

Tube Feeding in Patients With Advanced Dementia

A Review of the Evidence

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PATIENTS WITH ADVANCED DEMENTIA commonly develop difficulty eating, often when they become bedridden and dependent in all activities of daily living. They may resist or be indifferent to food, fail to manage the food bolus properly once it is in the mouth (oral phase dysphagia), or aspirate when swallowing (pharyngeal phase dysphagia). Enteral tube feeding is intended to prevent aspiration pneumonia, forestall malnutrition and its sequelae, including death by starvation, and provide comfort. We reviewed data about whether any type of tube feeding can accomplish these goals in this group of patients. Studies limited to patients with cancer, burns, trauma, dysphagic stroke, mechanical obstruction, critical illness, pediatric patients, or patients receiving ventilatory assistance were not considered. We did not include discussion of ethical issues, since our focus was on clinical evidence.

We searched MEDLINE from 1966 through March 1999 and found no relevant randomized clinical trials comparing tube feeding with oral feeding in the severely demented. Thus, a meta-analysis was not possible; rather, we have presented a summary of the data

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Patients with advanced dementia frequently develop eating difficulties and weight loss. Enteral feeding tubes are often used in this situation, yet benefits and risks of this therapy are unclear. We searched MEDLINE, 1966 through March 1999, to identify data about whether tube feeding in patients with advanced dementia can prevent aspiration pneumonia, prolong survival, reduce the risk of pressure sores or infections, improve function, or provide palliation. We found no published randomized trials that compare tube feeding with oral feeding. We found no data to suggest that tube feeding improves any of these clinically important outcomes and some data to suggest that it does not. Further, risks are substantial. The widespread practice of tube feeding should be carefully reconsidered, and we believe that for severely demented patients the practice should be discouraged on clinical grounds.

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available. In each section, we describe how articles were identified and summarize the findings. Our goal is to present the relevant data in a way that is useful to clinicians, patients, families, and perhaps policy makers.

DOES TUBE FEEDING PREVENT ASPIRATION PNEUMONIA?

Aspiration pneumonia is often an imprecise diagnosis both conceptually and clinically. Mendelson¹ described a group of parturient women who underwent ether anesthesia and vomited and aspirated gastric contents. All developed tachypnea, wheezing, rales, and cyanosis and all recovered uneventfully in a few days. Some authors use "aspiration pneumonia" to refer to this syndrome, a pneumonitis that follows aspiration and resolves spontaneously without antibiotics.² The term is also used to describe pulmonary infection

due to misdirection of contaminated pharyngeal contents, especially oral secretions, into the airway. This syndrome is usually insidious in onset, associated with fever, and when a microbiologic diagnosis can be made, polymicrobial. Infection probably results when normally nonpathogenic organisms arrive in high enough inoculum to overcome host defenses.

Tube feeding cannot be expected to prevent aspiration of oral secretions, and no data show that it can reduce the risk from regurgitated gastric contents. In fact, in children³ and in animal models,⁴ gastrostomy tube placement may reduce lower esophageal sphinc-

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ter pressure and increase the risk of gastroesophageal reflux, with "a change in the gastroesophageal angle (as) the suspected mechanism."⁴ No comparable studies have been reported in the elderly.

A 1996 review of tube feeding to prevent aspiration pneumonia conducted by 1 of the authors (T.E.F) and Bynum⁵ found that "No randomized trials of the intervention have been done, and some data suggest ineffectiveness." A MEDLINE search from 1966 through March 1999 using the same search terms as that article, *enteral nutrition*, *deglutition disorders*, and *aspiration pneumonia*, confirmed these observations. Three additional case-control studies identified tube feeding as a risk factor for aspiration pneumonia and demonstrated high rates of pneumonia and death in tube-fed patients.⁶⁻⁸ In a nonrandomized, prospective study,⁹ orally fed patients with oropharyngeal dysphagia had significantly fewer major aspiration events than those fed by tube. The authors conclude, "Artificial feeding does not seem to be a satisfactory solution for preventing pneumonia in elderly prandial aspirators." Jejunostomy is not associated with lower rates of pneumonia than gastrostomy.^{10,11} We found no published studies suggesting that tube feeding can reduce the risk of aspiration pneumonia.

DOES TUBE FEEDING PREVENT THE CONSEQUENCES OF MALNUTRITION?

Demented patients with problems eating frequently lose weight and develop other abnormal markers of nutritional status such as lowered serum albumin levels or total lymphocyte count, diminished triceps skin fold or body mass index, or impaired skin-test reactivity. Tube feeding may then be initiated to try to prevent or correct consequences of malnutrition including pressure ulcers, infection, debility, and death.

However, in several clinical situations, provision of increased nutrients to patients with abnormal markers of nutritional state had no effect on mean-

ingful clinical outcomes. For 40 patients receiving tube feeding in long-term care (the majority due to neurologic impairment), "adequate calories and protein were provided . . . still, subjects showed weight loss and severe depletion of lean and fat body mass. . . . Despite administration of apparently adequate formula, micronutrient deficiencies and marasmic malnutrition exist in chronically ill patients."¹² In 2 additional clinical situations, patients with abnormal markers of nutritional status did not benefit from increased administration of nutrients. Of 17 trials studying patients with advanced cancer, most of whom were emaciated, no trial showed a survival benefit from parenteral nutrition.¹³ Megestrol acetate in patients with acquired immunodeficiency syndrome (AIDS)-cachexia improved intake and nutritional markers; however, death rates in each of 4 treatment groups were more than double that of placebo controls.^{14,15} For wasting disorders associated with AIDS and cancer, a 1997 conference sponsored by the National Institutes of Health, the American Society for Parenteral and Enteral Nutrition, and the American Society for Clinical Nutrition concluded that "there are no published observations providing direct evidence that wasting is a cause of death or that reversal of wasting improves outcome."¹⁶

For patients with advanced dementia and eating difficulties, the relationships among nutritional intake, markers of nutritional status, and clinically meaningful outcomes remain uncertain. For some patients with catabolic illness, delivery of additional nutrients may not provide benefit. For others, additional nutrients might provide benefits, but these may be outweighed by adverse effects of tube feeding. The relevant clinical question is whether tube feeding improves outcomes putatively ascribed to malnutrition.

IS SURVIVAL IMPROVED BY TUBE FEEDING?

We conducted a MEDLINE search of the terms *survival* and *enteral nutrition* from 1966 through March 1999 as well

as the bibliographies of many articles related to these topics. Four lines of evidence undermine the apparently commonsense practice of tube feeding emaciated, demented patients to prevent death due to starvation.

First, survival of very low-weight, hand-fed demented patients can be substantial. Survival of demented and nondemented patients was not different in a long-term care facility with a program of careful feeding by hand.¹⁷ A 2-year prospective observation of 71 demented patients in long-term care found similar mortality rates among 4 groups: those who fed themselves, those who required assistance but otherwise had no eating difficulties, those who refused food, and those who coughed and choked on food. Only 1 patient was tube fed.¹⁸

Second, feeding tube placement itself can cause death. Mortality during percutaneous endoscopic gastrostomy (PEG) tube placement ranges from 0% to 2%^{19,20} and perioperative mortality ranges from 6% to 24%.²¹⁻²⁵ In a study of 882 fluoroscopic nasogastric tube placements, 3 patients died of arrhythmia during the procedure.²⁶

Third, mortality among tube-fed patients is substantial. Several retrospective studies describe survival after feeding tube placement in patients with eating difficulties, although none are restricted to those with dementia. A review of studies of PEG tubes, each comprising more than 50 patients, found mortality rates of 2% to 27% at 30 days and 50% or more at 1 year.²⁷ Mortality data from articles not included in that review show 1-month mortality rates ranging from 8% to 67%, and median survival appears to be well under 1 year (TABLE 1). The 2 largest studies included 7369 and 81 105 patients, respectively. The former reported that median survival after PEG tube placement was 7.5 months.²⁵ The latter found that 63% of patients had died by 1 year after PEG or surgical gastrostomy tube placement and 81.3% were dead by 3 years.²³

Finally, nonrandomized, retrospective observations of nursing home residents have found no survival advantage with tube feeding. No difference in sur-

vival was found between groups treated with and without tube feeding among 1386 patients with recent progression to severe cognitive impairment. This finding persisted after adjustment for age, prior history of pulmonary aspiration or stroke, presence of swallowing disorder, decubitus ulcer, functional state, resuscitation wishes, and cognitive status.³⁷ A separate article based on the same data set described 5266 residents with chewing and swallowing problems and reported a significant increase in 1-year mortality among tube-fed patients (risk ratio, 1.44).³⁸

We found no published studies suggesting that tube feeding can prolong survival in demented patients with dysphagia.

ARE PRESSURE ULCERS PREVENTED OR IMPROVED BY TUBE FEEDING?

Data linking poor nutrient intake or abnormal markers of nutritional status to pressure ulcers are extremely limited. In a 1995 review³⁹ that excluded orthopedic and spinal cord injury patients, 13 studies found very weak associations between nutritional status and pressure sores. Data relating nutrient intake to pressure sores were similarly inconclusive. No prospec-

tive trials of tube feeding were found, and retrospective studies found only an increased risk or no benefit associated with tube feeding.³⁹ A MEDLINE search of *enteral nutrition* and *decubitus ulcer* from 1966 through March 1999 found no controlled clinical trials of tube feeding in those with or at risk for pressure ulcers. Two studies that used an administrative database of more than 800 patients during 6 months of follow-up reported that tube feeding was not associated with healing of preexisting pressure sores,⁴⁰ nor with protection from new pressure sores.⁴¹

Bedfast, incontinent patients with dementia who are tube fed are more likely to be restrained⁴² and will probably make more urine and stool. Pressure sore outcomes could be worsened. We found no published studies suggesting that tube feeding can improve pressure sore outcomes.

IS THE RISK OF OTHER INFECTIONS REDUCED BY TUBE FEEDING?

Aspiration pneumonia and pressure ulcers, conditions that are sometimes infectious, have already been considered. We searched MEDLINE from 1966 through March 1999 using the terms *en-*

teral nutrition and *infection* and limited our search to studies involving humans. We found no studies of tube feeding to reduce the risk of other infections—eg, urinary tract, viral, gastrointestinal, or eye infections. In contrast, feeding tubes can cause infection. Nasogastric tubes predispose to infections of the sinuses and middle ear. Gastrostomy tubes have been associated with diarrhea (infectious and noninfectious), cellulitis and abscess (at a rate of 3% to 8%), and rarely with necrotizing fasciitis and myositis.⁴³ Enteral feeding solutions can be contaminated with bacteria, perhaps leading to gastrointestinal symptoms.⁴⁴ Case reports have described streptococcal bacteremia following insertion of a PEG tube⁴⁵ and contaminated enteral solution causing nosocomial bacteremia.^{44,46,47} We found no published studies suggesting that tube feeding can reduce the risk of infection in dysphagic patients with dementia.

CAN TUBE FEEDING IMPROVE FUNCTIONAL STATUS?

Providing an emaciated patient with artificial feeding is sometimes intended to improve strength, function, or self-care. We reviewed a MEDLINE search of the terms *function*, *functional status*, *recovery of function*, *strength*, or *activi-*

Table 1. Mortality After Feeding Tube Placement: Observational Studies*

Study, y	Intervention	Type of Patient, No.	Outcome
Heimbach, ²⁸ 1970	Surgical feeding tube	Neurogenic, 100	63% Mortality by 1 mo
Matino, ²⁹ 1981	Jejunostomy tube	Neurogenic, 54	33% Mortality by 1 mo, 50% mortality among survivors by 6 mo
Golden et al, ³⁰ 1997	PEG tube	Mixed population, 102	24% Mortality by 6 mo, 55% mortality by 2 y
Kaw and Sekas, ³¹ 1994	PEG tube	Mixed population, 46	20% Mortality by 1 mo, 59% mortality by 18 mo
Hull et al, ¹⁹ 1993	PEG tube	Mixed population, 49	8% Mortality by 1 mo, mean survival <6 mo
Kohli and Block, ²⁰ 1995	PEG tube (review of 4 studies)	Mixed population, 612	16%-30% Mortality by 1 mo
Nevins, ²¹ 1989	PEG tube or gastrostomy tube	Neurogenic, 22	41% Mortality by 3 wks
Fay et al, ³² 1991	PEG vs nasogastric tube	Mixed population, 109	50% Mortality by 4 mo for both populations
Hassett et al, ²² 1988	Gastrostomy tube	Neurogenic, 87	20% Mortality by 1 mo, 40% mortality by 1 y
Grant et al, ²³ 1998	PEG tube or gastrostomy tube	Mixed population, 81 105	24% Mortality by 1 mo, 63% mortality by 1 y, 81.3% mortality by 3 y
Finocchiaro et al, ²⁴ 1997	PEG tube	Mixed population, 136	9.5% Mortality by 1 mo, 58% mortality by 1 y, 65% mortality by 2 y
Loser et al, ³³ 1998	PEG tube	Mixed population, 210	66% Mortality by 1 y
Fisman et al, ³⁴ 1999	PEG tube	Mixed population, 175	18% Mortality by 30 d, 61% mortality by 1 y
Light et al, ³⁵ 1995	PEG tube	Mixed population, 416	9% Mortality by 1 mo
Bergstrom et al, ³⁶ 1995	Gastrostomy tube	Mixed population, 77	21% Mortality by 1 mo, 64% mortality by 1 y

*Neurogenic indicates dementia, cerebrovascular accident, trauma, anoxic brain injury, Parkinson disease, Guillain-Barré syndrome, or motor neuron disease; PEG, percutaneous endoscopic gastrostomy; and mixed population, patients with neurogenic mechanical disorders and cancer.

ties of daily living, and enteral nutrition from 1966 through March 1999. In stroke patients, emaciation may be associated with slower functional improvement,^{48,49} but we found no study in which a nutritional intervention facilitated recovery of function. Among 100 frail nursing home residents, oral protein supplements produced no improvement in measures of strength or function unless combined with resistance strength training.⁵⁰ A retrospective review found that no nursing home patients had improvement in functional status as measured by the Functional Independence Measurement scale during 18 months after PEG tube placement.³¹ We found no published studies suggesting that tube feeding can improve function or mitigate its decline in dysphagic demented patients.

DOES TUBE FEEDING IMPROVE PATIENT COMFORT?

We searched MEDLINE from 1966 through March 1999 using the terms *palliative care* and *enteral nutrition*. For many demented patients, data about symp-

oms and symptom control can be based only on inference. In a prospective observation of palliative care for terminally ill patients with anorexia, primarily with cancer or stroke, few experienced hunger or thirst. Of those who did, relief was achieved with small amounts of food and fluids or by ice chips and lip lubrication.⁵¹

Patients with amyotrophic lateral sclerosis and dysphagia who had feeding tubes placed continued to cough, have difficulty managing oral secretions, and develop aspiration pneumonia. Hunger and nausea often began or increased after tube placement, and human contact was diminished.⁵² Tube-fed patients may be denied the pleasure of eating or made uncomfortable by the tube or frequent repositioning; some require restraints. We found no published studies suggesting that tube feeding makes dysphagic demented patients more comfortable.

ADVERSE EFFECTS

We searched MEDLINE from 1966 through March 1999 using the terms

complication and *enteral nutrition* and limited our search to studies of humans age 65 years or older. The many adverse effects of tube feeding have been divided into 4 major categories: local or mechanical, pleuropulmonary, abdominal, and other (TABLE 2). The most common adverse effect associated with all types of tube feeding is aspiration pneumonia (0%-66.6%⁵). For PEG tubes, common adverse effects are tube occlusion (2%-34.7%^{19,31,37}), leaking (13%-20%^{31,32}), and local infection (4.3%-16%^{19,31,32,60}). Approximately two thirds of nasogastric tubes require replacement.^{32,68}

CONSERVATIVE ALTERNATIVES

Discontinuing nonessential medications may reduce eating difficulties. Among psychiatric patients, swallowing dysfunction and choking have been associated with certain medications, especially those with anticholinergic effects.^{71,72} Several drugs cause inattention (eg, sedatives), movement disorders (eg, major tranquilizers), xerostomia (eg, anticholinergics), esophagitis (eg, alen-

Table 2. Burdens and Complications Associated With Tube Feeding

Adverse Effect Category	Type of Tube		
	Nasogastric	Gastrostomy and/or Jejunostomy	Both
Local/mechanical	Erosion/necrosis, bleeding of nose, pharynx, and/or esophagus ^{52,53,55} ; poststricoid perichondritis ⁵⁴ ; tube misplacement into lung or brain ^{43,56} ; high extubation rate; otitis media; sinusitis	Wound dehiscence; bleeding at insertion site; closure or stenosis of stoma; skin excoriation; hematoma; erosion of bumper into abdominal wall	Knotting of tube; tube malfunction ⁶⁴ ; tube migration; discomfort from tube; tube placement failure
Pleuropulmonary	Tracheoesophageal or bronchopleural fistula ⁵⁵ ; hemothorax, hydrothorax, pneumothorax ^{53,55,57} ; tracheobronchial perforation; pneumonitis, lung abscess; pneumomediastinitis; airway obstruction; infusion into lung	Erosion of tube into pleural cavity	Aspiration of feeding
Abdominal	Perforation of esophagus or duodenum; esophageal stricture; esophageal bezoar ⁵⁸ ; reflux esophagitis	Gastric perforation ⁶⁰ ; gastric prolapse; gastrocolic fistula ⁵⁹ ; pneumoperitoneum; pneumatosis intestinalis ⁶¹ ; prolonged ileus; evisceration ⁶² ; acute gastric dilatation ⁶⁵ ; intussusception ⁶⁶ ; gastric wall defects ⁶⁶ ; laceration of esophagus ⁵⁴ ; peritonitis ^{54,60,64,67,68} ; cellulitis ^{59,62} ; necrotizing fasciitis; abdominal or subphrenic abscess ⁶⁷	Diarrhea; gastrointestinal bleeding ^{62,67} ; bowel obstruction ⁶⁴ ; nausea ⁶² ; vomiting; promotion of gastroesophageal reflux ⁷⁰
Other	Agitation ^{53,68} ; requirement for frequent repositioning; increased secretions or frequent suctioning	Arrhythmia ^{26,62} ; laryngospasm; shock; mediastinitis ⁶²	Fluid overload; increased skin moisture; death; use of restraints ^{63,68,69} ; weight loss ⁵³ ; metabolic disturbance ⁵³ ; loss of gustatory pleasure; anorexia; loss of dignity; loss of social aspects of feeding; altered cosmesis ^{43,59}

dronate), or anorexia (eg, nonsteroidal anti-inflammatory drugs). Careful attempts to limit use of such medications may yield small but critical increments in eating ability.

Several conservative feeding strategies have been tried. In nursing home patients who were previously less than 80% of ideal body weight, an 8-week trial including staff education, ad lib diets, medication adjustment, assistive devices, changes in the environment, dental care, swallowing evaluations, and augmented energy intake during illness demonstrated that 50% of patients gained an average of 4.5 kg without feeding tubes.⁷³

While body position during feeding is poorly studied in patients with dementia, supine (vs semirecumbent) position and length of time supine are risk factors for aspiration of gastric contents in patients receiving ventilatory assistance who are fed by nasogastric tube.⁷⁴ Potentially useful techniques include the use of finger foods and preferred foods,⁷⁵ strong flavors, hot or cold rather than tepid food, gravy or juices, and enrichers such as cream.^{54,76,77} Other helpful techniques are reminders to swallow and swallow multiple times per bolus,^{75,77} gentle coughs after each swallow,⁷⁷ bolus size of less than 1 teaspoon,⁷⁷ liquid supplements,⁷⁵ and facilitation techniques such as vibration, gentle brushing, and icing of the cheeks and neck.⁵² Additional methods include increasing personal assistance with meals⁷⁵; altering size and frequency of meals; evaluating for other illnesses, especially depression⁷⁵; placing food and fluid well into the mouth⁵²; and modifying environmental aspects such as noise level and the company of disruptive patients. These techniques require increased staff time and have not been rigorously studied. They do offer less invasive alternatives to tube feeding.

CONCLUSIONS

We identified no direct data to support tube feeding of demented patients with eating difficulties for any of the commonly cited indications. Tube feeding is a risk factor for aspiration pneumonia;

to our knowledge, it has never been shown to be an effective treatment, and neither regurgitated gastric contents nor contaminated oral secretions can be kept out of the airways with a feeding tube. Survival has not been shown to be prolonged by tube feeding. Periprocedure mortality is substantial and prolonged survival of very underweight, dysphagic, demented patients without tube feeding is common. Feeding tubes have not been shown to improve pressure sore outcomes, and in fact, the relationship between nutrient intake and pressure sores is tenuous at best. Improved delivery of nutrients via tube has not been shown to reduce infection, but, on the contrary, feeding tubes have been shown to cause serious local and systemic infection. Functional status has not been improved and demented patients are not made more comfortable with tube feeding while dozens of serious adverse effects have been reported. Conservative measures are available although these are not well studied. Randomized clinical trials of this intervention in this population would be tremendously complex both ethically and clinically.

Several factors likely contribute to the widespread use of tube feeding in elderly patients with dementia. Artificial sustenance retains special status in some discussions about life-sustaining treatment. The apparent validity of tube feeding is very persuasive; if patients have trouble eating, it seems sensible to feed them by any means. Several other factors probably also contribute—administrative convenience, ease of use by nursing staff, and misunderstanding by health care professionals and family members.

A demented patient with eating difficulty can present formidable clinical challenges. We believe that a comprehensive, motivated, conscientious program of hand feeding is the proper treatment. If the patient continues to decline in some clinically meaningful way, tube feeding might be considered as empirical treatment; however, all who help make the decision should be clearly informed that the best evidence suggests it will not help.

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