

Tube Feeding Versus Assisted Oral Feeding for Persons With Dementia: Using Evidence to Support Decision-Making

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Abstract: Many reports in the medical literature indicate that percutaneous endoscopic gastrostomy (PEG) tube placement does not improve quality of life or provide mortality benefits to patients with late-stage dementia. Despite such findings, PEG is often performed in this population. Although assisted oral feeding may be more challenging to undertake in patients with late-stage dementia, particularly in the nursing home setting due to time and resource constraints, this method of providing sustenance is often favored by patients and their families. Clinicians should counsel families of persons with advanced dementia with regard to assisted oral feeding, helping them make an informed decision regarding the care of their loved ones.

Key words: Percutaneous endoscopic gastrostomy (PEG), assisted oral feeding, dementia care, late-stage dementia, feeding tube complications.

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Dementia is an incurable and devastating disease that has profound health effects on affected persons and presents significant emotional and practical challenges to healthcare providers and caregivers. Affecting 36 million people worldwide, the disease typically progresses over 3 to 7 years.¹ Late-stage dementia is characterized by apraxia, alterations in sensory processing, and bulbar dysfunction, often resulting in complex problems with gait, continence, feeding, and self-care.² Feeding problems are nearly universal among patients with dementia. In CASCADE (Choices, Attitudes, and Strategies for Care of Advanced Dementia at the End-of-Life), a detailed prospective cohort study of nursing home residents with advanced dementia, 86% of patients had problems with food intake or swallowing.³ When faced with the clinical consequences of malnutrition or undernutrition, including weight loss, dehydration, and aspiration, family caregivers of patients with dementia often consider percutaneous endoscopic gastrostomy (PEG) tube feeding as an alternative to oral feeding.

When considering feeding options, families weigh not only their loved one's medical information, but they must also consider ethical, religious, and cultural factors.^{4,5} Nutrition is fundamental to survival, but from a cultural standpoint, food is sometimes considered an expression of human compassion and nurturing during illness. Family decision-makers often report feeling unprepared and unsupported when deciding on a treatment for a loved one with dementia, and decisions about feeding are the most common and the most difficult ones to make.⁶ Two studies examining perceptions of tube feeding found that families expect to see benefits in survival, relief from aspiration risk, relief from pain, and improved function, but these benefits were not realized later for many patients due to the progression of their underlying illnesses.^{7,8} Physicians may also be more optimistic about tube feeding outcomes than is supported by evidence, which can influence this choice.^{9,10}

Current State of Medical Evidence to Guide Tube Feeding Decisions

Ideally, clinicians are fully informed of the evidence when making feeding decisions for any patient population or when advising family caregivers on such decisions. As persons with dementia develop difficulty eating, they receive increasing levels of assistance. Assisted oral feeding may include verbal cueing, feeding by hand, using modified-texture foods and flavor enhancers, encouraging supportive dining environments, and adding high-calorie supplements to diets. When these interventions fail or pose difficulties, PEG placement may occur.

To more comprehensively compare tube feeding with assisted oral feeding in advanced dementia care, an ideal study would be a well-designed, randomized, controlled trial with adequate power to examine patient-centered outcomes, such as survival, aspiration pneumonia, wound healing, and quality of life. Ideally, study enrollment would be based on a clearly defined stage of dementia and the severity of feeding problems. Outcomes would be assessed by individuals blinded to treatment assignment. Because such a trial has not yet been conducted, the current evidence base consists of descriptive studies in which persons with dementia who receive a feeding tube are compared with a control group. Some of the higher quality descriptive studies use statistical methods to adjust for other factors, besides tube feeding, that may account for differences in how well the two groups do over time. What follows is a review of what the literature shows regarding several key questions surrounding feeding issues faced by patients with dementia.

Do Patients With Dementia Have Better Outcomes Than Other Patients Who Receive a Feeding Tube?

Descriptive studies comparing persons with dementia with persons who have other diagnoses requiring tube feeding are designed to determine whether patients with dementia do better or worse than nondementia patients who receive a feeding tube. Since tube feeding is only used in seriously ill patient populations, 30-day mortality following placement of a feeding tube averages 18% to 28%, and 1-year mortality is approximately 50%, with reports ranging from 39% to 90% for persons with dementia.¹¹⁻¹⁴ Most studies reporting tube feeding outcomes have found that survival following this procedure does not differ by underlying diagnosis, yet advanced age, low albumin levels, and greater comorbidity are associated with shorter survival.^{8,15-18} A few studies have reported higher mortality in persons with dementia than for other diagnoses.^{19,20} The results of these studies provide evidence that patients who have feeding problems *and* nutritional decline are at significant risk of death during the following year, regardless of underlying diagnosis. However, these studies do not provide the evidence needed to choose between tube feeding or assisted oral feeding for persons with advanced dementia.

Do Dementia Patients Have Better Outcomes With a Feeding Tube Than With Assisted Oral Feeding?

There are descriptive studies comparing persons with dementia who have a PEG tube with a control population group receiving assisted oral feeding. Eleven controlled, observational studies compare persons with dementia or nursing home residents, a population within which 50% to 70% have dementia, to those who do not receive a feeding tube, and therefore continue assisted oral feeding.²¹⁻³¹ The burden of evidence from these studies clearly demonstrates no survival benefit from tube feeding (**Table**). Several of these studies provide data that specifically address this question for persons with advanced dementia.^{23,27,31} Additional studies addressing the outcome of wound healing have found scant evidence for wound healing with tube feeding, and persons with advanced dementia who had insertion of a feeding tube during an acute care hospitalization were at higher risk of developing a pressure ulcer.^{32,33} Bereaved family members report that nearly 40% of patients dying with dementia were bothered by the feeding tube, 26% were physically restrained, and 29% were restrained with pharmacological treatment.³⁴

Assisted oral feeding represents a viable evidence-based option to maintain weight and caloric intake for patients with dementia.

How Can We Provide High-Quality Care to Dementia Patients With Feeding Problems?

Assisted oral feeding represents a viable evidence-based option to maintain weight and caloric intake for patients with dementia.³⁵ In the final weeks of life, feeding for comfort is an option for persons with end-stage dementia, when weight gain is no longer a goal of medical care.³⁶ Assisted hand feeding, including assistance taking high-calorie supplements, is more labor-intensive than tube feeding in nursing homes, and must be done well to be effective.³⁷ This can be challenging in nursing home care, as staff who face increasing demands on their time may prefer tube feeding to assisted oral feeding; additionally, Mitchell and colleagues³⁸ suspected a higher potential fiscal incentive to tube feeding residents with advanced dementia, as tube-feeding generates a higher daily reimbursement rate from

Table. Controlled Studies of Tube Feeding Outcomes in Dementia Care

Reference	Setting	Population	Design and Quality	Outcomes of Tube Feeding vs Assisted Feeding
Peck ²¹	Nursing home	n=52 dementia patients receiving tube feeding vs n=52 controls without tube feeding (71% with dementia)	Retrospective; no adjustment for other differences between the two groups; look-back period 6 months	Persons with feeding tubes had greater weight gain (48% vs 17%); higher rates of pneumonia (58% vs 17%), decubitus ulcers (21% vs 14%), and use of physical restraints (71% vs 56%)
Bourdel-Marchasson ²²	Nursing home	n=58 patients with varied diagnoses (55% dementia) and tube feeding vs n=50 controls refusing tube feeding	Retrospective; no adjustment for other differences between two groups; variable follow-up time	Mortality did not differ; higher rates of pneumonia for persons with feeding tubes (40% vs 30%)
Mitchell ²⁴	Nursing home	n=5266 residents aged ≥65 years with chewing/swallowing problems (79% dementia of any stage); 11% with feeding tubes vs 89% without feeding tubes	Retrospective; multivariate analysis to adjust for other differences; follow-up period of 12 months	Mortality risk higher for persons with feeding tube (RR, 1.44)
Rudberg ²⁵	Nursing home	n=1545 residents aged ≥65 years with a swallowing problem and new progression to total dependence for feeding (95% dementia of any stage); 23% with new feeding tube vs 78% without	Retrospective; multivariate analysis to adjust for other differences; follow-up period of 12-24 months	Mortality risk lower for persons with feeding tube (RR, 0.71)
Nair ²⁶	Hospital	n=56 patients with dementia and new feeding tube vs n=36 patients without feeding tube, matched on age, sex, and comorbidity	Prospective; multivariate analysis to adjust for other differences; follow-up period of 9 months	Mortality risk higher for persons with feeding tube (44% vs 26%)
Meier ²⁷	Hospital	n=99 patients with advanced dementia admitted to hospital; 67% had existing or new feeding tube vs patients without feeding tube	Prospective; multivariate analysis to adjust for other differences; follow-up period of 1.3 to 4.2 years	No difference in mortality
Tokuda ²⁸	Hospital/nursing home	n=106 nursing home residents aged ≥65 years who were hospitalized (62% dementia); 15% received a new feeding tube	Retrospective; multivariate analysis to control other differences; follow-up period variable	Mortality rate 51% at 6 months; in multivariate analysis feeding tube predicted higher mortality risk (OR, 2.29)
Murphy ²⁹	Hospital	n=41 patients with advanced dementia recommended for tube feeding; 23 with new feeding tube vs 18 who refused	Retrospective; no adjustment for other differences; follow-up period 2 years	No difference in mortality
Jaul ³⁰	Psychogeriatric ward	n=62 patients with nasogastric feeding (68% dementia) vs 26 oral feeding (36% dementia)	Retrospective; multivariate adjustment for other differences; follow-up period variable	No difference in mortality
Arinzon ³¹	Psychogeriatric ward	n=57 severe dementia patients aged ≥65 years with tube feeding vs n=110 oral feeding matched on age, sex, comorbidity, cognition, function	Prospective; adjustment for other differences by matching; follow-up period not specified	No difference in mortality
Mitchell ³⁸	Nursing home	n=1386 residents aged ≥65 years with recent progression to severe cognitive impairment; 10% new feeding tube vs 90% without feeding tube	Retrospective; multivariate analysis to adjust for other differences; follow-up period of 24 months	No difference in mortality

Abbreviations: OR, odds ratio; RR, relative risk.

Medicaid. Families tend to prefer and accept the hand feeding option when they receive effective information and education. At one hospital, a palliative care consultation team and system-wide educational efforts promoted more systematic informed decision-making with families, which resulted in decreased use of feeding tubes for persons with dementia.³⁹ A structured decision aid that was tested in a randomized trial in 24 nursing homes was effective to reduce families' decisional conflict regarding feeding options, and to increase communication with healthcare providers and use of assisted feeding options.⁴⁰ This decision aid is now available at no cost on the University of North Carolina Website at www.med.unc.edu/pcare/resources/feedingoptions.

Conclusion

The literature supports the view that PEG tube feeding in patients with dementia is not beneficial in terms of forestalling morality or improving quality of life; however, it appears that assisted oral feeding is better accepted both by patients and by their families during the patients' waning months of life. After reviewing this body of evidence, it is advisable for clinicians to provide effective counseling to the families of persons with advanced dementia, helping to support the choice of assisted oral feeding in the late stage of this disease. ♦

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