"Momma's got to eat…"

Artificial Nutrition and Alternatives in the Chronically Ill

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Disclosures and Preface

Objectives

- To discuss the benefits and burdens of artificial nutrition in various patient populations
- To discuss the importance of and how to achieve a thorough informed consent process regarding starting or continuing artificial nutrition
- To discuss alternatives to artificial nutrition

Case #1 – What would you recommend?

Mrs. H. is an 80 yo female with dementia who resides in a SNF. She has been bedbound for the past 9 months, is mostly nonverbal but seems to recognize family members. She has lost 20 pounds in 3 months and staff reports that she "refuses to eat" and often pockets food in her mouth. Mrs. H.'s daughter is very concerned, and says "Momma's got to eat – we've got to do something!"

- a) PEG placement
- b) dobhoff tube feeds short-term
- c) have staff be more assertive when feeding Mrs. H.
- d) family conference to discuss goals of care and plan

Case #2 – What would you recommend?

Mrs. C. is an 80 yo female admitted to the hospital last night with a large left MCA stroke. Prior to this hospitalization, she had been living independently and drove. She is alert, cannot move her right side and failed a bedside swallowing evaluation. Mrs. C.'s son is very concerned, and says "Momma's got to eat – we've got to do something!"

- a) PEG placement
- b) dobhoff tube feeds short-term
- c) instruct staff to feed Mrs. C. a modified diet
- d) family conference to discuss goals of care and plan

Case #3 – What would you recommend?

Mr. T is a 60 yo male has had difficulty swallowing and was diagnosed 3 weeks ago with laryngeal cancer which is locally advanced but without distant mets. He also has moderately severe COPD. He is agreeable to surgery and radiation. Mr. T.'s daughter is very concerned, and says "Daddy's got to eat – we've got to do something!"

- a) PEG placement
- b) dobhoff tube feeds short-term
- c) recommend a pureed diet
- d) family conference to discuss goals of care and plan

Case #4 – What would you recommend?

Mr. B. is 62 yo male diagnosed with ALS two years ago. He is wheelchair bound and cachectic in appearance. Eating makes him short of breath and wears him out. Mr. B.'s son is very concerned, and says "Daddy's got to eat – we've got to do something!"

- a) PEG placement
- b) dobhoff tube feeds short-term
- c) instruct the son to feed him assertively
- d) family conference to discuss goals of care and plan

History

- Feeding into the upper GI tract through a nasopharyngeal tube was first documented in the 16th century.
- Surgically placed feeding tubes began in the mid-late 1800's.
- PEG (percutaneous endoscopic gastrostomy) placement was pioneered in 1981.

History

Number of PEGs placed in the US in patients 65 and older:

1989 – 15,000

1995 – 123,000

Non-Evidenced Based Indications

1992 – 22%

2002 – 31%

Studies in 1999 and 2003 revealed that 34% of severely cognitively impaired NH residents had PEGs.

History

- All NC hospitals 1989-2000, highest rates of PEG placement were in patients over age 75.
- Over time, higher percentages being discharged to NH's
- Expanded to patients with poorer prognoses
- Historically and today, most PEGs placed during a hospitalization

Regional Variability

Rates of PEG use in severely impaired NH residents

5% - Maine

40% - Ohio

Hawaii has one of the highest rates in the nation, yet also has one of the highest rates of advanced directive completion (relationship usually inverse).

Physicians may be influenced by local practice.

Variability

- NH residents are more likely to get a PEG if:
  - Urban location
  - No dementia unit
  - > 100 beds
  - Smaller proportion have DNR orders
  - Higher presence of nonwhite residents
  - No NPs or PAs on staff
- Racial variability (1999 study 60% of black vs. 28% of white severely cognitively impaired NH residents)

Variability

- PEGs more prevalent in Southern states, especially Southeast
- Regions with higher rates of health care transitions have higher rates of feeding tube insertions.
  - Due to poorly executed transitions?
  - Miscommunication?
  - Medical culture favoring more aggressive treatment?

Cultural Differences

- African American physicians tend to desire more aggressive EOL for themselves than Caucasian physicians and are less likely to view tube feeding as a "heroic measure".
- When responding to a hypothetical case, African American and Asian physicians were more likely to recommend PEG than Caucasian physicians.
- African American physicians more likely to recommend PEG for AA patient than Caucasian patient.

Patient Populations

- Advanced dementia*
- Failure to thrive
- Stroke
- Cancer
- Parkinson's
- ALS
- Other neurodegenerative
- Trauma
- Severe esophageal dysmotility

Advanced Dementia

- No prospective randomized trials, all data are from retrospective analyses and prospective uncontrolled cohort studies.
- Washington DC VA study 2003
  - 41 patients offered PEG
  - 23 received PEG, median survival 59 days
  - 18 declined PEG, median survival 60 days

Advanced Dementia

Tube feeding is NOT effective for:

- Prolonging life
- Preventing aspiration or aspiration pneumonia
- Improving nutritional status
- Reducing risk of pressure sores
- Reducing overall infection risk
- Improving function
- Providing comfort

There is a pervasive failure by both physicians and the public to view advanced dementia as a terminal illness and there is a strong conviction that technology can be used to delay death.

Stroke

- About 20% have dysphagia, 80% of the time it resolves within one month.
- In those that do have dysphagia, no evidence that a PEG reduces the risk of aspiration pneumonia.

Stroke

- FOOD trial
  - No significant improvement in mortality with early enteral nutrition (1st 7 days), but early group had more survivors with poor functional outcome.
  - PEG group more likely to require long-term PEG, discharged to a SNF, have pressure sores, and have poorer QOL.

Stroke

- One year after PEG placement
  - 45% - dead
  - 30% - alive still with PEG
  - 25% - alive with PEG removed
- Offer NG feedings within first week but avoid PEG for at least 4 weeks. This gives more time to help determine prognosis and goals.

ALS (Amyotrophic Lateral Sclerosis)

- PEG may improve QOL and weight but not mortality in ALS patients with bulbar dysfunction.
- Survival similar to those with advanced dementia
  - 30-day mortality about 25%
  - Median survival < 5 months

ALS

- Consider PEG:
  - Before significant decrease in body mass
  - Before VC falls to below 50% of predicted
  - Frequent choking
  - Exhaustion with eating
  - Patient is willing!
- Patients should continue to eat for pleasure, if able.

Parkinson's and Related Disorders

- Not likely to help if end-stage.
- May help if inadequate nutrition/hydration is accelerating their decline.
- May help to afford time to reach non-medical goals.

Multiple Sclerosis

- Rarely needed, dysphagia is modest in prevalence.
- Compensatory strategies are usually sufficient.

Cancer

Studies have failed to demonstrate benefit in most cancer patients, with a few exceptions:

- Pre-XRT or intraoperative for head and neck or proxmial GI tract – improved morbidity but not mortality.
- Proximal GI obstruction with good functional status – improved QOL and mortality.

Cancer

- G-tube for decompression in malignant bowel obstruction is beneficial but median survival is about 8 weeks
- 85% improve with Octreotide, Metoclopramide, and Dexamethasone so may be spared from g-tube

Others Who May Benefit

- Catabolic state with a reversible illness, such as acute sepsis, severe trauma
- Certain AIDS patients
- Severe esophageal dysmotility with good level of function and all else has failed

Burdens of Tube Feeding

- Peri-procedure morbidity/mortality low
- High intermediate and long-term mortality: 20-30% one month and 60% one year
- Characteristics of those who do worse:
  - Advanced age
  - CNS pathology (includes dementia)
  - Cancer except early head and neck
  - Disorientation
  - Low albumin

Burdens

- ASPIRATION PNEUMONIA IS THE MOST COMMON CAUSE OF DEATH AFTER PEG PLACEMENT!!
- Jejunostomy feeding does not reduce this risk.
- Dysphagic patients probably aspirate MORE when tube fed than when carefully hand fed.

Burdens/Risks

- Other infections
- Clostridium difficile
- Mechanical complications
- Nausea, diarrhea, GI discomfort
- Pressure sores
- Fluid overload
- Use of restraints
- Deprived of pleasure of eating
- Less interaction
- Loss of dignity
- Increased ED utilization
- Increased rates of hospitalization

Informed Consent

Informed Consent/History

- In 1983, a President's commission found no distinction between artificial nutrition and other LST.
- 1986 - Elizabeth Bouvier case established the constitutional right of patients to refuse forced enteral feeding even if they are not imminently dying
- 1990 – Nancy Cruzan
- Terri Schiavo battle 1998-2005

Informed Consent/History

- 1990 – Patient Self Determination Act, gave individuals rights to make decisions about EOL care through use of advanced directives. Also requires health care facilities that receives government funds to determine if patients have ADs and if not, offer the opportunity to complete.

Informed Consent/History

- Stopping artificial nutrition is ethically and legally indistinguishable from never starting it, but the decision to stop is often MUCH harder. ANH is typically the last life-supporting measure withdrawn.

Informed Consent/History

- NC Medical Society Subcommittee 2003 Statement
  - Includes guidelines for physicians
  - Promotes patient and family education

David Weissman's Tube Feeding Death Spiral

1. Hospitalization for complications due to brain failure or other predictable end organ failure due to primary illness
2. Poor swallowing noted and/or evidence of aspiration and/or weight loss associated with poor PO intake
3. Swallow eval followed by reccs for non-oral feeding
4. Feeding tube placed followed by increasing patient agitation, resulting in feeding tube dislodgement
5. Re-insertion of feeing tube; restraints placed
6. Aspiration pneumonia
7. IV antibiotics
8. Repeat steps 4-6 two or more times
9. Family conference
10. Death

Informed Consent

Study at a large community hospital revealed that informed consent that included benefits and burdens was only documented in 0.6% of PEG placements

61% capable of MDM but only 36% signed own consent, 24% surrogates consented over phone

1/3 died either during hospitalization or within 30 days

Informed Consent

- Often assumed that any patient who fails a swallow study is a candidate for a PEG with little thought about broader implications or discussion of alternatives.
- This avoids the difficult and time-consuming discussions of poor prognosis and goals of care.

Informed Consent

- Many physicians unfamiliar with the evidence-based indications and continue to recommend in situations with no proven efficacy.
- In a study from 2000-2002, physicians tended to overestimate benefit. Estimated life expectancy without PEG 1-2 months and with PEG 1-3 years.
- Surrogate decision-makers grossly overestimated benefit as well.

Pressure on Surrogates

- Often presented a bleak choice with no alternatives– agree to PEG or let your loved one "starve to death".
- May fear being viewed as compassionless.
- Decision often made in the context of an acute illness.

Pressure on Surrogates

- Symbolic power of feeding
  - Still often seen as nurturing even though drastically different conventional eating (not unlike delivering O2 through a ventilator compared with ordinary breathing).
  - "Food" links a human being to the world of the living.

Pressure on Surrogates

- No decision is more anguishing and families truly desire to do the right thing.
- Watching a loved one "waste away" may provoke a well-intentioned and desperate attempt to "do something".
- Decision may be influenced by lack of realism. Some Americans view death as an option, not an eventuality.

Pressure on Surrogates

- Anyone caring for the patient knowingly or unknowingly may be conveying the message that not providing AN is morally wrong, just one "well-meaning" comment can derail a true informed decision in process.
- Very important for team to avoid sending mixed messages.

Pressure on Surrogates

- Nursing Homes
  - Higher reimbursement for patients with PEGs
  - Lower staffing needs
  - Concern for liability
  - May be penalized for residents' weight loss

Religion

- No group is homogeneous in their views!
- Protestants and Buddhists tend to accept withdrawal of AN.
- Catholics, Greek Orthodox, Muslims, some Orthodox Jews, and some evangelical Protestants reject withdrawal of AN.

Catholicism

- Views AN not as a medical intervention but as basic care.
- God is the creator of life and God alone maintains ultimate sovereignty over it.
- God gives humans the responsibility to care for that life.
- Historically obligates a person to strive towards prolongation of life except "when great effort is required or little hope exists".

Achieving True Informed Consent

- First must include assessment of the patient's capacity for making this decision at this time, this may fluctuate!
- If non-decisional, verify who is the legal surrogate, examine advanced directives if applicable and help surrogate interpret.
- Inquire about patient's previously expressed wishes and if not known, dig a little deeper to learn the essence of who that person is.

Achieving True Informed Consent

- Conversations must include:
  - Discussion of risks, benefits and alternatives beyond those present in the peri-procedure period
  - Expectations of what AN will and will not accomplish
  - Overall goals of care/what is important to the patient at this time

Achieving True Informed Consent

- Shared Decision Making
  - Inform patient/surrogate about condition and options.
  - Invite them to express their values and opinions.
  - Allow them to participate in the decision at the level they are comfortable.
  - Provide expert knowledge and make recommendations.

Achieving True Informed Consent

- Surrogates may need to be redirected many times…
  - back to the PATIENT'S wishes
  - back to achievable goals of care
- Redirect them gently.
- Choose your words carefully.
  - "I wish" statements
  - Emphasize what can and will be done to care for their loved one
- Be patient.

Achieving True Informed Consent

- Families need support and guidance over an extended time.
- Communication at transitions very important.
- Thorough and clear documentation in the medical record.

Achieving True Informed Consent

- When you don't agree with the decision –
  - Continue to provide support.
  - Propose a time-limited trial with agreed upon parameters and date for re-evaluation.

Achieving True Informed Consent

Resources

- Hard Choices for Loving People
- Making Choices: Long-Term Feeding Tube Placement in Elderly Patients (booklet, audio tape and worksheet)
- Palliative Care or Hospice Consultation

Achieving True Informed Consent

- Do interventions work?
  - Ex: Lenox Hill Hospital examined two 6-month periods pre and post implementation of staff education and palliative care consultations
  - PEGs overall before 71, after 27
  - PEGs in dementia pts before 40, after 8
- We need high quality advance care planning well upstream of these decisions!

It's never too early to start the conversation.

Alternatives to Artificial Nutrition

- Address reversible causes of eating problems
  - Depression
  - Metabolic disorders
  - Constipation
  - Poor oral hygiene
  - Poor access to food
  - Medication side effects
  - Too many pills to take
  - Diet too restrictive
  - Consider appetite stimulant?

Comfort Feeding

- Allow patient to eat anything he/she wants
- Appropriate textures/precautions
- Small amounts when interested
- Feed when upright and comfortable
- Offer foods in a variety of colors, textures and temperatures

When intake ceases

- Families may need reassurance that their loved one is dying of their terminal disease and not "starvation".
- Loss of appetite and thirst often parallels the body's inability to utilize nutrition and fluids.
- Focus on other ways to care and nurture (ex: music, massage).

Benefits of Terminal Anorexia

- Ketosis and endorphin release
- Less likely to have GI discomfort, n/vom
- Less UOP
- Less respiratory secretions
- Less pressure around tumors
- Less swelling and pulmonary edema

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Questions????