COMMENTARY

Ethical Considerations Concerning Use of Percutaneous Endoscopic Gastrostomy Feeding Tubes in Patients With Advanced Dementia

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INTRODUCTION

Feeding tubes are a form of medical technology that may be used to replace or supplement natural eating in a wide variety of medical conditions. Percutaneous endoscopic gastrostomy (PEG) has become the most universally available method of feeding tube placement. To the extent that artificial nutrition through a feeding tube fully replaces a patient's oral intake, it becomes a form of life support.

Advanced dementia is one condition for which PEG is used. The broad term "dementia" encompasses a variety of specific diseases, including the best known form of dementia, Alzheimer's.[a] Our purpose here is to explore significant issues and ethical considerations relating to use of PEG in advanced dementia patients.

BACKGROUND

Advanced Dementia

The Center for Disease Control and prevention lists Alzheimer's, the most common form of dementia, as the sixth leading cause of death in the US and the fifth for people over the age of 65.[1] Currently, there are more than 5 million Americans living with Alzheimer's. This number is expected to triple by 2050, as life expectancy continues to increase and the population ages—a phenomenon known as the "Silver Tsunami."[2]

Up to 90% of dementia patients need help eating at some point in the progression of their illness, and many lose the ability to swallow altogether. Consequently, many dementia patients have undergone PEG to support nutrition. As shown in Figure 1, by the time a dementia patient becomes a candidate for artificial hydration and nutrition (AHN), the patient has entered the terminal stage of the disease.

Evolution of PEG Tube Feeding

There is evidence that enteral feeding by nasogastric (NG) tube was used as early as the 17th century. In 1921, a major development occurred when Abraham L Levin, MD introduced a flexible rubber tube that could be readily inserted through the nose and esophagus to deliver liquid nutrition directly into the stomach.

At that time, the only alternative was to insert a tube directly into the stomach via a surgical procedure (open laparotomy) under general anesthesia. Because this surgery presented far too great a risk for the debilitated individuals who most commonly were candidates for enteral feeding, insertion of the NG tube became a regular function of nursing practice.[3] However, the NG tube insertion procedure is quite uncomfortable for most patients because it requires swallowing the tube as it passes through the throat, which triggers the gag reflex. After insertion, the tube is taped in place, often damaging skin integrity. The constant, irritating presence of the tube in the patient's nostril, particularly when the patient lacks understanding of the reason for it, frequently causes the patient to pull on the tube. To prevent dislodging the tube, the patient's hands must be restrained. Additionally, there is considerable risk that an NG tube may be inserted into the lungs via the trachea instead of into the stomach or become dislodged prior to feeding, and lead to life-threatening complications such as pneumonia or sepsis.

In 1980, PEG was introduced as a simpler and less invasive alternative to enteral feeding tube placement by open laparotomy.[4] PEG rapidly became the procedure of choice for patients requiring long-term AHN. Twenty years later, PEG pioneer Michael Gauderer, MD warned of inappropriate PEG use:

> *". . . [B]ecause of its simplicity and low complication rate, this minimally invasive procedure also lends itself to overutilization. Therefore, as percutaneous endoscopic gastrostomy enters its third decade, much of our effort in the future needs to be directed toward the ethical aspects associated with long-term enteral feeding. In addition to developing new procedures and devices, or to perfecting existing ones, we as physicians must continuously strive to demonstrate that our interventions truly benefit the patient."*[5]

Nevertheless, in 2001 the annual PEG insertion rate in the US was estimated at over 216,000.[6] In particular, PEG use in the advanced dementia patient population continues to be widespread, despite consensus in the

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Abbreviations: AHN, artificial hydration and nutrition; NG, nasogastric; PEG, percutaneous endoscopic gastrostomy

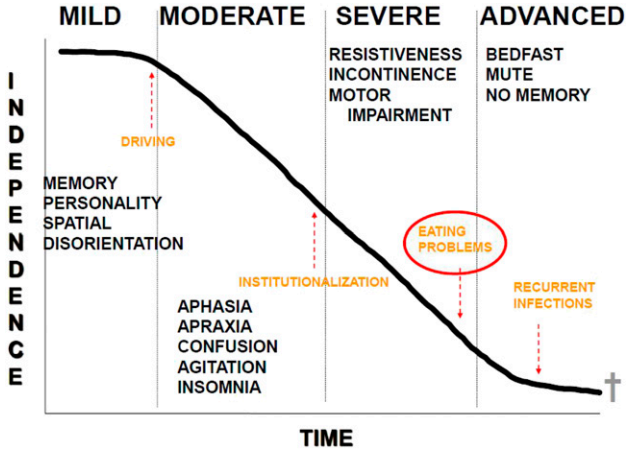

Figure 1. Stages of Dementia. Courtesy of Ladislav Volicer, MD, PhD.

medical literature that such use not only is nonbeneficial but often is harmful. Recently, a growing proportion of feeding-tube placements are done by a newer technology—fluoroscopically guided gastrostomy[7]—which is performed by interventional radiologists. There is strong reason to believe that the guidance offered here also applies to this successor technology.

Concerns About PEG Tube Feeding in Patients With Advanced Dementia

Much has been learned about both the benefits and the harms of AHN in general and PEG use in particular. Over the past 2 decades, numerous studies have been published assessing the effectiveness of feeding tubes in advanced dementia.[8,9] These studies conclude that tube feeding in advanced dementia has not been demonstrated to be beneficial, and instead is often harmful:

1. In a variety of studies, nutrition via PEG has not been shown to prolong survival. In 1 example, no difference in survival was found among 1,386 patients treated with or without tube feedings.[10] A Cochrane Database systematic review of 7 published observational controlled studies in 2009 concluded that there was no evidence of increased survival.[11]
2. PEG also has not been shown to improve quality of life, and frequently a PEG tube is placed without regard to this important factor[12]—although quality of life suffers, particularly if restraints or medications are necessary to prevent the patient from removing the PEG tube. Additionally, when feeding is by PEG, the beneficial human-to-human interaction of oral hand feeding is lost.
3. Feeding via PEG has not been shown to prevent aspiration pneumonia either. Patients fed solely in this manner are no longer at risk of orally aspirating fed food or liquid, but they are at continued risk of aspiration from esophageal reflux or oral secretions, and are in fact at increased risk of aspiration pneumonia. For example, 1 study of 104 severely demented patients showed that the rate of aspiration pneumonia more than doubled with PEG feeding.[13]
4. Providing nutrition via PEG also has not been shown to promote the healing of pressure ulcers[14] or to improve the biochemical parameters that reflect nutrition.[15] And, if restraints are necessary to prevent the patient from pulling on the tube, the risk of developing pressure ulcers is increased.
5. Potentially burdensome and even life-threatening complications of PEG include infection, hemorrhage, gastric ulceration, stoma (the opening where the tube is inserted) irritation, dislodging and/or clogging of the tube, etc.[16]

Thus, numerous studies provide compelling cumulative evidence that in most advanced dementia patients, PEG has negligible benefit, if any, and instead causes actual harm. Several national professional organizations, including the American Geriatrics Society,[17] the Alzheimer's Association,[18] the Academy of Nutrition and Dietetics,[19] and the American Society of Parenteral and Enteral Nutrition,[20] have taken positions against the practice of performing PEG for reasons other than anticipated medical benefit to the patient. Although no prospective, randomized, controlled study (the gold standard for medical research) has been conducted on this subject, likely due to the intensely personal nature of the decision making, the evidence is robust and unrefuted; it should be accepted as the best obtainable in this ethically charged area.

Despite the clear consensus that PEG offers no benefit and can cause harm, PEG is still provided frequently to advanced dementia patients. Families may believe strongly in the *possibility* that life will be prolonged by PEG feeding, and value this factor above all others. They may experience great emotional trauma over the perceived adverse consequences of withholding artificial nutrition, and may demand tube placement, even though the evidence suggests it has no medical benefit. Families may resist withholding AHN because they mistakenly believe this would be tantamount to starvation. The natural instinct is to "keep going," to do everything possible. Additionally, the medical literature suggests some members of certain patient populations and/or their families may favor aggressive medical treatment (including PEG tube placement) regardless of prognosis, based on a variety of social and cultural factors such as fear of discrimination or a religious conviction that life should be prolonged by medical interventions to the greatest extent possible.[21-24]

Some facility personnel may share family members' bias in favor of treatment. In certain cases, health care providers

may, for reasons of conscience, object to participating in withdrawal of artificial nutrition. In 2006, this Joint Committee offered the following guidance regarding providers' conscientious objection to withdrawal of AHN:

> *"Health care providers should evaluate medically administered nutrition and hydration, such as nasogastric tubes, gastrostomies, intravenously administered fluids and hyperalimentation in the same way as any other medical treatment. However, nutrition and hydration have a powerful symbolic significance to many people, including health care providers. Therefore, it is particularly important that people who take care of the patient fully understand the rationale for any order to forgo medically administered nutrition and hydration. A health care provider who disagrees with an order to forgo hydration and nutrition is permitted to withdraw from caring for the patient once an equally qualified health care provider assumes care of the patient."*[25]

Economic issues can also compromise decision making. Every hospital is under economic pressure to decrease patients' length of stay. This may result in transferring a patient to a post-acute facility such as a skilled nursing facility (SNF), many of which operate within extremely tight profit margins. A PEG tube medicalizes the process of eating (as contrasted with hand feeding, which takes more time but is provided by less-skilled staff), and if a patient has a PEG, the patient's Medicare reimbursement is substantially higher for the first 100 days of SNF care following hospitalization.[26] Inserting a PEG, therefore, is a "win-win" situation economically for both the hospital and the SNF. The presence of a PEG tube facilitates speedier discharge from the hospital and higher reimbursement for the SNF. Also, SNFs are under constant scrutiny from regulators, and a SNF may face sanctions if a patient experiences significant weight loss. Therefore, PEG placement may be used, inappropriately, to support the assertion that the facility is not neglecting the patient. As a result, physicians may confront pressure from a hospital, or a SNF, or both, to perform PEG on a hospitalized patient as a precondition to SNF admission.

ETHICAL CONSIDERATIONS IN DECIDING ABOUT PEG TUBE FEEDING

Autonomy

By the time patients reach the advanced stage of dementia, they have lost decision-making capacity. Respecting a patient's autonomy requires that the patient's surrogate(s) understand what the patient—before the illness—would have wanted in the event of disabling dementia, and act accordingly. This, in turn, may require a diligent effort to ascertain the patient's values before his/her illness. Due diligence in this regard may include seeking help from a clergy member, dietitian, social worker, and/or ethics committee, and a detailed review of the medical record. The necessary understanding also may be gleaned from sources such as an advance directive, a Physician Orders for Life-Sustaining Treatment form, or any discussion the patient had with a family member or friend about these subjects. Traditional advance directives, though, may not be ideally suited to decision-making specifically for dementia patients.[27]

Surrogates may also seek understanding from the demented patient's conduct. While patients commonly make gestures that may appear to indicate their feeding preferences, such as pulling on feeding tubes, these gestures must be interpreted with great caution—because they do not necessarily reflect patient wishes.[28] Therefore, surrogates should not rely upon such gestures exclusively to make decisions about AHN.

Although honoring autonomy to the extent possible is extremely important, it is not necessarily controlling. Other ethical considerations, in particular beneficence and nonmaleficence, should also enter into the decision making process, as discussed below. It may never be possible to know the wishes or values of some patients, and in any such case, the best interests of the patient should guide decision making.

Often a surrogate decision maker asserts one or more reasons why the decision maker's loved one *should* have AHN in the presence of advanced dementia, which may include a reference to the patient's religiosity, fighting spirit, pre-morbid wishes, or AHN's perceived power to effect clinical improvement. We examine the first three here, and the last further below.

The religious faith and practice of a patient or surrogate decision maker can be very powerful motivators. Often the surrogate attests to the patient's strict or orthodox expression of that faith. However, the surrogate may be unable to demonstrate the veracity of this attestation through either a history of the patient participating regularly in that faith's communal practice (eg, congregational attendance) or of the patient holding that faith's articulated current position on end-of-life care. The degree to which a claim of religiosity should be a controlling factor in granting a request for AHN in the presence of advanced dementia is controversial. At a minimum, clinicians should consult a faith leader of the patient's religious tradition in such a case. If the faith leader's input does not support the surrogate's religious claims, the ethics committee should engage in further mediation with those involved. Additionally, faith claims that reference only the faith of the surrogate decision maker, rather than those of the patient, are not a tenable ethical basis for implementing AHN in an advanced dementia

patient. Acceptance of religious claims without taking the above steps is ethically questionable.

The surrogate's assertion of the patient's fighting spirit should be accepted as the attestation of one who knows the patient better than the clinicians do, unless a member of the clinical care team has had a long-term relationship with the patient, and the patient-appointed surrogate has not. However, it is ethically appropriate to respond with an explanation of the terminal nature of the patient's condition, and the fact that AHN cannot and will not change that prognosis. Being a fighter has amazing value in healthcare, but when a requested intervention has been proven medically ineffective, the lack of efficacy is the controlling factor. A fighting spirit will not make a nonbeneficial treatment efficacious. In this situation, use of the institution's nonbeneficial treatment policy, with reference to the corresponding provisions in California's Health Care Decisions law, is ethically justifiable.

To the extent that the surrogate can demonstrate it was the patient's premorbid wish that caregivers exert all efforts to prolong the patient's life despite a terminal diagnosis, and despite the burdens to the patient, the ethical course *may* be to provide AHN. However, patient wishes cannot compel clinicians to provide care that is below the community standard. Additionally, when the surrogate asserts but cannot demonstrate the patient wanted "everything" regardless of consequences, there is no consensus as to the right course of action, other than to act in accordance with the standard of care. Ethics committees' recommendations may differ in this situation, and each case should be assessed individually.

Beneficence and Nonmaleficence

In general, it is ethical to propose or agree to invasive procedures only when the potential benefits outweigh the potential risks and burdens. Doing otherwise violates the ethical principles of beneficence and nonmaleficence. Since PEG in patients with advanced dementia is not beneficial and may be harmful, it should not be performed unless there are compelling reasons to do so.

Actions and Approaches Providers Can Take to Help Ensure Ethical Decision Making About PEG Tube Feeding

Because PEG in patients with advanced dementia is not demonstrably beneficial and is more likely to be harmful, it is not ethical to offer PEG routinely for these patients.

Physicians and other health care providers should present to decision makers—as sensitively as possible—the well-documented evidence that PEG tube placement is medically ineffective in patients with advanced dementia and may well cause harm. Clinicians should point out that these patients have entered the terminal stage of their illness and that forgoing AHN is ethically acceptable in such situations. Although PEG tube feeding is easier for facility staff, the practice of "comfort feeding" by hand may be more acceptable to families, as an alternative to either PEG placement or no feeding at all. A comfort feeding order provides for the patient to be hand fed so long as feeding does not cause distress.[29,30]

Inserting a PEG to facilitate patient placement solely for financial or other reasons unrelated to the patient's welfare is a violation of ethical principles. The financial interest of a hospital, SNF, family, or physician should never be the primary motivating factor behind any medical decision. Licensing and certifying agencies must accept that such patients are terminally ill. SNFs should not be penalized solely because a patient with advanced dementia is not receiving AHN.

Providers and others should advocate that reimbursement to SNFs must be aligned with the costs of care and should not create perverse incentives to perform medically ineffective procedures.

Some health care facilities have instituted use of a checklist[31] or other protocol for ordering a PEG, to ensure—as well as document—that medically *and* ethically appropriate decision making has occurred. We recommend this approach.

CONCLUSION

The practice of inserting feeding tubes has become so ingrained in medical and nursing culture that recommending otherwise often is difficult. Because of the multiple complexities discussed above, ethically inappropriate PEG will likely continue. But to quote Gauderer once again, "*We as physicians must continuously strive to demonstrate that our interventions truly benefit the patient.*"[32] (Emphasis added.)

PEG is a technological advance that benefits many patients.[b] However, when PEG, or any other medical intervention, is unlikely to benefit the patient, we should neither offer nor continue it. We strongly encourage the medical-provider community to pursue legislative, regulatory, and medical educational changes that will reduce the current pressures to provide PEG inappropriately to patients with advanced dementia. ❖

[a] *Although there are different types of dementia, the terms "dementia" and "Alzheimer's" often are used as if they were interchangeable. References to "advanced dementia" in this paper refer to the advanced stage of any form of dementia.*

[b] *For example, a patient with cancer of the head, neck, esophagus or stomach often is unable to take food orally during the course of treatment. If surgery is required, the upper aerodigestive tract may require temporary bypass to allow healing. Additionally, certain neuromuscular diseases such as amyotrophic lateral sclerosis (Lou Gehrig's disease) and Parkinson's disease often compromise*

swallowing as they advance, as do some cerebrovascular events. If patients with these disorders, or their surrogates, are fully informed of the risks and benefits, and the patients are not suffering from advanced dementia or other contraindications for tube feeding, such as peritonitis, then enteral feeding via PEG is ethically appropriate.

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Ethical Considerations Concerning Use Of Percutaneous Endoscopic Gastrostomy In Patients With Advanced Dementia

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