

Nutrition Dilemmas for Palliative Care And Hospice Patients

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Objectives

- Define artificial nutrition and hydration (ANH)
- Review the history and ethics of ANH
- Identify patients who are unlikely to benefit from ANH
- Understand risks and benefits of ANH
- Recognize and address emotional and medical concerns of patients and families.

Definitions

- **Artificial Nutrition:** non-oral, enteral or parenteral delivery of nutrients
 - Includes NG, PEG, PEG-J or GJ tubes; PIV or CV access
 - Goal is to provide nourishment for patients in whom life expectancy or quality of life is expected to improve
- **Artificial Hydration:** delivery of fluids by any route other than oral
 - Includes IV, SC, dermal (dermoclysis), rectal (proctoclysis)
- **Artificial nutrition and hydration (ANH) are considered medical interventions**
 - They are NOT a basic provision of comfort
- **Oral assisted feeding (spoon or hand feeding) is not ANH**

Case Study

Case Study

- 89-year-old female with end-stage Alzheimer's dementia
 - FAST 7C
 - Dysphagia
- Transferred from SNF with suspected aspiration pneumonia
- Improves over several days with antibiotic treatment
- Swallow study and nutrition consultation
 - Confirms severe dysphagia, recommendation for NPO status
- Family concerned she will “starve to death”
 - Requests feeding tube placement

History, Ethics, and Law



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History of ANH

- Anorexia and dehydration often develop in advanced illness
- May be perceived as failure of medical treatments
 - Patients, families AND clinicians
- ANH developed in attempt to improve these disease states
- Provided to patients who cannot meet their daily requirements orally
 - Resulting in malnutrition, electrolyte and/or metabolic derangements
 - Examples: ALS, post-CVA, head and neck cancers with expectation of recovery

History of ANH

- 3500 years ago: ancient Greeks and Egyptians infused nutrient solutions rectally in patients with bowel disorders
- 1598: Capivacceus inserted a tube into the esophagus for upper GI feeding
- 17th century: Boerhaave developed nasogastric feeding tube
- 1845: Sedillot performs first gastrostomy for feeding purposes
- Feeding solutions usually consisted of some combination of milk, eggs, and alcohol (wine, whiskey, brandy)
- 1973: Ensure was introduced by Abbot Laboratories
 - First “all-purpose” nutritionally complete formula for adults

Ethical History of ANH

- Up to 1960's: religion guided end-of-life decision making for many patients
 - Life prolonging medical technology considered idolatry by Catholic Church
- 1970's: advent of early bioethics
 - Emphasis shifted to patient rights and autonomy
- 1980's: medical ethicists divided about ANH
 - Some consider it basic standard of care, some consider it extraordinary care that may be withheld or withdrawn
- Early 1990's: Supreme Court ruling in Cruzan case
 - AN is a medical treatment that may be terminated under appropriate conditions
 - Convergence of ethics and law

Patient Self-Determination Act (PSDA)

- 1990 Congressional act
- Goals:
 - To prevent cruel treatment of patients for the motive of profit
 - To reduce end-of-life care costs
- Establishes the right of patient or surrogate to forego medical interventions
 - In theory, this would include withholding or withdrawing ANH

Ethical History of ANH

- Late 1990's: focus on empirical data
 - Studies showing use of ANH futile in terminally ill patients
 - Disconnect between evidence and practice remained
- 2003: Terry Schiavo case
 - Bioethics seen as promoting a “culture of death”
 - Many states introduced laws restricting the right of patients or surrogates to withdraw or withhold ANH

Ethical History of ANH

- Present day: ethics of withholding or withdrawing ANH are well-defined and should be considered in context of ethical principles
 - Autonomy: patients have the right to decide to withdraw or withhold ANH
 - Beneficence and non-maleficence: decisions to withhold or withdraw ANH in patients approaching the end of life should be informed by evidence regarding its benefits and risks, and should take into account the wishes of the patient

Legal Views

- Federal regulations do not address the right to refuse ANH
- This is dictated by state law
- In states where ANH is viewed as a provision of comfort (vs. life-sustaining treatment) the PSDA may not apply
 - Greater burden of proof
- Wisconsin:
 - Advance directive may authorize withholding or withdrawing of ANH
 - Legal precedent is that other evidence may be presented in the absence of an advance directive or POLST

To Summarize

- Withdrawing and withholding ANH are considered ethically equivalent
- Withdrawing and withholding ANH are considered legally equivalent
- It remains legal in all 50 states to withdraw or withhold ANH
- Federal and State courts have consistently upheld the status of ANH as a medical intervention, and the right of patient or surrogate to forego treatment

Clinical Scenarios

End-Stage Dementia

- Common scenario: aspiration pneumonia due to dysphagia → hospitalization → placement of feeding tube
- Stated indications may include:
 - Prevent aspiration
 - Improve nutritional status
 - Improve strength
 - Promote wound healing
 - Extend life expectancy
 - Improve well-being

End-Stage Dementia

- Research evidence fails to show any of these goals are attained
- Considerable burdens may result
- Compelling body of evidence
- American Geriatrics Society, American Medical Directors Association, American Academy of Hospice and Palliative Medicine:
 - Number 1 recommendation for ABIM's Choosing Wisely Initiative is avoiding insertion of percutaneous feeding tubes in patients with advanced dementia

Widely Metastatic or Late Stage Cancer

- Generally fails to improve:
 - Anorexia/cachexia
 - Strength or functional status (ECOG)
 - Hunger or thirst
 - Nausea
 - Ability to tolerate therapy
 - Life expectancy
- Burdens often outweigh benefit

Widely Metastatic or Late Stage Cancer

- Exceptions where ANH may provide net benefit
 - Patient with good performance status, expected improvement, and:
 - Radiation enteritis (parenteral)
 - Malignant bowel obstruction (parenteral)
 - H&N cancer (parenteral or enteral)

Advanced Bulbar Amyotrophic Lateral Sclerosis

- Patients early in disease course benefit from enteral ANH
 - Relieves hunger
 - Improves quality of life
 - Extends life expectancy
- Important to consider patient's stated goals, and whether ANH will reasonably achieve those goals
- Many patients with advanced ALS regard ANH as prolonging their suffering

End-Stage Chronic Illness

- Evidence base is lacking
- Expert consensus
 - Does not prolong life
 - Does not improve quality of life
 - Harms are likely to ensue
- Recommending ANH routinely is not clinically indicated

Artificial Nutrition: Science, Literature, Data

Artificial Nutrition

- Studies show that artificial nutrition has no effect on meaningful life-prolongation, improved functional status, or quality of life in terminally ill patients
- Studies are observational or retrospective, mostly mediocre quality
 - Lack of randomized trials in palliative care literature
 - However, data is consistent that AN does not confer benefit in advanced dementia or terminally ill patients

AN in Advanced Dementia

- Dysphagia, weight loss and aspiration are common in dementia
- Aspiration is clearly established risk factor for death
 - Studies have shown 1 year mortality of >60% in patients with abnormal swallow studies
- However, tube feeding (TF) is also a mortality risk factor
 - Multiple studies show in-hospital mortality for patients who start TF is about 15-25%
 - 30 day mortality is ~25%
 - One year mortality 55-65%

AN in Advanced Dementia

- TF does not change risk of aspiration, and likely increases it
 - Aspiration pneumonia is likely due to multiple microaspirations of oral contents rather than large aspirations of gastric contents
- TF does not increase functional status or improve healing of decubitus ulcers
- TF has potential to cause harm
 - Pain at tube placement site
 - Discomfort from bloating or not tolerating feeds
 - Increased fecal incontinence
 - Decreased physical activity
 - Increased need for restraints

AN at End of Life

- Concerns that stopping AN will hasten death
 - No definitive studies
 - It is possible that AN may marginally prolong life due to hydration
 - However, patients are dying regardless of nutrition/hydration status
- Concerns about suffering from hunger or thirst
 - Multiple studies show thirst common but unrelated to food or fluid intake
 - Scarce literature regarding hunger, but anecdotal evidence is that dying patients may experience hunger only transiently
- If dying patients are hungry, then feed them by hand
 - Goal is to treat symptoms, not provide nourishment

Artificial Hydration: Science, Literature, Data

Fluid Homeostasis: Healthy Patient

- Maintenance of constant and stable composition of body fluids
- Daily fluid intake is matched to fluid loss
- Average fluid loss in an adult is 2500 mL/day
- Regulated by:
 - Kidney (~1650-1700 mL/day)
 - GI tract, lungs, skin (insensible water loss; ~800-850 mL/day)

Fluid Homeostasis: Terminally Ill Patient

- Fluid deficit etiology is usually multifactorial
- End result is total body water depletion and decreased renal function
- Two broad categories of fluid deficits
 - Dehydration (total body water depletion)
 - Hypovolemia (loss of salt and water from intravascular space)
- These may present separately or together

Clinical Manifestations

- Dying process is characterized by diminished oral intake, leading to:
 - Progressive fluid deficits, leading to:
 - Progressive accumulation of drugs and metabolites, causing:
 - New symptoms and/or exacerbating existing ones (fatigue, dizziness, sedation, hallucinations), leading to:
 - Further decline in patient's ability to take oral hydration or nutrition
- Patients will often have decreased awareness
 - Decreases perception of hunger and thirst

Signs and Symptoms

- Signs and symptoms of dehydration and hypovolemia are not highly specific in terminally ill patients
- Studies have shown:
 - Sensation of thirst associated with overall poor condition, stomatitis, oral breathing, certain medications (opioids, anticholinergics, etc.)
 - No association between thirst and objective measures (e.g., fluid intake, plasma osmolality, serum sodium/creatinine/BUN)
- This may be difficult for clinicians...we associate thirst with dehydration

Artificial Hydration

- Burdens vs benefits are not as clear-cut as artificial nutrition
- Higher quality research about AH vs AN
 - Randomized trials
- Reasonable to consider in patients with longer life expectancy or severe symptoms from dehydration
- Multiple studies show that AH does not improve outcomes at end-of-life
 - But does AH improve symptoms?

Artificial Hydration

- 2013 randomized trial of 129 patients in hospice with advanced cancer
 - Hydration arm: 1L normal saline daily
 - Placebo arm: 100mL normal saline daily
- No difference in delirium score or dehydration score (based on fatigue, myoclonus, sedation, hallucinations)
- No statistically significant difference in survival
 - 21 vs 15 days... clinically significant?
- Both groups noted improvement in symptoms at day 4
- Is six more days of life (with possible slight improvement in symptoms) significant to the patient and/or family?

Artificial Hydration

- Interviews of patients and caregivers in hydration arm of the 2013 study
- AH viewed as:
 - Hope and comfort
 - Enhancing quality of life
 - Reducing fatigue and increasing alertness
 - Reducing pain
 - “Nourishing the body, mind, and spirit”
- Patients and caregivers in placebo arm were not interviewed
- Does hydration address some of the existential distress surrounding the dying process?

Impact of AH on Symptoms

- Mostly low to mediocre quality studies available
- One small trial showed modest improvement in nausea
 - An observational study showed slower progression of dehydration symptoms, but increased incidence of edema, pleural effusion and ascites
- Lack of proven benefit, but patients and families may still request a trial of hydration

Impact of AH on Symptoms

- Thirst
 - Little correlation between hydration status and thirst in this patient population
 - No high-quality studies showing that IV fluids relieve thirst
- Delirium
 - Usually multifactorial in terminally ill patients
 - However, very distressing for patients and family
 - Some higher-quality evidence that rehydration does not prevent or improve delirium
- Sedation
 - Often due to decreased renal function and accumulation of metabolites
 - Several small studies do show benefit in reducing sedation

Burdens of AH

- Respiratory distress
- Peripheral edema
- Ascites
- Vomiting if fluids administered enterally
- Increased urine output, possibly leading to catheterization
- Pain associated with IV insertion
- Increased agitation with IV presence, possibly leading to restraints

Trial of AH

- Mode of hydration should be specific to patient's situation
- Communication about expectations is critical
 - Symptoms may not improve
 - Awareness of risks and burdens
 - What defines a perceived “improvement”
 - Timeframe (how long do we wait for a change in symptoms)
- Fluid volumes <1000mL per day appear to be relatively low-risk and can improve symptoms as much as higher volumes

Decision Making



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Approach to Decision Making

- Two important considerations
 - Views and preferences of patient and family
 - Individual goals of care
- Patient and family should be educated
 - Lack of benefit of ANH at end of life (does not change disease course or improve survival outcomes)
 - Potential for worsening of symptoms
 - It is ethical to withhold/withdraw ANH
- Emotions and concerns should be addressed
 - Patient is likely not suffering from starvation or dehydration
 - Symptoms such as dry mouth and thirst will be controlled

Why Is This So Difficult?

- Food equals love in most cultures
- Feeding the sick or vulnerable is seen as a fundamental act of dignity
 - Involves feeling of community, morality
- Hunger and thirst are universally experienced
 - Unpleasant sensations

Discussing ANH: Difficult Conversations

- Lack of knowledge by patients, families, clinicians
 - Not recognizing evidence base that exists
- Unrealistic expectations of patients and families
 - Research shows families tend to opt for less aggressive treatments when presented with all relevant information
- Emotionally laden content
 - Symbolism of caring and love
- Lack of formal training for physicians about how to have difficult conversations
 - Use a validated framework for conversation

SPIKES: A Framework for Conversation

- Developed by Dr. Rob Bruckman
- British physician and stand up comedian (!)
 - He worked with Monty Python
- Became ill with dermatomyositis and nearly died
- The emotional experience of his own illness led him to become an expert in the field of breaking bad news
- 1992: published “How To Break Bad News,” the first medical textbook on the subject
- 2003: developed SPIKES protocol

SPIKES

- **S**etting
- **P**atient perception
- **I**nformation
- **K**nowledge
- **E**mpathize and explore emotion
- **S**trategize and summarize

Discussing ANH

- Frame the medical information in context of patient's goals and specific case
 - Patient is dying of the underlying disease, not starvation or dehydration
 - Hunger, thirst, and other symptoms are unlikely to arise but can be managed if they do
 - ANH is not helping to treat the disease or prolong life
 - ANH may worsen suffering and burden
 - Decreased PO intake is an expected part of dying (normalize the process)
 - It is ok to offer PO intake as desired and tolerated
 - Discuss alternatives to ANH
 - Oral assisted feeding
 - Alternative food and fluid consistencies
 - Offer prognosis

Length of Survival

- Terminally ill patients only live for a short time following cessation of ANH
- Nursing home patients with dementia who had ANH withdrawn
 - 59% died within a week
 - 75% died within two weeks
- Prognostication may help the family to come to a decision
- It's ok to acknowledge that uncertainty exists

Make A Recommendation

- Your patients and their families will often expect this
- It is our moral obligation to make a recommendation
 - AMA Code of Medical Ethics Opinion 10.01
 - “Patients should receive guidance from their physicians as to the optimal course of action.”
 - ACP Ethics Manual
 - “The physician’s presentation should be understandable to the patient and should include the physician’s recommendation.”
- This helps the patient and family to not feel like they have to make a “life or death” decision

Make Compromises

- When patient, family and/or providers cannot agree on the best course
- Time limited trial of ANH with explicit goals
- This is most appropriate in patients with longer life expectancies or uncertainty about prognosis or role of ANH
- Continue to support patient and family
- Confirm commitment to best care for patient despite any conflict

Surrogate Decision Maker

- In the situation that there is a surrogate or proxy decision maker, “substituted judgement” should be used
- The wishes of the patient should prevail over “best interest”
- This may override beneficence
- This is why it is critical to have discussions with patients about ANH early in their disease course
 - Patient/decision maker aware of risks, benefits
 - “Informed consent”

Case Study: Conclusion



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Case Study: Conclusion

- Family conference: Attending physician establishes
 - What was important to the patient in her life
 - What the family understands about end-stage dementia
 - What the family understands about feeding tubes
- Explanation of natural course of dementia, leading to death
- Discuss complications of feeding tube insertion
- Discuss lack of proven benefit in this patient population
- Describes alternative: oral assisted feeding with appropriate consistency foods and fluids
- Family opts for oral assisted feeding and no ANH
- Patient discharged back to SNF with plan in place

References

- Andrews M, et al. Dehydration in terminally ill patients. Is it appropriate palliative care? *Postgrad Med* 1993; 93:201.
- Arenella C. Artificial nutrition and hydration: Having the conversation. *Today's Geriatric Medicine* 2014; 7(5):24.
- Brody H, et al. Artificial Nutrition and Hydration: The evolution of ethics, evidence, and policy. *J Gen Int Med* 2011; 26(9):1053.
- Bruera E, et al. Parenteral hydration in patients with advanced cancer: a multicenter, double-blind, placebo-controlled randomized trial. *J Clin Oncol* 2013; 31:111.
- Casarett D, et al. Appropriate use of artificial nutrition and hydration—fundamental principles and recommendations. *N Engl J Med* 2005; 353:2607.
- Chernoff R. An overview of tube feeding: From ancient times to the future. *Nutr Clin Pract* 2006; 21:408.
- Cohen MZ, et al. The meaning of parenteral hydration to family caregivers and patients with advanced cancer receiving hospice care. *J Pain Symptom Manage* 2012; 43:855.
- Cowen E, Simpson S and Vetesse T. Survival estimates for patients with abnormal swallowing studies. *J Gen Int Med* 1997; 12:88.
- Dy SM. Enteral and parenteral nutrition in terminally ill cancer patients: a review of the literature. *Am J Hosp Palliat Care* 2006; 23:369.
- Fainsinger RL and Bruera E. When to treat dehydration in a terminally ill patient? *Supp Ca Care* 1997; 5:205.
- Geppert C, Andrews M and Druyan M. Ethical issues in artificial nutrition and hydration: A review. *J Parenter Enteral Nutr* 2010; 34:79.
- Good P, et al. Medically assisted nutrition for palliative care in adult patients. *Cochrane Database Syst Rev* 2008; CD006274
- Grant M, et al. Gastrostomy placement and mortality among hospitalized Medicare beneficiaries. *JAMA* 1998; 297:1973.
- Marcolini E, Putnam A and Aydin A. History and perspectives on nutrition and hydration at the end of life. *Yale J Bio Med* 2018; 91:173.
- Morita T, et al. Association between hydration volume and symptoms in terminally ill cancer patients with abdominal malignancies. *Ann Oncol* 2005; 16:640.
- Murphy L and Lipman T. Percutaneous endoscopic gastrostomy does not prolong survival in patients with dementia. *Archives Int Med* 2003; 163:1351.
- Pisman HR, et al. Discomfort in nursing home patients with severe dementia in whom artificial nutrition and hydration is foregone. *Arch Intern Med* 2005; 165:1729.



Questions?



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