Key Clinical Considerations on Tube Feeding for Guiding Policy and Decision Makers in Catholic Health Care*

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Executive Summary

In response to the Papal Allocution on March 25, 2004 and the further clarification by the Congregation for the Doctrine of the Faith's *Responsum* about the care and feeding of patients in a persistent vegetative state, the United States Conference of Catholic Bishops (USCCB) is currently preparing to promulgate a new revision or update for the *Ethical and Religious Directives for Catholic Health Care Services* (Directives), Part Five, as it relates to feeding patients. Although we do not know what the revisions will be precisely, the Supportive Care Coalition would like to offer the following clinical considerations regarding medically-assisted feeding devices ("feeding tubes") for guiding policy and decision makers who will be charged with the practical application of the newly revised Directives.

Formed in 1994, the Supportive Care Coalition: Pursuing Excellence in Palliative Care, has grown to 19 member organizations with Catholic health care facilities in 48 states. The coalition focuses its activities on advancing palliative care leading practices that address the continuum of living with life-limiting illness from time of diagnosis to end of life. Building on our Catholic tradition of respect for life, human dignity and care for the poor and most vulnerable among us, we know that by working together and by sharing and creating proven practices we can enhance palliative and end-of-life care. We are committed to:

- bringing about cultural change in the care of those with chronic and life-threatening illness;
- excellence in pain and symptom management;
- a comprehensive, multi-disciplinary approach to understanding how to bring relief of suffering to body, mind and spirit;
- helping patients live more fully in community.

Coalition members work collaboratively to improve palliative and end-of-life care through education, program development, networking, demonstration projects and advocacy. Clinical agreement exists that people should be given tube feeding when medically necessary for maintaining nutritional status and hydration, including for persons in the acute phase of stroke or head injury. There is similar clinical agreement that for terminal patients who are dying, feeding tubes may be contraindicated due to risks and complications, such as persons with renal failure who are not on dialysis for whom feeding would cause fluid overload, and respiratory distress.

The Supportive Care Coalition adheres to the Catholic Moral Tradition, which proscribes inappropriate termination of treatment that is a proportionate means (i.e., euthanasia) and acknowledges that under certain circumstances persons can licitly forgo treatments that are a disproportionate means (i.e., excessively burdensome with no reasonable hope of benefit.)

1. What are feeding tubes?

- There are a variety of types of feeding tubes that provide nutritional support and hydration for persons, for example, who cannot swallow.
- These tubes can be placed on a temporary or permanent basis.
- All types of feeding tubes are sometimes referred to as

* This document was prepared by a task force of the Supportive Care Coalition. It was initially shared with members of the coalition. Because of its value, we have asked permission of the Executive Director of the Coalition, Sr. Karin Dufault, if we could share the document with a broader audience.

"artificial nutrition and hydration" (ANH.)

- Nasogastric tube (i.e., through the nose, down the back of the throat and esophagus)
- Parenterally through peripheral or central intravenous lines (IV)
- PEG tubes: (percutaneous endoscopic gastrostomy tubes)
- Jejunostomy or J-tubes (i.e., below the stomach)
- Hydration alone can be provided by subcutaneous infusion

2. What are commonly perceived benefits of tube feeding?

- Common perceptions of benefits may, in fact, be inaccurate.
- Prevent aspiration pneumonia.
- Promote healing.
  - Improve nutritional status, which in turn is associated with reducing or preventing pressure ulcers and infections, improving functional status, and prolonging life
  - Prevent bedsores and other consequences of malnutrition.
  - Reduce incidence of post-surgical complications, infections, and length of stay
- Improve quality of life.
- Prolong survival.
- Prevent suffering.
- (These perceptions and misperceptions are addressed below.)

3. What is the psycho-social context of feeding tubes?

- Because ANH is commonly viewed as a simple way to feed patients, medical professionals and the wider public in the U.S. tend to overestimate the benefits for terminally ill patients.[1]
- Fear of pain and suffering from starvation either by patient, family, or staff lead to ANH use.
- Often times the patient is unable to make the decision.
- The reflex by families and clinicians to provide nutrition for patients who cannot swallow is overwhelming. It is now common for such patients to undergo a swallowing evaluation and if the patient fails the test, then to move forward with tube feeding placement.[2]
- The original purpose for which ANH was developed was for temporary use but with greater frequency the purpose is permanent placement.
- The moral fallacy of the "technological imperative"—if we have it we must use it.
- Difficult to discuss, especially since the Terri Schiavo case.
- Feeding is a symbol of caring—not feeding feels like abandonment of the vulnerable.

4. When (or for whom) may feeding tubes be indicated (not exhaustive)?

- Support for patients who cannot swallow during the acute phase of neurological events like stroke or head injury3 and patients receiving short term critical care.[4]
- ANH may improve the nutritional status of patients with advanced cancer who are undergoing intensive radiation therapy (e.g., obstructions due to head and neck cancer)[5] or have proximal obstruction of the bowel (e.g., obstruction in upper intestinal tract or bowel obstruction).[6]
- Use of parenteral ANH can prolong the lives of patients with short bowel syndrome,[7] and prolong the survival and quality of life of patients with bulbar amyotrophic lateral sclerosis (i.e., Lou Gehrig's Disease).[8]
- Supplement inadequate nutritional or fluid intake arising from severe illness or failure to thrive.

5. When (or for whom) are ANH contraindicated because of the risks and complications (not exhaustive)?

Sometimes ANH is used as a means of ease and convenience because of the length of time it would require to spoon feed a patient. ANH can preserve life in some situations, but in other situations, after placement, there is substantial mortality related to underlying illness.[9]

Examples of possible contraindications are:

- The inability to maintain nutrition though the oral route, in the setting of a chronic life-limiting illness and declining function, which is usually a marker of the dying process.
- Most dying patients do not experience hunger or thirst.[10] Dry mouth is a common problem with those who are dying; however, there is no relation to hydration status and the symptoms of dry mouth.
- Numerous observational studies have demonstrated a high incidence of aspiration pneumonia in those who have been fed by nasogastric tube.[11] This is sometimes accompanied with vomiting.

- The bulk of the available evidence suggests that ANH does not improve the survival rates of patients with dementia.[12] Some studies suggest that ANH does not improve survival rates and in comparison to spoon feeding might shorten survival rates. In short, spoon feeding might be preferred to ANH in these circumstances.
- Patients with advanced dementia who receive ANH through a gastrostomy tube are likely to be physically restrained and at increased risk of aspiration pneumonia, diarrhea, gastrointestinal discomfort and problems associated with patient removing the feeding tube. [13]
- When a patient's renal function declines in the last days of life, ANH may cause choking due to increased oral and pulmonary secretions, dyspnea (i.e., difficulty breathing) due to pulmonary edema,[14] and abdominal discomfort due to ascites (i.e., accumulation of fluid between tissue and organs in the abdomen).[15]
- For patients who are in the last stages of dying from cancer, treating them for nutritional needs can grow their tumors and might escalate the patients'pain and suffering.[16]
- Increased risk of infection such as urinary tract, viral, gastrointestinal, and eye.[17]
- Increased risk of pressure sores.[18]
- ANH will also likely cause patients to produce more urine and stool and possible diarrhea.[19]
- Long-term placement of PEG tubes can also result in swelling of the brain.[20]

6. Clinicians and decision-makers, especially palliative and end-of-life care specialists, need to be informed and to educate themselves about Catholic moral teaching and the Directives in this matter.
All need to incorporate relevant clinical considerations into their ethical decisions and vice versa. The Catholic Moral Tradition acknowledges that in some situations, forgoing of treatment would be morally permissible and in other situations it would be morally impermissible (i.e., euthanasia). While every person is obligated to use ordinary means to preserve his or her life, no person should be obligated to submit to a health care procedure that the person has judged, with a free and informed conscience, not to provide a reasonable hope of benefit without imposing excessive risks and burdens on the patient. The provision of food and water are, in principle, proportionate means even when delivered through a feeding tube. This means that while obligatory overall, under certain circumstances the provision of a feeding tube can nevertheless be disproportionately burdensome, especially for the dying, when it does not provide a reasonable hope of benefit or causes harm. For example, if someone is dying, feeding that person will not increase a reasonable hope of recovery or cure, and it may cause disproportionate harms including aspiration and choking, surgical complication, confusion and discomfort from being restrained to stop the patient from extubating him/herself. Or, especially invasive surgery for tube placement and its associated risks, possible restraints and tubes down the throat might constitute a grave burden in the judgment of some patients under certain conditions.

Tube feeding persons who are dying should be thought about along a continuum from simplest cases where there is broad moral agreement to the other end of the continuum with difficult cases where there is reasonable disagreement. The simplest cases are terminal patients who are known to be dying and for whom feeding would cause observable physical burdens or harms, such as a person with renal failure where feeding by any manner can promote fluid overload and respiratory distress. This case suggests that the general obligation to feed is not required in every case.

Clinicians, caregivers and others need to exercise caution when speaking of the obligation to feed persons who have a serious life-threatening illness, especially terminal patients who are dying. A poor explanation of the church's teaching or a misapplication of the *Ethical and Religious Directives* can lead to unfortunate consequences.

Poor explanations or misapplications can:
- Provide further rationale for those who support physician assisted suicide legislation (PAS);
- Give the wrong impression that Catholic hospitals will not honor a patient's wishes about proportionate and disproportionate means;
- Conflict with the Patient Self-Determination Act (PSDA);
- Foster a public perception that Catholic hospitals are not a good place for compassionate care, leading to some patients and families "losing faith" in Catholic health care;
- Likely run counter to good medical practice as indicated in the above statistics;

- Lead to disinformation, which would likely hamper the ability of Catholic health care ministries to collaborate with other-than-Catholic entities in mergers.

The misuse of quotes from recent papal and Vatican statements, in particular, when taken out of context of the Catholic Moral Tradition, could have a serious harmful impact on the healing mission of the church. The Supportive Care Coalitions offers this clinical background on ANH and potential impact on the mission and ministry of Catholic health care for the consideration of policy and decision makers charged with the practical application of the newly revised Directives.

NOTES

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