Dysphagia in End of Life Patients

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Dysphagia in End of Life Patients

Angela Mansolillo, MA/CCC-SLP, BRS-S

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It is difficult to accept death in this society because it is unfamiliar. In spite of the fact that it happens all the time, we never see it.

Elisabeth Kubler-Ross
Goals

- Identify dysphagia characteristics in the end of life patient
- Discuss the role of the SLP in palliative/end of life care
- Discuss risks/benefits of tube feeding in end of life patients
- Review legal and ethical issues pertinent to end of life care

An Historical Perspective

- In the past, end of life care took place in homes with family members as primary caregivers
- Now...most end of life care takes place in long term care facilities
- And...
- Technology like Ventilators and PEG tubes have changed the landscape of end of life care

End of Life Care

- Growing awareness of the value of palliative care...and of the SLP’s role on that care team
- But...
- Much variability in practice patterns

For the SLP:
- Requires a paradigm shift...this is not rehabilitation
Barriers to SLP care

- Limited recognition of role of SLP (and other therapies) in palliative care
- Timing of referrals – often in later rather than early stages
- Patients/family members may misinterpret role of therapist
- Negative perceptions regarding “palliative care”
  Waldon, et al, 2011

Palliative Care

- Focus on relieving and preventing the suffering of patients
- All disease stages – chronic disease, curable illnesses, end-of-life
- Multidisciplinary approach
- Goals include addressing physical, emotional, spiritual, and social concerns that arise with advanced illness

Hospice Care

- Actively dying patients (prognosis is <6 mos by definition)
- Management, palliation of patient's symptoms in end of life care
- Goal is management of pain and other symptoms to improve quality of life
- Focus is care, not cure
Who are our patients?

- Cancer
- Dementia
- Neuromuscular disease
- Frail, medically complex elderly

What happens when you die?

- The body cannot utilize nutrition, hydration effectively
- Patients stop wanting food, drink
- Dehydration, not starvation

What happens when you die?

Dehydration
- Analgesic effects
- Reduced oral secretions
- Reduced pulmonary secretions

End of life patients receiving hydration are more likely to experience pain, discomfort than those who were not

Hoefler, 2000
End of Life Issues

Cancer Cachexia (wasting syndrome)
Loss of body mass that cannot be reversed nutritionally
› Weight loss
› Muscle atrophy
› Fatigue
› Weakness
› Loss of appetite
› Immune dysfunction
› Metabolic disturbances
Increasing caloric intake does not improve status

Dysphagia in End of Life
› Common in end of life patients
› Complicated by reduced immune system function, fatigue, nutritional compromise, etc

So what to do?

Goal-setting
› Expect, anticipate fluctuations in patient status
› Consider patient/family needs, preferences, values
› Consider burden of care
› Consider quality of life
› Symptom control rather than cure
**Assessment**

Clinical swallow assessment

- What is the likelihood that this patient is aspirating?
- Why might this patient be aspirating? (fatigue, level of arousal, structural issues, neurological issues...)
- What are other complicating factors (medication effects, radiation effects, cognitive impairment...)
- How can we mitigate (not eliminate) risk?

**Risk Assessment**

_Dysphagia in Dementia Patients in Acute Care_

- Potentially transient or reversible cause?
- Patient’s wishes known?
- Functioning over the last few days, weeks, months?
- Could medication effects be a contributing cause?
- Actively dying?

Smith, HA, et al., 2009

**Artificial Hydration/Nutrition**

Decision Making Process

- What is the likelihood that the tube will improve the patient’s _status_?
- What is the likelihood that the tube will increase the patient’s _comfort_?
- What is the _caregiver burden_ associated with the tube?
Tube Feeding

- Increased likelihood of aspiration pneumonia associated with tube feeding
- TF cannot prevent aspiration of oral secretions
- May improve nutrition in some patient populations – not including cancer cachexia and dementia
- Associated with a decrease in QOL in many studies

Tube Feeding and Quality of Life

TF reported to reduce QOL parameters:
- Physical well being
- Pain
- Fatigue
- Body image
- Socialization

**Improved in patients who...**
- Have more than one caregiver
- Are younger
- Are independently managing the tube

*Brotherton and Judd, 2007*

Tube Feeding

Survey of SLPs re: practice with dementia patients
- Agreed/strongly agreed that PEG improved *nutrition*: 78%
- Agreed/strongly agreed that PEG reduced *aspiration risk*: 46%
- Agreed/strongly agreed that PEG improved *QOL*: 10%

*Sharp and Shega, 2009*
Tube Feeding

But...
› QOL influences recommendation: 77%

And...
› Probably/definitely would not want PEG for themselves: 80%

Survey of SLPs re: practice with dementia
› Agreed that PEG would not reduce aspiration risk: 22%
› Understood PEG would not prolong life: 50%
› Understood PEG would not improve status: 54%
› Understood PEG would not improve QOL: 63%
› Willing to recommend PEG: 70%

Vitale, et al, 2011

Making the Recommendation
› More experienced clinicians have more "aspiration tolerance", less likely to recommend NPO
› Top three deciding factors: "amount of aspiration," "frequency of aspiration," and "medical diagnosis"
› "Patient's wishes" was 11th of 13 items

**Tube Feeding**

Survey of MDs re: practice with dementia patients
- Agree PEG reduces aspiration pneumonia: 76%
- Agree PEG improves healing of pressure ulcers: 74%
- Agree PEG increases survival: 61%
- Agree PEG improves nutrition: 93%

A majority reported placing PEG because of SNF or SLP/RN request


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**Tube Feeding Outcomes**

Survey of family members who had decided for a TF reported that...
- Patient seemed bothered by feeding tube: 40%
- Patient’s hands or upper body tied down to prevent them from pulling at feeding tube: 26%
- Patient given medications to calm them down to prevent from pulling at feeding tube: 29%
- Patient sent to emergency department of hospital because of problem with feeding tube: 27%

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**Tube Feeding**

But despite negative outcomes...

62% of family members reported that they felt they had made the right decision by placing the tube

Only 23% regretted their decision

Teno et al, 2011
Expectations vs. Outcomes

Surrogate decision makers interviewed
- Majority rated QOL "poor" or "very poor"
  But...
- 78% reported that the tube was "beneficial"
- 62% would make the same decision again

Satisfaction with decision?

Interview of surrogate decision makers after 5 weeks of PEG use
- 84% reported that they would make the same decision again
  But...
- 31% said they felt the patient would not want the tube
  McNabney, et al, 1994

OK, So how do you feel now?

Interview with surrogate decision makers one week and two months post PEG placement
- High satisfaction with tube and with decision at one week post placement
- 70% would make the same decision for themselves in a similar situation
  But...two months later
- Satisfaction both with the tube itself and their decision had decreased significantly
- Percent who would make the same decision for themselves dropped to 53%
  Berger, 2011
And…
- 25% of respondents reported that they had or would make a decision to place the tube despite patient’s previous expression of contrary preference

Clear disconnect between what is known about tube feeding in end of life patients
And
What is felt about tube feeding in end of life patients
Not just on the part of family members, but the team as well

Incentives for TF
- Financial – cost of hand feeding; increased reimbursement rates for TF in SNFs
- Fear of legal liability
- Perceived pressure from team members, family members
- Need to “do something”
Alternatives to Tube Feeding
Careful hand feeding ("comfort feeding")
- Reduction of bolus size
- Slow rate
- Consistent verbal, visual cues to swallow
Reduce texture as needed
Consider fluids rather than solids
Offer food when patient is awake, alert, interested (not necessarily on a mealtime schedule)

Oral Care/Comfort
Dry mouth is common complaint in end of life patients (medications, dehydration, radiation effects)
- Reduced mastication
- Reduced swallow response
- Pain, discomfort
- Increased flora → infection
- Mucositis
- Reduced taste
- Impaired articulation

Oral Care/Comfort
- Regular cleaning, rinsing of dentition, oral cavity (every 2–4 hours?)
- Moistening mouth, lips with water soluble gel
- Ice chips, water sips as desired
- Choose moist foods
Communication/Cognition

SLP is qualified to assess communication/cognitive skills...

To assist in assessment of decision-making capacity...

And to assist patients and their families in strategy implementation to facilitate meaningful communication...

Communication/Cognition

Provide strategies for...
- Communication re: decisions about end of life care
- Communicating re: end of life goals
- Communicating needs, wishes, concerns
- Facilitating intimacy
- Facilitating closure in social relationships

Right to Refuse Care

Well established
- For individuals
- For surrogate decision-makers

Living will, advance directives, proxy

If no advanced directive or proxy, MD is legally able to make determinations to withdraw or withhold care
Legal Issues

Capacity
› Ability to comprehend the problem, evaluate options, and communicate a choice with a rationale
› Not a legal standard

Competence
› Legal determination

SLP Assessment
To assist in determination of capacity
› Ability to process auditory, written information – what is optimal mode of presentation of information?
› Reasoning skills; ability to compare/contrast options
› Stability of cognitive/communicative skills
› ID of optimal communication mode

Legal Issues
Criterion for TF placement in end of life patients
› Autonomy
› Substituted judgment – what would the patient have wanted in this situation?
› Do the benefits outweigh the burdens?

McGowan, 2011
Do we really have autonomy?

Review of medical records of patients undergoing gastrostomy tube placement
› Only one patient record clearly documented discussion re: the decision

Brett and Rosenberg, 2001

But here’s the bigger problem...

In that same study:
› 18 patients were clearly defined in the medical record as competent but only 11 of those 18 signed the consent form – the remainder were signed by surrogate

Surrogate Decision Makers

Often not a legal determination
› Spouse
› Adult child
› Parent
› Sibling
› Other relative
Substituted judgment: What would the patient choose if s/he could?
“Best interest”: Assessment of risks/benefits of each option
Substituted Judgment

What is the desire for intervention?
Interviewed established SNF residents over time re: desire for intervention in present state of health and in projected states of disability (dementia, stroke, etc).
Interventions included CPR, mechanical ventilation (temporary or permanent), IV antibiotics, and feeding tube placement.

Desire for Intervention (cont)

- Decisions remained largely stable over time but there was a trend toward less desire for care.
- Residents made a distinction between short term, time limited interventions and indefinite procedures – with a clear preference for time limited interventions.
- Preference for intervention in imagined state of disability was significantly less than in current state of health. (Berger and Majerovitz, 1998)

Substituted Judgement

- SLPs do not consistently take patient’s wishes into account when making a recommendation for TF (Logemann, 2008).
- Family members often state that the patient would not want the tube, yet agree to placement anyway (McNabney, 1994; Berger, 2011).
Burden vs. Benefits?

- TF does not reduce aspiration or aspiration pneumonia
- TF does not always improve nutrition
- TF does not prolong life in dementia patients

So...

What are the benefits?

Prolonged life? In that case, need to discuss QOL

Expectations vs. Outcomes

Interview of surrogate decision makers 3 mos post tube placement

- Reported unfavorable outcomes including medical complications, aspiration pneumonia, decubitus ulcers, reduced QOL

But...

- Continued to have high expectations re: improvement

Carey, et al 2006

Assistance for Decision Making

Provide

- Information re: likelihood of improvement with PEG
- Information re: potential complications
- Assistance with consideration of previously expressed wishes
- Opportunities for questions
- Opportunities for discussion re: feelings of guilt, pressure, conflict
End of Life

Suggestions re: TF in End of Life
www.eperc.mcw.edu

Recognize that the inability to maintain nutrition through the oral route...is usually a marker of the dying process.

- Discuss overall end of life goals
- True informed consent prior to feeding tube insertion
- Provide alternatives (e.g., hand feeding, comfort measures)
- Discuss goals and prognosis

End of Life

Suggestions (cont)

- Provide ongoing support, even after the decision has been made
- If a feeding tube is placed, establish clear goals and establish a timeline for re-evaluation to determine if goals are being met (typically 2–4 weeks)

End of Life

SLP Role

- Consultation to patient, family in areas of cognitive function, communication, swallowing
- Provision of strategies to support decision making, self-expression
- Optimization of comfort, satisfaction with eating
- Enhancement of quality of life
- Communication with the team
- Offer options; assist with assessment of risks and benefits of each option
**End of Life**

**SLP Role**

**Swallowing Goals**
- Maximize swallow function
- Reduce aspiration pneumonia risk factors – not necessarily the aspiration itself (oral hygiene, reflux management, positioning, activity…)
- What are favorite foods? How can we support their continued incorporation into the diet?
- Support nutrition as long as is feasible
- Support social aspects of eating

**Cognitive/Communication Goals**
- Strategies for optimal communication of needs, wishes
- Facilitation of social communication
- Strategies for presentation of information

**Goal** is symptom control rather than rehabilitation
To that end…
- Flexible goals – consider prognosis, patient/family wishes, caregiver burden
- Time-limited – let the goals, not the disease, dictate the discharge (Roe and Leslie, 2010)
Nutritional Interventions

- Frequent, small meals
- High nutrient density
- Appetite stimulants (megestrol acetate, dexamethasone)

Challenges

- Management rather than treatment
- Lack of training
- Managing our emotions, guilt, values
- Assessing our personal “risk tolerance”

Resources for Patients/Families

Ottawa Decision Making Guide
http://decisionaid.ohri.ca/decaids.html

Personal Worksheet
http://decisionaid.ohri.ca/docs/Tube_Feeding_DA/worksheet.pdf

Tube Feed or Not Tube Feed
http://www.eperc.mcw.edu/EPERC/FastFactsIndex/ff_010.htm
The act of dying is one of the acts of life

Marcus Aurelius