Feeding Tubes in Patients with Severe Dementia

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Patients with advanced dementia are among the most challenging patients to care for because they are often bedridden and dependent in all activities of daily living. Difficulty with eating is especially prominent and distresses family members and health care professionals. Health care professionals commonly rely on feeding tubes to supply nutrition to these severely demented patients. However, various studies have not shown use of feeding tubes to be effective in preventing malnutrition. Furthermore, they have not been demonstrated to prevent the occurrence or increase the healing of pressure sores, prevent aspiration pneumonia, provide comfort, improve functional status, or extend life. High complication rates, increased use of restraints, and other adverse effects further increase the burden of feeding tubes in severely demented patients. Feeding tubes should be avoided in many situations in which they are currently used. The preferable alternative to tube feeding is hand feeding. Though it may not be effective in preventing malnutrition and dehydration, hand feeding allows the maintenance of patient comfort and intimate patient care. (Am Fam Physician 2002;65:1605-10. Copyright© 2002 American Academy of Family Physicians.)

See page 1515 for definitions of strength-of-evidence levels contained in this article.

The use of artificial nutrition and hydration in patients in the final stages of dementia is a controversial and emotional issue. This topic will become increasingly important because the prevalence of dementia will continue to rise as the population ages. The most common form of dementia is Alzheimer's disease, and its prevalence will nearly quadruple in the next 50 years, by which time approximately one in 45 Americans will have the disease.[1] In the end stages of dementia, patients are typically incapable of having relationships with other people, bedridden, incontinent, and unable to eat and drink for various reasons. Problematic eating patterns may include indifference to food, refusal of food, or failure to manage the food bolus properly once it is in the mouth.[2,3]

Family members and physicians are often attracted to the perceived benefits of providing artificial nutrition and hydration to patients with severe dementia. These techniques have been promoted as a method to improve nutrition, maintain skin integrity by enhanced protein intake, prevent aspiration pneumonia, minimize suffering, improve functional status, and extend life. Additionally, providing artificial nutrition and hydration has been associated with caring and nurturing whereas forgoing these measures has been equated with neglect and abandonment.[4,5] Thus, when caretakers are faced with the decision of whether or not to provide artificial nutrition and hydration, it seems sensible to provide it by any means. Percutaneous endoscopic gastrostomy (PEG) tubes often have been used for this purpose, and it is estimated that approximately 30 percent of all PEG tubes are placed in patients with dementia.[6]

Tube feeding does not prevent weight loss or improve nutritional markers such as hemoglobin, hematocrit, albumin, and cholesterol levels.

Unfortunately, most of the data regarding feeding tubes in severely demented patients are based on observational studies, retrospective studies, or data extrapolated from mixed populations. These factors may significantly confound the ability to appropriately assess the risks and benefits of feeding tube placement. Variability in aspiration pneumonia, functional status, and mortality rates may be

Data do not support the use of tube feeding in the prevention of pressure sores.

related to differences in patient cohorts. Patients who receive feeding tubes may be more debilitated than those who do not.

Another major research obstacle is the designation of an appropriate control group.[2,7] For example, results may vary if patients in the control group were hand-fed by loving family members versus nursing assistants in long-term care settings. Past studies are further confounded by the fact that the stage at which tube feeds are initiated varies among patients because there is no standard guideline for this procedure. In the absence of unequivocal evidence that demonstrates the positive or negative consequences of tube feeding, patients, family members, and physicians may still feel that the insertion of a feeding tube is appropriate.[8]

Despite these limitations, studies have shown that feeding tubes are of unproved benefit in ensuring adequate nutrition, preventing pressure sores, preventing aspiration pneumonia, providing comfort, improving functional status, or extending life in patients with advanced dementia. The procedure can be burdensome through tube-related complications and the use of restraints.

This article will examine whether artificial nutrition and hydration in patients with severe dementia actually provide the assumed medical benefits associated with them.

Malnutrition

Demented patients who stop eating become malnourished rapidly. Development of abnormal markers of nutritional status are often used to justify feeding-tube placement in the belief that tube feeding would help prevent the consequences of malnutrition, which include pressure sores, infection, and death.

A sample[9] of 40 chronically tube-fed patients with poor functional and cognitive status demonstrated that weight loss, severe depletion of lean and fat body mass, and micronutrient deficiencies persisted even if generous amounts of standard enteral formulas were provided. [Evidence level B: clinical cohort study] Other studies have demonstrated that weight loss increased in amount and frequency as the duration of the tube feeding lengthened.[10,11] Other nutritional markers such as hemoglobin, hematocrit, albumin, and cholesterol levels also did not show any significant improvement after a feeding tube was placed.[10,11]

The persistent malnutrition in these chronically tube-fed patients in the face of adequate amounts of formula suggest that "the long-term effects of chronic disease, immobility, and neurologic defects may undermine attempts at long-term nutritional support."[9] Negative outcomes may be unavoidable in these patients despite tube feeding.

Pressure Sores

The data linking malnutrition to the development or worsening of pressure sores are limited. Two retrospective cohort studies[12,13] did demonstrate that during six months of follow-up, poor oral intake was associated with nonhealing pre-existing pressure sores and the formation of new pressure sores. Malnutrition is often cited as a risk factor for developing pressure sores, and feeding tubes are often placed to improve nutritional status and theoretically improve skin integrity. However, one retrospective study[14] observed that the incidence of decubitus ulcers was not statistically different between those patients with (21 percent) and without (13 percent) feeding tubes.

A MEDLINE search[15] from 1985 to 1994 was performed to review the relationship between malnutrition and pressure sores and to gauge the effectiveness of tube feeding in improving the outcomes of pressure sores. The conclusion suggests that the data linking malnutrition and the development of pressures sores were incomplete and contradictory and that "the routine use of tube feeding to prevent or treat pressure sores is not clearly supported by data."[15] In a follow-up review,[2] there were still no data to support the use of feeding tubes to improve pressure sores.

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Aspiration Pneumonia

Interrupting the cycle of eating, aspiration, and subsequent pneumonia is one of the most commonly cited reasons for using a feeding tube. However, there are no data that show feeding tubes reduce the risk of aspiration pneumonia in patients with dementia.[7,16] In fact, some data have shown that the risk of aspiration is increased. One study[14] examining the risk of aspiration pneumonia in 104 severely demented nursing home patients found that patients with feeding tubes experienced significantly more episodes of aspiration pneumonia (58 percent) than the patients without feeding tubes (17 percent; $P < 0.01$).

In assessing whether one site of feeding tube placement was superior to others, investigators compared the incidence of aspiration between patients with jejunostomy tubes and those with gastrostomy tubes. A meta-analysis[17] of 45 studies between 1978 and 1989 with a total of 2,976 gastric tubes and 386 jejunal tubes found that aspiration rates were highly variable across different patient populations and studies. The authors concluded that there were no data to demonstrate decreased risk of aspiration at one feeding tube site compared with another.[17] The continued risk of aspiration despite feeding tube placement may result from continued reflux of gastric contents and aspiration of oropharyngeal secretions.[18]

Quality of Life

Caretakers and physicians often project sensations of hunger and thirst onto severely demented patients with poor oral intake. "We can't just let him starve to death," is a common refrain heard from family members. Clearly, it is impossible to ask patients suffering from severe dementia if they are truly uncomfortable in such a state. Data about thirst and hunger can be extrapolated from patients dying with other terminal illnesses.

One study[19] surveyed 32 patients dying of cancer and stroke. The patients had anorexia or profound dysphagia, and they retained sufficient awareness to express sensations of hunger and thirst at least 75 percent of the time from initial admission until their death. All those who experienced hunger received small amounts of food for alleviation. Patients who complained of thirst and dry mouth were given mouth swabs, sips of water, ice chips, and lubrication of the lips. It is important to mention that the amount given to attempt to alleviate these symptoms was much less than the amount needed to replenish losses.

Giving patients small amounts of food, or using mouth swabs, sips of water, ice chips and lubrication of the lips, may be sufficient to alleviate hunger and thirst.

Interestingly, an overwhelming majority of these patients (84 percent) reported that their thirst and hunger were successfully alleviated by these minimal interventions.

In another prospective study,[20] there were no significant differences in the mean patient comfort scores between the predehydration and dehydration phases. [Evidence level B: clinical cohort study] A perfect comfort score was realized in 85 percent of cases. The results of these studies suggest that patients with a terminal illness can experience comfort despite minimal intake of food and fluids.

Functional Status and Survival

Artificial nutrition and hydration are often provided to improve functional status and survival. Currently, there are limited data about the impact of feeding tubes on improving functional status in patients with advanced dementia. One retrospective observation[11] of nursing home residents who received feeding tubes found no improvement in bowel and bladder function, mental status, speech, activities of daily living, or ambulation during the 18 months after PEG tube placement. Patients in one community-based study[21] did experience some improvement in upper and lower body function over a period of four months.

Patients and their surrogate decision makers often expect the prolongation of life to be the outcome of feeding-tube placement.[8] A few cohort studies[22,23] comparing nursing home residents with and without feeding tubes have not shown a survival advantage in patients with feeding tubes. [References 22 and 23, Evidence level B: clinical cohort study] In a recent MEDLINE review,[24] only 38 percent of the patients were alive one year after placement of a feeding tube. For acutely ill patients with severe dementia, there was no survival advantage among patients who received a feeding tube during their index hospitalization, compared with those without a feeding tube.[25] With or without a feeding tube, these patients have a 50 percent six-month median mortality rate. Perhaps the inability to eat marks the point at which the patient has entered the final stages of the illness

TABLE 1
Potential Complications Related to Percutaneous Endoscopic Gastrostomy Tubes

Category	*Complications*
Local	Local pain
	Suture breakage
	Cellulitis of the abdominal wall
	Abscess of the abdominal wall
	Stomal inflammation
	Skin excoriation
	Bleeding from the site
	Closure or stenosis of stoma
	Hematoma
Mechanical	Erosion of bumper into abdominal wall
	Tube leakage
	Tube blockage
	Tube migration or loose fixation plate
	Tube malfunction
	Fractured tube
	Kinked tube
Pleuropulmonary	Erosion of tube into pleural cavity
	Aspiration pneumonia
Gastrointestinal	Flatulence
	Nausea
	Vomiting
	Diarrhea
	Ileus
	Gastroesophageal reflux
	Bowel obstruction (requiring laparotomy)
	Intra-abdominal leak
	Intra-abdominal peritonitis
	Intra-abdominal bleeding
	Gastric mucosal erosion
	Gastric perforation
	Upper gastrointestinal bleed
	Necrotizing fasciitis
Other	Anorexia
	Fluid overload
	Increased skin moisture
	Agitation, self-extubation
	Use of restraints
	Metabolic disturbances
	Loss of social aspects of feeding
	Altered cosmesis
	Fever
	Sepsis

Information from references 2, 6, 10, 11, and 26 through 28.

that may be intractable even in the face of aggressive intervention. This would account for the lack of improvement in functional status and survival rates.

Other Considerations

Nonclinical factors may greatly influence the ultimate decision of placing a feeding tube. Clinicians may fear that they are more vulnerable to legal action if they do not place a feeding tube in a terminally ill patient. A physician may fear that not having a feeding tube in a cachectic patient with progressive weight loss and bedsores will insinuate neglect and have negative legal consequences. The alternative to tube feeding is hand feeding, which is time consuming and labor intensive. Nursing homes may not be willing to devote more time to each patient, especially without financial compensation. This may explain why residence in a nursing home is associated with an increased risk of receiving a new feeding tube.[25]

Patients with end-stage dementia often rely on surrogate decision makers to decide if a feeding tube should be placed. Hopefully, an advance directive would be in place to represent the patient's wishes. In many cases, no such instructions are available. Patients or their surrogates who choose tube feedings may feel that denying a demented person the provision of nutrition and hydration is morally wrong. This belief may be grounded in their cultural or religious background. It is important to be sensitive to all of these variables because they will influence the decision of whether or not a feeding tube is inserted.

Placing a feeding tube may increase patient suffering. The mortality rate related to the placement of the PEG tube is generally low, ranging from zero to 2 percent.[3] However, the complication rates of PEG tube placement can range from 15 to 70 percent.[2,6,10,11,26-28] Tube leakage, cellulitis, gastroesophageal reflux, ileus, and diarrhea are all possible adverse consequences associated with use of a feeding tube and can cause extreme discomfort to patients *(Table 1)*.[2,6,10,11,26-28]

Another potential adverse consequence of tube feeding is the increased use of restraints. Patients with severe dementia often do not understand why a tube is protruding from their abdominal wall, and they frequently attempt to pull it out.[29] Caretakers often respond by ordering restraints. One study[14] found that severely demented patients with feeding tubes were 90 percent more likely to have their hands enclosed in "mittens," and 71 percent of these patients required additional restraints. This action

often causes the patient to become more agitated, which may lead to the use of pharmacologic sedation.[29] With such potential negative outcomes as tube dysfunctions and increased use of restraints, tube feeding may actually result in more suffering than comfort.

TABLE 2
Recommendations for Oral Feeding in Patients with Severe Dementia

Preventing aspiration pneumonia for those patients at risk
Sit the patient upright (45 degrees) while eating
Bolus size of less than one teaspoon
Restrict clear liquids
Place food well into the mouth
Encourage gentle coughs after each swallow
Remind to swallow multiple times after each mouthful of food to clear the pharynx
Strategies to improve food intake
Basic tenet: Alter flavors, amounts, consistency, and availability of food.
Use strong flavors
Hot or cold (not tepid)
Gravy
Juices
Enrichers (e.g., cream, spices)
Sweets (e.g., miniature chocolate bars)
Use varying amounts of food
Try finger foods (e.g., sandwiches, chicken fingers)
Use preferred foods in large quantities (e.g., ice cream)
Adapt food consistency to suit the individual
Try liquid supplements (Should be given one and one half to two hours before the next meal; should never be given with the meal as it can promote satiety)
Try slightly thickened food (e.g., puddings, milkshakes)
Try blending foods (e.g., cereals mixed with eggnog or pudding)
Make food available to the patient
Lengthen mealtimes because it takes longer for demented patients to ingest, chew, and swallow food
Allow patients to keep their supplements (e.g., liquid supplements and/or candy bars) at the bedside
Modify environmental factors
Capitalize on the midday meal when patients demonstrate maximal cognitive function
For those resistive or combative at mealtime, try holding hands or reassuring touches on the arms, or try cheerful conversations or singing softly

Information from references 5, 13, and 30 through 33.

Caretakers should be encouraged to hand-feed patients instead of placing feeding tubes. The patient's oral intake may increase by altering flavors, amounts, consistency, and availability of food *(Table 2)*.[5,13,30-33] If hand feeding is failing, tube feeding should not be the next "logical" choice. Every effort should be made to educate caretakers about the benefits and risks concerning tube feeding of severely demented individuals. Caretakers need to be reminded that advanced dementia is a terminal illness and that patients with severe dementia can be comfortable without feeding tubes in place. If a feeding tube is instituted, this intervention should be made with highly specific goals in mind. If a complication ensues or the goals are not met after a specified period of time, then withdrawing the feeding tube should be considered.[5]

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