Ethical and End of Life Issues with Advanced Illness: Feeding tube use, overuse, & care approaches

Joseph W. Shega, MD

Financial Disclosure

• Financial Disclosures
  • The speaker is receiving a small honorarium from ISHA to present this topic

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  • The speaker has no nonfinancial disclosures

Objectives

• Appreciate trajectories of advanced illness and factors associate with poor prognosis
• List factors that contribute to the rapid growth of feeding tubes in individuals with advanced illness and conditions for which feeding tubes have and have not been shown to be effective
• Utilize effective strategies to overcome the challenge of feeding tube overuse
• Suggest alternatives to feeding tubes for individuals who are at high risk for dysphagia and aspiration but with a goal of comfort feeding and no tube
• Incorporate an ethical framework when considering swallowing issues in advanced illness
Rehabilitation Roles and SLP

- Preventive
- Restorative
- Supportive – ongoing decline for illness, maintain function as much as possible
- Palliative – advanced disease and near the end of life minimize complications and enhance quality of life


Dysphagia Increases Risk of Death

Trajectories of Advanced Illness
Theoretical Trajectories of Dying


Prognosis Considerations

<table>
<thead>
<tr>
<th>Clinical judgment</th>
<th>Would you be surprised if this patient passed within 6 months?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nutrition</td>
<td>20% of normal body weight in 6 months, 5% in 1 month</td>
</tr>
<tr>
<td>Physical function</td>
<td>Dysphagia</td>
</tr>
<tr>
<td>Cognition</td>
<td>PPS, ADL (3/4), Falls</td>
</tr>
<tr>
<td>Health care utilization</td>
<td>ED, hospital, clinic</td>
</tr>
<tr>
<td>Symptoms</td>
<td>Delirium, shortness of breath, and fatigue</td>
</tr>
<tr>
<td>Disease-specific decline</td>
<td>Cardiac, pulmonary, dementia, end, Cancer, liver disease, AIDS</td>
</tr>
</tbody>
</table>

Dementia: Epidemiology

- Current estimate: 5.1 million in US (ADAMS)
  - 3.2 million women
  - 1.8 million men
- Projected for 2050: 14 million
- 1 in 3 women will develop dementia during her lifetime
- Almost 1/3 of people over age 85 have dementia
- Someone new develops dementia every 67 seconds in the US
Dementia at the End of Life

- 1 in 3 older adults who die each year have a diagnosis of dementia
- Diagnosis of dementia cuts one's life expectancy in half
- 5th leading cause of death in persons over the age of 65
- 500,000 dementia deaths per year in US attributed to dementia

Etiologies of Dementia in the US

<table>
<thead>
<tr>
<th>Dementia Diagnosis</th>
<th>Relative Frequency</th>
<th>Pathophysiology</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer's disease</td>
<td>35-55%</td>
<td>amyloid plaques and neurofibrillary tangles</td>
</tr>
<tr>
<td>Mixed-vascular and Alzheimer's disease</td>
<td>25-35%</td>
<td>Combination of Alzheimer's disease and vascular disease</td>
</tr>
<tr>
<td>Lewy Body Dementia</td>
<td>0-30%</td>
<td>alpha-synuclein protein</td>
</tr>
<tr>
<td>Vascular Dementia</td>
<td>10-20%</td>
<td>cortical infarcts, subcortical infarcts, and leukoaraiosis</td>
</tr>
<tr>
<td>Frontotemporal Dementia</td>
<td>&lt;5%</td>
<td>tau protein</td>
</tr>
</tbody>
</table>

Dysphagia Impact

- Poor nutritional status
- Dehydration
- Pulmonary complication

Median survival was 478 days, 24.7% within 6 mos
54.8% died, 93.8% in NH
6 mo mortality 38.6%
6 mo mortality 44.5%
6 mo mortality 46.7%

Natural History of Dementia

Tube Feed Insertion Rates NH Residents with Advanced Dementia

Mitchell SL JAMA 316 (7) 2016
Questions Generated

Do feeding tubes:
- prevent aspiration pneumonia?
- prevent malnutrition?
- decrease the mortality rate?
- prevent pressure sores or hasten their healing?
- improve patient comfort?
- improve functional status?

Do Feeding Tubes Prevent Aspiration Pneumonia - No

- No RCT of the intervention has been done
- No data shows feeding tubes decrease the risk of aspiration pneumonia
- Still have aspiration of oral secretions
- Not shown to reduce the risk of regurgitated gastric contents

Studies of Tube Feeding and Aspiration Pneumonia

Aspiration pneumonia rates in tube fed vs orally fed:

<table>
<thead>
<tr>
<th>Study</th>
<th>Pts</th>
<th>F/U</th>
<th>Tube</th>
<th>Oral</th>
</tr>
</thead>
<tbody>
<tr>
<td>Croghan</td>
<td>22</td>
<td>1yr</td>
<td>66.6%</td>
<td>14.3%</td>
</tr>
<tr>
<td>Peck</td>
<td>104</td>
<td>6mo</td>
<td>58%</td>
<td>17.0%</td>
</tr>
</tbody>
</table>

Effect of History of Aspiration Pneumonia in Tube Fed Patients

Aspiration pneumonia rates in tube fed patients by history of prior aspiration or not:

<table>
<thead>
<tr>
<th>Study</th>
<th>Pts</th>
<th>F/U</th>
<th>+ History</th>
<th>- History</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jamagin</td>
<td>60</td>
<td>6mo</td>
<td>37.5%</td>
<td>11.1%</td>
</tr>
<tr>
<td>Weltz</td>
<td>100</td>
<td>Death</td>
<td>11.1%</td>
<td>7.3%</td>
</tr>
<tr>
<td>Cogen</td>
<td>109</td>
<td>Var</td>
<td>40.7%</td>
<td>17.0%</td>
</tr>
<tr>
<td>Hassett</td>
<td>87</td>
<td>54mo</td>
<td>62.1%</td>
<td>29.3%</td>
</tr>
</tbody>
</table>


Why Tube Feeding May Not Decrease Aspiration Pneumonia

- Cricopharyngeal incoordination
- Decreased esophageal motility
- Altered esophageal sphincter tone
- Impaired gastric emptying
- Ineffectiveness of elevation of head of bed

Questions Generated

Do feeding tubes:

- prevent aspiration pneumonia?
- prevent malnutrition?
- decrease the mortality rate?
- prevent pressure sores or hasten their healing?
- improve patient comfort?
- improve functional status?
Studies of Tube Feeding and nutrition

• 40 LTC residents lost weight and depleted lean body mass over 1 year despite tube feeding
• Despite adequate formula, micronutrient and protein malnutrition existed
• Pressure ulcer number unchanged
• Chronic disease, immobility, and neurologic deficits probably undermine nutritional support


Studies of Tube Feeding and nutrition

• 126 pts receive a PEG, 75% neurologically impaired and dependent in ADL’s
• Over 1 year, improvement in albumin of 1g/dl occurred in only 13.4% of pts; 5% had a decline
• No significant improvement in any nutritional parameters
• Stabilization of nutritional status may have occurred

Callahan C. Et al. Outcomes of PEG Among Older Adults in a Community Setting JAGS 2000

Questions Generated

Do feeding tubes:
prevent aspiration pneumonia?
prevent malnutrition?
**decrease the mortality rate?**
prevent pressure sores or hasten their healing?
improve patient comfort?
improve functional status?
Does Tube Feeding Prolong Survival Significantly - No

- No published studies suggest tube feeding prolongs survival in dementia patients with dysphagia
- Mortality rates following PEG placement in older adults with significant neurologic burden remains consistently high
  - 30-day 20-40%
  - 6-month 50%

Survival Between NH Residents With and Without Feeding Tube: Logistic Regression

Survival Between NH Residents With and Without Feeding Tube: Propensity Matching
Questions Generated
Do feeding tubes:
prevent aspiration pneumonia?
prevent malnutrition?
decrease the mortality rate?
**prevent pressure sores or hasten their healing?**
improve patient comfort?
improve functional status?

PEG Tubes and Pressure Ulcers in Advanced Cognitive Impairment
• Compared to patients without PEG tubes placed, those with PEG tubes
  –2.27 times more likely develop pressure sore
  –0.70 times less likely to have existing sore heal

Why Not?
• Tube fed patients can have increased incontinence which can increase risk of pressure ulcers
• Tube fed patients produce more urine, stool, and upper airway secretions
• Tube fed patients are more likely to be restrained
Questions Generated

Do feeding tubes:
- prevent aspiration pneumonia?
- prevent malnutrition?
- decrease the mortality rate?
- prevent pressure sores or hasten their healing?
- improve patient comfort?
- improve functional status?

Does Tube Feeding Increase Patient Comfort – No
- Unable to communicate with advanced dementia patients, so one must extrapolate from others
- In hospice literature, only transient hunger and thirst in patients who stop eating – can be relieved with ice chips and swabs
- Cancer patients feel worse with enteral feeding
- Older adults impaired thirst mechanism

McCann R et al. Comfort Care for Terminally Ill Patients: The Appropriate use of Nutrition and Hydration. JAMA, 1994

Dementia, Discomfort, and Cessation ANH

Pasman H et al. Discomfort in Nursing Home Patients with Severe Dementia in whom Artificial Nutrition and Hydration is Forgone. Arch Intern Med 2005
Feeding Tube Complication

- **PEG short-term**
  - Local irritation
  - Infection 4-16%
  - Peg Occlusion 2-34%
  - Aspiration 0-66%
  - Bleeding
  - Reflux
  - Diarrhea 12%
  - Tube migration

- **PEG long-term**
  - Restraint use
  - Diminished QOL
  - Frequent replacement/removal
  - No oral intake
  - Limit socialization
  - Poor mouth care
  - Burdensome transitions

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Overuse: Barriers & Solutions

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Physician Knowledge

- **Agree:** Dementia is a terminal diagnosis 78%
- **But:**
  - Reduced aspiration pneumonia 76%
  - Improved pressure ulcer healing 75%
  - Improved survival 61%
  - Improved nutritional status 94%
  - PEG is standard of care 51%
  - PEG should be standard of care 28%
SLP Knowledge

Agree, PEG Tubes:
- Reduced aspiration pneumonia: 46%
- Improved pressure ulcer healing: 47%
- Improved survival: 43%
- Improved nutritional status: 78%
- Are standard of care: 38%
- PEG should be standard of care: 15%

Sharp and Shags ASNP 2009

Table 1. Adjusted Odds of Feeding Tube Insertion Among Nursing Home Residents with Advanced Crematosis Improvement Resulting in Regions Varying on Rate of Health Care Transitions*

<table>
<thead>
<tr>
<th>Quantile of health care transitions</th>
<th>Mean rate of health care transitions per 100 decedents</th>
<th>Adjusted odds ratio</th>
<th>95% confidence interval</th>
</tr>
</thead>
<tbody>
<tr>
<td>1st Quantile</td>
<td>254.6</td>
<td>Reference</td>
<td></td>
</tr>
<tr>
<td>2nd Quantile</td>
<td>307.7</td>
<td>1.1</td>
<td>0.95-1.7</td>
</tr>
<tr>
<td>3rd Quantile</td>
<td>329.0</td>
<td>1.3</td>
<td>1.1-2.3</td>
</tr>
<tr>
<td>4th Quantile</td>
<td>559.6</td>
<td>1.9</td>
<td>1.5-2.4</td>
</tr>
<tr>
<td>5th Quantile</td>
<td>451.3</td>
<td>2.3</td>
<td>2.0-3.2</td>
</tr>
</tbody>
</table>

*Adjusted for efficacy, gender, order of care transitions, restrictions on the use of artificial hydration and nutrition, medical diagnosis, skill level of nursing, activities of daily living, weight loss, and the number of health care transitions. Functional status (MOS-CHISS) is improving or declining, and the MDS-CHISS score.

Financial Incentives

- Initial placement $2,200/person
- Complications year after insertion $2449/person
- New feeding tubes qualify for 100 days of Medicare skilled nursing benefits
- Medicaid per diem reimbursement higher for persons with TF ($190 vs. $151/day)

Decision-Making and Outcomes after PEG

Decision Itself
- 71.6% reported no conversation
- Risks not discussed 1/3 cases
- Discussion shorter 15 minutes
- 51.8% thought MD strongly in favor of tube placement
- 12.6% felt pressure by MD to place tube
- Worse end of life care

Adverse Outcomes
- Improved QOL 32.9%
- Patient bothered 39.8%
- Physical restraint 25.9%
- Chemical restraint 29.2%
- ED due to tube placement 26.8%
- Feelings related to tube placement
  - Regret 23.4%
  - Right decision 61.9%

Caregiver’s Perspective
- Feeding tubes are inevitable
- There are no alternatives
- Only aware of procedural risk
- Unclear about the patient’s prognosis
- Expect TF will improve comfort, nutrition, and longevity

Tube Feeding Rates by Ethnicity

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>2000</th>
<th>2001</th>
<th>2002</th>
<th>2003</th>
<th>2004</th>
<th>2005</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>124</td>
<td>123</td>
<td>120</td>
<td>118</td>
<td>116</td>
<td>114</td>
</tr>
<tr>
<td>Black</td>
<td>86</td>
<td>87</td>
<td>88</td>
<td>89</td>
<td>90</td>
<td>91</td>
</tr>
<tr>
<td>Asian</td>
<td>125</td>
<td>126</td>
<td>127</td>
<td>128</td>
<td>129</td>
<td>130</td>
</tr>
</tbody>
</table>

Source: JAGS 2011
Decision-Making

1. Review the clinical situation
2. Establish the Goals of Care
3. Present options to manage feeding problem
4. Weighing risks and benefits with values and preferences
5. How is the decision affecting the family member
6. Offer additional sources of decisional support
7. Provide ongoing support and recognize the need to revisit the decision

Cervo et al. Geriatrics 2006; Teno et al Health Aff 2015

Educational Intervention and Decisional Conflict

<table>
<thead>
<tr>
<th>Variable</th>
<th>Initial</th>
<th>Adjusted</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>65.12</td>
<td>65.12</td>
<td>0.99</td>
</tr>
<tr>
<td>Gender</td>
<td>Female</td>
<td>0.45</td>
<td>0.45</td>
</tr>
<tr>
<td>Education</td>
<td>Low</td>
<td>0.34</td>
<td>0.34</td>
</tr>
<tr>
<td>Income</td>
<td>Low</td>
<td>0.34</td>
<td>0.34</td>
</tr>
<tr>
<td>Health status</td>
<td>Poor</td>
<td>0.34</td>
<td>0.34</td>
</tr>
<tr>
<td>Decisional conflict (4-7)</td>
<td>High</td>
<td>0.34</td>
<td>0.34</td>
</tr>
<tr>
<td>Communication</td>
<td>Poor</td>
<td>0.34</td>
<td>0.34</td>
</tr>
<tr>
<td>Family support</td>
<td>Low</td>
<td>0.34</td>
<td>0.34</td>
</tr>
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<td>Decisional conflict (4-7)</td>
<td>High</td>
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<td>0.34</td>
<td>0.34</td>
</tr>
</tbody>
</table>

Cervo et al. Geriatrics 2006; Teno et al Health Aff 2015
Encourage physicians, patients, and other health care stakeholders to think and talk about medical tests and procedures that may be unnecessary, and in some instances can cause harm.

Five things physicians and patients should question:

1. Don’t recommend percutaneous feeding tubes in patients with advanced dementia; instead offer oral assisted feeding.

2. Don’t recommend percutaneous feeding tubes in patients with advanced dementia; instead, offer oral assisted feeding.

3. Don’t insert percutaneous feeding tubes in individuals with advanced dementia. Instead, offer oral assisted feedings.

Alternatives to Feeding Tubes and Role SLP
Dysphagia Management in Hospice

- Person centered care
  - Decision about whether to consume foods or drinks that pose a high risk of aspiration
  - Withdraw or withhold a feeding tube
  - Withhold oral food and fluids
- Cited area of uncertainty for SLPs
- Consider ethical principles that may be in conflict

Autonomy and Self-determination

- Patients have the rights to make their own decisions about their medical care
  - For patients without decision-making capacity it is their POA
  - Patient statement>Previously stated wishes>Best Interest Standard
- Informed consent required for a medical assessment and treatment including dysphagia
  - Patients and families can refuse assessment and treatment
  - Artificial nutrition and hydration is a medical treatment
  - A person may therefore refuse therapeutic diets and fluids, and other dysphagia therapies

Autonomy and Self-determination, Cont...

- As conduct assessment may want to foreshadow potential treatment options
- An understanding of previously stated wishes if available can be helpful
- Conduct an assessment and inform on treatment options including best supportive care
- Clarify risks and benefits of each approach
- Document and coordinate care
Documentation Components

- People present
- Person consenting to the plan of care
- Information/education given
- Recommendations made and reasons for giving them
  - Risks and benefits of all possible alternatives (including no treatment)
  - Questions asked and answers given
- Indication of the level of understanding of those present
- Ultimate care plan which incorporates patient wishes

Beneficence and non-maleficence

- SLP actions are undertaken to benefit their patient
- Aim to prevent harm
- Actions should not knowingly cause harm

Justice (Fairness)

- Information provided is accurate
- Patients are provided with services that meet their wishes and values
  - Not your values
  - Not your legal concern
Conflicting Ethical Principles

• SLP must determine which takes precedence for the patient for each specific clinical situation
• Autonomy is respected in giving information that supports a patient to choose a course of action that optimizes their quality of life with respect to eating and drinking.
• Beneficence/non-maleficence conflict as decision may hasten their decline with aspiration pneumonia. - May still be upheld by not subjecting patients to dysphagia treatments that would be considered futile.

SLP’s Assistance

• Swallowing problem?
  – nature
  – cause
• Reduce dysphagia risks
• Optimize safe hydration
• Optimize safe nutrition

General Recommendations

• Clean mouth
• Throughput
• Positioning
• Conscious
• Airway
• Education
An 89 y/o female with end stage AD presents to the ED with a second episode of aspiration pneumonia in the last month. She is awake and alert, but very confused. The family is asking what is the most appropriate thing to do at this point as they are afraid they are making mom worse by feeding her as she chokes a lot of the time. What would be the most appropriate next step in the patient’s care plan?

A. Consult palliative care to discuss the role of hospice
B. Consult GI or IR for a possible PEG tube placement
C. Consult a speech pathologist to discuss management approaches
D. Consult case management due to hospital readmission for pneumonia within 30-day period

Goals of Dysphagia Consult

- Educate families about dysphagia and dementia including its inevitability as part of the disease process
- Recommend safest diet
- Reiterate techniques to minimize aspiration risk
  - Awake and alert
  - Sitting up
  - Diet modification
  - Minimize distractions, one on one approach

VITAS 40 Years of Care
A 78 y/o retired judge with ALS noticed that people had begun having difficulty understanding his speech, which had become increasingly soft and slurred. Most recently, he has stopped going out to dinner with friends because it takes so long to finish his food. He has questions about percutaneous endoscopic gastrotomy (PEG) feeding as a way to obviate this issue. He is confused as doctor friends have given him conflicting advice with some supporting the decision and others recommending against it. Which of the following statements is true regarding the use of PEG tubes in someone with ALS?

A. Artificial feeding via a PEG tube may improve symptoms such as choking, fatigue while eating, and overall stamina in patients with ALS.
B. Artificial feeding via a PEG tube decreases life expectancy.
C. Artificial feeding via a PEG tube prevents aspiration pneumonia for patients with ALS.
D. Artificial feeding via a PEG tube has not been well studied so that an evidence‐based decision can not be made.

ALS and PEG Tubes

• PEG Tube Indications
  –accelerated weight loss with dysphagia
  –frequent choking
  –exhaustion with eating
  –impaired quality of life due to the stress surrounding eating
• PEG may prolong survival if placed early in the disease course, not found in all studies, ? bulbar dysfunction
• Feeding tube placement may improve QOL
• Place PEG prior to FVC dropping below 50%.