death marks the end of our earthly existence, but at the same time it opens the door to immortal life. Therefore, all must prepare themselves for this event in the light of human values, and Christians even more so in the light of faith. As for those who work in the medical profession, they ought to neglect no means of making all their skill available to the sick and dying; but they should also remember how much more necessary it is to provide them with the comfort of boundless kindness and heartfelt charity. Such service to people is

> also service to Christ the Lord, who said: "As you did it to one of the least of these my brethren, you did it to me" (*Mt*. 25:40) (*Declaration on Euthanasia*, 1980).

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Feeding Decisions

Feeding decisions come in many varieties, and not all are linked to artificially administered nutrition and hydration. Health care professionals committed to health, well-being and good dying need to reflect on the nursing and ethical challenges present in each of the situations below. I have used these scenarios in many professional settings and each time was struck by the diversity of opinions about what qualified as an ethically good response. One of the scenarios is a clear example of suicide by omission as described in the *Declaration on Euthanasia* and another describes the sort of individual in a permanent vegetative state who is the object of the papal allocution on artificial nutrition and hydration and the response by the Congregation for the Doctrine of the Faith.

In the Roman Catholic tradition, the *sensus fidelium* is the "sense of the faithful," one of the valid sources of truth in Catholic theology. This source of truth represents the combined beliefs, consciences and experiences of good and honest Catholics. It operates in a close relationship of mutual conditioning with all of the other varied components of the Roman Catholic tradition. When it comes to feeding decisions Catholic health care professionals are obligated to reflect on the situations in which individuals with altered nutrition and hydration find themselves. In doing so, as committed Christians, they have the opportunity to enrich their insights with the church's magisterial teaching and the best of theological thought.

In my experience, as both a nurse and ethicist, the growing tendency today to abdicate medical decision making to patients and families—even when their expectations are unrealistic and their decisions ill-advised—is simply wrong. The primary object of all clinical decision making ought to be to secure the patient's interests, health, well-being, good dying—and to do this in a manner that respects the integrity of all who participate in the decision making process, patient, family, *and* health care professionals. To the extent this is true, health care professionals must continually reason prudentially about what constitutes good care and make appropriate recommendations to patients, families and their church.

- Mrs. Gleason is a 92-year-old nursing home resident with end-stage dementia. Until now she has been spoon fed. She was admitted to the hospital for recurrent aspiration pneumonia and respiratory difficulties. She has been receiving intravenous fluids. Her altered blood chemistries and frail condition result in her being considered for placement of a PEG feeding tube before being discharged back to the nursing home. She has no family.

- Mr. Suarez is a 49-year-old attorney who was found collapsed at the foot of his stairs at home two weeks ago. He had a massive cerebral head bleed and surgery revealed extensive, irreversible neurologic damage. His medical condition is now stabilized and his doctors are asking his family if they want to "peg and trach him"—in which case he might live for some time with good nursing care. The other option is to transition at this point to primarily palliative goals (not administer medical nutrition and hydration), in which case he will most likely die within 7-21 days. His wife is certain that he would not want to live in his present condition, "he always lived in his mind," but the suddenness of his condition

leaves her wondering if a decision to transition to purely palliative goals isn't premature.

- Jean Bridges is a 24-year-old survivor of an accidental strangling episode. Jean has a long history of schizophrenia. While hospitalized for dehydration, she was found dangling over her bedside with her posey vest restraint around her neck. This was 15 months ago and she has now been diagnosed as being in persistent vegetative state. Her case manager approaches her parents for the first time asking if they had ever considered stopping her medical nutrition and hydration.

- Ms. Apold is an educated, articulate, and until recently, healthy 78-year-old single woman. She does have advanced osteoporosis. A recent fall resulted in a leg fracture. She has lived a rich and full life and sees nothing but diminishment in her future with a life increasingly constricted to her apartment. When she told someone that she wished she could just fall asleep and never wake up, her friend told her that she should just stop eating and drinking—if she really wants to die. Her friend works for hospice. Ms. Apold is now asking this hospice to care for her until she dies.

- Mr. Phan was found dead in his bed at home. Aged 97, Mr. Phan lived alone in an apartment in the city. He had no family of record but friendly neighbors. His closest neighbor described Mr. Phan's multiple health problems, congestive heart failure, chronic obstructive pulmonary disease, diabetes mellitus, peripheral vascular disease and said that she had noticed him really "slowing down" the past year. "I used to bring him food all the time but he just seemed to lose his appetite this year and most of what I brought him was untouched. He wouldn't hear of going to a nursing home. Should something else have been done?"

- Mr. Spivac, aged 80, has the type of dementia which has resulted in his being physically assaultive. He was dismissed from nine residential treatment facilities because the staff's inability to control his behavior. His assaultive behavior is now being managed pharmacologically which has simultaneously impaired his physical functioning. His wife, whom everyone describes as "long-suffering," is now repeatedly asking the doctors and nurses not to help feed her husband. "Bring him a tray but don't encourage him. He never wanted to live like this." He is physically able to feed himself and to swallow but needs encouragement to eat and drink enough to keep him nutritionally balanced. Staff believe that eating is one of his few pleasures at this time. His wife stated that society is going to have to decide what to do with all the people we are now "warehousing" in nursing homes.