Pause and Reflect …

You are seeing a patient with end-stage dementia — bed bound, no recognizable speech, incontinent. The patient’s son is insisting that a feeding tube be placed so that Dad will not “starve to death”.

Write down your feelings about such an encounter.
Learning Objectives

1. Describe the benefits and burdens of artificial hydration/feeding (ANH) at the end of life
2. Review ethical and religious issues associated with ANH
3. Discuss communication strategies with family and staff concerning EOL hydration/feeding
4. Describe a model of dealing with conflicts over ANH

Definitions

ANH refers to any route whereby food/water is provided other than chewing/swallowing.

1. Non-Oral Feeding
   Provision of food by:
   - Nasogastric Tube (NG)
   - Gastrostomy Tube (G tube)
   - Gastro-Jejunostomy (G-J tube)
   - Total Parenteral Tube (TPN)

2. Artificial Hydration
   Provision of water or electrolyte solutions by any non-oral route (intravenous, hypodermoclysis, NG/G/GJ tube)

Dying From a Chronic Illness: Facts

Weight loss in chronic diseases portends a higher mortality
   - Dementia
   - CHF
   - COPD
   - Metastatic cancer

Thus, most decisions regarding ANH near the end of life fall to families or other surrogate decision makers
Who are we feeding?

- On the rise: 15,000 in 1969, 123,000 in 1995
- Approximately 10% of older nursing home residents in US
- More commonly used in elderly dementia (26%) than elderly cancer patients (10%) in acute care setting
- Wide state variations in PEG use (7.5–40%)

Who: Risk factors

- Ethnicity (9.43)
- Pneumonia in past year (8.44)
- NH resident (4.9)
- No PC Physician (2.46)
- Pressure Ulcer (1.8)

More in Nursing Homes...

- 34% of pt-registered in MDS in 1999 with advanced cognitive impairment had feeding tubes
- Same individual risk factors found
- System issues
  - For profit residence
  - Urban location
  - >100 beds
  - Lacking dementia care unit
Why: Barriers

- Reduce aspiration pneumonia (76.4%)
- Improve pressure ulcer healing (74.6%)
- Survival (61.4%)
- Nutritional Status (93.7%)
- Functional Status (27.1%)

Other Influences

- Do Speech Therapist recommend a PEG in advanced dementia? (70%)
- Do Speech Therapists recommendations influence your decision? (66%)
- Do nurses influence your decision to recommend a PEG? (94%)
- Do nurses influence families about PEG placement? (95%)
- Do hospital nutrition teams routinely recommend PEG? (67%)

What are the benefits of PEG?

Benefits of Artificial Nutrition
- May prolong life in selected patients
- Head and Neck Cancer—Improve QOL, not mortality
- ALS—In two small studies improve QOL; median survival 5 months
- Cochrane Review—No adequate data in MD or other chronic muscle disease
- Stroke-FOOD Study—No benefit of early vs delayed PEG feeding and increase death/poor neurological outcome with PEG compared to NG
**What are the benefits of PEG? (cont’d)**

**Benefits of Artificial Hydration**
- May prolong life in selected patients
- May improve or forestall delirium
  
  Recent data in *J Clin, Oncology*

**Where PEG Does Not Help**
- Dementia/Aspiration
- Does not improve aspiration; mortality controversial
- Cancer
- Can increase weight slightly and improve nutritional markers (using both TPN, tube feeding and pharmacological means)
- Does not improve mortality
- Outliers

**Functional and Nutritional Status**

46 patients receiving PEG over 18 months
- No improvement in functional status (FIM)
- No improvement in nutritional status
- Age and serum albumin level at placement closely related to mortality?

*Dig Dis Sci. 1994;39:738-743*
Complications

- 1% mortality rate
- 3% major complication
- 13% minor complication
- 20% replacement or reposition
- 30% wound infection, buried bumper syndrome, leakage/peitotitis, gastrecolic fistula, enlargement of gastrostomy stoma, pneumoperitoneum, neoplastic seeding, foreign body skin reaction.

Death Rates

All comers
- 15% mortality rate in the hospital
- 23% mortality rate first thirty days
- 50% mortality rate 6-12 months

Dementia in Nursing Homes
- Average one hospitalization, 9 hospital days
- 1-year mortality rate is 64.1%
- Median survival of 56 days

Palliation

- 471 bed long-term care with 10 bed comfort care unit
- Outcomes were: sx of thirst, hunger, dry mouth, 11/32 pt experienced, initial hunger
- All received mouth care (candy, ice)
- No patient had ongoing hunger, all relieved with small amts of food and liquid
Summary: Benefits/Burdens

- Few medical benefits
- Substantial morbidity
- Positive psychological benefits for family

No subject provokes greater distress and uncertainty, among both families and health professionals, than issues surrounding the use of artificial nutrition and hydration in the dying person. **Why?**

Issues in Using ANH

Oral intake is a symbol

- Eating represents living; the most basic of human needs
- Family role as protector and provider, especially true for spousal relationship: “I love him, therefore I must feed him”

Confusion that withholding ANH is equal to euthanasia, assisted suicide or murder

- Fear of legal, ethical or religious misconduct
Conflicts

What happens when you are in disagreement?
- Natural reaction is an emotional one: fight or flight
- So, the first step is to notice this and let it go
- Ask yourself: “Why is this reasonable person doing something I disagree with?”

So why do families demand PEGs?
- The differential diagnosis:
  - The “what happened” conversation
  - The feelings conversation
  - The identity conversation
- In each of these three areas we make predictable errors that distort the conversation

Misunderstanding the Facts
- Who said what?
- What are the medical facts?
- Disagreements about what has happened or what should happen?
- Cognitively focused
The Truth Assumption

- The “False Consensus Effect”
  - People tend to see their own views as more common than they actually are…
- “Naïve Realism”
  - A person’s unshakable conviction that they know the truth and others will perceive it, provided they are reasonable and rational
  - The solution is to assume disagreements can be solved by saying it again

Why might the other person not understand our “facts”?

- Cognitive
  - Too many facts
  - Different information
  - Conflicting information
- Emotional factors
- Environmental factors

Dealing With These Issues

- Figure out what they know: “Could you tell me more about what others have told you is happening?”
- Be careful about language: Don’t ask what they think is happening—misses information from hopes
**Surrogates’ Expectations**

- At baseline, expectations were high (mean 3.23 on a 4-point scale)
- 96% thought improvement in nutrition
- 87% better QOL
- 90% Live Longer
- 93% health to be better
- 79% more comfortable

**Surrogates’ Expectations**

- 61% of surrogates thought 90% of death would occur within 1 year
- Baseline mean QOL = 4.6; surrogates estimated that it would rise to 8 in 6 months.
- At 3 months, 67% thought death would occur within 1 year
- At 6 months, 61% thought death would occur within 1 year

**What happened to the patients?**

- 21% died in 3 months
- 30% died at 6 months
- Age and baseline ADL predicted mortality over 6 months
Dealing With Conflicting Facts

- Remember if there are factual disagreements—both are reality!!
- Your job is to find common areas of agreement and build from that!
  - The importance of “AND”

The Feelings Conversation

- Difficult questions involve emotions
  - Love
  - Loss
  - Legacy
- Differential diagnosis of feelings
  - Guilt
  - Fear
  - Denial

How do I attend to feelings?

Nurse:
- Naming “It sounds like…”
- Understanding “I’m hearing you say…”
- Respecting “I am impressed that…”
- Supporting “I’ll be available for you…”
- Exploring “It would help me to know more about…”
Dealing with Specific Syndromes

Guilt
- Ask the right question of surrogates
- Take responsibility
- Symbolic importance of food

Denial
- Give some control
- Attend to the emotion behind the denial

The Identity Conversation

Who are we and how do we see ourselves?
- Sets up what we think our role is
- Keys frustration and satisfaction

What is the doctor’s role?
What is the daughter’s role?
- How does this affect our answering difficult questions?

As a doctor can I forgo AHN?

- There is no professional mandate to provide ANH when burden/risk is greater than benefit
- The AMA says:
  1. Life-sustaining treatment prolongs life without reversing the underlying medical condition.
As a doctor can I forgo ANH? (cont’d.)

The AMA says: (cont’d.)

2. Life-sustaining treatment may include, but is not limited to: mechanical ventilation, renal dialysis, chemotherapy, antibiotics, artificial nutrition and hydration. There is no ethical distinction between withdrawing and withholding life-sustaining treatment.

3. A competent, adult patient may, in advance, formulate and provide a valid consent to the withholding or withdrawal of life-support systems in the event that injury or illness renders that individual incompetent to make such a decision. A patient may also appoint a surrogate decision maker in accordance with state law.

www.ama-assn.org; E-2.20; Withholding or Withdrawing Life-Sustaining Medical Treatment.

Ethical and Religious Values

Withholding or withdrawing ANH IS NOT:

- Euthanasia
- Physician-Assisted Suicide

www.ama-assn.org; Policies E-2.21 and 2.211; Euthanasia, Assisted suicide.

Am I breaking the law?

Supreme Court:
ANH is a medical treatment, not ordinary care
Am I violating my/their religious beliefs?

Religious/Cultural Issues
- Most, but not all, religions and cultures recognize that when someone is dying, ANH may be withdrawn /withheld if the burden exceeds benefit.

Areas of Controversy
- Orthodox Jews
- Catholic tradition (some interpretations)

Time Limited Trial
- Find a common ground
- Define the:
  - Time of the trial
  - What counts as a positive outcome
- Requires continuity of care

Helpful Phrases for Discussing ANH
- What do you know about artificial ways to provide food?
- All dying patients lose their interest in eating in the days to weeks leading up to death, this is the body’s signal that death is coming.
- I am recommending that the tube feedings, hydration be discontinued (or not started) as these will not improve his/her living; these treatments, if used, may only prolong his/her dying.
- Your (relation) will not suffer; we will do everything necessary to ensure comfort.
- Your (relation) is dying from (disease); he/she is not dying from dehydration or starvation.
Learning Points

List 3 new things you learned from this presentation
1. 
2. 
3. 

Congratulations!

You have successfully completed the learning material for this module.

Thank you,
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