Quality vs. Quantity: Management of Feeding Issues in End of Life

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The Dysphagia Diagnosis

• Consult
• Diagnosis of dysphagia (moderate, severe, profound)
  • Modified diet
    • Is there a “safe” diet?
    • Does the patient want it?
  • NPO
    • Is it consistent with GOC?
    • Does the patient/family want to consider Artificial Nutrition & Hydration (ANH)?
    • Is ANH appropriate?

What is a “safe” diet?

• Thickened Liquids & modified food textures?
• Increasing research & literature stating fewer benefits to thickened liquids than previously thought
• Which is worse?
  • Aspiration thin liquids vs aspiration thick liquids
  • Aspiration thin liquids vs dehydration, discomfort, UTI’s, hyperkalemia on thick liquids
• Frazier Free Water Protocol

A Different Conversation

• Old conversation: Find a “safe” diet
• New conversation: Find the “best” diet
• How?
  • What is “best”?
  • How does the SLP help? What is our role?

The Role of the SLP

• Chronic dysphagia
• End of life situations
  • Advanced dementia
  • Cancer with poor prognosis
  • Progressive lung disease/ Chronic VDRF
  • Vegetative state
• Are we obligated to recommend ANH in the case of inability to identify a “safe” oral diet?
• What can we do instead?
  • Suggest Palliative Care consult
  • Suggest discussions regarding GOC

Patient’s Goals of Care?

• Live as long as possible?
• Live as well as possible?
**Who gets to participate in the conversation?**

- The Patient
- The Family
- The Physician
- The Speech Pathologist
- Dieticians
- Social Workers
- Chaplains
- Psychologists
- Nurses
- Pharmacists

**Who makes the decision?**

- The Patient
- The Family
- The Physician?
- The Speech Pathologist?

**What Does the Law Say?**

- In Pennsylvania ANH provided is the default
- Different from state-to-state
- What about waivers?

**Family Involvement**

- Can be helpful or can complicate the situation
- Can be purely legal or involved and supportive
- Influenced by beliefs, culture, background
  - Geography
  - Religion
  - Race
  - Cultural identity
- What is the family’s role from their point of view?

**Ethical Considerations: Patient Autonomy**

- Informed Consent (and refusal)
  - patient understands the information from the provider
  - Has the ability to understand options/ consequences
  - Able to make a choice
- Capacity
  - Decision making ability in the “now”
  - May come & go, based on pt’s condition
  - Not the same as competence (est. in a court of law)

**Artificial Nutrition & Hydration (ANH)**

- The use of enteral (PEG, G-tubes, G/J tubes) or parenteral access
- Initially conceived as a temporary means of supporting a patient through a Recovery process
- So why is it being used as a long term source of nutrition? Or in cases where recovery is unlikely?
Artificial Nutrition & Hydration cont...

- Fear of death?
- Because we don’t know how to have the conversation?

We Can provide ANH...but Should we?

- What are the goals of care?
- What would the patient want?
  - Everything to prolong life (quantity)?
  - Pleasure/comfort taking precedence (quality)?

Adverse Effects of ANH

- Decreased human contact
- Aspiration/aspiration PNA
- Tube occlusion
- Infections
- Bleeding
- Diarrhea
- Gastric perforations

Adverse Effects of ANH cont...

- Discomfort
- Nausea
- Volume overload
- Pulmonary & peripheral edema
- Skin irritation/wounds
- Agitation
- May necessitate restraints

Alternatives to ANH

- Progression to comfort care/hospice
- Allowing preferred diet
  - Role for precautions/strategies to minimize risk if possible
- Case presentation

Alternatives to ANH

- For dementia patients
  - Careful hand feeding
  - Offering preferred foods
  - Finger foods
Are they starving?

- How do we help families/patients feel more comfortable with decisions?
- How do we manage expectations?
- Natural process of withdrawal
- Facts:
  - Desire for food/fluids declines
  - Decreased feelings of hunger/thirst
  - Endogenous opiates
  - Dehydration is part of dying

Tools to facilitate GOC discussions

- There are ways to help frame/guide conversations with families and pts
- Palliative Care service they should be consulted
- Not a means of swaying them
- Helping to clarify their own thoughts/wishes
- SLP can and should be present for family meetings when possible

Best Case/Worst Case

- Best Case/Worst Case
  - Two columns
  - Head of each column both choices being considered
  - Example: thickened liquids vs thin liquids
  - List what could happen in each scenario, best case and worst case

Position Statements: ASPEN

- American Society for Parenteral/Enteral Nutrition
- 17 points including:
  - ANH may not provide any benefit and may have associated risks in patients with severe dementia
  - Artificial hydration of terminally ill patients may lead to increased discomfort
  - Healthcare professionals should not be ethically obligated to offer ANH if in their clinical judgment there is not adequate evidence for the therapy, or the burden or risk of the intervention far outweighs its benefit
  - Multidisciplinary team

Position Statement(AGS, AMDA, AAHPM): Choosing Wisely

- Based on strong evidence, the American Geriatrics Society, the American Medical Directors Association, and the American Academy of Hospice and Palliative Medicine’s No.1 recommendation for the ABIM
- The Choosing Wisely Initiative
  - The avoidance of percutaneous feeding tubes in individuals with advanced dementia
  - Offer assisted oral feeding instead

Position Statement (AGS, AMDA, AAHPM): Choosing Wisely cont…

- Strong evidence that ANH does not prolong life or improve quality of life in patients with advanced dementia
- Imposes possible burdens such as need for hospitalizations, surgical procedures, fluid overload, diarrhea, abdominal pain, local complications and less human interaction
- Fail to decrease (and possibly increase) episodes of aspiration PNA
Position Statement: ASHA

- No formal position statement on management of dysphagia/ANH in patients with dementia
- Special Interest Division 13 (Swallowing and Swallowing Disorders) does provide responses to concerns & guidance regarding this population

ASHA- SIG 13 Guidance

- Complex situations require advanced knowledge about ANH
- Decision making should be collaborative, relying on multiple medical and allied health specialties
- The patient and family wishes are central and need to be informed

ASHA- SIG 13 Guidance cont...

- Randomized trials to examine the benefits of PEG placement in dementia
  - Survivability & nutrition are main outcome measures. Survivability 80% at 1 month, 50% at 6 months, 38-40% at 1 year (Finucane & Christmas, 2000)
  - Conflicting info regarding benefit for nutrition/wound prevention
  - Does not necessarily prevent aspiration & may increase aspiration pneumonitis

Other Helpful Ideas

- Early conversations about patient values and goals
- Linked to better serious illness care
- Fewer hospitalizations
- Goal concordant care
- Earlier transition to hospice
- Better patient and family coping

The Serious Illness Conversation Guide

- Gap between what pts want and what they get
  - Pts with serious illness have priorities besides living longer
  - Most would rather be at home (86%)
  - Aggressive care is often harmful (for pts & caregivers)
  - Conversations too little, too late & not great

The Serious Illness Conversation Guide: A framework for best communication practices
**Chronic Not Terminal**
- What about persistent dysphagia in patients who aren’t dying?
- What if they refuse enteral nutrition but oral intake may result in death from respiratory infection?
- Ethical obligation to non-maleficence

**REMAP: Another Tool for Guiding Conversations**
- R: reframe: review the situation/diagnosis
- E: expect emotion: anger, sadness, attend to the pts emotions
- M: map goals: find out what the patient wants
- A: align: reflect goals back, match treatment goals to pt goals
- P: propose a plan: discuss options for meeting patient’s goals, what needs to be done

**Conclusion**
- Can’t “fix” the problem with ANH and modified consistency diets
- Can help determine what the patient’s goals are
- Provide “best” care vs “safest” care
- Managing expectations/prognosis
- Balance is key
  - Between quantity and quality
  - Recognition of when balance has shifted

**Questions?**