Hospice, Palliative Care and SLP management of dysphagia

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Need for palliative care

• Strong correlation between aging and chronic illness
• Need to provide symptom and disease management for hospitalized patients not facing death within prescribed time
  – Not eligible for hospice services
  – Ross, Mathis & Brockopp (2008)

Cost of managing chronic illness

• Management of chronic illness that is not life-threatening accounts for approximately 75% of available health care resources in U.S.
  – Institute of Medicine (2001)

Palliative or Hospice?

• Traditionally palliative care and hospice care are provided to individuals diagnosed as terminally ill
• More recently, palliative services are available to patients with chronic conditions who do not meet qualifications for hospice

Needs of patients with chronic conditions

• Management of symptoms:
  – Pain
  – Nausea
  – Fatigue
• Psychosocial issues
• Spiritual issues

Challenges to establishing a palliative care program

• Shift in philosophy of the staff providing the care
  – Change from focus on cure to focus on management
• Fear that the program will drain resources
The development of CBH Palliative Care Program

- Goals of the program to develop a system of care that would address:
  - Unique needs of patients with symptomatic illness regardless of diagnosis or place on the illness trajectory
  - Patients’ needs in context of social system
  - Holistic care including curative measures and management of symptoms

  - Ross, Mathis and Brockopp 2008

What is the role of rehabilitation in hospice and palliative care?

- With disease progression, patients have:
  - High levels of functional loss
  - Dependency for activities of daily living
  - Mobility dysfunction

  - Cheville (2009)
  - Santiago-Palma, Payne (2001)


Why do hospice & palliative care patients need rehabilitation?

- Multiple factors contribute:
  - De-conditioning
  - Fatigue
  - Complications from therapies
  - Under-nutrition
  - Neurologic and musculoskeletal problems
  - Pain
  - Bowel and bladder dysfunction
  - Thrombo-embolic disease
  - Depression
  - Co-existing co-morbidities
    - Multiple sources

Do hospice & palliative care patients want rehabilitation?

- Most hospice patients express desire to remain physically independent during the course of their disease

  - Wallston, Burger, Smith & Baugher 1988
  - Ebel, Langer (1993)
  - Mayer (1975)

Benefits of palliative rehabilitation

- Improved quality of life
- Improved mobility
- Better control of pain and other symptoms
- Improved mood
- Gains in motor and cognitive function
- Shorter lengths of stay
  - Various sources

Role of the SLP (Pollens 2004)

- Provide consultation to patients, families and the care team re:
  - Communication
  - Cognition
  - Swallowing

- Develop strategies in area of communication skills to support the patient’s role in decision making, maintain social closeness and assist patient in achieving fulfillment of end-of-life goals
Role of the SLP
• To assist in optimizing function related to dysphagia symptoms to improve patient comfort and satisfaction
  – Promote positive feeding interactions with family members
• Communicate with the care team related to overall care of the patient

Differences in palliative and hospice
• How does the SLP’s approach differ in palliative vs. hospice?
  – Use of instrumentals
  – Facilitations vs compensations
  – How conservative we are with recommendations

What resources can the SLP use when working with patients and families?
• ASHA Code of Ethics
• Principles of Biomedical Ethics
• Case law

ASHA Code of Ethics
• Principle of Ethics I: Individuals shall honor their responsibility to hold paramount the welfare of persons they serve professionally
  – Rule D: Individuals shall fully inform the persons they serve of the nature and possible effects of services rendered and products dispensed
• Principle of Ethics I
  – Rule F: Individuals shall not guarantee the results of any treatment or procedure, directly or by implication; however, they may make a reasonable statement of prognosis

Autonomy
• Respect for Autonomy
• Patients have right to make independent choices about their care
• Free from controlling influences and have capacity to make independent decisions
• If the patient can’t make independent choice, involve “surrogate decision makers”

Non-maleficence
• Above all, do no harm
• Do not cause harm or impose the risk of harm
• Closely tied to the principle of beneficence
• Provide positive benefits to patients
• Action done for the benefit of others
• Implies an obligation to help others
• Paternalism sometimes necessary in order to do good
• Paternalism is in conflict with autonomy
Patient rights

- Right to predetermine medical treatment limits
- Right to discontinue or refuse treatment
- Right to refuse to follow swallowing safety recommendations

SLP ethical responsibilities

- Determination of efficacious treatment approaches
- Responsibility to educate/explain potential risks and outcomes
- Responsibility to accept patient/family decisions
- Responsibility to advocate for treatment or no treatment
- Responsibility to continue or discontinue treatment

History of PEG

- Ponsky adapted it in the early 1980s for use with adults
- Used with stroke patients initially
- Use quickly spread to patients with terminal cancer and elderly with dementia
- Device generally low cost ($200-$600)
- Short recovery time meant patients could be discharged quickly

Increase in PEG use

- Embraced by nursing homes b/c it was a quick way to feed patients who couldn’t feed themselves
- Question: Is it easier for the physician to order a PEG placed than to have a difficult conversation with the family?

PEGs in nursing homes

- In 1999, nearly 34% of residents with severe dementia in U.S. nursing homes were living with PEG
  
  - A recent five-state survey found that 11% of persons dying with dementia had a feeding tube
  - Teno, Mitchell, Kuo et al (2011)

PEGs and economics

- Medicare considers PEGs to be skilled nursing
  - Hand feeding is not skilled
- Nursing homes get more money for patients with PEG and they also do not have the cost of paying someone to feed
  - CNA making $8/hr can hand-feed perhaps 2 patients in an hour
  - Can hook up 10 feeding tubes in same amount of time
- Tube-fed residents in nursing homes generate a higher daily reimbursement rate from Medicaid, but require less expensive care
  - Mitchell, Buchanan, Littlehale & Hamel 2003
Advance directive

- Legal, written statement of medical choices or the way the patient wants medical choices to be determined
- Written prior to need for such decisions
- Goes into effect when patient can no longer decide for him/herself or can no longer tell others of decision
- Cannot be required to have advance directive

Living wills may include:

- Directions that life-prolonging treatment not be provided, or once started, that such treatment be stopped
- Directions that food (nutrition) and water (hydration) not be provided through artificial means like tubes, or once started, that they be stopped
- A choice of one or more persons to act as your surrogate and make decisions for you

Healthcare surrogate/Durable Power of Attorney

- Person you appoint in your living will or in another written document to make medical decisions for you if you are not able to speak for yourself
- Advance directive that lets you name someone (attorney-in-fact) to make medical decisions for you if you’re unable to speak for yourself
- Similar to healthcare surrogate, but may also give attorney-in-fact power to make decisions about personal and financial affairs

Why those arguments don’t work

- Artificial nutrition and hydration = medical procedure
- Virtually every reported appellate case has rejected these objections
- Nutrition and hydration may be forgone according to same standards as any other medical treatment
- AMA classifies artificial nutrition and hydration as “life-prolonging medical treatment”

Medicare and Medicaid requirements

- For long-term care facilities - recognize that competent residents have unqualified right to refuse treatment, including artificial nutrition and hydration when state law permits
- Cause of death is patient’s inability to eat, brought about by disease or injury, and cannot be characterized as starvation

Artificial nutrition and hydration carries own set of risks, discomforts and drawbacks

- Courts view PEG as highly intrusive
- NG can contribute to progression of disease
- Persistent vegetative state -- continuing artificial nutrition and hydration denies dignity
Dehydration and starvation

- It may not result in more pain than the termination of any other medical treatment
  - In conscious patients, if adequate analgesic medication is provided, death should be painless
  - In persistent vegetative state, will certainly be painless

Risk of aspiration with tubes

- Aspiration pneumonia most common cause of death after PEG placement
- Feeding tubes (NG & PEG) actually increase the risk of aspiration pneumonia
  - GERD?
  - Oropharyngeal colonization?

Aspiration and tubes

- Non-randomized prospective study
  - Orally fed patients with dysphagia had fewer major aspiration events than those tube fed
- Non-randomized, retrospective observation of SNF residents found no survival advantage with tube feeding
  - Reported in Finucane et al 1999

Burdens and complications of PEG

- Pain at site of tube
- Diarrhea
- Nausea
- Hematomata
- Fistula
- Peritonitis
- Abdominal abscess
- Loss of dignity
  - Plonk 2005

Poor prognostic factors for PEG placement

- Older than 75 years
- Male
- Diabetes Mellitus
- COPD
- Advanced cancer
- Previous aspiration
- NPO x 7 days
- UTI
- Low BMI
- Hospitalized
- Bedridden
- Pressure sores
- Confusion
- Cardiac disease

How do families make decisions?

- Families of individuals with dementia engage in choices about feeding more often than any other treatment, but report quality of decision-making is poor
  - Givens et al 2009
- Provide patients and families with structured information about a clinical choice
- Used to enhance clinical decision-making
- Present balanced, evidence-based information about risks, benefits, and alternatives to a particular decision
  - Elwyn, O’Connor, Stacey, et al 2006
A Decision Aid for Long-Term Tube Feeding in Cognitively Impaired Older Adults (Mitchell, Tetroe & O’Connor 2001)

- Substitute decision-makers for 15 cognitively impaired inpatients being considered for placement of PEG
- Questionnaires used to compare the decision-makers’ knowledge, decisional conflict and predisposition regarding feeding tube placement before and after exposure to the decision aid
- Results: Increased their knowledge and decreased their decisional conflict regarding long-term tube feeding after using the decision aid
- Impact of the decision aid on predisposition toward the intervention was greatest for those who were unsure of their preferences at baseline

Improving Decision-Making for Feeding Options in Advanced Dementia (Hanson et al 2011)

- Surrogates in both groups experienced the same level of decisional conflict at time of study enrollment
- After three months, surrogates who received the decision aid had significantly lower scores on each subscale
- Decisional regret was low and satisfaction high at 3 months for both groups
- After 3 months, residents in the intervention group:
  - Had greater use of some assisted oral feeding techniques than those in the control group
  - Were more likely to receive a dysphagia diet
  - Trend towards greater use of specialized assistance for feeding
- Mortality similar for both groups

Why is oral feeding a challenge in advanced dementia for patients in SNFs?

- Lack of attention to individual food preferences, especially related to ethnic choices
- Dysphagia is common, and instead of feeding slowly, residents are fed quickly
- Dysphagia complicated by poor oral health and ill-fitting dentures
- Placed on pureed diets which are unappealing
- Inadequate staffing and lack of supervision

Poor oral intake leads to...

- Weight loss
- Malnourished state
- Placement on pureed, unappealing diet
- Commercial supplements added
- May decrease appetite for regular food
- Unable to express food preferences

General strategies for optimizing oral intake in persons with dementia

- Adapt to the Person’s Food Preferences and Reduce mealtime confusion
  - Regular schedule of mealtimes
  - Preserve rituals (e.g. blessing; who sits where)
  - Memory aids (e.g. clocks, bulletin board)
  - Eye glasses and hearing aids
  - Calm environment
  - Simplify (e.g. one food item on plate, one utensil)
  - Avoid patterned plates, placemats
  - Solid and contrasting colors
  - Appropriate cueing (e.g. speak slowly, clear directions)
  - Patience! Don’t criticize eating habits or urge to eat faster
General strategies for optimizing oral intake in persons with dementia

• Encourage independence
  – Serve finger foods or sandwiches
  – Have snacks available and within reach
  – Use modified utensils (e.g. spoons with large handles)
  – Use cups or mugs with lids to prevent spills, straws that bend, fill glasses half full
  – Use hand-over-hand technique to initiate self-feeding

• Experiment with solutions to decreased appetite
  – Serve preferred foods
  – Foods with strong flavors, temperature differences
  – Plan for several small meals
  – Increase physical activity
  – Consider food supplements (e.g. yogurt, milkshakes, egg nogs)
  – Use vitamin supplements only on recommendation of physician

• Minimize problems with chewing and swallowing
  – Remind frequently to chew, eat slowly, swallow
  – Position upright
  – Don’t return patient immediately to supine
  – Serve appropriate foods (e.g. bite size, soft foods)
  – Avoid foods that are choking hazards (e.g. nuts, popcorn, raw vegetables)
  – Moisten foods with gravy, broth if person has trouble chewing

• Other tips
  – Check for properly fitting dentures
  – Be sure foods served are not too hot
  – Check for pocketing of food in mouth
  – Place damp washcloth under plate/bowl to keep it from sliding

Careful Hand Feeding: A Reasonable Alternative to PEG Tube Placement in Individuals with Dementia - Other considerations (DiBartolo, 2006)

• Small bites
• Monitor to be sure patient has swallowed before offering another bite
• If person holds food in mouth, offering an empty spoon may cue patient to swallow

Many creative programs used in long term care facilities (Musson, et al 1990)

• Silver spoons
  – Volunteers recruited and trained
• Second seating
  – Patients grouped in dining room according to their need for modification/assistance
• Happy hour
  – Planned for group hydration
  – Daily afternoon gatherings-fluids and snacks offered
  – Also offered opportunity for socialization
Many creative programs used in long term care facilities

- Clock reminders (Nolan & Mathews 2004)
  - Reduced food-related repetitive questions
  - Reduced pre-mealtime agitation
- Social meals (Kayset-Jones and Schell, 1997)
  - Nurse’s aide focused on interpersonal aspects of meals
- Touch, verbal and musical encouragement (Coyne & Hoskins, 1997; Eaton, Mitchell-Bonair & Friedman, 1986; Lange-Alberts & Shott, 1996; Regnang, 1996)

Is PO necessary in terminally ill patients? (McCann et al 1994)

- Patients terminally ill with cancer generally did not experience hunger and those who did needed only small amounts of food for alleviation.
- Complaints of thirst and dry mouth were relieved with mouth care and sips of liquids far less than that needed to prevent dehydration.
- Food and fluid administration beyond the specific requests of patients may play a minimal role in providing comfort to terminally ill patients.

Risk of dehydration? (Gillick 2000)

- Many elderly have impaired thirst mechanism
- In terminal phase of Alzheimer’s disease, dehydration minimizes discomfort
- Hydration without nutrition causes discomfort because it prolongs process of dying
  - Increases production of urine and sputum

SLP Relationship with family

- Document discussions with the family regarding treatment options and the family’s reaction to those options
- Disclose to the family the risks involved in all treatment options, including the family’s desired options
- Document family’s understanding of the risks involved in all these options.
- Document instructions given to the family, including specific safety precautions.
  - Instructions should be written and included in the medical record.
- Document family’s response to instructions.
  - Did they understand reasoning behind the instructions?
  - Do they need further instruction/training?
SLP Relationship with family

• Document recommendations and clinical opinions about treatment options, including safety concerns regarding the various treatment choices.

• Document physician conferences concerning treatment options, family choices, and pressures.
  – Include physician’s response to family concerns.
  – Is physician leaning toward family’s choices even though these are inappropriate?

SLP Relationship with physician

• Document the presence of conferences with physician

• Clearly document the difference of opinion with the physician and the physician’s stated reasons for his or her opinion.

• Document the SLP’s safety concerns regarding the physician’s proposed options.

SLP Relationship with physician

• Document the SLP’s specific recommendations to the physician and reasons for these recommendations.

Have the medical and legal communities reached consensus?

• Some groups treat the PEG as an issue similar to stem-cell research and abortion
  
  Burke Balch, director of National Right to Life Committee’s Robert Powel Center for Medical Ethics:
  – Their interest in end-of-life care is equivalent to its concern over abortion

Have the medical and legal communities reached consensus?

• Some religious groups have actively challenged living wills that call for patients to die without having a tube placed
  – Agudath Israel case re: Lee Kahan

• February 2005 New York State Supreme Court Judge ordered patient’s daughter to keep her mother alive as long as medically possible
  – Note: living will was incomplete

Have the medical and legal communities reached consensus?

• Lawmakers in dozens of states have sought changes that would make it harder to remove feeding tubes
  
  Right to Life Committee has won sponsors in more than 10 states for legislation requiring courts to presume a mentally handicapped patient would want to live