Guiding the Decisions of Physicians and Families in End-of-Life Care:
The Case of Long-Term Feeding Tube Placement

Ethical and Judicial Affairs Committee, North Carolina Medical Society

The issue of long-term feeding tube placement for patients near the end of life who are unable to make decisions with regard to their own care is a complex issue for physicians and families. There is controversy about how appropriate the placement of percutaneous endoscopy gastrostomy (PEG) tubes might be in specific cases, and physicians have felt a need for clearer guidelines for their use. Consequently, the North Carolina Academy of Family Physicians asked that the 2001 House of Delegates of the North Carolina Medical Society (NCMS) undertake efforts to educate policymakers about the inappropriate use of long-term feeding tubes and to seek and support legislative and/or administrative actions supporting the adoption of the following language into law:

"Before placement of any long-term feeding tube, in a mentally incompetent patient, the hospital or nursing home ethics committee (whichever is appropriate) would have to review the case and render a non-binding written opinion. This opinion would have to be presented to the responsible parties. The rationale for this non-binding opinion would have to be explained to the responsible parties in easily understood layman's terms."

Resolution 1-2001 was referred for study to the Ethical and Judicial Affairs Committee of the NCMS, whose members undertook to develop an educational statement for physicians about the efficacy of long-term feeding tubes and then to convene a larger task force that would include representatives from external interest groups to develop a consensus on the statement.

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

A subcommittee was appointed and charged with developing a set of guidelines for physicians. The committee members were: Janelle Rhyne, MD, Chair; Darlyne Menscer, MD; Glenn Pickard, MD; Douglas Nelson, MD; Richard Stephenson, MD; and Lance Stell, PhD. The subcommittee met a number of times and produced a draft statement in the summer of 2003.

Given the sensitivity of the subject matter and the central role of patients and their families or loved ones in deciding whether a long-term feeding tube should be placed, the subcommittee also decided to promote the importance of patient and family education.

A task force, which included the subcommittee as well as representatives from nursing homes, hospitals, hospice, home health, elder law, speech pathology, the Medical Directors Association, was convened in September 2003. Members of the task force agreed that educational information was definitely needed on this issue for providers and patients alike. After significant discussion, the task force approved the following draft with some modifications. The task force also agreed that educational pieces for patients and their families should be promoted. The statement was subsequently approved by the House of Delegates of the North Carolina Medical Society in November 2003 and is presented here with the hope that it will be of value to physicians and families struggling with these issues in the care of patients and family members in these complex situations. **NCMJ**

Long-Term Feeding Tubes: Ethical Issues in Physicians' Decision Making

Statement Adopted by the North Carolina Medical Society House of Delegates, November 2001

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 (by mouth) intake
3. Swallowing evaluation followed by a recommendation for nonoral 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.
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 of 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, healthcare powers of attorney, etc., enable decisionally capable patients to anticipate and plan for the contingency of losing their ability to communicate healthcare 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.

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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. Sixty-one percent 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 the dying patient by enhancing quality of life nor by reducing suffering.

- 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.

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

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ADDITIONAL HELPFUL INFORMATION

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