Artificial Nutrition
and Hydration Issues
in Palliative Care

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Disclosures

- I have no financial relationships to disclose for this presentation.

Learning Objectives

- Introduce various methods of artificial nutrition and hydration
- Discuss possible benefits and possible risks to artificial nutrition and hydration
- Briefly introduce the ethical and legal questions surrounding artificial nutrition and hydration
- Discuss possible framework for discussion with patients and families
Have you ever heard this?

- “I can’t watch my mom starve to death.”
- “Are her IV fluids going to continue on hospice?”
- “You mean we aren’t going to feed her at all, so she’s going to starve?!?”
- “But he’s aspirating. A feeding tube can help the aspiration, right?!”
- “Consult needed about goals of care related to whether or not to place PEG as he is aspirating”

Difficult and Broad Topic

- Artificial Nutrition and Hydration (ANH) is a very broad topic
- 8 Different Palliative Care Fast Facts address ANH:
  - 10: Tube Feed or Not Tube Feed?
  - 84: Swallow Studies, Tube Feeding, and the Death Spiral
  - 128: The Speech Pathologist and Swallowing Studies
  - 133: Non-Oral Hydration in Palliative Care
  - 134: Non-Oral Hydration Techniques in Palliative Care
  - 190: Parenteral Nutrition in Advanced Cancer Patients
  - 220: Hypodermoclysis
  - 300: Non-Pharmacologic Management Strategies in ALS
  - 318: Prophylactic Feeding Tubes in Head and Neck Cancers  https://www.mypcnow.org/

Different Names/Same Thing

- “Artificial Nutrition and Hydration”
- TPOPP “Medically Administered Nutrition”
- “Artificial Hydration and Nutrition”
- “Medical Hydration and Nutrition”
Basic Definition/Methods

Artificial Nutrition and Hydration (ANH) is a treatment intervention that delivers fluids and/or nutrition by means other than a person taking something in his/her mouth and swallowing.

Enteral:
- Nasogastric Tube
- Gastrostomy
- Jejunostomy

Parenteral:
- IV/SQ

Hydration Methods

- Peripheral or Central IV
- Hypodermoclysis
  - SQ infusion of fluids
  - PC Fast Facts suggests placement in upper chest
  - Lower abdomen/Upper thigh may cause scrotal edema
  - Up to 120mL/hr continuous or 500mL bolus BID or TID
- Proctoclysis
  - Nasogastric tube inserted rectally or Macy Catheter
  - 100-400mL/hr unless leakage
  - Reasonable goal volume is 1-1.5L/day

Pros/Cons of Hydration

Pros
- Dehydration
- Possible Accumulation of Drug Metabolites
  - Delirium, Myoclonus, Seizures
- Thinner Secretions
- Giving fluids is “doing something”

Cons
- Prolongation of dying process…?
- Less urine = Less Voiding
- Less fluid
- Less GI fluid = Possibly Less N/V
- Less pulmonary edema
- Less peripheral edema
**Conditions where ANH indicated by evidence**

- **ALS**
  - Enteral feeding can actually be palliative
  - Improves nutrition
  - Lessens fatigue
  - Relieves struggle and effort to eat
  - Reduces time spent on meals and meds
  - Helps fear of choking
  - Another way to provide medications
  - Data on prolonging life is less clear

- Mitsumoto, et al 2003
  - ALS Patient Care Database
  - ALS Functional Rating Scale-bulbar subscale (ALSFRSb) scores <5
  - 137 with PEG compared with 187 matched controls
  - No survival benefit
  - However, PEG was placed late in disease course & patients were more disabled

- Forbes, et al 2004
  - The Scottish MND Register
  - 142 PEG Insertions between 1989-1998
  - Median survival 5 months
  - No increased survival compared to no placement

**ALS Continued**

- Especially indicated in bulbar involvement
- Earlier in course of disease is better
- Placement when FVC > 50%
- Statistics
  - Neurologists who treat ALS report talking to 80% of patients about PEG repeatedly
  - Of those informed, 80% decline and only 13% of ALS patients ever receive PEG tubes
- Benefits of PEG are lost at end of disease

Conditions where ANH indicated by evidence continued

- Proximal GI Obstruction due to Cancer if patients have good functional status
- Selected HIV patients
- Possibly Head and Neck Cancer... but watchful waiting may be equivalent
- Refractory cachexia: Avoid PEG
- Desire minimal interruptions: watchful waiting
- Desire maximal nutrition: consider PEG

Conditions where ANH is not indicated by evidence

- Advanced Dementia
  - AAHPM, AMDA, and AGS all have position papers about not using ANH in advanced dementia and instead recommend careful hand feeding

Choosing Wisely

American Academy of Hospice and Palliative Medicine

Five Things Physicians and Patients Should Question

Don't recommend percutaneous feeding tubes in patients with advanced dementia; instead, offer oral assisted feeding.

In advanced dementia, studies have found feeding tubes do not result in improved survival, prevention of aspiration pneumonia, or improved feeding of nutrition. Feeding tube care in such patients has actually been associated with worsened decline in mental function and decline in physical and psychological health, and patient distress about the tube itself. Assistance with oral feeding is an evidence-based approach to promote nutrition for patients with advanced dementia and feeding problems, in the final phase of this disease, assisted feeding may focus on comfort and human interaction more than nutritional goals.
Aspiration

Approximately 35% of patients with dementia show signs of liquid aspiration. Orally fed patients had significantly fewer events than those fed by tube.

Aspirate oral secretions

Continue to regurgitate, may increase reflux by decreasing lower esophageal sphincter tone

ANH does not prevent weight loss
Advanced Dementia Continued

- Pressure Ulcers
  - Retrospective trials show only increased risk and no benefit with tube feeding
  - Tube feeding increased restraints, worsened skin breakdown
- Functional Status
  - Nutritional intervention did not improve function after stroke
  - No nursing home patients had improvement in functional status with tube feeding

Advanced Dementia Continued

- Survival
  - PEG placement mortality ranges from 0-2% during procedure and 6-24% perioperatively
  - Mortality rate at 1 year: 50%
  - 2001 JAMA study
    - 99 dementia patients, 51 with PEG
    - Median Survival with PEG 198 days
    - Median Survival without PEG 189 days
    - No significant difference
    - Dysphagia is leading cause of death in dementia

Very Polarizing Issue

- Terry Schiavo case brought ANH to the forefront of societal debate
- Most physician societies agree that ANH is a medical intervention and should be treated the same way in regards to withholding or withdrawing
- However, individual religious principles and state laws influence these decisions
- ANH is intentionally separated from Life-Sustaining Therapies in next year’s proposed new reporting milestones due to the nuances and emotional context
- This is especially difficult in pediatrics, more to follow....
Catholic Institutions

- Catholic hospitals follow the “Ethical and Religious Directives for Catholic Health Care Services”
- Pope John Paul II responded to Schiavo case saying that nutrition and hydration should never be withheld
- Directive 58 states there is an “obligation to provide patients with food and water” including in a persistent vegetative state
- However, it also states that ANH may become morally optional when “excessively burdensome for the patient or cause significant physical discomfort”

State Laws

- Many states have a “clear and convincing evidence standard” around withholding or withdrawing life support including ANH
- This is not always clearly defined
- Written directives are strongest
- Some states acknowledge strong verbal statements
- Some states like Texas and California allow physicians to determine futility and withdraw or withhold life support

State Laws

- Oklahoma law states “It shall be presumed that every incompetent patient has directed his health care providers to provide him with hydration and nutrition to a degree that is sufficient to sustain life”
- Only way to withhold or withdraw in OK: patient discussion with physician, court determines clear and convincing evidence, advance directive specifically mentions ANH
- DPOA or Surrogate Decision Maker cannot make the decision to withhold or withdraw ANH
ANH Issues in Children

- American Academy of Pediatrics has report about forgoing ANH in children
- Forgoing or withdrawing ANH more controversial because of the inability of children to make autonomous decisions and the emotional power of feeding as a basic element of child care
- Conclusion: withdrawal is ethically acceptable in limited circumstances, i.e., child never attains consciousness
- Ethics strongly recommended

AS PEN Ethics Position Paper

- American Society for Parenteral and Enteral Nutrition
- Decisions regarding ANH should be based on EBM, best practices in discussion with patient and family
- Limited time trials are an acceptable alternative when benefits are questionable
- ANH may not provide benefit and may have risks in severe dementia or in persistent vegetative state
- Religious, cultural, and ethnic background need to be respected
- Ethics consult for dilemmas

Framework for Discussion

- As always, the goals of care drive the plan of care
- Feeding is loving and symbolic of love for many people
- Providing food meets a basic human need
- Often conversations cannot involve patients (AMS, etc)
- Conflicts in conversation usually arise from 3 areas:
  - Facts and Information
  - Emotion
  - Identity
Conflicts with Facts/Information
- Misunderstanding of Facts
  - "Could you tell me more about what other people have told you about tube feeding?"
  - "What do you know about how ANH is provided?"
- Misunderstanding of Expectations
  - "Tell me what your hoping for with starting tube feeding?"
  - "What do you expect for your loved one?"
- Share facts about ANH including benefits and risks
  - Include relevant clinical data in an approachable way

Conflicts with Emotions
- NURSE
  - Naming
    - "I sense that you're feeling..."
  - Understanding
    - "I'm hearing you say..."
    - "I can't imagine..."
  - Respecting
    - "I'm impressed by..."
    - "I respect..."
  - Supporting:
    - "What is your source of support?"
    - "What can I do to support your through this?"
  - Exploring:
    - "It would help me to know what your worries are?"
    - "Can you share with me what you're feeling?"

Conflicts with Emotions
- Guilt
  - Redirect to patient’s thoughts and feelings
  - Offer to provide a recommendation
  - Replace the symbolic importance of food
    - Mouth Care
    - Other loving gestures
- Denial
  - Give them some control
  - Attend to emotion behind denial
Conflicts of Identity

- What is the role of everyone involved?
- Role as surrogate
  - Ask what the patient would say or has said in the past
  - "If your [relation] could tell us what he wanted, what do you think he would say?"
  - "If he could see himself right now, what would he tell us?"
- Role as family member
  - Acknowledge the role and societal expectation
  - The "good" son, daughter, husband, wife, etc
- Role as physician
  - Remember and reflect on role in patient care
  - Offer to provide a recommendation to those struggling

Tips for Conversations

- If the idea of "starving" arises, ask if the patient seems hungry
- Talk about the fact that as the body shuts down, the hunger and thirst drives lessen and go away
- Remind the person that the patient is dying from their disease and not dying from dehydration or starvation
- "Calories feed the cancer, not the body"
- Offer alternatives such as hand feeding or comfort feeding
- Suggest ways for families to help other than feeding such as oral care or swabs of things the person likes to drink
- Reassure that feeding for comfort doesn’t go away

Tips for Conversations

- Find common areas of agreement and build on that instead of trying to convince or persuade
- Offer a time trial, including follow up regardless of decision to be sure goals are still being met
- Reassure that the person will not suffer and that everything will be done to ensure comfort
- Ensure that all members of the treatment team understand the goals and the relevant EBM data to avoid confusing the patient and family
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Summary

- ANH is a very complicated and polarizing issue in healthcare
- Methods for ANH include enteral (NG, PEG, GJ, proctoclysis) and parenteral (TPN, IV fluids, hypodermoclysis)
- PEG should be offered early in ALS
- ANH should not be offered to patients with advanced dementia

Summary

- PEG does not prevent aspiration pneumonia, and in fact, may increase risk
- There are several ethical questions that can arise from situations with ANH
- It is important to know the policies of one’s institution and the state laws involved as they are variable
- ANH should always involve shared decision making with patients and families
Summary

- Consideration should be given to time trials of ANH with reevaluation of consistency with goals at a set interval
- Alternatives such as hand feeding, comfort feeding, or watchful waiting should be offered and discussed
- If there is any moral distress on the part of anyone involved, consider ethics consult

References

References