“Artificial Nutrition in the Setting of Advanced Dementia”

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Artificial Nutrition in the Setting of Advanced Dementia

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Learning Objectives

In case-based interactive discussion you will be able to:

- Identify the questions and concerns of families and clinicians surrounding the use of AN in patients with advanced dementia.
- Formulate two possible medical recommendations that match family preferences.
- Review literature on artificial nutrition in advanced dementia
The patient: Mr. B.

89 y/o M with Advanced Dementia

Hypertension
High cholesterol

Hospitalization (3 weeks ago)
Treated for UTI
Developed stage 1 sacral ulcer

Upon return to long term care facility
Sleeping more
Communicating less
Coughing on thin liquids
Developed fever and respiratory distress

Readmitted to hospital
Treated for aspiration pneumonia
Daughter Paula is at bedside
“Big picture” considerations:

What is happening to Mr. B?
- He has advanced dementia

Would you be surprised if he were to die within the next 6 months?
- He is at risk for dying within weeks to months.

What is Paula likely to be feeling? Is this conversation likely to be a high-intensity or low-intensity emotionally?
- High. Potential for feeling grief, fear, or perhaps even shame.

What do we know about artificial nutrition in this setting?
Review of Literature

American Academy of Hospice and Palliative Medicine

Released February 21, 2013; Revised January 14, 2021

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 healing of pressure ulcers. Feeding tube use in such patients has actually been associated with pressure ulcer development, use of physical and pharmacological restraints, and patient distress about the tube itself. Assistance with oral feeding is an evidence-based approach to provide 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.

Following the patient/families cues…

EMOTIONAL  vs.  COGNITIVE
Advanced communication skills -

Do not use the phrase “I understand…”

- 50% of clinician’s believed stating “I understand” conveys empathy, 75% of patients in prior studies perceive “I understand” statements from clinicians as dismissive and disrespectful
  - “Clinician’s views on empathy is a barrier” - Comer, A et al. Indiana University JPSM June 2020

Use empathic statements....

- “I can’t imagine how difficult this must be”
- “I wish I could make this into better news”
Emotional Cue or Cognitive Cue?

- “There must be something you can do.”
  - Respond to emotion: “I wish that I could make this into good news.”

- “I want a second opinion.”
  - Respond to emotion: “I can’t imagine how difficult this must be.”

- “We’re hoping for a miracle.”
  - Respond to emotion: “That would be awesome. If it happens, we will celebrate that miracle with you. And… is it OK if we also talk about how we will care for mom if what we’re hoping for doesn’t happen?” aligning hope / intention

*It is crucial to leave spiritual sources of strength and hope intact.*
What are the possible options for ongoing care?

Options to consider:

- Artificial feeding via PEG tube - does not positively impact weight nor pressure ulcers, may increase morbidity, does not improve survival vs those who are carefully hand fed
- Time-limited trial of tube feedings via Dobhoff / Keofeed with specific goals
- Comfort feedings: 1:1 hand feeding (every 4 hours while awake), managing symptoms, engaging Hospice and allowing natural death.
- What about TPN?
  - No. TPN is meant as a short-term intervention to foster recovery after surgery, chemotherapy, radiation etc.
Family concerns vs clinician concerns regarding AN in Advanced Dementia

What concerns families?  

What concerns clinicians?
Why do we eat?

Write top 2 reasons you eat in chat box.
Of the possible options for Mr. B, which is the best match for the reasons most of us eat?

A) Artificial feeding via PEG tube
B) Time-limited trial of tube feedings via Dobhoff / Keofeed with specific goals
C) Comfort feedings: 1:1 hand feeding (every 4 hours while awake), managing symptoms, engaging Hospice and allowing natural death.
Advanced communication skills-

Support decisional surrogates...

- A 2011 review of 40 studies looked at over 2,000 surrogate decision makers, most of whom were involved in medical decision making at end of life. **33% of those surrogates reported lasting psychological trauma associated with their experience!**

- Just giving “the facts” isn’t enough- a web based decision aid for surrogates of critically ill ventilated patient resulted in 43% choosing a more aggressive treatment plan than what they identified as the patient’s treatment preference - Dionne-Odom, PHD, RN and White, MD, MAS ‘Reconceptualizing How to support Surrogates Making Medical Decision for Critically Ill Patients. JAMA, June 1, 2021 Vol 325 No 21

Elicit substituted judgement....

- “If mom were sitting in this empty chair, what would she tell us to do?”
- “If dad was aware of his current medical condition, how would he want us to care for him?”
The patient’s story

Will each of you please type one question you would like to ask Paula in the chat box?

Let’s practice using the house model starting with relationship building and obtaining the patient’s story.......
What if Paula doesn’t accept your recommendation?

- Go up to the roof of the house: collaborative decision making
  - Affirm their decision
    - Offer a time-limited trial
      - Establish a specific endpoint

........Finish with Teach-back
Facilitating collaborative decision making

Paula: “I just feel like I’m not ready to give up on the possibility that dad might get better if we feed him. I think we should try the tube feedings.”

Clinician: “It sounds like it’s really important to you that we try tube feedings with your dad.” (affirming decision) “I’d like to suggest a time limited trial of feedings through a temporary tube x 1 week.” (timed trial) “If it is helping we would expect to see your dad being more alert and engaged with caregivers. We may consider stopping the trial early if your dad develops additional symptom burden such as agitation or shortness of breath.” (specific end point) “So that I know I’ve done a good job communicating, can you tell me in your own words what we’ve talked about?” (teach back)
Thank You!!
Identifying the Three Levels/Components of every conversation

Harvard Negotiation Project @ Harvard Business School 2012 (Difficult Conversations Publication)

**Level 1**
- What do I know about what is happening?
  - My brain needs consumable information *(use clear headlines)*

**Level 2**
- How do I feel about this information?
  - I need to feel felt *(respond to emotions)*

**Level 3**
- What does this mean to me?
  - I need help figuring this out *(recommendations that align with their goals)*
- WHAT CAN WE DO ABOUT THIS SITUATION?