

Ethics of artificial nutrition and hydration at end of life

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Case #1 A

An 84-year-old man with advanced dementia is admitted to the hospital with aspiration pneumonia, his third episode in 6 months. He has been steadily declining, with a 10 pound weight loss over 10 months and a stage III sacral pressure ulcer. ADLs are all dependent. His wife cares for him at home, with the help of aides.

After the pneumonia resolves, a swallowing study suggests that all food consistencies are unsafe. The speech therapist suggests a PEG.

The patient's advance care plan made his wife his agent; it documents that no extraordinary measures are to be taken to extend his life, specifically, no CPR, mechanical ventilation, or artificial nutrition.

What is the most appropriate recommendation for this patient?

- A) PEG placement and discharge to a nursing facility
- B) NG placement, discharge to SNF for Part A rehab
- C) discharge home with home health
- D) discharge home with hospice

Case #2 A

A previously well 87-year-old woman comes to the ED due to dysphagia. She also has productive cough, dyspnea, elevated blood pressure, and fever. Physical examination and CXR suggest a left lower lobe pneumonia. On bedside testing, she immediately sputters and coughs after drinking a small amount of water from a cup. There are no other neurologic findings. She is mildly dehydrated and has a slightly elevated WBC count. MRI demonstrates a new brain stem infarction.

She is treated for pneumonia. A formal swallowing evaluation shows aspiration with most food consistencies. The patient's advance directive shows that she wants treatment of reversible conditions.

What is the most appropriate recommendation for this patient?

- A) PEG placement
- B) soft diet with thickened liquids
- C) TPN for 1 week
- D) oral supplements between meals

Case #3 A

The daughter of a 93-year-old woman with Alzheimer's disease calls to discuss her mother's weight loss. The patient lives with her daughter and has been demented for 6 years. Her average adult weight was 160 pounds; she weighed 122 pounds last week. She has not walked in the last 3 months and has required assistance with ADLs for the last year. Her albumin is 2.1 g/dl and her total cholesterol 93 mg/dl. Other lab tests are unremarkable. When last examined, the patient was frail and well cared for, but she did not engage with either you or the daughter.

What is the most appropriate recommendation for this patient?

- A) Prescribe nutritional supplements.
- B) Place a PEG.
- C) Prescribe megestrol 400 mg oral suspension daily.
- D) Arrange for a swallowing evaluation.
- E) Recommend hospice care.

Case #4 B

The children of a 40 year old woman with end stage multiple sclerosis come to the hospital advocating for aggressive medical care, as they have before. The patient is moaning and cannot communicate further. Her sister states that the patient never wanted aggressive medical care but underwent TRACH and PEG in a past admission. After lengthy discussions, the family opts for hospice with the mandate that patient continues tube feeding.

What is the most appropriate recommendation for this patient?

- A) Continue aggressive medical care.
- B) DC to hospice, discontinue tube feeding when she arrives.
- C) DC to hospice, continuing tube feeding.

Case # 5 B

A 90 year old female nursing home resident has been losing weight. The nursing home suggests PEG placement on the grounds that the treatment will keep the patient strong and prevent weight loss.

Two months later, the patient is hospitalized with pneumonia. At the hospital, she decompensates and is intubated before her daughter can arrive.

An ethics consultant is consulted and speaks with the daughter. She explains that she never wanted the PEG in the first place, but now she feels uncomfortable withdrawing the patient.

Case # 6 B

A 60 year old male nursing home resident with schizophrenia is hospitalized with aspiration pneumonia. A surgeon recommends PEG.

There was no speech involved, no psych involved and no family. The patient loved food, per nursing home. The patient had infection and respirator issues. No other pertinent comorbidities

Ethics is consulted to discuss what patient wants. He states “I don’t want to live with wires”

He does not understand implications of aspiration. Psych declares no capacity

Tube feeding (PEG, NG) may be most helpful in patients with:

severe head injury/trauma and unclear prognosis

stroke (selected patients)

severe proximal bowel obstruction

short bowel syndrome

severe critical illness (“Trach & PEG”)

ENT cancers who are undergoing aggressive chemo/surgery/
radiation therapy

selected congenital or neuro-degenerative conditions

chronic vegetative states

Beneficial effects of ↑ ketones

Analgesia, probably via release of endogenous endorphins

“Religious or inspirational experience”

Euphoria

Alertness, preservation of mental function until late

↓↓ **Hunger**

Nutritional support in cancer

In more than 30 trials of both TPN and PEG feeding in cancer patients, the intervention did not alter mortality or morbidity. However, they were twice as likely to have an infection, and the tumor response rate was lower.

In patients with esophageal/gastric/pancreatic cancer, a trial of parenteral nutrition support started pre-operatively showed a reduction in post-op complications.

Perhaps explain this as

The cancer is using all of her calories, or

She isn't dying because she's not hungry, she isn't hungry because she is dying.

TPN in cancer: a guideline

Consider a trial of TPN in cancer patients when ***all of these criteria are met***:

bowel obstruction, short bowel, or malabsorption, where it is likely that death by starvation would occur earlier than death from disease progression, and enteral nutrition is not possible

life expectancy of at least months and TPN duration ≥ 6 weeks

high quality of life

sufficient functional status and home environment:

- ★ other problems manageable at home
- ★ Karnofsky score ≥ 50
- ★ family member/other to assist with care
- ★ easy monitoring for clinical follow-up and labs
- ★ family can cognitively and psychologically manage TPN at home
- ★ home environment clean and safe

FOOD trials (Feed or ordinary diet)

2 randomized, non-blinded trials of patients with acute stroke (< 7 days), with dysphagia

Excluded sub-arachnoid hemorrhage

Stratified by country, age (< 75 years, >75), gender, predicted probability of poor outcome

Followed for six months

Primary outcome = death or poor outcome

Modified Rankin Scale: stroke recovery

- 0** no symptoms at all
- 1** no significant disability despite symptoms, able to carry out all usual duties & activities
- 2** slight disability, unable to carry out all previous activities but able to look after own affairs w/o assistance
- 3** moderate disability, requiring some help, but able to walk w/o assistance
- 4** moderately severe disability, unable to walk w/o assistance & unable to attend to own bodily needs w/o assistance
- 5** severe disability, bedridden, incontinent, requiring constant nursing care & attention
- 6** dead

Poor outcome = MRS Grades **4-6** for *dysphagic* stroke

The FOOD trials

Trial 1: *clinician uncertain when to start tube feeding*

- ✦ R → early enteral feeding (PEG or NGT)
- ✦ → avoid tube feeding for at least a week

Trial 1: *clinician uncertain whether to use PEG or NGT*

- ✦ R → PEG within 3 days
- ✦ → NGT within 3 days

Trial 1

859 pts (mean age 76 years) with new (< 7 days) dysphagic stroke randomized to

- ◆ early tube feeding – PEG or NGT within 3 days, or
- ◆ avoid tube feeding for at least 7 days

Outcome	Early (n = 429)	Avoid (n = 430)	Odds Ratio (95% CI)
MRS 4-5 (poor outcome)	157 (37%)	137 (32%)	1.15
Dead (MRS 6)	182 (42%)	207 (48%)	0.79 (0.60 - 1.03)
MRS 4-6	339 (79%)	344 (80%)	0.93 (0.67 – 1.30)

Conclusion: Avoid early use of tube feeding in dysphagic stroke patients.

Trial 2

321 pts (mean age 76 years) with new (< 7 days) dysphagic stroke.

Clinician chose to use tube, unsure whether to use PEG or NGT.

Randomized to

- ◆ PEG within 3 days, or
- ◆ NGT within 3 days

Outcome	PEG (n = 162)	NGT (n = 159)	Odds Ratio (95% CI)
MRS 4-5 (poor outcome)	65 (40%)	53 (33%)	1.20
Dead (MRS 6)	79 (49%)	76 (48%)	1.04 (0.67 – 1.61)
MRS 4-6	144 (89%)	129 (81%)	1.10

Conclusion: If tubes are used, use either NGT or PEG.

In advanced dementia, tube feeding does not:

prevent aspiration pneumonia,

prolong survival,

prevent or improve pressure sores,

reduce the risk of infection,

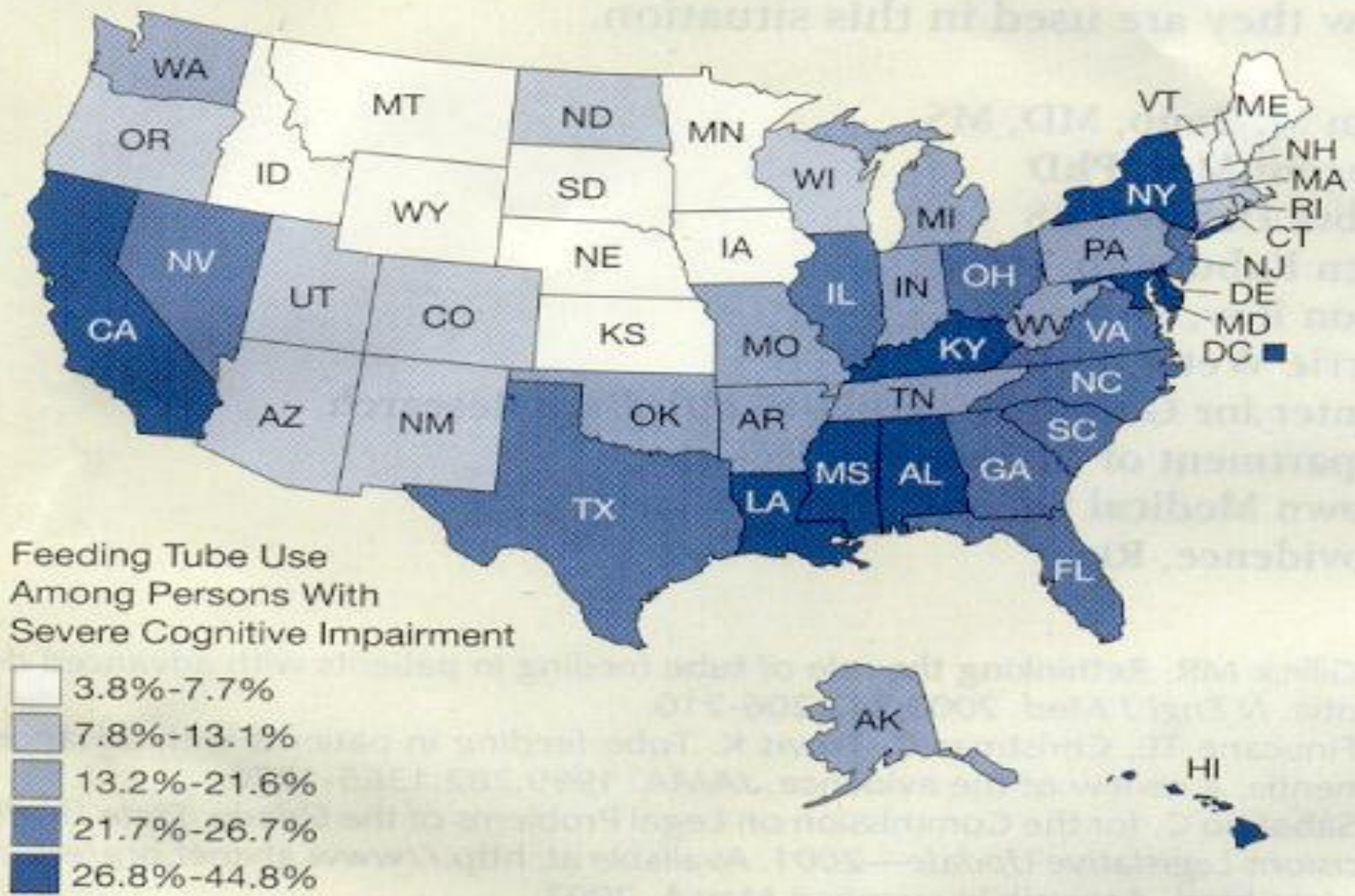
improve functional status or

make patients more comfortable.

Functional Assessment Staging (FAST) in patients with dementia A

- 1 no objective or subjective difficulties
- 2 subjective forgetfulness
- 3 decreased job functioning, difficulty traveling to new locations
- 4 loss of IADLs
- 5 requires assistance to choose clothes
- 6a cannot dress without assistance
- 6b cannot bathe without assistance
- 6c cannot toilet without assistance
- 6d incontinent of urine
- 6e incontinent of bowels
- 7a speech < 6 intelligible words
- 7b speech only 1 intelligible word
- 7c unable to independently ambulate
- 7d cannot sit up independently
- 7e cannot smile
- 7f cannot hold head up independently

How they are used in this situation



Prepared by Brown Medical School, Center for Gerontology and Health Care Research.

Aspiration pneumonia & feeding tubes

518 NH patients NOT critically ill, no rapidly terminal illness, severe CHF/lung disease, or artificial feeding

152 got video-swallowing evaluations (VSE)

96 women, 56 men, mean age 86 years

reason:	oropharyngeal dysphagia	81
	esophageal symptoms	19
	abdominal symptoms	52

Definitions

Aspiration = barium entering laryngeal ventricle

Minor aspiration = small volume, inconsistent

Major aspiration = large volume, consistent

Pneumonia = new infiltrate lasting ≥ 5 days, plus supporting clinical picture

Pneumonia & feeding tubes, cont.

For the 100 with dysphagia, speech pathologist intervened - alter diet, behavioral/environmental change, rehab, positioning, tube feeding.

Results of evaluation: 51 nonaspirators, 51 minor aspirators, and 51 major aspirators.

All major aspirators were recommended for tube feeding.

Follow-up for 36 months. Repeat VSE if symptoms changed.
Periodic visits by speech pathologist.

Results

Endpoint	Category			
	No aspiration	Minor aspiration	Major aspiration/ oral	Major aspiration/ tube
% Pneumonia/ month	7 (0.6%)	13 (0.9%)	14 (1.3%)	22 (4.4%)*
Death	7 (19%)	9 (24%)	21 (45%)*	26 (87%)*
Pneumonia as cause of death	3/7 (43%)	3/9 (33%)	7/21 (33%)	14/26 (54%)*

Does TF prevent malnutrition?

In 17 trials of advanced cancer pts given parenteral nutrition, no trial showed survival benefit.

Megestrol in AIDS patients improved nutritional markers, but mortality is double that of controls.

In 40 LTC patients receiving total parenteral nutrition, adequate calories and protein were provided... Still, subjects showed weight loss and severe depletion of lean and fat body mass."

NO

Is survival improved by TF?

Survival of very low weight, hand-fed demented patients is substantial.

Many demented patients are inadequately hand-fed.

Tube-feeding is often used because it is more convenient than hand-feeding.

Feeding tube placement is associated with death.

Mortality among tube-fed patients is high.

Cohort study of 16,000 NH patients over age 65 with advance cognitive impairment and a new need for assistance in feeding, controlled for confounders.

median survival 17 days among tube-fed and hand-fed

Are pressure sores prevented by TF?

Correlation between nutritional markers (weight, albumin, etc.) and pressure sores is weak.

Correlation between nutrient intake and pressure sores is weak.

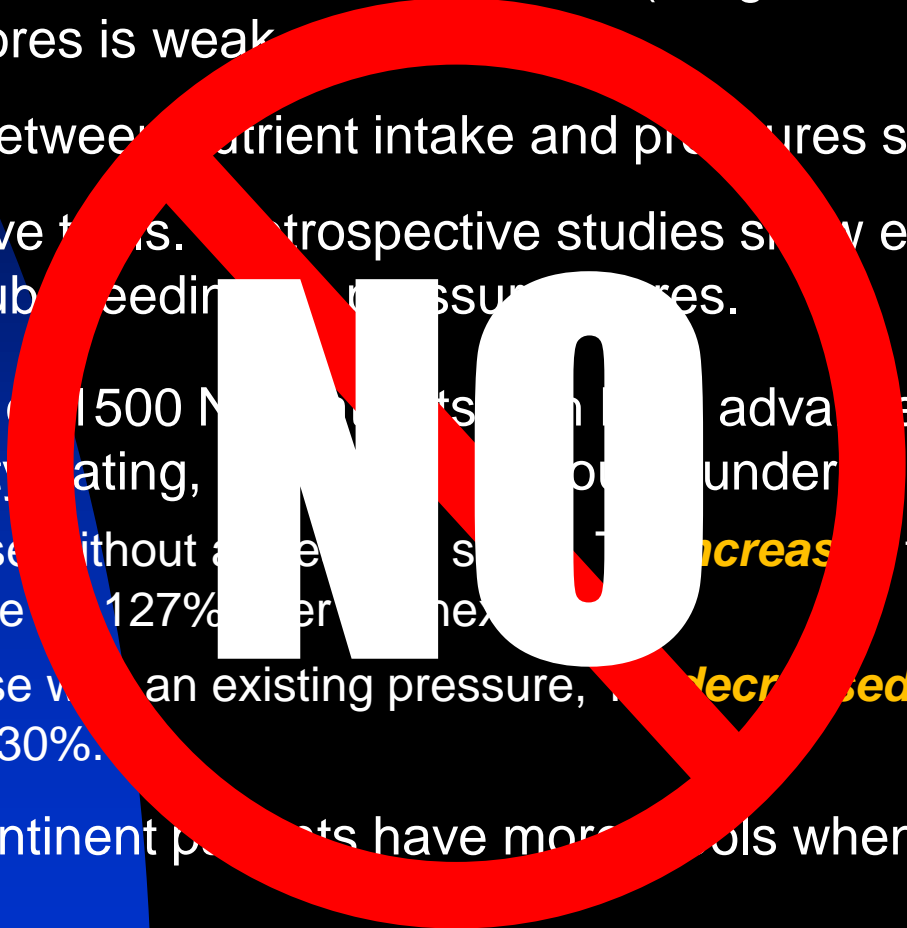
No prospective trials. Retrospective studies show either increased or no benefit of tube feeding for pressure sores.

Cohort study of 1500 Medicare patients with advanced cognitive impairment and difficulty eating, comparing tube feeding to oral feeding under

Of those without a pressure sore, tube feeding **increased** the risk of a new pressure sore by 127% over the next 6 months.

Of those with an existing pressure, tube feeding **decreased** the likelihood of healing by 30%.

Bedfast, incontinent patients have more falls when tube-fed.



NO

Is the risk of infection reduced by TF?

There are no studies showing reduced infection risk.

Feeding tubes can cause otitis, sinusitis, diarrhea, cellulitis, skin abscess, & necrotizing fasciitis.

Enteral formula can be contaminated because of lax.

PEG insertion can cause bacteremia.



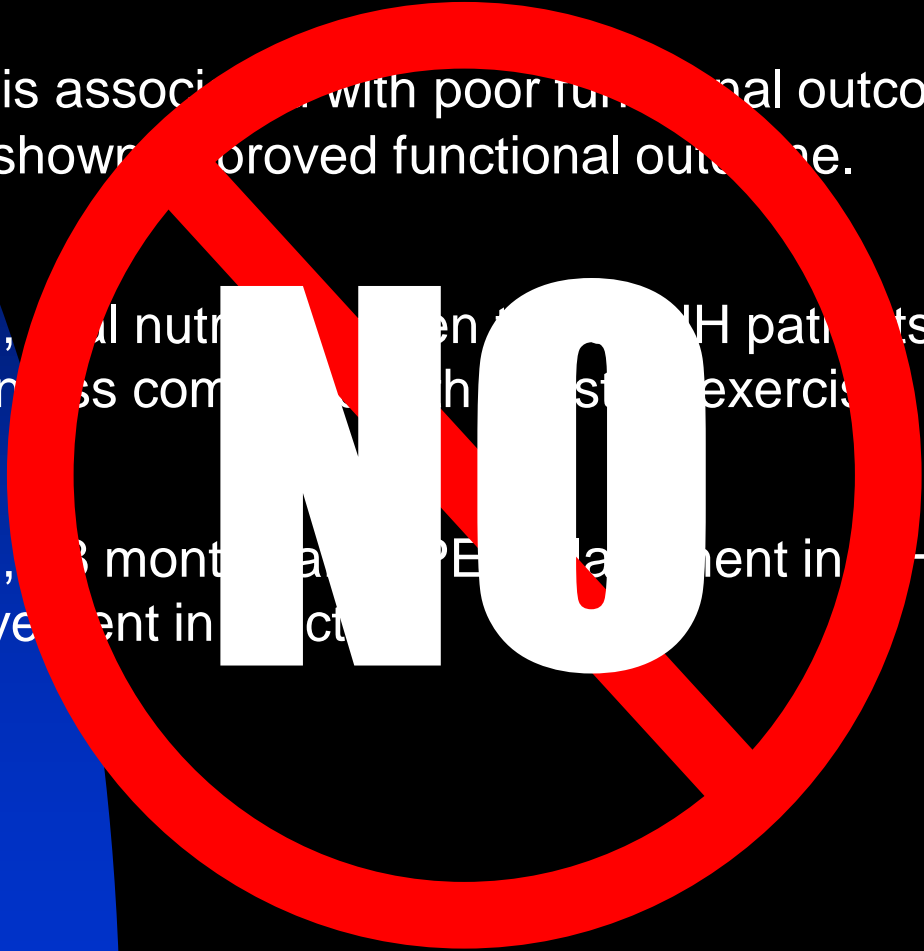
NO

Can TF improve functional status?

Malnutrition is associated with poor functional outcome, no nutritional study has shown improved functional outcome.

For example, oral nutritional supplements in CH patients did not improve function, unless combined with structured exercise.

For example, 8 month oral PE supplementation in CH patients, no patient had improvement in function.



Does TF improve comfort?

In a prospective observational study of palliative care of terminally ill patients with anorexia (cancer, stroke), few experienced hunger or thirst.

In ALS patients with dysphagia, who were tube-fed, aspiration pneumonia increased and hunger and nausea worsened.

No study suggests that dysphagic or tube-fed patients are more comfortable with tube feeding.



NO

Benefits of tube feeding in dementia:

none

No effect or an increase in aspiration pneumonia

No reversal of the consequences of malnutrition

No difference in survival

No improvement in pressure sore outcomes

No reduction in infectious complications

No improvement in functional status

No beneficial effect on patient comfort or suffering

So what is the clinician to do?

Complications of TF

Knotting of tube, tube migration, tube discomfort

Tube placement failure

Aspiration of feeding

Diarrhea, gastrointestinal bleeding, bowel obstruction

Nausea, vomiting, increased gastroesophageal reflux

Fluid overload

Increased skin moisture

Use of restraints

Choosing Wisely

Guideline from both the American Geriatrics Society and the American Academy of Hospice & Palliative Medicine, based on the ABIM Foundation's Choosing Wisely campaign.

Recommend against percutaneous feeding tubes in patients with advanced dementia; instead, offer assisted oral feeding.

In advanced dementia, studies have found that 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 pharmacologic 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.

Eligibility for Medicare Hospice in patients with dementia A

FAST 7c (unable to independently ambulate, with loss of everything above that) PLUS

At least one of the following:

- aspiration pneumonia

- upper tract UTI

- septicemia

- pressure sores, multiple, stages 3-4

- recurrent fever after treatment with antibiotics

- malnutrition – weight loss > 10% over prior 6 months or serum albumin < 2.5 g/dl)

Stanford criteria for Medicare Hospice in patients with dementia A

Patient must be dependent in all ADLs and either living in a nursing home or admitted to the hospital

Plus at least one of the following:

malnutrition (BMI < 18.5 kg/m², ↓ PO intake, or weight loss

≥ 1 pressure ulcer

≥ 1 comorbid illness

male gender **and** age > 90 years

placement of an NG or PEG tube, due to inability to eat or history of aspiration pneumonia

Counseling about ANH in dying patients

ANH is not a basic intervention that can be administered by anyone, like food. Rather, it is a medical therapy administered for a medical indication that is performed by trained personnel, like other surgical procedures.

Unlike the provision of food, warmth, or shelter, ANH has uncertain risks and benefits, and it generally causes discomfort.

In dying patients, the goal of ANH is not to enhance comfort.

Comfort feeding only

No tube feeding, no artificial hydration & nutrition, do not tube feed can be interpreted as *no care*, rather than focusing on what will be done – careful hand feeding to promote comfort and respect the patient’s wishes.

Reframe the order as “comfort feeding only” (CFO)

It emphasizes the patient will be fed as long as it is not distressing.

It refers to the goals of the feeding.

The case of Mrs. P

Mrs. P is a 92-year-old NH resident with advanced dementia, FAST 7D. She presents with increasing difficulty in eating. She pockets food and occasionally chokes on her food. A speech therapist has changed her diet, yet she continues to have difficulty with eating and is losing weight.

Physician: “Mr. P, I know this might be difficult for you, but I’m sure you’ve noticed that your wife has been having increasing difficulty eating, and I feel it’s important that we discuss what we might expect for her in the next several months. Over the past weeks, the nurses have noted her choking on her food despite modifying the food textures. This is causing her distress.”

Mr. P: “Yeah, I noticed she’s been having a harder time when I’ve tried to feed her as well. Do you think she’ll get better?”

Physician: “As we’ve discussed, dementia is a progressive illness that always results in death. This means that we do not expect her condition to improve, and her condition will inevitably worsen over time.”

Mr. P: “How much time do we have left?”

Physician: “It’s difficult to say exactly. I can’t tell you when she will die, but it’s something you should prepare for. Her bout with aspiration pneumonia last month and her current difficulties swallowing are not good signs. Over the next few months, we can expect that her eating difficulties will progress to the point that she is unable to safely swallow either food or fluids.”

Mr. P: “So we’ll have to put her on a feeding tube?”

Physician: “That is an option. However, the best available evidence suggests that for patients such as your wife, a feeding tube would not prolong her life, reduce her chances of getting pneumonia again, or even prevent her from getting malnourished. Feeding tubes also cause complications. The tube could make her agitated, or it could become blocked, requiring a trip to the emergency department. She might also have nausea, vomiting, or reflux, and it’s possible that a serious infection or severe diarrhea would require her to be hospitalized.”

Mr. P: “That doesn’t sound like the way she would want to live, but else can we do?”

Physician: “Another option is to focus on keeping your wife comfortable through feeding her by hand instead of through a tube. We call this order Comfort Feeding Only. The goal of this order is to focus on your wife’s comfort and provide feeding to her as long she is not showing signs of distress like choking or coughing. If hand feeding causes her distress, the person feeding her will stop. Over time, of course, her ability to eat will further decline. This is the natural progression as someone approaches the end of life. The Comfort Care Order places a premium on her comfort during meals; she will still likely continue to lose weight.”

Mr. P: “It sounds like that might be best, all considering. If it was me, I would just want to be comfortable.”

Physician: “What do you think your wife would decide for herself if she could?”

Mr. P: “She always told me not let her linger or suffer when her time came, to just let her go.”

Physician: “I understand. Based on what you have told me, I recommend that she be made Comfort Feeding Only.”

Mr. P: “Yeah, it’s what she would have wanted.”

Ethical considerations B

ANH is not a basic intervention that can be administered by anyone, as food is.

Rather, ANH is a medical therapy used for a medical indication (e.g., dysphagia), with the use of devices placed by trained personnel.

Unlike provision of food and other comforts (warmth, shelter), ANH has uncertain benefits and considerable risks and discomfort.

The goal of ANH is almost never the patient's comfort.

ANH is a choice.

Patient preferences B

It is often harder to withdraw than withhold; however, consider a trial of ANH.

If the patient lacks decision-making capacity, the surrogate should use “substituted judgment.”

Decisions about ANH should not be held to a higher standard of evidence (some state laws require this).

- same approach to benefits and risks

- most people have not left written instructions

Without an advance directive, the assumption should not automatically be to provide ANH.

Palliative care *without* ANH B

Most patients will not have increased symptoms when ANH is withheld or withdrawn.

Aggressively manage discomfort and other symptoms.

Hunger & thirst – ice chips, mouth rinse, moistened swabs

Altered mental status – reducing noise, orienting cues, pharmacologic treatment

Comprehensive palliative care, including hospice.

Institutional policies B

Nursing homes with lower ANH use:

- home-like, not institutional environment, centered on food as an important part of every day life
- adequate mealtime staff who value hand-feeding
- advance care planning

Hospitals with lower ANH use:

- not-for-profit
- smaller size
- less ICU use
- palliative care services

Ways to improve decision-making B

Better communication between providers and patients.

ANH decisions, especially in NHs, need to be shielded from financial and regulatory pressures.

State laws should allow the same standard of evidence for ANH as other medical decisions.

Promote advance directives that include preference for ANH.

Patient preferences need to be transferrable among institutions (POLST).

Starting ANH in dying patients B

When the patient/decision maker, after receiving counseling, chooses this intervention to reflect personal values.

When the primary goal is to maximize the quantity of life.

When the patient is stable/improving, or the evolution of the disease is uncertain. Consider a trial.

As a short-term intervention (e.g., for acute neutropenic infection, perioperative use).

When a patient can't swallow and remains hungry/thirsty.

When delirium may be due to dehydration.

To maintain life for a period, while the decision maker struggles with end-of-life decisions.

When there is no decision-maker, or no consensus.

When the quality of life is good, as defined by the decision maker.

Steps in decision-making B

Clarify the clinical situation – dementia is terminal, feeding problems are end-stage, other comorbidities, modifiable factors (e.g., dentures)

Establish the primary goal of care – life prolongation, maximizing function, comfort?

Present treatment options, with benefits/burdens

Weigh options against patient values and preferences – what would the patient want? Advance directives? Promote cultural/religious sensitivity.

Provide ongoing decision support – re-address decision as course evolves, engage inter-disciplinary team, use outside advisors, decision aids

Burden versus Benefit of Care B

Care that is appropriate for a patient at one time may be inappropriate at end of life.

Treatment becomes overly burdensome when

- Pain and suffering outweighs the benefit

- Treatment will not prolong life with reasonable quality of life

To assess burden versus benefit, it is important to know a patient's wishes

- Relayed directly from patient

- Advanced Directive, POLST, etc.

- Health care proxy

ANH and Decision Making B

ANH does not always offer any benefit for the patient at end of life

ANH generally causes discomfort for patients at end of life

For the patient's family, food is often a way to nurture

Families may have a hard time understanding reasons to make decisions against artificial nutrition

Food is laden with social norms. It does not feel good to stop feeding a loved one.

B Culture and Religion Matters...

ERDs

56. “A person has a moral obligation to use ordinary or proportionate means of preserving his or her life.”
57. “A person may forgo extraordinary or disproportionate means of preserving life.”
58. There is an obligation to provide food, water, and ANH for patients unless the patient, “cannot reasonably be expected to prolong life or when they would be ‘excessively burdensome for the patient or [would] cause significant physical discomfort.’” At end of life, ANH may become, “excessively burdensome and therefore not obligatory.”

[Citation?]

Things to Remember B

Early conversations and POLST completion

Educating through churches and community meetings

Allowing out-of-box situations for compassion of family and protection of the family

Your thoughts...

QUESTIONS??