THE ETHICS OF EATING (OR NOT EATING) AT THE END OF LIFE

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No subject provokes greater distress and uncertainty, among both families and health care professionals, than issues surrounding eating (or the inability to eat) at the end of life.

OBJECTIVES

- Describe the benefits and burdens of medically assisted nutrition and hydration (MANH) at the end of life
- Describe communication strategies to facilitate ethical decision-making regarding nutrition and hydration at the end of life

CONSIDER THESE CASES….

1. An 87 y/o female with dementia from a NH admitted 3 times in the past year with aspiration pneumonia. One of the doctors has recommended a feeding tube. The patient has a DNR but family is conflicted about this decision, not wanting her to "starve to death." They ask you what you recommend.

   What do you say?

CONSIDER THESE CASES….

2. A 52 y/o male with head/neck cancer experiencing dysphagia after surgery and radiation. He has been told he will likely have to rely on a feeding tube for the rest of his life for his nourishment.

   How would you discuss this decision with him?

CONSIDER THESE CASES….

3. A 19 y/o undocumented female with anoxic brain injury following prolonged resuscitation efforts after her family found her unresponsive and without pulse for an unknown period of time, calling EMS. After 3 weeks in the hospital without neurological improvement, she is extubated and made comfort care. However, a week later this patient is still alive and breathing on her own, still with no change neurologically. Her family is insisting on a feeding tube.

   Is it ethically appropriate to place a surgical feeding tube in this patient?

WHAT DO WE NEED FOR NUTRITION & HYDRATION?

Life Phases

(Brungardt)

BASIC PRINCIPLES

- We always provide the food & water needed.
- The "need" for food and water at the end of life changes.
- It is normal as a person enters the dying process to eat and drink less.
- Our best guide is comfort and enjoyment.
- MANH is a medical treatment, not ordinary care.

DEFINITIONS

- Anorexia
  - Loss of appetite → inability to eat → weight loss
  - Often a result of disease
  - Common in cancer and other chronic diseases (end-stage heart, lung, and liver disease)
  - Major contributing factor to cachexia syndrome
- Cachexia
  - State of malnutrition and wasting resulting from anorexia

(Weissman, 2015)

DEFINITIONS

- Primary Cachexia
  - Involuntary weight loss as a result of illness
  - Metabolic rate > caloric intake
  - Inability to conserve protein
  - AIDS, cancer, sepsis, major trauma
- Secondary Cachexia
  - Dysphagia (head & neck cancer)
  - Oral and esophageal candidiasis
  - Poor oral hygiene
  - Gastric or bowel obstruction

(Weissman, 2015)

DEFINITIONS

- MANH refers to any method whereby food or water is provided other than chewing/swallowing.
  - Non-oral feeding
    - Nasogastric tube (NG)
    - Gastrostomy (G tube or PEG)
    - Gastrojejunostomy (G-J tube)
    - Total Parenteral Nutrition (TPN)
  - Artificial hydration
    - Provision of water or electrolyte solution by any non-oral route (IV, subcutaneous, NG/G/GJ tube)

(Weissman, 2015)

2 SCENARIOS

- Anorexia with early weight loss
- Correctable conditions addressed
- Oral supplements used with short-term weight stabilization
- Dietary counseling

- Continued weight loss
- Increasing family concern – usually greater than patient concern
- Discussion about the use of MANH (g-tube or TPN)

TREATMENT - DRUGS

- Drugs
  - Progestin (Megace)
  - Cannabinoids (dronabinol)
  - Steroids (dexamethasone)
- Impact
  - Modest weight gain at best
  - Minimal or none on survival duration
  - Side effects
  - Generally not helpful in cases of massive weight loss

(Weissman, 2015)

IS IT STARVATION?

	Starvation	Cachexia
Appetite	Suppressed in late phase	Suppressed in early phase
Body mass index	Not predictive of mortality	Predictive of mortality
Serum albumin	Low in late phase	Low in early phase
Total lymphocyte count	Low, responds to refeeding	Low, unresponsive to refeeding
Inflammatory disease	Usually not present	Present
Response to refeeding	Reversible	Resistant

(Giokas, 2013)

"It is easy to lose sight of the fact that not eating may be one of the many facets of the dying process and not the cause"

Robert McCann, JAMA Oct 13, 1999

COMMON CONCERNS

- Oral intake is a symbol
  - Eating = living (the most basic of human needs)
  - Family role as protector and provider
    - "I love you, therefore I must feed you"
- Confusion that withholding MANH = euthanasia, assisted suicide or murder
  - Fear of legal, ethical, or religious misconduct

QUESTIONS FOR HEALTH PROFESSIONALS

- What are the benefits and burdens of MANH?
- What are the ethical issues surrounding MANH?
- How do we discuss this with our patients and families?

3 PRINCIPLES TO WEIGH BENEFIT VS BURDEN

- Are we adding **time** to your life?
- Are we improving (or maintaining) your ability to **function** in your day to day life?
- Are we improving (or maintaining) your **quality** of life?

BENEFITS AND BURDENS OF MANH

Benefits

- May prolong life in selected patients
  - Younger
  - Trauma
  - ALS
  - Head & Neck cancer
- May improve delirium

Burdens

- Maintaining access
- Increased secretions, ascites, effusions, edema, urine output, diarrhea
- Risk of aspiration pneumonia is ≥ than without

BENEFITS AND BURDENS OF MANH

Benefits

- Maintains appearance of life giving sustenance
- Maintains hope for clinical improvement
- Avoidance of guilt by family members

Burdens

- Wound infection
- Increased need for restraints
- Tube-related discomfort
- Loss of pleasure with oral intake
- Less human interaction

BENEFITS AND BURDENS OF PEG PLACEMENT

	Dysphagic Stroke [illegible]	Dysphagic Stroke [illegible]	Amyotrophic Lateral Sclerosis (ALS) (Lou Gehrig's Disease)	Persistent Vegetative State (PVS)	General Frailty [illegible]	Advanced Dementia [illegible]	Advanced Cancer [illegible]	Advanced Organ Failure [illegible]
Prolongs Life	Likely	Likely in the short term / Not Likely in the long term	Likely	Likely	Not Likely	Not Likely*	Not Likely	Not Likely
Improves Quality of Life and/or Functional Status	up to 25% regain swallowing capabilities	Not Likely	Uncertain	Not Likely	Not Likely	Not Likely	Not Likely	Not Likely
Enables Patient to Receive Curative Therapy/Reverses the Disease Process	Not Likely	Not Likely	Not Likely	Not Likely	Not Likely	Not Likely	Not Likely	Not Likely

(Giokas, 2013)

Don't insert percutaneous feeding tubes in individuals with advanced dementia. Instead, offer oral assisted feedings.

Strong evidence exists that artificial nutrition does not prolong life or improve quality of life in patients with advanced dementia. Substantial functional decline and recurrent or progressive medical illnesses may indicate that a patient who is not eating is unlikely to obtain any significant or long-term benefit from artificial nutrition. Feeding tubes are often placed after hospitalization, frequently with concerns for aspirations, and for those who are not eating. Contrary to what many people think, tube feeding does not ensure the patient's comfort or reduce suffering; it may cause fluid overload, diarrhea, abdominal pain, local complications, less human interaction and may increase the risk of aspiration. Assistance with oral feeding is an evidence-based approach to provide nutrition for patients with advanced dementia and feeding problems.

AMDA – Dedicated to Long Term Care Medicine

Choosing Wisely

amda

Five Things Physicians and Patients Should Question

http://www.choosingwisely.org/wp-content/uploads/2013/09/AMDA-5things-List_Final.pdf

ALTERNATIVES TO NON-ORAL FEEDING

- Allowing patient to eat/drink as desired, even with aspiration risk
- Careful hand feeding by family or caregiver
- No food or water with expectation that death will result in days to a few weeks
- Meticulous mouth care

ETHICAL ISSUES

- There is no professional mandate to provide MANH when burden/risk is greater than benefit.
  - Beneficence
  - Non-maleficence
- The AMA says:
  - Life-sustaining treatment is any treatment that serves to prolong life without reversing the underlying medical condition....may include mechanical ventilation, renal dialysis, chemotherapy, and artificial nutrition and hydration. (AMA Code of Ethics 2008-9 2.20)

ETHICAL ISSUES

- In principle, there is an obligation to provide patients with food and water (including MANH) for those who cannot take food orally…extends to patients in chronic and presumably irreversible conditions…who can reasonably be expected to live indefinitely.
- MANH becomes morally optional when they cannot reasonably be expected to prolong life or when "excessively burdensome for the patient."

Ethical and Religious Directives for Catholic Health Care Services

ETHICAL ISSUES

- "The truth that life is a precious gift from God has profound implications for the question of stewardship over human life…the duty to preserve life is not absolute, for we may reject life-prolonging procedures that are insufficiently beneficial or excessively burdensome."
- Two extremes are avoided….insistence on useless or burdensome technology (or) the withdrawal of technology with the intention of causing death.

Ethical and Religious Directives for Catholic Health Care Services

TWO EXTREMES

Subjectivism **Vitalism**

Subjectivism – primary obligation to oneself
Medical treatment based solely on personal choice

Vitalism – life at all cost, taking into account the biological/physiological aspect of a person

THE BALANCE

- The means to protect and preserve a particular life must take account of concrete circumstances and be objectively **proportionate** to the prospect of improvement. When medical treatment no longer is **proportionate** to the real situation of the patient, such treatment can be forgone or withdrawn because it has become a burden to the patient and amounts to nonacceptance of the actual human condition of the patient

(Coleman, 2014)

COMMUNICATION STRATEGIES

- Advance Care Planning
  - Living Will
  - TPOPP
- When patients cannot make their own decision
  - Check for advance care document
  - Present all medical facts and treatment options to surrogate
  - Solicit input from patient's voice
    - *If ______ were sitting here, what would he/she say/want?*
  - Make a recommendation: give permission to stop or not start MANH
  - Explain the option for a comfort-oriented solution

HELPFUL PHRASES

- *Tell me about your concerns regarding your loved one's eating and drinking?*
- *When people are dying, their body rejects food. They usually do not feel hungry, and eating may cause them to feel worse.*
- *Here are my concerns about using a feeding tube…*
- *These are some of the problems that we see when we force food/fluid into a person at this stage….*
- *If this were my (mother/father/sister…) I would …..*
- *Your loved one is not dying because he/she is not eating…he/she is not eating because he/she is dying.*
- *All dying patients lose their interest in eating in the days to weeks leading up to death; this is the body's signal that death is coming.*

COMING TO A DECISION

- Assess what patient/family understand about the patient's condition.
- Find the patient's voice if possible.
- Review goals of care for the patient.
- Review your knowledge of the literature and your experience in similar situations.
- Normalize the difficulty in making this decision.
- Treat is as a "we" decision – make a recommendation.
- Use time as an ally.

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