Dysphagia Management in Individuals with Dementia

2020 South Carolina Speech Language Hearing Association Convention
February 13, 2020

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Objectives:

1. Consider literature on the effects of diet modification for individuals with dementia with dysphagia
2. Identify research that contraindicates the use of long-term enteral nutrition in the advanced dementia population
3. Recognize how culture plays a role in shaping end-of-life approaches
4. Discuss how SLPs can facilitate discussions regarding goals of care for those with dementia

Case Study: T. P.

- 81yo AAF admitted 10/24 with c/o SOB, decreased PO intake
  - PMH: Advanced AD, COPD
  - 24/7 care
  - Progressive decline: stage 1 sacral ulcer x1 wk, unable to ambulate x1 month, FTT x1-2 mths
- Dx: SIRS without infection, SVT, AKI possibly d/t dehydration

Case Study: T. P.

- 10/25:
  - BSE: Nectar-thick liquids, puree snacks
  - MD: “Family is set on” PEG
  - GI evaluation. PEG tentatively planned 10/28
- 10/26:
  - Continue diet
  - “Daughter wants every form of aggressive measure including feeding tube”
- 10/27:
  - Thin liquids with puree snacks
  - “Son is leaning towards feeding tube”

Case Study: T. P.

- 10/28:
  - “They have not come to a decision if they want a feeding tube”
  - Dietician: severe muscle fat wasting
  - Initial PC evaluation
  - PEG placement attempted
- 10/29
  - PEG placed
  - Family requested tx evaluations for rehab

Case Study: T. P.

- 10/30
  - PT: More appropriate for hospice vs rehab
  - PC: Not rehab candidate
  - MD note: “Per PC notes, the patient's son is aware of her poor prognosis but this is not made apparent to me…as he still thinks that she will go to rehab.”
  - Hospice consulted
- 11/4:
  - Son deferred hospice
  - D/c’ed on Path program
  - Full code

Case Study: T. P.

- Readmission 12/9
- Dx: Severe sepsis with borderline septic shock
  - Suspected 2/2 large sacral decubitus ulcer (exposed bone)
- Persisting leukocytosis despite abx
  - “Family still wanted to continue aggressive care”
  - Poor candidate for sx
- D/c on hospice
  - “Primary dx of E coli sepsis”
  - Continue abx, TF

What could have been done differently?

Dementia Overview

“a syndrome resulting from acquired brain disease… characterized by a progressive decline in memory and other cognitive domains that, when severe enough, interferes with daily living and independent functioning.”

(ASHA)

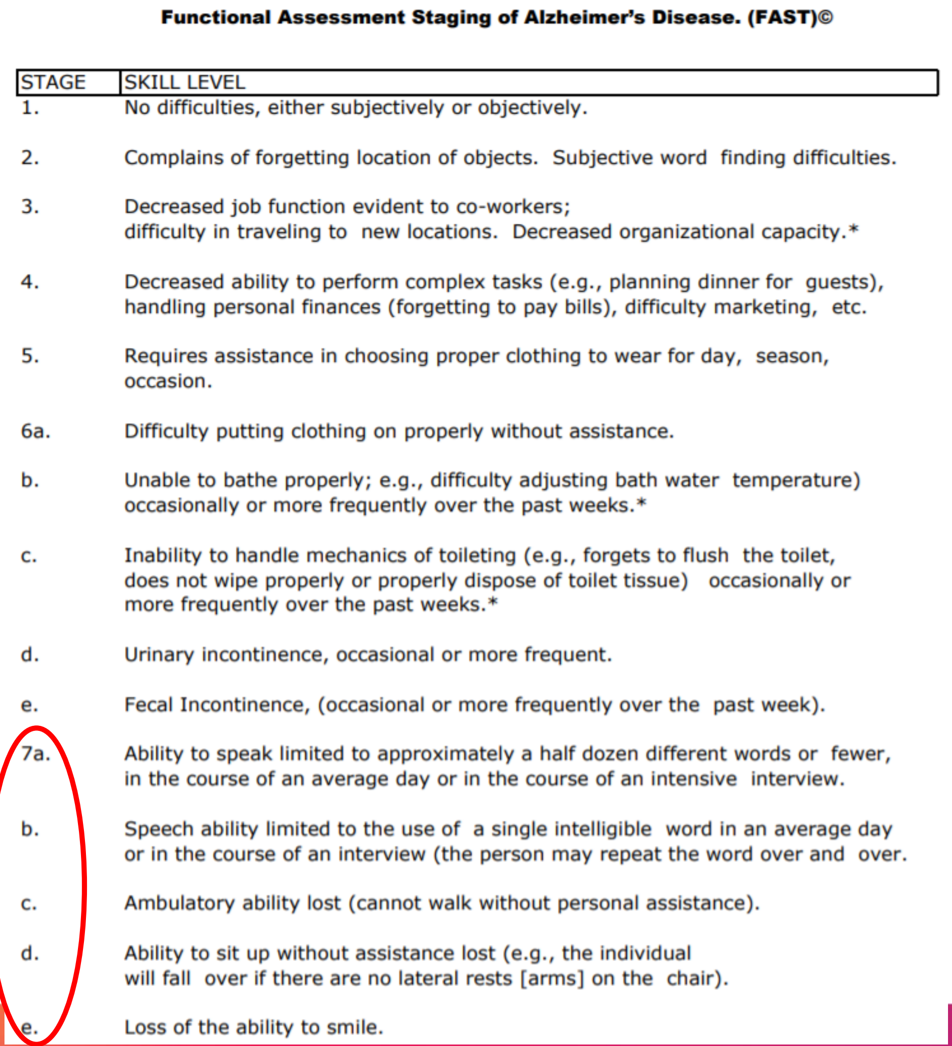
Dementia Overview

- Prevalence:
  - 50M people worldwide ; 152M in 2030
  - 5.8M Americans ; 13.8M in 2050
- 6th leading cause of death in the US
  - Variable survivability
- In 2019, $290 billion cost in US
  - $1.1 trillion by 2050

(World Health Organization; Alzheimer's Association)

Types of Dementia

- Alzheimer’s disease
- Vascular
- Lewy body dementia
- Frontotemporal dementia
- Huntington’s disease
- Parkinson’s disease



Functional Assessment Staging of Alzheimer's Disease. (FAST)©

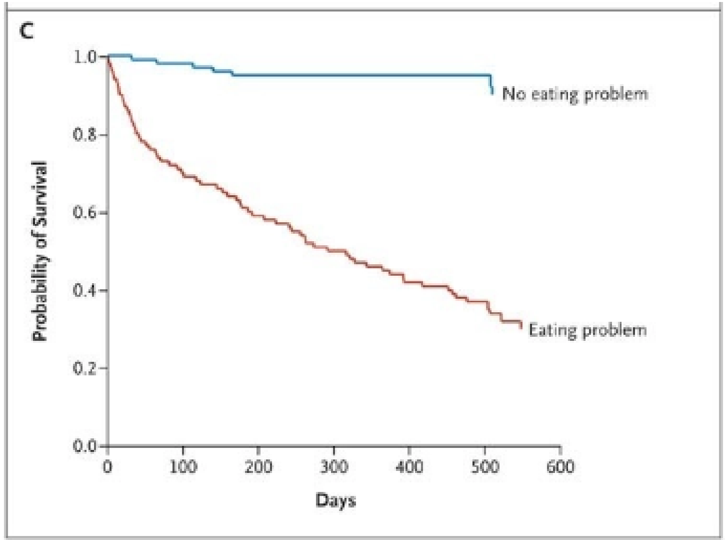
STAGE	SKILL LEVEL
1.	No difficulties, either subjectively or objectively.
2.	Complains of forgetting location of objects. Subjective word finding difficulties.
3.	Decreased job function evident to co-workers; difficulty in traveling to new locations. Decreased organizational capacity.*
4.	Decreased ability to perform complex tasks (e.g., planning dinner for guests), handling personal finances (forgetting to pay bills), difficulty marketing, etc.
5.	Requires assistance in choosing proper clothing to wear for day, season, occasion.
6a.	Difficulty putting clothing on properly without assistance.
b.	Unable to bathe properly; e.g., difficulty adjusting bath water temperature) occasionally or more frequently over the past weeks.*
c.	Inability to handle mechanics of toileting (e.g., forgets to flush the toilet, does not wipe properly or properly dispose of toilet tissue) occasionally or more frequently over the past weeks.*
d.	Urinary incontinence, occasional or more frequent.
e.	Fecal Incontinence, (occasional or more frequently over the past week).
7a.	Ability to speak limited to approximately a half dozen different words or fewer, in the course of an average day or in the course of an intensive interview.
b.	Speech ability limited to the use of a single intelligible word in an average day or in the course of an interview (the person may repeat the word over and over.
c.	Ambulatory ability lost (cannot walk without personal assistance).
d.	Ability to sit up without assistance lost (e.g., the individual will fall over if there are no lateral rests [arms] on the chair).
e.	Loss of the ability to smile.

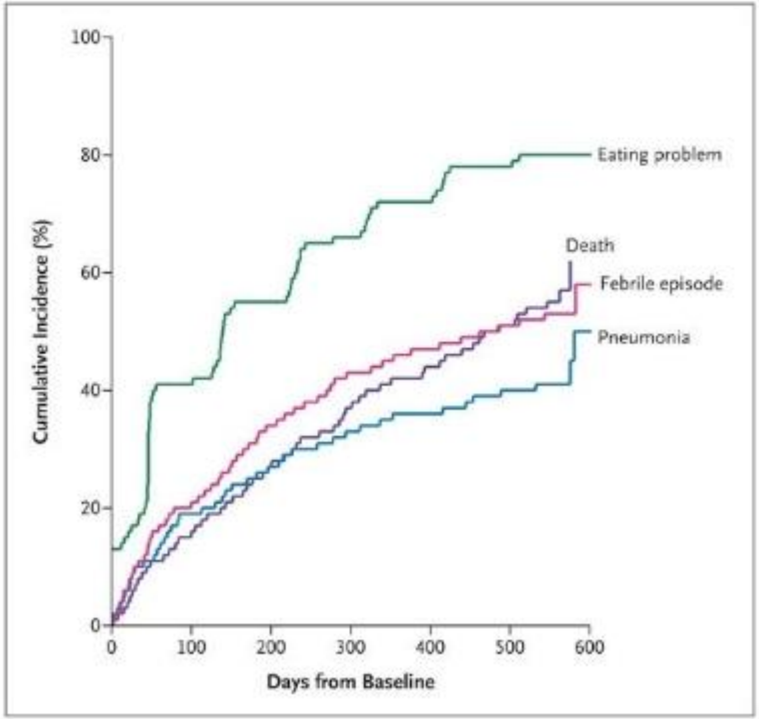
Severe
dementia

Dysphagia Trends in Dementia

Dysphagia is correlated with end-of-life (Mitchell et al., 2009)

- Only 7 sentinel occurred during last 3 months of life





Dysphagia Trends in Dementia

- Systematic review:
  - Prevalence of dysphagia in dementia patients: 13-57%
    - In long-term care facilities: Up to 53%
      - 68% silent aspiration
- CSE overestimated and underestimated aspiration

(Alagiakrishnan et al., 2013)

Thickened Liquids and Aspiration Elimination

- In order of effectiveness:
  - Honey-thick > Nectar-thick > Thin with chin tuck
  - More likely to aspirate HTL when presented last
- 55% participants aspirated all
  - 20% did not aspirate
- Importance of VFSS

(Logemann et al., 2008)

To Modify or Not to Modify?

- Hines et al., 2009
  - “Cautiously inferred” that thickened fluids are effective for residents with dementia
    - Participants had no weight loss (2 studies)
    - Increased dehydration risk

Considerations for Diet/Liquid Modifications

- Aspiration
- Nutrition/hydration
- PO acceptance
- Quality of Life

American Geriatrics Society Position Statement

“Feeding tubes are not recommended for older adults with advanced dementia...hand feeding is at least as good as tube feeding for the outcomes of death, aspiration pneumonia, functional status, and comfort. Tube feeding is associated with agitation, greater use of physical and chemical restraints, greater healthcare use due to tube-related complications, and development of new pressure ulcers.”

- AMN does not prevent aspiration PNA

  (Langmore et al., 1998; Sampson et al., 2009; Dharmarajan et al., 2001)

- Increased rates of PNA for pts who were NPO with AMN versus eating orally
  - PNA due to aspiration of reflux or secretions

  (Langmore et al., 2002; Sampson et al., 2009)

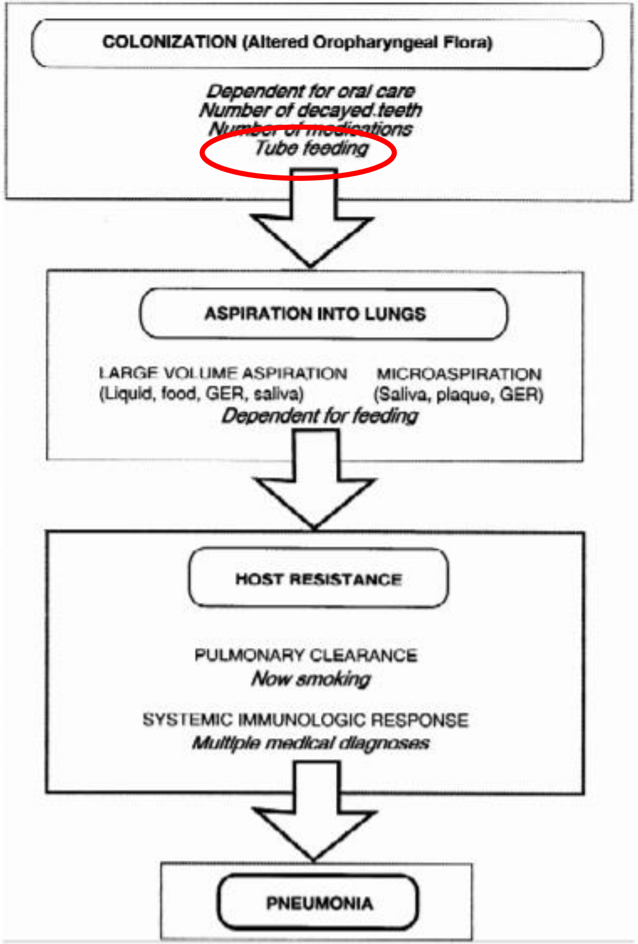


Fig. 1. Significant predictors of aspiration pneumonia (in bold italics) positioned in the model.

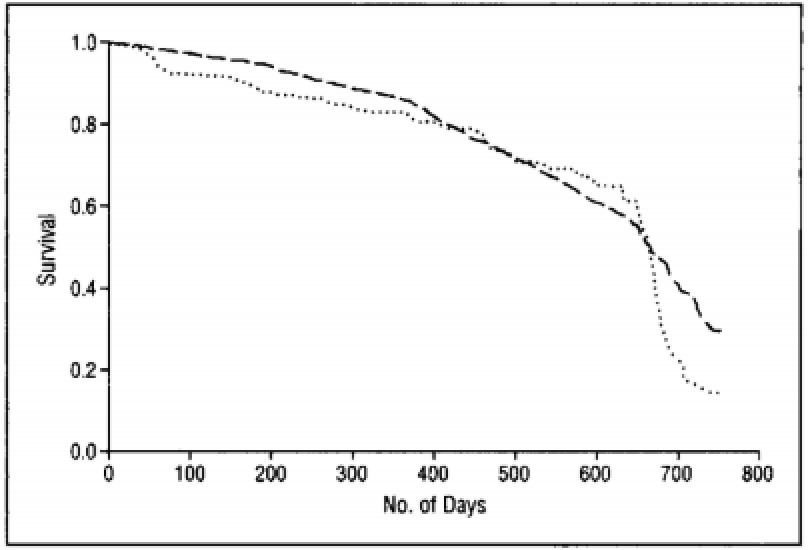
Mortality Comparison: PEG versus No PEG

Median survival:
(+)PEG = 59 days
(-)PEG = 60 days

Median mortality at 6 months:
(+)PEG: 195 days
(-)PEG: 189 days

Mortality at 6 months:
(+)PEG: 44%
(-)PEG: 26%

Only 50% survive >6 months s/p PEG



A 24-month survival comparison of residents with severe cognitive impairment with (dotted line) and without (dashed line) feeding tubes.

(Goldberg & Altman, 2014; Mitchell et al., 1997)

Effects on Nutrition

- PEG made no difference in BMI or body composition (Kimyagarov et al., 2013)
- NGT with no effect on BMI, albumin levels, hematocrit, cholesterol, hemoglobin (Sampson et al., 2009)

Minimal Intake during End-of-Life

- Hunger and thirst were only present in a minority of pts
  - Thirst > hunger
    - Satisfied with small amounts of intake
  - Overeating resulted in abdominal discomfort and nausea
- 84% were comfortable until death; 13% had “some discomfort”
- Conclusion: Patients with terminal illness can experience comfort despite minimal PO intake

(McCann et el., 1994)

Comfort Feeds

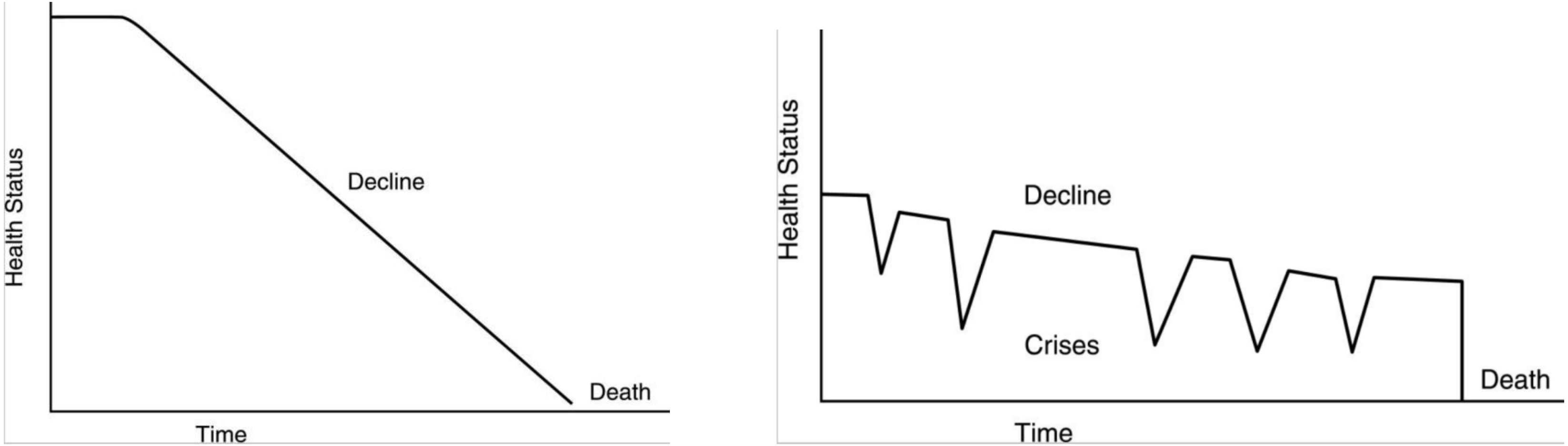
- Benefits to decreased PO intake during end-of-life:
  - Decreased nausea/vomiting, abdominal pain, diarrhea
  - Less urinary output
  - Decreased pulmonary secretions
  - “Mild euphoria” leading to increased pain tolerance
  - Manageable symptoms of discomfort
  - Unconscious state resulting in death

(McCann et el., 1994; Hoefler, 2000)

How comfortable are we with discussions regarding comfort feeds?

Challenges to Recognizing End-of-Life for Dementia

- Not viewed as a terminal illness
  - Longer time from diagnosis to death
  - Not seen as the cause of death



Death trajectory in cancer versus chronic diseases

(Sachs et al., 2004)

Challenges to End-of-Life Care for Dementia

- Treatments are usually routine, relatively inexpensive, effective
  - Difficult to forego
- Unknown pt's wishes
- Prolonged care and bereavement

(Sachs et al., 2004)

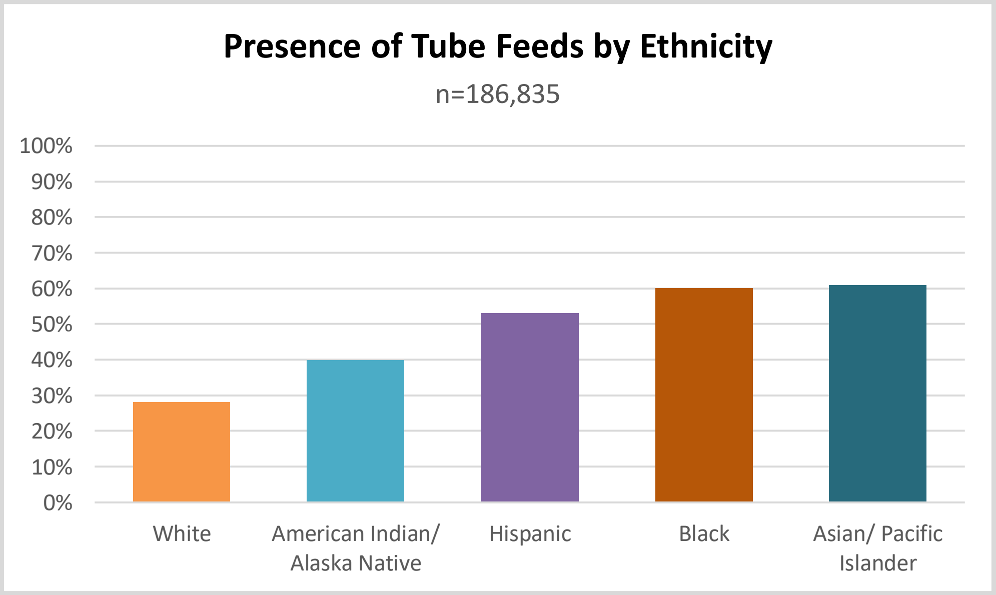
Challenges to End-of-Life Care for Dementia

- Lack of medical knowledge
- Difficult for medical staff to discuss end-of-life
- Death perceived as a medical failure instead of as a part of life

(Reinhardt et al., 2014)

The Role of Ethnicity

- Ethnic minority groups have higher rates of artificial nutrition within dementia populations



(Connolly et al., 2012; Mitchell et al., 2003)

The Role of Ethnicity

- More likely to receive aggressive care in last 90 days of life
- Less likely to have advanced directives
- Ethnicity of physicians played a role

(Mitchell et al., 2003)

Ethnicity and Attitudes towards Life-Sustaining Technology

- More positive attitude towards life-sustaining technology:
  - High religiosity
  - Lower educational level
  - Lower income

- Less positive attitude:
  - Personal experience with illness or withholding care

(Blackhall et al, 1999)

Ethnicity and Attitudes towards Life-Sustaining Technology

- European-Americans: Least likely to accept and personally want life-support
  - Avoid lack of control and being a burden
  - Fear of being a “vegetable”

- Mexican-Americans: More positive about life-support and more likely to personally want it
  - Believed that life support would not be suggested if the case was truly hopeless

(Blackhall et al, 1999)

Ethnicity and Attitudes towards Life-Sustaining Technology

- Korean-Americans: Very positive regarding life-support but did not personally want it
  - Decision made by the family
  - Family is obligated by filial piety to prolong life

- African-Americans: In favor of withdrawing life support but personally wanted it
  - Distrust towards health care system

(Blackhall et al, 1999)

Ethnicity and Attitudes towards Life-Sustaining Technology

- Note: variations within ethnic groups affected by life experiences, SES, gender, access to care, etc.

- Consider stating a recommendation in addition to providing options

(Blackhall et al, 1999)

Ethnicity and Attitudes towards Life-Sustaining Technology

- Double disadvantage of dementia and ethnic minority status

- Factors contributing to use of life-sustaining treatments:
  - Mistrust of medical providers
  - Fear of under-treatment
  - Poor communication of advance directives to minorities by health care providers
  - Different cultural attitudes towards death and dying

(Connolly et al., 2012; Mitchell et al., 2003)

Caregivers' Perceptions

- Caregivers who believed patients had <6 months to live and understood dementia's clinical course were less likely to pursue aggressive interventions

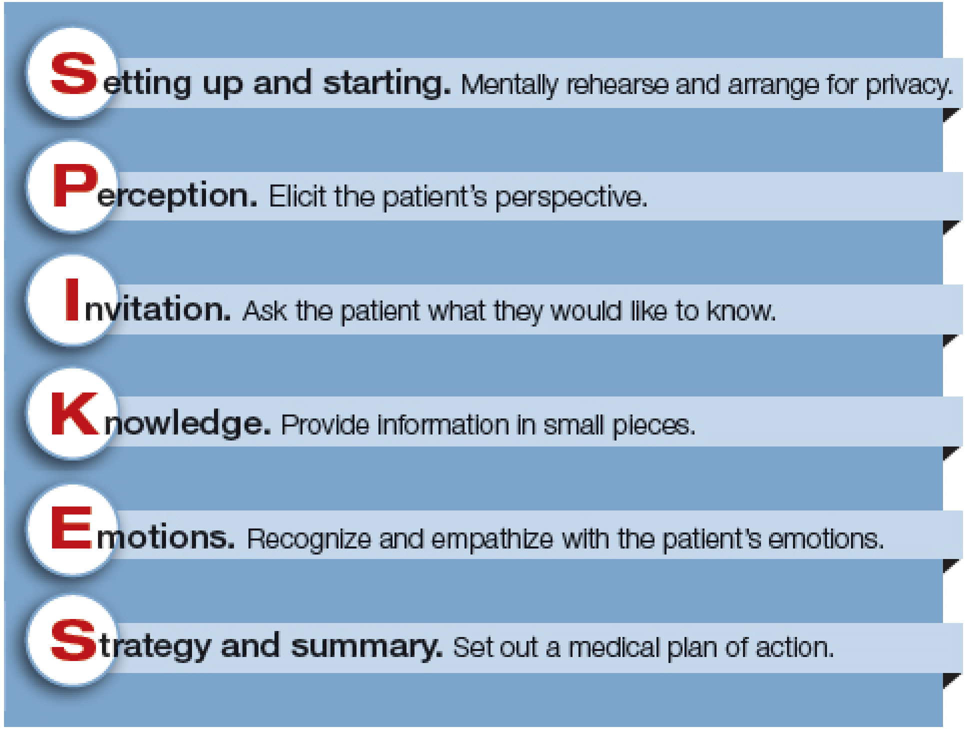
(Mitchell et al., 2009)

Palliative Care (PC)

- Structured, face-to-face discussions between PC team and family resulted in:
  - Higher symptom control
  - Advanced directives with trend towards comfort care
    - DNR, DNI, DNH, no Feeding Tube
  - Higher satisfaction with care

(Reinhardt et al., 2014)

Facilitating Decision-Making Discussions



Setting up and starting. Mentally rehearse and arrange for privacy.

Perception. Elicit the patient's perspective.

Invitation. Ask the patient what they would like to know.

Knowledge. Provide information in small pieces.

Emotions. Recognize and empathize with the patient's emotions.

Strategy and summary. Set out a medical plan of action.

Reframe the Discussion: “Starvation” Versus Comfort Feeds

- Typical dichotomy:
  - Care versus no care. Feed versus don’t feed.

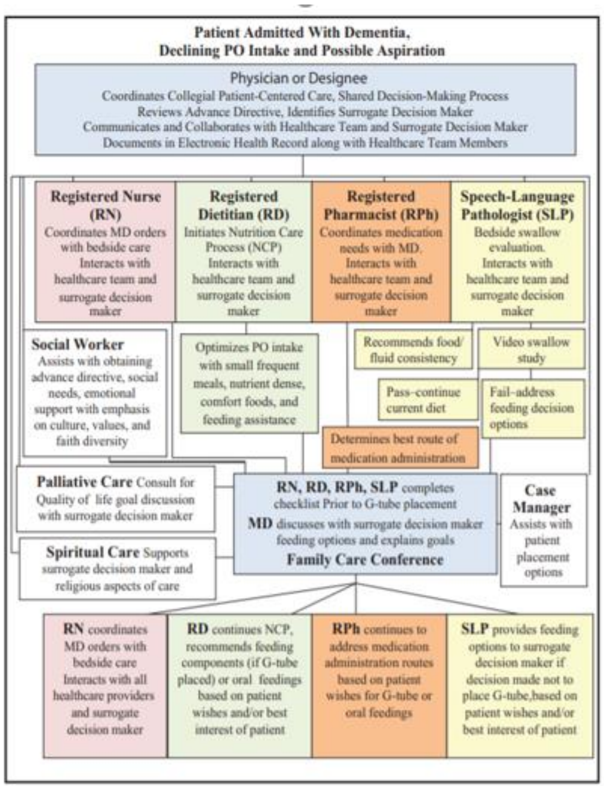
- Reframe:
  - Not withholding care but promoting comfort

Facilitating Decision-Making Discussions

- Change our verbiage
  - “Consider pleasure feeds given advanced dementia and progressive nature of disease. Consider conversation regarding goals of care given that tube feedings are not typically recommended in this population.”

- Open the door to conversation

Multidisciplinary Decision-Making



Patient Admitted With Dementia, Declining PO Intake and Possible Aspiration

Physician or Designee
Coordinates Collegial Patient-Centered Care, Shared Decision-Making Process
Reviews Advance Directive, Identifies Surrogate Decision Maker
Communicates and Collaborates with Healthcare Team and Surrogate Decision Maker
Documents in Electronic Health Record along with Healthcare Team Members

Registered Nurse (RN) Coordinates MD orders with bedside care Interacts with healthcare team and surrogate decision maker

Registered Dietitian (RD) Initiates Nutrition Care Process (NCP) Interacts with healthcare team and surrogate decision maker

Registered Pharmacist (RPh) Coordinates medication needs with MD. Interacts with healthcare team and surrogate decision maker

Speech-Language Pathologist (SLP) Bedside swallow evaluation. Interacts with healthcare team and surrogate decision maker

Social Worker Assists with obtaining advance directive, social needs, emotional support with emphasis on culture, values, and faith diversity

Optimizes PO intake with small frequent meals, nutrient dense, comfort foods, and feeding assistance

Recommends food/ fluid consistency

Video swallow study

Pass–continue current diet

Fail–address feeding decision options

Determines best route of medication administration

Palliative Care Consult for Quality of life goal discussion with surrogate decision maker

Spiritual Care Supports surrogate decision maker and religious aspects of care

RN, RD, RPh, SLP completes checklist Prior to G-tube placement
MD discusses with surrogate decision maker feeding options and explains goals
Family Care Conference

Case Manager Assists with patient placement options

RN coordinates MD orders with bedside care Interacts with all healthcare providers and surrogate decision maker

RD continues NCP, recommends feeding components (if G-tube placed) or oral feedings based on patient wishes and/or best interest of patient

RPh continues to address medication administration routes based on patient wishes for G-tube or oral feedings

SLP provides feeding options to surrogate decision maker if decision made not to place G-tube,based on patient wishes and/or best interest of patient

(Schwartz et al., 2014)

“The autonomy of the patient or surrogate decision maker should be respected and considered above all other ethical principles. Emphasis should be placed on functional status and quality of life. Cultural, religious, social, and emotional sensitivity is essential in the process.”

(Schwartz et al., 2014)

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