“But I Can’t Let Mama Starve to Death!”

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Objectives

- Be aware of different types of ANH
- Be familiar with current evidence regarding effectiveness of ANH at EOL
- Understand ethical issues related to use of ANH at EOL
- Describe alternatives to ANH for patients with advanced illness.
- Feel more comfortable discussing ANH and other difficult issues with patients and families.

Cases

- Mr. H. – 92 yo pt recently admitted to SNF. Dementia. Multiple medical problems. Alert, w/c bound, cats in DR.
- Ms. E. -- 86 yo pt with h/o CVAs. Lives at home w/dtr. Admitted with MS change. Found to have “massive” CVA. Unresponsive.
- Mr. R. – 62 yo pt w/ ALS. PEG/TFs for approx 6 years. Unable to communicate.

Artificial Nutrition & Hydration (ANH) In Hospice Patients

- Types of Artificial Nutrition & Hydration (ANH)
- Goals of ANH in Advanced & Terminal Illness
- When is ANH used?
- Is ANH Effective?
- ANH Data
- Alternatives to ANH
- Medical Ethics
- Medical Decision Making
- Other Issues Specific to ANH
- Position Statements
- Difficult Discussions
- Conclusions

Natural Course of Terminal Illness
Types of Artificial Nutrition & Hydration

- **Enteral Nutrition:**
  - Hand Feeding*
  - Nasogastric or Orogastric
  - Percutaneous Endoscopic Gastrostomy (PEG)
  - Feeding Jejunostomy tube

- **Parenteral Nutrition:**
  - IV (TPN) – Central Line or PICC Line

- **Hydration:**
  - Enteral
  - IV
  - Hypodermoclysis (subcutaneous infusion)

Potential Goals of ANH in Terminal Illness

- Improve Survival
- Improve Nutritional Status
- Improve Wound Healing
- Decrease Aspiration Pneumonia
- Provide Comfort

Situations Where ANH Is Sometimes Considered:

- **Symptom or Condition:**
  - Anorexia, Cachexia, Dysphagia, Aspiration

- **Diagnosis:**
  - CNS/Neurodegenerative: PVS, ALS, CVA, Dementia, etc.
  - Cancer: Head & Neck Cancer, Other Malignancies
  - Other: Depression, Adult FTT, etc.

Reasons for NET or PEG Placement

- 10 primary studies between 1988 and 2004
- Most common reason: dysphagia secondary to advanced neurological disorders, usually dementia or CVA
- ANH is much more common in advanced dementia than in advanced malignancy

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Patients Who Receive ANH
- Younger age
- Nonwhite race
- Male
- Divorced
- Lack of Advance Care Directives
- Recent decline in functional status
- No DX of Alzheimer disease

Facilities Where ANH is Used
- More likely to use ANH if:
  - Urban
  - Larger (More than 100 beds)
  - For Profit
  - No Dementia Special Care Unit
  - Less DNR orders
  - No NP or MD
- Varies by geography
  - Overall – 34% of NH pts w/ ACI had TF
  - DC – 90% of NHs had >40% pts TF
  - TN – 34% of NHs had >40% pts TF

Is ANH Effective?
Categories:
- “Probably”
- “Possibly”
- “Mixed Results”
- “ Probably Not”

Markers:
- Survival
- Nutritional Status
- Wound Healing
- Aspiration Pneumonia
- Comfort

Is ANH Effective?
- PROBABLY:
  - Reversible illness/catabolic state (sepsis) – Survival
  - PVS – Survival
  - Amyotrophic Lateral Sclerosis (ALS) – Survival
  - Chemo/XRT prox GI tract – Survival
  - Good fxnl status & prox GI obstr due to CA – Survival
  - Select HIV pts – Survival

Is ANH Effective?
- POSSIBLY:
  - CVA (When swallowing likely to improve) – Survival

Is ANH Effective?
- MIXED RESULTS:
  - Early H&N CA (prox GI obstruction):
    - YES – Survival
    - NO – Aspiration PNA

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Is ANH Effective?

- PROBABLY NOT:
  - Advanced CA - Survival, Nutrition, Aspiration, PNA, Decubitus Ulcers, Comfort
  - Neurodegenerative Conditions:
    - Dementia - Survival, Nutrition, Aspiration PNA, Decubitus Ulcers, Comfort
    - CVA (When swallowing not likely to improve) - Survival, Nutrition, Aspiration PNA, Decubitus Ulcers, Comfort

ANH Data in Advanced & Terminal Illness

Literature has significant limitations:

- No randomized, controlled, prospective trial of survival
- Mostly small, observational retrospective cohort studies
- Data-base (MDS) studies offer larger numbers but limitations in data available

ANH Data in Advanced & Terminal Illness

Outcomes – Survival

- Overall: 30 day mortality after PEG – 22%-35%
  1 yr mortality after PEG – 50%-63%
- One study showed increased survival with PEG. Many showed no difference. Several showed decreased survival with PEG.

Outcomes – Nutrition

- 4 studies between 1988 and 2000
- Pts w/TF. Assessed body weight, body mass index, serum albumin, cholesterol, hemoglobin and hematocrit.
- All documented progressive decline of these markers over 1 to 6 month periods.

Outcomes – Decubitus Ulcers

- Two primary studies from early 1990s
  Examined prevention or healing of decubitus ulcers in patients receiving ANH via PEG vs. pts w/o ANH
  Both demonstrated increased incidence of decubitus ulcers among LTC pts receiving ANH compared to controls.
**ANH Data in Advanced & Terminal Illness**

**Outcomes – Decubitus Ulcers**

- MDS study
- Propensity-matched cohort study.
- 8 years of data (1999-2007)
- 1124 pts with PEG + 2082 pts without
- Pts with PEG > 2 times more likely to develop pressure ulcer (OR 2.27)
- And existing pressure ulcers less likely to heal.

**ANH Data in Advanced & Terminal Illness**

**Outcomes – Pneumonia**

- Seven studies published between 1988 and 1997
- NET, PEG, Jejunal feedings
- No documented prevention or decrease in aspiration events.
- Two studies showed increase in Aspiration PNA after PEG placement.
- Swallowing studies lack sensitivity and specificity.

**ANH Data in Advanced & Terminal Illness**

**Outcomes – Comfort**

- Discomfort in Nursing Home Pts w/ Severe Dementia in Whom ANH Is Forgone
- Netherlands. Prospective, longitudinal, observational.
- 178 NH pts with severe dementia who stopped eating & drinking.
- Measured discomfort with observational scale.
- Conclusion: Foregoing ANH in such pts is not associated with high levels of discomfort and therefore seems to be an acceptable decision.

**ANH Data in Advanced & Terminal Illness**

**Outcomes – Comfort**

- 2003 study of 307 nurses experiences with hospice pts who refuse food and fluids
- 33% had pts who voluntarily refused food and fluids
- 85% of those pts died within 15 days of stopping food and fluids
- On scale of 0 (very bad death) to 9 (very good death), median score for the quality of these deaths was 8.

**ANH Data in Advanced & Terminal Illness**

**Outcomes – Comfort - Summary**

- No studies available which demonstrate improved quality of life with ANH
- Most actively dying patients do not experience hunger or thirst (dry mouth is a common problem, but no relationship between hydration status and the symptom of dry mouth.)

**ANH Data in Advanced & Terminal Illness**

**Outcomes – Comfort - Physiology**

- Physiologic adaptations to fasting: decreased UOP, resp secretions, coughing, nausea, vomiting and diarrhea. Decreased metabolism.
- Consequences of fasting – mediated by endogenous hormonal changes and the anorexic effects of circulating ketones. “Complete starvation may be easily tolerated and even associated with a sense of euphoria and well-being, especially as compared with the effects of ingesting inadequate calories.”

ANH Data in Advanced & Terminal Illness

Physicians

- NCMS – Cross-sectional Survey of 2058 Internal Med & Fam Med Physicians – 53% (1,083) responses
- Recs re PEG for a case pt w/advanced dementia. Varied race of pt.
- 18% for PEG, 80% against PEG or no rec
- No signif difference by race of pt
- Signif difference by race & specialty of MDs/DOs:
  "For" PEG:
  - Cau 13%/Asian 54.3%/AA 40%
  - FM 13.8%/Geriatrics 9.1% vs. FM 23.4%
- Race Concordance: AA/AA – 51.4% AA/Cauc 24%


- Mail survey to physicians
- Use of PEG/TFs in pts w/adv dementia
- Rate importance of recurrent asp PNA, abnl swallowing eval, abnl nutritional parameters, preventing an uncomfortable death, etc.
- Discrepancies between physician knowledge and current evidence
- Rec improved education of primary care physicians about these issues in order to provide better end of life care for pts with dementia.


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Alternatives to ANH In Advanced & Terminal Illness

Consider instead:

- “This treatment isn’t working, so we need to stop it now and try something else.”
- “It’s time to shift to a different type of treatment.”
- “We can’t ‘fix’ this problem or ‘make it go away’, but there are a lot of things we can do to treat these symptoms and keep this patient very comfortable.”
Alternatives to ANH
In Advanced & Terminal Illness
High Quality Palliative Care
- “Comfort” or “Pleasure” food &/or drink
- Attention to mouth dryness (ice chips, glycerin swabs)
- Aggressive treatment of pain, dyspnea and other symptoms
- Emotional & spiritual support
- Support for family
- Bereavement services

Medical Ethics
- Beneficence – “do good”
- Nonmaleficence – “do no harm”
- “Burden vs. Benefit”

Medical Ethics – Burden of ANH
Direct complications of PEG procedure (216 to 71% of pts)
- Minor (213%)
  - Wound infection, wound leakage, wound bleeding, cutaneous or gastric ulceration, pneumoperitoneum, and temporary ileus, nausea, bloating, abdominal pain, diarrhea
- Major (23%)
  - Necrotizing fasciitis, esophageal perforation, gastric perforation, colocutaneous fistula, buried bumper syndrome, inadvertent PEG removal, and tube feeding aspiration
- More likely in elderly pts, or pts w/comorbid condition, infection or h/o aspiration

Medical Ethics – Burden of ANH
Quality of life issues with PEG/ANH:
- May limit pt’s mobility
- May impact pt’s feeling of dignity
- May require restraints
- May result in limitation of “pleasure feeding” or “comfort feeding”
- May result in less human-to-human interaction
- May cause diarrhea or GI discomfort
- May limit care options (ALF vs. SNF, etc.)

Medical Ethics
Potential Harm vs. Benefit of ANH
Summary of Issues of Burden vs. Benefit:
- Studies fail to show significant benefit in many conditions.
- Strong evidence that ANH is associated with some risk and uncomfortable side effects.

Medical Decision Making
- Informed consent/refusal/withdrawal
- Patient Autonomy, Self Determination & Bodily Integrity
  (Right to refuse any unwanted intervention)
- Decision Making Capacity
  (different than competency)
- Living Will, Advanced Directives, HCPOA
- Surrogate Decision Making
  (Pts expressed wishes vs. Pts “best interest”)

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Other Issues of Medical Ethics & Decision Making

ANH is often an issue for person who cannot speak for self

fear that certain groups will not be protected

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Other Issues of Medical Ethics & Decision Making

- Withholding vs. Withdrawing ANH
  - Ethically & Legally Equivalent
  - When starting ANH, helpful to discuss stopping ANH

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Other Issues of Medical Ethics & Decision Making

- “Natural” vs. “Artificial”
- Is ANH “different” from other treatments? (“extraordinary” vs. “ordinary”, “basic humane care”)
- Is TF/ANH “medical treatment”?

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Other Ethical Issues/Medical Decision Making - Summary

- We have a well-accepted process for making such decisions.
  - Incompetent patients have the right to all medical choices available to competent patients (including right to refusal/discontinuation).
  - Surrogates are asked to use ethical principal of proportionality – how they think pt would weigh burdens of intervention against benefit.
- Process is grounded in concepts of self-determination and bodily integrity. Pts (or surrogates) have right to refuse any unwanted intervention, medical or otherwise.

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ANH – Position Statements

- Risks
- Legal and Ethical standards exist re MDM
- NC – no unique restrictions re TF
- Withdraw = Withhold
- Advance care directives
- Surrogates – pts wishes or pts best interest (consent or refusal or withdrawal)


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ANH – Position Statements

American Academy of Hospice and Palliative Medicine, November 16, 2001:

“...Hydration and nutrition are traditionally considered useful and necessary components of good medical care. They are provided with the primary intention of benefiting the patient. However, when a person is approaching death, the provision of artificial hydration and nutrition is potentially harmful and may provide little or no benefit for the patient and at times may make the period of dying more uncomfortable for both patient and family. For this reason, the AAMPM believes that the withholding of artificial hydration and nutrition near the end of life may be appropriate and beneficial medical care.

Clinical judgment and skill in assessment of individual situations is necessary to determine when artificial hydration and nutrition are appropriate measures to apply.”

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ANH – Position Statements

- American Medical Association (AMA)
- American Nurses Association (ANA)

“Benefit vs. Burden”

ANA: “As in all other interventions, the anticipated benefits must outweigh the anticipated burdens for the intervention to be justified.”


“Percutaneous endoscopic gastrostomy tubes are being placed with increasing frequency in the US among elderly patients with dementia. Health care providers believe there may be long-term benefits for enteral feeding in this population, yet previous study of this topic has failed to yield any convincing evidence to support this hypothesis. In this study, we review the evidence regarding outcomes for artificial enteral feeding in older individuals with dementia. We found that there is a lack of evidence supporting artificial feeding in the specific outcomes of survival, pressure ulcers, nutrition, and aspiration pneumonia…”

Difficult Discussions

Try not to delay in addressing
Allow time for discussion
Fire “Warning shot”
Be mindful of language used
Be honest
Reassure
Allow time for consideration & further discussion

ANH in Advanced & Terminal Illness

Conclusions

- ANH is often considered at End of Life
- Little evidence of benefit in many conditions
- Weigh burden vs. benefit for each patient
- Consider alternatives to ANH
- Use good medical decision making – informed consent, refusal or withdrawal.
- Offer good Palliative Care to all pts at End of Life
Cases

- Mr. H. – 92 yo pt recently admitted to SNF. Dementia. Multiple medical problems. Alert, w/c bound, eats in DR.
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Questions?

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