Innovation AND Excellence

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"But I Can't Let Mama Starve to Death!"

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Hospice of Davidson County, Lexington, NC
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"But I Can't Let Mama Starve to Death!"

Artificial Nutrition & Hydration (ANH) In Hospice Patients

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.

Artificial Nutrition & Hydration In Advanced and Terminal Illness

- 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

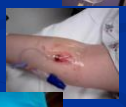
Cases

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

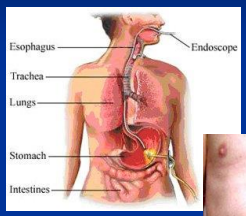
Natural Course of Terminal Illness

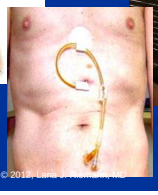
Types of Artificial Nutrition & Hydration

- **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)


PEG Tube






Potential Goals of ANH in Terminal Illness

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

When is ANH used?

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

(Level II, III, IV) Koesel/Barkley

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

(MDS study of pts w/ "Adv Cognitive Impairment")

Mitchell, et al., JAMA, 2003.

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

(MDS study of pts w/ "Adv Cognitive Impairment") Mitchell, et al., JAMA, 2003.

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*

Hallenback, J. EPERC FF, 2005

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*

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

- 14 primary studies related to ANH published between 1991 and 2003.
- 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.

(Level III, IV) Koesel/Barkley

ANH Data in Advanced & Terminal Illness

Outcomes – Survival

Examples: MDS Retrospective Cohort Studies

3 large studies of TF in pts with Dementia

- **Mitchell, 1997.**
  1386 pts. No difference in mortality.
- **Mitchell, 1998.**
  5266 pts. Higher Mortality in TF pts.
- **Rudberg, 2000.**
  1545 pts. At 1yr: TF pts 50% Mortality
  Control pts 61% Mortality

ANH Data in Advanced & Terminal Illness

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.

(Level II, IV) Koesel/Barkley

ANH Data in Advanced & Terminal Illness

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.

(Level III, IV) Koesel/Barkley

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.

Teno, et al. Arch Intern Med, 2012

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.

(Level II, IV) Koesel/Barkley

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.

Pasman, et al. Arch Intern Med, 2005.

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.

Ganzini, et al. NEJM, 2003.

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."

Winter, SM. Amer J Med, 2000.

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.)

Hallenback, J. EPERC FF, 2005

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:
  - Cauc 13%/Asian 54.3%/AA 40%
  - IM 13.8%/Geriatrics 9.1% vs. FM 23.4%
- Race Concordance: AA/AA – 51.4% AA/Cauc 24%

Modi SC, et al. J Palliat Med. 2007 Apr; 10(2): 359-66.

ANH Data in Advanced & Terminal Illness

Physicians

- 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.

Vitale CA, et al. Care Manag J. 2006 Summer; 7(2): 79-85.

ANH Data in Advanced & Terminal Illness

Physicians

- Mail survey to 195 of 500 primary care physicians from AMA database
- Knowledge, beliefs, self-reported practices re PEG in adv dementia
- Signif number believe: reduce asp PNA(76.4%), impr healing (74.6%), incr survival (61.4%), impr nutritional status (93.7%), impr functional status (27.1%).
- More than half:

-Underestimate 30 d mortality & believe PEG is standard of care

-Believe speech therapists, nurses & nutritional support teams rec PEG and this influences physician decision

-Have had SNF request PEG, leading to physician rec of PEG

Shega SW, et al. J Palliat Med. 2003 Dec; 6(6):885-93.

Alternatives to ANH In Advanced & Terminal Illness

- "Pet Peeves":
  - "There's ***nothing more we can do***."
  - "We're going to ***stop everything***."
  - "We're ***just*** going to keep the patient comfortable."

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."

"Pleasure Feeding"

- Any food or drink
- Of any consistency
  - Regular/Ground/Soft/Pureed
  - Thin/Thick
- In any amount
- That patient wants

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
(?16 to 70% of pts)

- Minor (?13%)
  - wound infection, wound leakage, wound bleeding, cutaneous or gastric ulceration, pneumoperitoneum, and temporary ileus, nausea, bloating, abdominal pain, diarrhea
- Major (?3%)
  - 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

DeLegge, 2006.

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".)

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

Other Issues of Medical Ethics & Decision Making

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

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"?

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.

ANH – Position Statements

Long-Term Feeding Tubes: Ethical Issues in Physicians' Decision Making, Nov 2001.

- 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)

Ethical and Judicial Affairs Committee, NC Med Society, 2004.

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 AAHPM 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."

ANH – Position Statements

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

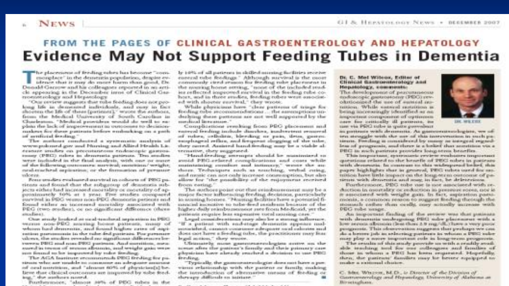
"Benefit vs. Burden"

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

Feeding Alternatives in Patients with Dementia; Examining the Evidence. Garrow D, et al. CGH, Dec 2007; 5 (12): 1372-78.

"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. . ."

Feeding Alternatives in Patients with Dementia; Examining the Evidence. Garrow D, et al. CGH, Dec 2007; 5 (12): 1372-78.


6 NEWS | GI & Hepatology News • December 2007

FROM THE PAGES OF CLINICAL GASTROENTEROLOGY AND HEPATOLOGY

Evidence May Not Support Feeding Tubes in Dementia


Dr. C. Mel Wilcox, Editor of Clinical Gastroenterology and Hepatology, comments:

The development of percutaneous endoscopic gastrostomy (PEG) revolutionized the use of enteral nutrition. While enteral nutrition is being increasingly identified as an important component of optimum care for critically ill patients, its use via PEG tube is quite prevalent in patients with dementia. As gastroenterologists, we often struggle with the use of this intervention in such patients. Feeding is considered by many as integral regardless of prognosis, and there is a belief that nutrition via a PEG in such patients provides long-term benefits.

DR. WILCOX

This important, systematic review evaluates important questions related to the benefit of PEG tubes in patients with dementia. In contrast to this widespread belief, this paper highlights that in general, PEG tubes used for nutrition have little impact on the long-term outcome of patients with dementia and may, in fact, be deleterious.

Furthermore, PEG tube use is not associated with reduction in mortality or reduction in pressure sores, nor is it associated with weight gain. In fact, aspiration pneumonia, a common reason to suggest feeding through the stomach rather than orally, may actually increase with PEG tube usage.

An important finding of the review was that patients with dementia undergoing PEG tube placement with a low serum albumin (less than 2.8 mg/dL) have a very poor prognosis. This observation suggests that perhaps we can do a better job in selecting patients in whom a PEG tube may play a more important role in long-term prognosis.

The results of this study provide us with a readily available teaching tool for our colleagues and families of those in whom a PEG has been requested. Hopefully, then, the patients' families may be better equipped to make a rational choice.

C. Mel Wilcox, M.D., *is Director of the Division of Gastroenterology and Hepatology, University of Alabama at Birmingham.*

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.
- Ms. E.- 86 yo pt with h/o CVAs. Lives at home w/dtr. Admitted with MS change. Found to have "massive" CVA. Unresponsive.
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