To Tube or Not To Tube
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Outline
- Dysphagia: Etiologies and Diagnosis
- Dysphagia and Its Consequences
- Aspiration Pneumonia – Consequences
- Artificial Nutrition and Hydration
- Effects of PEG tube feedings
- When are tube feedings beneficial? contra-indicated?
- Informed Consent
- Withholding or withdrawing tube feedings
- Where do we go from here?

Dysphagia Management – Role of Speech Pathologist
- 80-90% of caseload of speech pathologists practice in acute, subacute or LTC setting
- Weekly ethical dilemmas
  - Not safe for oral eating
  - Consider alternate means of meeting nutrition and hydration needs
  - Frequently asked, does pt need a FT?

Dysphagia
- Etiologies
  - Neurological
    - Stroke
    - TBI
    - Degenerative disease
  - Mechanical
    - Surgical
    - Fibrosis
  - Aging; disuse dysfunction
  - Sarcopenia
  - Psychogenic
    - behavioral

Swallowing Stages
- Anticipatory
  - Acceptance of bolus
- Oral preparatory
  - Chewing and bolus formation
- Oral transit
  - Passing bolus to posterior oropharynx
  - Pharyngeal
    - Bolus passes airway through hypopharynx
- Esophageal
  - Entering and through UES

Etiologies and Dysphagia
- Glossectomy, ALS: oral prep/transit
- Post-stroke: oropharyngeal
- Radiation bx: pharyngeal-esophageal
- Dementia: Anticipatory
  - Indifference to food
  - Refusal of food
  - Failure to manage food bolus once in mouth
  - (Ina, 2002)
Procedures for Diagnosing Dysphagia

- Clinical - bedside
- Endoscopic - FEES
- Videofluoroscopy

Dysphagia and Its Consequences

- Can be mild and improve with increased neurological recovery
  - Often seen post-acute cortical CVA
- Severity based on presence/absence of penetration/aspiration
  - Frequency and quantity of bolus
  - Severity based on patient’s pulmonary status and overall health
  - Most healthy people tolerate occasional aspiration
  - Elderly, medically fragile, severely demented at highest risk

Aspiration Pneumonia

- Risk factors for AP
  - Dependent for feeding
  - Dependent for oral care
  - Number of decayed teeth
  - Tube feeding
  - More than one medical diagnosis
  - Number of medications
  - Smoking
    - Langmore et al, 1998

Artificial Nutrition and Hydration

- Nasogastric tubes
  - Problems
    - Nasopharyngeal irritation
    - Risk of accidental extubation
  - J-tubes
- Percutaneous endoscopic gastrostomy tubes (PEGs)
  - Best for long-term enteral feeding
  - Easy to insert and relatively low risk
  - No difference in rates of aspiration or other complications between g-tube and j-tube (Fox et al, 1995)

PEG Tube Feedings

- PEG tubes first introduced in 1980 and have become preferred choice for long-term enteral nutrition
- More than 1/3 of severely cognitively impaired residents in US nursing homes have feeding tubes
  - Shah, 2005
  - In 1989, 15,000 PEG tubes placed; in 2000, more than 216,000 tubes were placed
    - Approx 30% placed in pts with dementia
      - Cervo et al, 2006

PEG Insertion: Why so common?

- Relatively easy procedure
- Requires only local anesthesia
- Takes only 10-30 min
- Covered by Medicare
- Complications related to placement generally minor
  - Migration, obstruction, esophageal perforation, bleeding, wound infection, necrotizing fasciitis, tube discomfort
- Mortality rates for placement <1%
  - Verhoef & Van Rosendaal, 2001
Feeding Tubes
- Recommended to prevent aspiration
- To improve pressure ulcer healing
- To improve survival
- To provide nutrition and hydration

Aspiration Pneumonia (AP)
- Aspiration on MBS is not associated with the risk of pneumonia
- Feeding tube placement (vs. no FT) in patients who aspirated significantly increased the risk of pneumonia and pneumonia-death
  - (Croghan, 1994)
- No data show that feeding tubes decrease the risk of aspiration pneumonia (Park et al, 1992)
- No RCT comparing PEG tube feeding to hand feeding

Studies
- Multiple studies have shown that feeding tubes seldom
  - Improve nutrition
  - Maintain skin integrity
  - Prevent aspiration pneumonia
  - Minimize suffering
  - Improve functional status
  - Extend life
  - Finucane et al, 1999; Cervo et al, 2006

Tube Feeding and AP
- Feeding tubes do not prevent AP in neurogenic population
- High rates of AP in tube fed patients
  - From contaminated oral secretions
  - From regurgitated gastric contents
  - (Finucane, 1996)

Mortality Rates following PEG Placement
- 30 day ranged from 8% to 31%
- Death most often attributed to factors secondary to underlying illness
  - Rather than to PEG procedure
- Median survival time = 7.5 months
  - Long term flu studies:
    - PEG removal due to regained ability to swallow range between 14% and 26% (Rabeneck et al, 1996)

PEG Outcomes in Stroke
- 27% of stroke patients (N=83) had swallowing recovery following stroke
- 75% have long-term need for PEG
- Ng tubes often fail
- Early PEG placement (2 weeks) beneficial for some
  - Ha & Hauge, 2003
- Enteral feedings resulted in better outcomes for severe stroke patients
  - Horn et al, 2005; James et al, 2005
**PEG Outcomes in H&N Cancer**

- PEG during or after surgery resulted in fewer complications than those who underwent preoperative PEG (N=43)
  - No statistical difference with regard to tumor location or postop x-ray therapy in PEG complications
  - Raynor et al, 1999
- PEG placement before radiation treatment led to better outcomes
  - More complications requiring hospitalizations occurred when PEG was placed after treatment
  - Median duration of tube use was a 165 days
  - Scolapio et al, 2001

**Complications of PEG in H&N Cancer Patients**

- N=156 of 171 patients (15 failed attempts)
  - 29 pts had stage III tumor (19%)
  - 91 had stage IV tumor (58%)
  - 144 underwent radiotherapy (92%)
  - 29 received PEG before xrt
  - 37 received PEG during xrt
  - 78 received PEG after xrt
  - 12 pts not candidates for xrt
  - 95 had surgical resection; 77 received preop xrt and 17 postop xrt
  - 39 PEG < 12 weeks (25%); 112 (72%) > 12 weeks
  - 57 (37%) dead within 6 months
  - 30% continued to need PEG one year later
  - Efrisson et al, 2004

**Dementia**

- Estimated 4.5 million adults in US have dx of dementia today
  - Galicia-Castillo, 2006
- In final stages, they often are not conscious of people, things or events in their environment
- May lack awareness of food and liquid presentation
- May require maximum stimuli to arouse their responsiveness to bolus

**Advanced Dementia**

- Difficult to care for; often bedridden and dependent in all ADLs
- Unable to communicate or to have relationships with others
- Often unable to meet nutritional needs through oral nutrition and hydration
- Often decision is made to place PEG FT
  - Family members often believe they have no other option

**Family Perception – FT is necessary for...**

- Nutrition and hydration
- Prevent starvation and malnutrition
- Prevent aspiration pneumonia
- Improve or maintain function
- Improve survival
- Improve patient comfort

**Reality**

- Nutritional status does not necessarily improve
  - Diarrhea, clogging of tube, pulling out of tube
  - Clinical studies shown that increased nutrients do not necessarily result in meaningful clinical outcomes (with abnormal markers of nutritional state)
- Continued risk of aspiration; same as without FT
- Survival rates same for PEG and spoon fed patients
- Mortality rates of 2% to 27% at 30 days and 50% or more at 1 year
- Restraints often are required; discomfort and compromise autonomy
- Adverse effects with feeding tube; complications
- Denied pleasure of eating
Alzheimer’s Dementia
• Aging Americans with declining cognitive abilities are at risk for losing their autonomy in presence of advancing medical technology.
• Imperfect decision-making procedures
• Well-meaning but often paternalistic caregivers

Impact on Caregiver
• Burden is enormous
• Respect for patient wishes
  – Advanced directive or by close family members
  – Make decision that strive to maintain patient’s dignity
  – Regardless of neurologic status or nearness to the end of life

Failure to Thrive
• Common with severe AD
  – Deterioration in biologic, psychologic and social domains
  – Weight loss or undernutrition
  – Lack of any obvious explanation for the condition
• Results from combined effects of normal aging, malnutrition, physical, social or psychologic precipitants such as chronic disease, dementia, medication, dysphagia, depression, or social isolation

Burden of Feeding Tubes in AD
• When dysphagia is present in elderly patients with AD, typical medical response is placing a feeding tube.
• Goal of feeding tubes: prolongation of life, maintenance or improvement of life quality, or enhanced patient comfort.

Evidence for Feeding Tube Use with Advanced AD
• Lacking supportive data
• Poor prognosis
• High morbidity
• Poor skin integrity
• Aspiration pneumonia
• Sepsis
• Loss of dignity
• Discomfort
PEG Tube Feeding in Advanced AD

- Excessive burden without offsetting benefits
- No significant improvement in functional status, nutrition status, and survival in AD in nursing homes
  - (Kaw & Sekas, 1994)

Mortality Following PEG

- 42% 60-80 years survived 12-18 months after PEG
- Only 25% ages 80-100 survived
  - Sheiman, 1996
- 54% of dementia patients died within one month after PEG placement and 90% within one year
  - Sanders et al, 2000

Complications of Feeding Tubes in Patients with Advanced AD

- Weight loss
- Pressure ulcers
- Pain
- Infections
- Prolong and expensive hospitalizations
- Increased risk of death
- Exacerbation of GERD leading to aspiration of stomach contents into the lungs

Aspiration Pneumonia in Advanced AD

- Past hx of aspiration pneumonia are more susceptible to aspiration with tube feedings.
  - Cogen & Weinryb, 1989
- Among pts with hx of aspiration with AD, those with feeding tubes had higher risk of pneumonia and pneumonia death than those who aspirated but did not receive tube feedings.
- Pneumonia is the leading cause of hospitalization from nursing homes and leading cause of death in people with AD.

Loss of Dignity

- PEG feeding tubes lead to patient agitation
- Agitation leads to use of restraints
- Impacts patient’s autonomy and dignity

Why Do Families have Such a Difficult Time Making a Decision?

- Social, cultural beliefs related to caring for loved one
- Moral and religious beliefs
  - Value of life
  - Do no harm
  - Do everything possible
  - Judeo-Christian perspective
    - Provide hydration and nutrition as long as “sufficient benefit to outweigh the burdens involved to the patient.”
    - Rejection of interventions that cause or prolong suffering
  - Glick, 2000
How Does One Assess Quality of Life

- Patient comfort
- Prevent suffering
- Effectiveness of procedures?
  - (Gillick, 2000)
- .......

The Adequacy of Informed consent for Placement of PEG

Brett & Rosenberg, 2001

- Retrospective review of 154 medical records of adults undergoing PEG
  - Competence/incompetence indicated (67.5%) and surrogate decision-maker authorized procedure
  - Documentation of discussion with pt or surrogate describing benefits/burdens and alternatives to tube feeding (1 of 154 patients)
  - Hospital consent procedure (92.2%)
  - 53% died during a f/u (14-26 months)
    - In-hospital mortality = 17% and additional 15% within 1 month of hospital discharge = 50% mortality rate

Withholding or Withdrawing Tube Feedings

- Misperceptions of perceived changes in quality of life and anticipated outcomes
- Establishing inappropriate goals and expectations
  - Leads to placement of PEG tubes too often
  - Need to demonstrate that interventions truly benefit the patient
  - Need to better inform and educate pt/family
- Physicians often feel compelled to offer PEG tube placement
  - Believing it is ethically and legally obligated to provide ANH.

Ethical and Legal Perspective on ANH

- ANH is a medical treatment
  - Can be withheld or withdrawn
- It can be determined to be appropriate or inappropriate by the patient (an adult)
- Decide whether appropriate for specific pt by assessing effectiveness of achieving the goals of treatment
- Weighing risks and benefits
- As a medical treatment it can be withheld or withdrawn
- Recognize right of patient to choose to forego medical treatment

Considerations

- What is the patient’s medical prognosis?
- If the patient has a chance of survival will the quality of life be acceptable to him?
- Do the potential benefits of treatment outweigh the potential discomforts, pain, and suffering?
- What are the patient’s wishes in regard to use of life-sustaining treatment?
- Shared decision making; taking shared responsibility of decisions (Slomka, 2003)

Where Do We Go From Here?

- Discussion
Education

- Physicians need to be better informed
- Patients and Families need to be educated
  - Shega et al (2003): primary care physicians reported that they believed feeding tubes prevented aspiration, improved survival, healing, and nutritional status
- What message is being delivered to patients and caregivers?

Decision-Making Algorithm for PEG Tube Placement
(Rabeneck et al, 1997)

- Dysphagia without complications: recommend PEG
  - Patient unequivocally benefits from PEG
- Dysphagia with complications: discuss no PEG vs PEG trial
  - Pts unequivocally benefit from PEG
  - Potential comprise in quality of life
- Permanent vegetative state: rec against PEG
  - Patient unable to experience quality of life
- Anorexia-cachexia syndrome: do not offer PEG; no benefit