

Against the Flow: Tube Feeding and Survival in Patients with Dementia

Daniel D. Buff, MD FACP CNSP

During the past several years, articles have appeared in almost every major medical journal reviewing the use of enteral feeding tubes in patients with dementia.^{1–10} These articles have uniformly concluded that there is little evidence demented patients benefit from enteral feeds and, in fact, tube feedings may actually harm such patients. Indeed, some authors have stated that the standard of care should now be to withhold tube feedings in the setting of late stage dementia.^{2–4}

Despite these conclusions, enteral feeding of demented patients continues, and many physicians and caregivers still favor the use of feeding tubes in cognitively impaired patients. There appear to be several reasons for this discordance, but paramount among them is one simple fact that is difficult to contest: When a patient with dementia cannot or will not eat and drink, how is it possible that providing nourishment via a simple, usually well-tolerated means has not been shown to provide any meaningful benefits?¹¹ Given that patients who do not drink would be expected to die from dehydration in 7–10 days,¹² and that the median survival of tube-fed dementia patients is more than 6 months,^{2,13,14} can one rationally conclude that tube feeding does not provide a survival benefit?

These questions are difficult to answer. There has never been a randomized, controlled, prospective trial of survival related to tube feedings in patients with dementia. Because of ethical, religious, and technical reasons, a study with this design will probably never be attempted.^{1–10} Studies

available for analysis have been mostly observational retrospective cohort trials with small patient populations and minimal power. This article will analyze the available literature regarding survival of tube-fed patients with dementia, presenting a balanced view of the data. For the purposes of the review, I excluded older studies that include small, diverse patient populations. Also excluded were studies that include patients fed predominantly by nasogastric tube (NGT). This latter choice was made because the majority of enteral tubes currently placed are percutaneous endoscopic gastrostomy (PEG) tubes, and there appear to be significant differences in complications and possibly survival in patients fed via the two types of tubes.^{15–19}

Review of Study Data

Mortality is high in patients who have reached the stage in their dementing illness that they require artificial nutrition. In large cohort studies of patients receiving feeding tubes for a variety of conditions, the median survival is 7.5 months;²⁰ 30-day mortality, 20%; 1-year mortality, 50%–60%; and 3-year mortality, 80%.^{7,13,14,20} Data limited to patients with dementia show similar or worse survival statistics.^{21–25}

Although these data show that mortality is high in patients with dementia who required tube feeding, the question is whether tube feeding provides a survival benefit. To answer this question, six recent studies were located that compared survival of tube-fed dementia patients with a similar control group of dementia patients who were not tube

fed. Although these are the best studies identified on the topic, randomization was not performed; studies were generally retrospective in nature; and some patient populations did not exclusively comprise patients with dementia.

Bourdel-Marchasson and colleagues reported early and late mortality in a group of 108 frail nursing home patients (about half of whom were demented) who required artificial nutrition. Fifty-eight patients who received PEG tubes were compared with 50 other patients who were not tube fed based on the decision of staff and family. Early mortality at 2 months was 12%–14% in both groups. However, cumulative mortality at about 1 year was 45% in the PEG-treated group and 66% in the nonPEG-treated group. Although this difference did not reach statistical significance, the possible survival benefit of tube feeding in this study may have been underestimated. This is because the tube-fed and control patients differed in several ways, with the tube-fed patients appearing to have a greater risk of death. For example, tube-fed patients had a higher rate of cognitive impairment and higher frequency of pressure ulcers.²⁶

Important work on this subject has been conducted by Mitchell and colleagues who performed two large studies of nursing home patients from Washington state. They utilized the Minimum Data Set (MDS), a clinical assessment instrument that the Health Care Financing Administration requires to be completed for nursing home residents on admission and updated on a quarterly basis.

continued on page 2

Inside

Spiritual Assessment: A Chaplain's Perspective.....	5	Religion and the End of Life.....	9	Staying Soulful.....	15	2006 Is the Last Year to Gain Board Certification Through ABHPM.....	17
Does Beneficence Prevail Over Religious Beliefs?.....	7	Annual Assembly Highlights.....	10	Academic Palliative Medicine Forum.....	16		
		Treasurer's Report.....	12	Q & A on Malpractice Insurance.....	16		
		Student Paper.....	14				

Published quarterly by the American Academy of Hospice and Palliative Medicine

2006 Board of Directors

President

Ronald S. Schonwetter, MD FAAHPM

Executive Vice President

Porter Storey, MD FACP FAAHPM

President Elect

J. Cameron Muir, MD

Treasurer

Karen Cross, MD FAAHPM

Secretary

R. Sean Morrison, MD

Past President

Robert M. Arnold, MD

Directors at Large

Janet Abrahm, MD FAAHPM

Gail Austin Cooney, MD FAAHPM

Ronald J. Crossno, MD CMD FAAHPM

Neil M. Ellison, MD FAAHPM

Kathleen Faulkner, MD

Nancy Hutton, MD

Mark Leenay, MD MS

Kathleen McGrady, MD MA MS

Russell K. Portenoy, MD

Jorge I. Ramirez, MD FAAHPM

Neal Slatkin, MD

Jamie von Roenn, MD

Editor

Paul Rousseau, MD FAAHPM

PalliativeDoctor@aol.com

Editorial Board

Susan Blanchard, MSW

Karen Cross, MD FAAHPM

Dennis Pacl, MD

Jay Peitzer, MD FAAHPM

Reed Thompson, MD

Contributing Editor of Humanities

Lucille Marchand, MD BSN

AAHPM Staff

Executive Director

Anne M. Cordes

Administrator

Terrie A. McKissack

Managing Editor

Deborah Pinkston

Sales

Randi Romanek

Graphic Designer

Sonya Jones

Send address changes, administrative correspondence, or letters to the editor to AAHPM, 4700 W. Lake Avenue, Glenview, IL 60025-1485, 847/375-4712, fax 877/734-8671, e-mail info@aaahpm.org. AAHPM Bulletin is published by the American Academy of Hospice and Palliative Medicine, 4700 W. Lake Avenue, Glenview, IL 60025-1485, 847/375-4712, fax 877/734-8671, e-mail info@aaahpm.org. Web site www.aaahpm.org. ©2006 by the American Academy of Hospice and Palliative Medicine. Advertising is accepted. Contact Randi Romanek at 847/375-4848.

Against the Flow: Tube Feeding and Survival

continued from page 2

Their first study focused on 1,386 patients with recent progression to severe cognitive impairment, most of the decline presumably due to dementia. About 10% of these patients received feeding tubes, while 90% did not. With a median follow-up of 1.5 years and after controlling for independent risk factors for tube placement, survival in the two groups did not differ.²⁷

Mitchell and colleagues then expanded their study of the MDS to include 5,266 nursing home patients with chewing and swallowing problems. About half of these patients also had dementia. Again, 10% of patients received feeding tubes and the patients who did not formed the control group. This study found that 1-year mortality was higher in patients who received a feeding tube than in patients who did not receive a tube, although survival in both groups was significantly better than in most other studies. In this patient population, approximately 80% of those with a feeding tube were alive at 1 year, whereas more than 90% of those without a feeding tube survived to the end of the study.²⁸

The results of the two studies by Mitchell and colleagues are important, but their significance and relevance are limited by study design.^{27,28} Administrative database studies may be inherently flawed because the data are collected at fixed times during the year and important data between these times are not collected. These data are supplied by a variety of sources that may exhibit provider bias.²⁹ In addition, because individual patients were not evaluated personally by Mitchell and colleagues, the patients who received feeding tubes may have been sicker than those who did not. If this was indeed the case, it would not be surprising if tube-fed patients demonstrated similar or higher mortality.

An analysis of the clinical data presented in the two Mitchell studies does indicate that tube-fed patients were sicker on study entry. When compared to the control patients, those given enteral tube feeds had a higher degree of cognitive dysfunction, a lower functional status, and a poorer nutritional status. Another important point is that although their second study focused on patients with swallowing problems, the severity of swallowing disorders was not specified. It is probable that, based on the excellent 1-year survival data in the control group, patients who received feeding

tubes in the second Mitchell study had a higher degree of feeding dependence than the control patients.^{27,28,30}

To address some of these limitations, Rudberg and colleagues conducted a study of an updated version of the MDS, again focusing on nursing home patients with swallowing disorders and cognitive impairment. Their study of 1,545 patients included only patients who became totally dependent on staff for feeding because of a swallowing disorder that developed during their nursing home stay. Almost all patients had some degree of cognitive impairment, and two-thirds were severely impaired. A total of 353 patients (23%) received enteral feeding tubes, and the 1,192 patients who did not receive a tube formed the control group.

Unlike the studies reviewed so far, the treatment and control groups were closely matched in most clinical and demographic areas, including nutritional, cognitive, and functional status. In this study, 1-year mortality was 50% in the tube-fed patients and 61% in the control group, a statistically significant reduction in the risk of death (risk ratio 0.71; 95% confidence interval). Even when the analysis was restricted to those patients with both swallowing disorders and severe cognitive impairment, mortality was significantly reduced by provision of an enteral feeding tube.³⁰ Since the study by Rudberg and colleagues, two additional reports have been published, both of which did not find a survival advantage for tube feedings. These two studies add little to the discussion because study populations were small, control patients appear to have been sicker than tube-fed patients, and complete information about why tube feeding was withheld from controls is not available.^{23,25}

Therefore, a total of six studies (results in Table 1) have been located that used a control group to compare the effects of tube feeding on survival in patients with dementia. Four of these studies showed no change in mortality; one showed increased mortality; and one showed decreased mortality.

Discussion

Although the conclusions of the studies reviewed vary as to the survival effect of enteral feeding tubes in patients with dementia, it would be difficult to objectively conclude that tube feeding increases mortality in dementia patients. In fact,

Table 1. Studies Examining the Effect on Survival of Tube Feeding in Patients with Dementia

Study	Year	Participants n	Dementia %	Design	Mortality	Limitations
Bourdel-Marchasson ²⁶	1997	108	50	Retrospective	45% PEG 66% control*	Small study groups Control group sicker
Mitchell ²⁷	1997	1386	100	Retrospective	No change with tube feedings	Database study Control group sicker
Mitchell ²⁸	1998	5266	50	Retrospective	Higher in tube-fed patients	Database study Control group sicker Unknown degree of swallowing disorders
Rudberg ³⁰	2000	1545	95	Retrospective	50% tube fed patients 61% control**	Database study
Meier ²³	2001	99	100	Prospective	No change with tube feeding	How decision made for tube feeds unknown Control group sicker Small study groups
Murphy ²⁵	2003	41	100	Retrospective	No change with tube feeding	No clinical data on study patients Small study groups Short survival compared to other studies

* Difference not statistically significant.
** Difference statistically significant.

after a careful review of the data, the studies may actually show a decrease in mortality. This is because in most cases, the studies cited included a control group that was not adequately matched to the tube-fed group for many important prognostic factors. Usually the control patients were healthier from a neurologic, nutritional, and functional standpoint. If one chooses to look positively at the data, it would appear that the tube-fed patients should have had a higher mortality than controls, yet mortality in most studies was the same. This may indicate a survival advantage for tube feeding. Such a conclusion is bolstered by that fact that in the only study in which tube-fed dementia patients and controls were similar for important prognostic data, a statistically significant survival advantage for PEG tube feeding was demonstrated.³⁰

Despite the lack of high-quality data in either direction and the significant degree of uncertainty about the benefit for tube feeding of dementia patients, review articles on the subject routinely discourage the use of feeding tubes in patients with end-stage dementia.¹⁻¹⁰ Most major articles that review tube feeding and cognitive impairment were published before the Rudberg study,^{1-4,14} mention the study only briefly,⁶ or do not reference the study at all.^{5,7,8-10}

Conclusion

Before tube feeding of a patient with dementia is initiated, all other conservative means of providing nutritional support should be exhausted. However, in many patients with severe cognitive impairment, even the best efforts at oral feeding fail. As daunting as the numbers appear to some of the authors who reported them, about half of the cognitively impaired patients who require feeding tubes will be alive 1 year after artificial nutrition is begun, and, as this review demonstrates, the feeding tubes may have improved the odds of survival.

The relatively positive conclusions of this article are in contrast to the vast majority of previously published reviews on the topic. The major reason for this position is an attitudinal one. I believe that if available data on the withholding of a basic necessity of life such as food and water is inconclusive, physicians should err on the side of providing tube feedings to dementia patients in need. In other words, the glass (or tube-feeding bag) is half full, rather than half empty, at least until the day that conclusive data one way or the other become available. Physicians should be certain that tube feeding does not benefit patients with late-stage dementia before this practice is routinely discouraged.

References

1. Sheiman SL. Tube feeding the demented nursing home resident. *J Am Geriatr Soc.* 1996;44:1268-1270.
2. Rabeneck L, McCullough LB, Wray NP. Ethically justified, clinically comprehensive guidelines for percutaneous gastrostomy tube placement. *Lancet.* 1997;349:496-498.
3. Finucane TE, Christmas C, Travis K. Tube feeding in patients with advanced dementia: a review of the evidence. *JAMA.* 1999;282:1365-1370.
4. Gillick MR. Rethinking the role of tube feeding in patients with advanced dementia. *N Engl J Med.* 2000;342:206-210.
5. Kim YI. To feed or not to feed: tube feeding in patients with advanced dementia. *Nutr Rev.* 2001;59:86-88.
6. McNamara EP, Kennedy NP. Tube feeding patients with advanced dementia: an ethical dilemma. *Proc Nutr Soc.* 2001;60:179-185.
7. Dharmarajan TS, Unnikrishnan D, Pitchumoni CS. Percutaneous endoscopic gastrostomy and outcome in dementia. *Am J Gastroenterol.* 2001;96:2556-2563.
8. Li I. Feeding tubes in patients with severe dementia. *Am Fam Physician.* 2002;65:1605-1610.
9. Haddad RY, Thomas DR. Enteral nutrition and enteral tube feeding. Review of the evidence. *Clin Geriatr Med.* 2002;18:867-881.
10. Slomka J. Withholding nutrition at the end of life: clinical and ethical issues. *Cleve Clin J Med.* 2003;70:548-552.
11. Brett AS. Dementia, gastrostomy tubes, and mortality. *Arch Intern Med.* 2001;161:2385-2386.
12. Quill TE, Lo B, Brock DW. Palliative options of last resort: a comparison of voluntarily stopping eating and drinking, terminal sedation, physician-assisted suicide, and voluntary active euthanasia. *JAMA.* 1997;278:2099-2104.
13. Grant MD, Rudberg MA, Brody JA. Gastrostomy placement and mortality among hospitalized Medicare beneficiaries. *JAMA.* 1998;279:1973-1976.

continued on page 4

Against the Flow: Tube Feeding and Survival

continued from page 3

14. Mitchell SL, Tetroe JM. Survival after percutaneous endoscopic gastrostomy placement in older persons. *J Gerontol A Biol Sci Med Sci.* 2000;55:M735-M739.
15. Croghan JE, Burke EM, Caplan S, Denman S. Pilot study of 12-month outcomes of nursing home patients with aspiration on videofluorocopy. *Dysphagia.* 1994;9:141-146.
16. DeLegge MH. Aspiration pneumonia: incidence, mortality, and at-risk populations. *J Parenter Enteral Nutr.* 2002;26:S19-S24.
17. Fay DE, Poplausky M, Gruber M, Lance P. Long-term enteral feeding: a retrospective comparison of delivery via percutaneous endoscopic gastrostomy and nasogastric tubes. *Am J Gastroenterol.* 1991;86:1604-1609.
18. Mullan H, Roubenoff RA, Roubenoff R. Risk of pulmonary aspiration among patients receiving enteral nutrition support. *J Parenter Enteral Nutr.* 1992;16:160-164.
19. Park RH, Allison MC, Lang J, et al. Randomised comparison of percutaneous endoscopic gastrostomy and nasogastric tube feeding in patients with persisting neurological dysphagia. *BMJ.* 1992;304:1406-1409.
20. Rabeneck K, Wray NP, Petersen NJ. Long-term outcomes of patients receiving percutaneous endoscopic gastrostomy tubes. *J Gen Intern Med.* 1996;11:287-293.
21. Kaw M, Sekas G. Long-term follow-up of consequences of percutaneous endoscopic gastrostomy (PEG) tubes in nursing home patients. *Dig Dis Sci.* 1994;39:738-743.
22. Sanders DS, Carter MJ, D'Silva J, James G, Bolton RP, Bardhan KD. Survival analysis in percutaneous endoscopic gastrostomy feeding: a worse outcome in patients with dementia. *Am J Gastroenterol.* 2000;95:1472-1475.
23. Meier DE, Ahronheim JC, Morris J, Baskin-Lyons S, Morrison RS. High short-term mortality in hospitalized patients with advanced dementia: lack of benefit of tube feeding. *Arch Intern Med.* 2001;161:594-599.
24. Schneider SM, Raina C, Pugliese P, Pouget I, Rampal P, Hebuterne X. Outcome of patients treated with home enteral nutrition. *J Parenter Enteral Nutr.* 2001;25:203-209.
25. Murphy LM, Lipman TO. Percutaneous endoscopic gastrostomy does not prolong survival in patients with dementia. *Arch Intern Med.* 2003;163:1351-1353.
26. Bourdel-Marchasson I, Dumas F, Pinganaud G, Emeriau JP, Decamps A. Audit of percutaneous endoscopic gastrostomy in long-term enteral feeding in a nursing home. *Int J Qual Health Care.* 1997;9:297-302.
27. Mitchell SL, Kiely DK, Lipsitz LA. The risk factors and impact on survival of feeding tube placement in nursing home residents with severe cognitive impairment. *Arch Intern Med.* 1997;157:327-332.
28. Mitchell SL, Kiely DK, Lipsitz LA. Does artificial enteral nutrition prolong the survival of institutionalized elders with chewing and swallowing problems? *J Gerontol A Biol Sci Med Sci.* 1998;53:M207-M213.
29. Berlowitz DR, Brandeis GH, Brand HK, Halpern J, Ash AS, Moskowitz MA. Evaluating pressure ulcer occurrence in long-term care: pitfalls in interpreting administrative data. *J Clin Epidemiol.* 1996;49:289-292.
30. Rudberg MA, Egleston BL, Grant MD, Brody JA. Effectiveness of feeding tubes in nursing home residents with swallowing disorders. *J Parenter Enteral Nutr.* 2000;24:97-102.

Daniel D. Buff is chief, division of geriatrics, associate chief, division of clinical nutrition, department of medicine, St. John's Episcopal Hospital, Far Rockaway, NY, and clinical associate professor of medicine, State University of New York-Downstate Medical Center, Brooklyn, NY. He can be contacted via e-mail at dbuff@ehs.org.

Palliative Medicine Faculty Physician

The Section of Palliative Medicine of the Department of Anesthesiology at Dartmouth-Hitchcock Medical Center is seeking a dedicated, career-oriented academic palliative medicine physician to join our growing team. The position is currently 0.8FTE with the potential of expanding to full time.

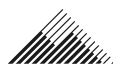
The Palliative Care Service is comprised of 3 board certified palliative specialist physicians and 3 advanced practice nurses working in an interdisciplinary fashion with social workers, pastoral care providers, and healing arts therapists. The Palliative Care Service provides consultative inpatient and outpatient care to patients with serious illness and operates in an environment that supports the value and philosophy of palliative care.

Dartmouth-Hitchcock Medical Center is committed to building on its history of innovation in palliative and end-of-life care. The Section of Palliative Medicine is actively involved in clinical education and training of doctors, nurses and allied health professionals at all levels. Opportunities for scientific inquiry and quality improvement abound. The successful candidate would become a member of the Dartmouth-Hitchcock Clinic – a collegial physician-managed group practice which values clinical care, administrative ability, education, and research – have a faculty appointment at Dartmouth Medical School and have clinical privileges at Dartmouth-Hitchcock Medical Center. Academic title and compensation will be consistent with experience and Medical Center policies. ABHPM Board Certification/eligibility in palliative medicine is required.

Dartmouth-Hitchcock Medical Center is a state-of-the-art facility located in the Upper Connecticut River Valley of New Hampshire, a spectacular setting in which to live and work. Outdoor activities abound in and around this idyllic New England college town environment. Superb schools and lifestyle are combined with a stimulating academic group practice.

Please send curriculum vitae and three letters of reference to:

Ira Byock, MD
Director of Palliative Medicine
Dartmouth-Hitchcock Medical Center
One Medical Center Drive
Lebanon, NH 03756



DARTMOUTH-HITCHCOCK
MEDICAL CENTER

Dartmouth Medical School and Dartmouth-Hitchcock Medical Center are affirmative action/equal opportunity employers and is especially interested in identifying female and minority candidates.

www.dhmc.org