To PEG or not to PEG

A review of evidence for placing feeding tubes in advanced dementia and the decision-making process

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Percutaneous endoscopic gastrostomy (PEG) has evolved into a common low-risk procedure in current medical practice. Clinical evidence supporting the use of tube feedings in patients with advanced dementia is clearly lacking, yet PEG procedures continue to be performed in a large number of these cases. In fact, multiple studies have shown that feeding tubes seldom are effective in improving nutrition, maintaining skin integrity by increased protein intake, preventing aspiration pneumonia, minimizing suffering, improving functional status, or extending life. The decision-making process is complicated, however, and involves the clinician considering such issues as advance directives, ethical considerations, legal/financial concerns, emotional factors, cultural background, religious beliefs, and the need for a family meeting incorporating all of these principles.

Cervo FA, Bryan L, Farber S. Feeding tubes in patients with advanced dementia: The decision-making process. Geriatrics 2006; 61(May):30-35.

Key words: feeding tube • gastrostomy • dementia • decision making nutrition • quality of life • ethical considerations

For patients with severe dementia, the decision to use or withhold artificial nutrition and hydration can be difficult. Frequently, the burden falls on the patient's family or other surrogate decision makers. As the population ages and the prevalence of dementia increases, this problem will arise with still greater frequency. By the year 2030, approximately 20% of the U.S. population will be over age 65.[1]

Patients with advanced dementia commonly develop problems with eating. Eating is typically the last activity of daily living (ADL) to become impaired, and loss of this function is associated with the final phase of the illness. The difficulty in eating may arise from indifference or resistance to food, failure to manage the food bolus properly once it has entered the mouth, or aspiration when swallowing.

Percutaneous endoscopic gastrostomy (PEG) tubes were first introduced in 1980 to provide enteral nutrition in children and young adults; currently, however, PEG tubes are primarily placed in older patients with chronic or degenerative diseases of the nervous system, heart, lungs, or kidneys. PEG tube feeding is the preferred device recommended by the American Gastroenterological Association (AGA) for providing long-term enteral nutrition to a patient no longer able to receive an adequate amount of food orally.[2] Significantly, PEG tubes are being placed in patients with increasing frequency: in 1989, 15,000 PEG tubes were placed; in 2000, more than 216,000 tubes were placed.[2] Approximately 30% of all PEG tubes are placed in patients with dementia, and as many as 10% of institutionalized older patients are being tube fed (table 1).[2,3]

One reason the rate of PEG tube placement has increased so dramatically is that tube placement is a relatively "easy" procedure. PEG tube placement can be performed by a radiologist, gastroenterologist, or surgeon. It requires only local anesthesia, takes between 10 and 30 minutes to complete, is covered by Medicare, and may

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Disclosures: The authors report no relevant financial relationships.

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be performed at bedside.[2] Complications related to placement are generally minor, although the long-term rate of complications has been reported to range from 32% to 70%.[4] Furthermore, the AGA guidelines allow for PEG tubes when:

1) the patient cannot or will not eat
2) the gut is functional
3) the patient can tolerate the placement of the device.[2]

These broad guidelines would allow for the placement of a PEG tube in the overwhelming majority of clinical scenarios. Therefore, it is imperative that clinicians be familiar with the data surrounding PEG tube placement, especially in individuals with severe dementia, so that families may be appropriately guided in their decision-making.

Physicians and family members often perceive feeding tube placement in severely demented patients as beneficial. There is no evidence to support this belief: most of the medical evidence is based on observational studies, retrospective studies, or data extrapolated from mixed populations.[3] There are no randomized controlled studies comparing PEG tube feeding to hand feeding. Nevertheless, multiple studies have shown that feeding tubes seldom are effective in improving nutrition, maintaining skin integrity by increased protein intake, preventing aspiration pneumonia, minimizing suffering, improving functional status, or extending life (table 2).

Percutaneous endoscopic gastrostomy use has risen dramatically since 1989. PEG tube placement is relatively easy: it requires only local anesthesia, takes 10-30 minutes, is covered by Medicare, and can be performed at bedside. Determining who is an appropriate candidate is not so easy. Illustration for Geriatrics by Alexandra Baker.

The evidence

NUTRITION: Patients with severe dementia can develop loss of appetite and dysphagia resulting in abnormal markers of nutritional status, which prompt feeding tube placement. Feeding tubes are often placed in an effort to prevent malnutrition, however, studies do not support this practice.[3] In a study by Henderson et al[5] of 40 chronically tube-fed, long-term care patients, anthropomorphic, biochemical, clinical, and dietary data were measured. Contrary to expected benefit, increasing weight loss and pressure ulcer development were associated with longer-term tube feeding.[5] In other studies, nutritional markers such as hemoglobin, hematocrit, albumin, and cholesterol levels did not show a significant improvement after placement of a feeding tube.[3]

SKIN INTEGRITY: Published reviews of

Table 1 Feeding tube: The facts

- Percutaneous endoscopic gastrostomy (PEG) introduced in 1980
- More than 216,000 feeding tubes were placed nationally in the year 2000
- Dementia patients account for 30% of all feeding tube placements
- Broad guidelines allow for "easy" placement
- Long-term complication rate ranges from 32% to 70%

Source: Created for Geriatrics by FA Cervo, MD, L Bryan, MD, and S Farber, MD.

Table 2 Feeding tube myths

It's believed that feeding tubes:	Evidence
Prevent malnutrition	No improvement of nutritional markers; may increase weight loss
Maintain skin integrity	Increased risk for pressure ulcer formation
Prevent aspiration pneumonia	May reduce lower esophageal sphincter pressure; no prevention of oral secretion aspiration
Improve quality of life	May increase suffering and discomfort
Increase functional status and survival	Terminal diseases not reversed by feeding tube placement

Source: Created for Geriatrics by FA Cervo, MD, L Bryan, MD, and S Farber, MD.

the medical literature[6,7] demonstrate that feeding tube placement is ineffective in the prevention or treatment of pressure ulcers. In fact, a positive correlation between pressure ulcers and long-term tube feeding has been demonstrated.[5] Bedfast, incontinent dementia patients who are tube fed are more likely to be restrained, putting them at greater risk for pressure ulcer formation.[8]

ASPIRATION PNEUMONIA: Prevention of aspiration pneumonia is often cited as one of the reasons patients with eating difficulties have feeding tubes placed. Aspiration occurs in up to 50% of patients with feeding tubes.[9] There is some evidence that PEG tube placement may reduce lower esophageal sphincter pressure, increasing the risk of gastroesophageal reflux, although there are no studies of this in older patients.[8] One study demonstrated that a history of previous aspiration is a poor prognostic factor for feeding tube insertion.[10]

The mechanisms of swallowing and dysphagia are complex, and the diagnosis of aspiration pneumonia is imprecise.[8] Therefore, the causal relationship between the presence and the absence of a feeding tube and aspiration pneumonia is often unclear. Aspiration of oral secretions is not prevented by the insertion of a feeding tube.

QUALITY OF LIFE: It is nearly impossible to obtain data on the subjective experience of patients with severe dementia who stop eating. Data about thirst and hunger can only be extrapolated from dying patients with other terminal illnesses. In a study by McCann and colleagues,[11] symptoms of hunger, thirst, and dry mouth were ameliorated with small amounts of food, fluids, application of ice chips, and lubrication of the lips. Moreover, many elderly patients do not feel distress from dehydration because they have an impaired thirst mechanism.[4] Dehydration results in decreased production of bodily fluids, which reduces the need for suctioning and toileting. Patients often have less discomfort when artificial nutrition and hydration are not undertaken.

When tube feeding is used as a permanent replacement to oral feeding, patients are deprived of the pleasure that comes from eating and the social interactions that occur with mealtimes. Conversely, hand feeding is an act of nurturing that involves human beings in close contact and touching.

It is possible that a severely demented patient's quality of life will worsen with tube feeding if restraints are needed. A patient with severe dementia cannot understand why a tube is protruding from the abdomen, which can lead to the patient trying to pull the feeding tube out.[4] One study found that severely demented patients with feeding tubes were much more likely to have their hands in "mittens" and often required additional restraints.[12] The experience of being restrained is distressing and can make the patient become still more agitated. This consequence, in turn, may result in the use of pharmacologic sedation.[4]

Based on the author's personal observations and understanding of available data, feeding tubes do not improve quality of life and may increase patient suffering and discomfort.

FUNCTIONAL STATUS AND SURVIVAL: Tube feedings are often intended to improve strength, function, or self-care; data about the impact of feeding tubes on functional status are limited, however. A retrospective review of nursing home residents with PEG tubes found no improvement in bowel or bladder function, mental status, speech, ADLs, or ambulation during the 18 months after PEG tube placement.[13]

Mortality among tube-fed patients is substantial. In one study of 7,369 patients who underwent PEG tube placement, 23.5% of patients died during the

hospital admission and median survival was only 7.5 months.[14] Another large study of 81,105 patients who underwent PEG or surgical gastrostomy tube placement found that 63% had died by 1 year after placement and 81.3% were dead by 3 years.[15] Severe dementia is a terminal illness that is not reversed by feeding tube placement.

Decision-making

The decision-making process regarding feeding tube placement is complicated because it is often influenced by multiple non-clinical, non-evidence based factors. The demonstrated lack of benefit for placement of feeding tubes in patients with advanced dementia only further complicates the physician's role in the process. To help guide the primary care practitioner in this process, the following is an overview of the different issues involved. These include advance directives, ethical considerations, legal/financial concerns, emotional factors, cultural background, religious beliefs, and the need for a family meeting incorporating all of these principles (table 3).

ADVANCE DIRECTIVES: Advance directives, such as healthcare proxies and living wills, are critical in the decision-making process. Healthcare practitioners should make every attempt to obtain these directives from their patients during office/clinic visits. The opportunity may be lost if the patient develops severe illness or loses decision-making capacity. Asking patients to make sure you have a copy for your chart is one option. Providing waiting room information on how/where to get one is another option.

Healthcare proxies should reflect the patient's specific wishes regarding artificial nutrition and hydration. Whereas living wills provide evidence of a patient's wishes, designation of a healthcare proxy may be preferable because the practitioner can explain options to a surrogate rather than interpreting a written document.

Table 3 Decision-making approach to tube feeding in patients with advanced dementia

- ▶ Obtain advance directives
- ▶ Consider ethical principles
- ▶ Be aware of legal and financial concerns
- ▶ Be sensitive to emotional factors
- ▶ Understand cultural background
- ▶ Respect religious beliefs
- ▶ Conduct a family meeting incorporating the above principles

Source: Created for Geriatrics by FA Cervo, MD, L Bryan, MD, and S Farber, MD.

Despite their importance, advance directives are not a panacea because they are often overruled by surrogates, thus compromising the ethical principle of autonomy.[16,17]

In the absence of an advance directive, substituted judgment dictates that decisions are made based on what a surrogate believes the patient would choose if he or she had capacity.[17] Surrogates are often uncertain or unaware of the patient's wishes regarding feeding tubes. In this case, decisions may need to be based on the patient's best interests.

Advance directive statutes and surrogate decision-making authority vary throughout the nation, making the decision-making process more difficult. Healthcare practitioners need to be knowledgeable of the laws governing advance directives in the individual states in which they practice.

ETHICAL CONSIDERATIONS: Healthcare practitioners have no obligation to offer, recommend, or perform an intervention that has no benefit. If an intervention has a benefit, then it should be offered and recommended. If a clinical benefit is uncertain, then decisions should be based on patient/family values and preferences in concert with discussion with the physician.[18] Tube feeding, as a form of medical therapy, can legitimately be withheld if the risks of the intervention outweigh the benefits.[4] Although the use of feeding tubes is not unequivocally futile in all cases, the overwhelming evidence indicates that feeding tubes do not improve health outcomes in patients with advanced dementia.[4]

LEGAL/FINANCIAL CONCERNS: Despite the lack of evidence of poor beneficial outcomes, healthcare practitioners may feel legally bound to provide tube feeding to a patient with advanced dementia who ceases to eat. In the highly regulated nursing home environment, practitioners may fear legal action based on the development of malnutrition or pressure ulcers.

Nursing homes are reimbursed at a higher rate for tube fed patients; furthermore, hand feeding, which is more nursing, labor intensive and time consuming may not occur in accordance with clinical trial protocols.[3] These non-clinical factors often lead to feeding tube placement.

In New York State, clear and convincing evidence is required for withholding/withdrawing artificial nutrition and IV hydration without a healthcare proxy. Reasonable knowledge of the patient's wishes is required in cases where a proxy has been designated.

EMOTIONAL FACTORS: Decisions concerning feeding tube placement in advanced dementia patients are regularly made by surrogates who are uncertain of their loved one's wishes and who feel emotionally distressed.[16] Decision-making is often emotionally charged, and surrogates may lack a clear understand-

ing and acceptance about the true nature of the illness.[16,17] Although most patients die despite tube feeding, a few individuals survive for many years. This occasional outcome may foster unrealistic expectations about the benefits of tube feeding.[19]

Feelings of guilt and desperation are likely to play substantial roles in the decision-making process.[16] Tube feeding may have a great symbolic value and be perceived as a last means of providing care.[19] Surrogates may be unable to bear the burden of allowing a loved one to die.[16] Healthcare practitioners must educate decision-makers to understand that a gradual disinterest in food is a normal and natural part of the dying process. This may help to alleviate much anxiety and restore a crucial sense of control.[20]

CULTURAL BACKGROUND: The cultural background of patients and their families may be a pivotal factor in decisions concerning tube feeding. The predominant Western biomedical model is based on a mechanistic model of the human body, separation of mind and body, and discontinuity of spirit and soul.

- Native American traditions are based on mind-body-spirit integration. Life and death may be viewed in a circular, rather than a linear, pattern.[21]
- Many African-Americans are skeptical and distrustful of mainstream medicine, especially when making decisions about end-of-life care. This may be due to experiences of segregation and memories of the Tuskegee experiment.[21]
- For many Asian-American elders, end-of-life decisions may be characterized by priority of family versus individual decision-making. Non-disclosure of terminal illness to protect the elder and the practice of not disturbing the body of a dying or dead person may also be prevalent.[21]

Cultural decision-making conflicts concerning tube feeding require that healthcare practitioners listen carefully to the views of patients and surrogates. Input from a source familiar with an individual's cultural background may need to be enlisted in order to resolve these differences.

RELIGIOUS BELIEFS: Religious beliefs of patients must be factored into the decision-making process. Physicians need to be mindful that not all members of a religious sect prescribe to all its tenets. Here again, advance directives are helpful if they spell out individual patient beliefs about such issues. Some Christian patients and families often demand aggressive medical care because they hope for a miracle, or refuse to give up faith, or believe that suffering may have redemptive value, or have a conviction that every moment of life is a gift from God (ie, preserve life at all costs).[22] Patients or surrogates may feel that their preferences override the physician's judgment (ie, futility).[22] Family members' religious beliefs may lead to aggressive end-of-life care despite evidence to the contrary.

Decision making is often emotionally charged, and surrogates may not understand the true nature of the illness

In Judaism, sanctity of life and the infinite value of human life are paramount principles. However, the process of dying must be respected when it is occurring, imminent, and irreversible.[23] Islam similarly values sanctity of life, yet respects the inevitability of death. Autonomy is of primary importance in the Christian faith. Jewish and Muslim faiths respect autonomy but consider it secondary to the patient's health and welfare as judged by clinicians.[23]

Participation by clergy or others trained in pastoral care may help resolve religious conflicts.[22] Some have suggested open discussion with patients and families of the clinical and theological basis for requests concerning aggressive care (ie, feeding tubes). Practitioners should use additional religious doctrines from patients' own traditions to balance the reasons behind such requests,[24] in this case, for tube feeding in the advanced dementia patient.

FAMILY MEETING: All of the factors previously described herein play an important role at the time of a family meeting. A family meeting is essential, for it allows patients and their families to shift the goals of care from unrealistic expectations of a cure to the provision of comfort. At this meeting it is important that the healthcare practitioner discuss, in a risk/benefit context, the lack of evidence supporting feeding tube placement in patients with advanced dementia. The risks and complications of feeding tube placement should also be explained in the context of the patient's illness and prognosis.[20]

Families may feel that their loved ones will "starve to death" if tube feeding is not initiated. By understanding the metabolic processes that occur when patients stop eating, this fear can be allayed. Patients with progressive dementia may be successfully managed by continued oral feeding, letting the natural course of their disease define the extent and duration of feeding.[20]

Summary

PEG tube placement has become a common, low-risk procedure in current medical practice. The clinical evidence supporting the use of tube feedings in patients with advanced dementia is clearly lacking, yet PEG procedures continue to be performed, and tube feedings provided in a large number of cases. We have described an overview that includes some more important factors inherent to the issue of tube feeding in the advanced dementia

patient. We hope this will guide and assist healthcare practitioners in this often difficult, confusing, and time-consuming decision-making process.

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