Long Term Feeding Tubes: Ethical Issues in Physicians' Decision Making[*]
North Carolina Medical Society

When a decisionally incapable patient who suffers from a chronic, progressive illness develops swallowing difficulty, physicians, families, nurses and other care providers have, with increasing frequency, elected non-oral nutritional support. However, recently accumulated outcome data make dubious a reflexive decision in favor of tube feeding in this setting.

- Feeding tube placement is associated with an in-hospital mortality of 15-25%, and a one-year mortality of 60%.
- Co-factors associated with increased risk of mortality include: advanced age, CNS pathology (CVA, advanced dementia), cancer (except early stage Head/Neck cancer), disorientation, and low albumin.
- Aspiration occurs in up to 50% of patients being tube fed.
- For patients with advanced dementia, feeding tubes have not proven effective in prolonging life, in preventing aspiration or even in providing adequate nourishment.[1]

David Weissman, MD, has outlined the ***tube feeding death spiral***: [2]

1. Hospital admission for complications secondary to brain failure or other predictable end organ failure due to primary illnesses (e.g. Urosepsis in the setting of advanced dementia)
2. Inability to swallow documented and/or direct evidence of aspiration and/or weight loss associated with low or no p-o intake
3. Swallowing evaluation followed by a recommendation for non-oral feeding.
4. Feeding tube placed followed by increasing patient agitation, resulting in feeding tube dislodgement.
5. Re-insertion of feeding tube; restraints placed.
6. Aspiration pneumonia
7. Intravenous antibiotics and pulse oximetry.

---

[*] This document was written with adult patients in mind; issues facing pediatric patients were not discussed by the authors and are not addressed herein.

[1] Ciocon J, Silverstone F, Graver LM, Foley C. Tube feedings in elderly patients. Arch Intern Med. 1988; 148:429-433. Quill T. Utilization of nasogastric feeding tubes in a group of chronically ill, elderly patients in a community hospital. Arch Intern Med. 1989;149:1937-1941; Finucane TE, Christmas C, Travis K. Tube feeding in patients with advanced dementia. A review of the evidence. JAMA 1999;282:365-370;Gillick MR. Rethinking the role of tube feeding in patients with advanced dementia. NEJM 2000;342: 206-210; Mitchell SL, Kiely DK, Lipsitz LA. The risk factors and impact on survival of feeding tubes in nursing home residents with severely advanced dementia. Arch Intern Med 1997;157:327-332;Kaw M. Sekas Gl Long-term follow-up of consequences of percutaneous endoscopic gastrostomy (PEG) tubes in nursing hom patients. Dig Dis Sci 1994;39:738-743.

[2] Fast Facts and Concepts #85 . Swallow studies, tube feeding and the death spiral. Weissman, DE; February 2003. End-of-Life Physician Education Resource Center www.eperc.mcw.edu.

8. Repeat steps 4-6 two or more times.
9. Family conference.
10. Death

- The specter of aggressive, over-treatment was a major factor motivating the patients' rights movement.
- Legal and ethical standards have been developed to support an informed decision to withhold or withdraw any medical intervention, including tube-feeding.[3]
- North Carolina does not prejudice with unique restrictions the medical decision whether or not to place a feeding tube.
- There is no ethical or legal warrant for the physician to evaluate differently a decision to withdraw tube-feeding from a decision to withhold tube-feeding.[4]
- Advance care directives, such as living wills, health care powers of attorney, etc., enable decisionally-capable patients to anticipate and plan for the contingency of losing their ability to communicate health care decisions, including a decision whether to withhold or withdraw tube-feeding.
- Persons authorized to give informed consent to feeding-tube placement on a patient's behalf may also make an ***informed refusal*** of tube placement.
- In the absence of advance care directives, a surrogate's decisions regarding feeding tube placement or removal should be based, whenever possible, on what the patient would choose in the circumstances. Otherwise, the surrogate's decisions should be guided by considering the patient's best interests.

The physician should not bias a discussion of the pros and cons of tube feeding with an implicit assumption that nursing home residents would prefer tube-feeding in the event they cannot swallow. On the contrary:

- A study of 421 randomly selected, competent persons living in 49 nursing homes found that only one third would favor feeding tube placement if they were unable to eat because of permanent brain damage. 61% opposed tube-feeding. Of those who initially favored tube placement, 25% changed their preference when they learned that physical restraints might be necessary to facilitate feeding tube use.[5]
- The desire for tube feeding decreases as the hypothetical degree of cognitive impairment increases.[6]

Tube feeding does not necessarily provide medical benefit to dying patient by enhancing quality of life nor by reducing suffering.

---

[3] NCGS 90-320ff

[4] CEJA 2.20, Withholding or Withdrawing Life-Sustaining Treatment. Available at: http://www.ama-assn.org/apps/pf_online/pf_online?f_n=browse&doc=policyfiles/CEJA/E-2.20.HTM&&s_t=&st_p=&nth=1&prev_pol=policyfiles/CEJA/E-1.02.HTM&nxt_pol=policyfiles/CEJA/E-2.01.HTM&

[5] O'Brien LA, Grisso JA, Maislin G et al. Nursing home residents' preferences for life-sustaining treatments. JAMA 1995;274:1775-9.

[6] Frankl D, Dye RK, Bellamy PE. Attitudes of hospitalized patients towards life-support: a survey of 200 medical inpatients. Am J Med. 1989;86:645-8. Cohen-Mansfield JC, Droge JA, Billig N. Factors influencing hospital patients' preference in the utilization of life-sustaining treatment. Gerontologist. 1992;32:89-95.

- Tube feeding is associated with increased agitation and may reduce quality of life and dignity because it increases the need for physical restraints;[7]
- Typically, dying patients do not experience hunger or thirst;
- Malnutrition, a concomitant of the natural dying process, should not be confused with "starvation";
- While dry mouth commonly occurs in dying patients, tube-feeding does not relieve it;
- Complete relief from symptoms associated with dry mouth may be achieved with ice chips, moist sponge, sips of liquid, lip moisteners, hard candy, and mouth care."[8]

Recommendations:

- Prior to feeding-tube placement in a decisionally incapable patient, it is the physician's ethical responsibility to determine whether the patient has executed an advance directive whose provisions may apply to the placement decision. Otherwise, the physician should take the lead in discussing with the patient's surrogate decision maker the pros and cons of long term tube feeding.
- The physician should be prepared to address the common tendency to confuse "malnutrition" (a concomitant of the natural dying process) and "starvation."
- The physician should relate decisions about tube feeding +/- to achievable goals of care. A summary of discussions regarding tube-feeding should be documented in the medical record.
- The goals of care should be reviewed regularly to determine whether or to what degree tube-feeding, promotes or contradicts them.
- Consultation with Hospice or with a Palliative Care Service facilitates setting realistic goals of care.
- Since tube feeding has not proven beneficial in patients with advanced dementia, but on the contrary, is associated with significant increased morbidity, mortality and indignity, physicians may, in good conscience, recommend that it be withheld or withdrawn in these circumstances.
- In the event a valid decision is made to forego tube-feeding, the physician should enter in the patient's medical record an order "Do Not Tube Feed."
- Patients who are genuinely hungry should be allowed to eat anything they please.

References

President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. *Deciding to Forego Life-Sustaining Treatment: A Report on Ethical, Medical and Legal Issues in Treatment Decisions.* Washington, DC: US Government Printing Office; 1983.

[7] Tinetti ME, Liu WL, Morottoli RA et al. Mechanical restraint among residents of skilled nursing facilities. JAMA 1991;265:463-467.
[8] McCann RM, Hall WJ, Groth-Junker A. Comfort care of terminally ill patients: The appropriate use of nutrition and hydration. JAMA. 1994;272:1263-1266.

American College of Physicians Ethics Manual, Third Edition. Ann Intern Med. 1992l117:947-960.

American Medical Association Council on Ethical and Judicial Affairs. Decisions near the end of life. JAMA. 1992;267:2229-2233.

Finucane TE, Christmas C, Travis K. *Tube feeding in patients with advanced dementia.* JAMA. 1999; 282:1365-1369.

Finucane TE, Bynum JP. *Use of tube feeding to prevent aspiration pneumonia.* Lancet. 1996; 348:1421-24.

Cowen ME Et al. *Survival estimates for patients with abnormal swallowing studies.* JGIM 1997; 12:88-94.

Rabeneck L, et al. *Long term outcomes of patients receiving percutaneous endoscopic gastrostomy tubes.* JGIM 1996; 11:287-293.

Grant MD, et al. *Gastrostomy placement and mortality among hospitalized Medicare beneficiaries.* JAMA 1998;279:1973-1976.

Ahronheim JC. *Nutrition and hydration in the terminal patient.* Clinic in Geriatrics. 1996;12(2):379-391.