Palliative Care
Swallowing Management

HEATHER STORIE M.S., CCC-SLP, BCS-S
SPEECH LANGUAGE PATHOLOGY, BOARD CERTIFIED SWALLOWING SPECIALIST
Objectives

- Gain a general understanding of normal swallowing
- Gain a general understanding of how swallowing changes as we age
- Discuss common etiologies for dysphagia
- Discuss the Speech Pathologist role in rehabilitation vs palliative care
- Gain a general understanding of how swallowing changes at the end of life
- Discuss frequently asked questions re: palliative care and swallowing
Normal Swallowing

- There are 3 main phases of swallowing
  - Oral Phase
  - Pharyngeal Phase
  - Esophageal Phase
Oral Phase

- Oral phase – The tongue is made of up 4 intrinsic and 4 extrinsic muscles, in addition to lips, buccal, and palatal musculature
  - Formation of food
  - Placement of food
  - Manipulation of food
  - Posterior movement of food into the pharynx
Pharyngeal Phase

- Shortest but most complex phase
  - 1-2 seconds to complete (uses 26 muscles to complete)
- Uses a Central Pattern Generator
  - But also has higher cortex involvement
**Esophageal Phase**

- The movement of the food through the esophagus into the stomach
- Difficulty in this area can be secondary to:
  - Dysmotility
  - Hiatal hernia
  - Strictures
  - Poor relaxation of upper or lower sphincters
Normal swallowing changes as we age

- Just because you are old, does not mean that you will have difficulty swallowing

**However**

- As many as 40% of adults 60yrs and older suffer from dysphagia
- Swallowing muscles work like all other skeletal muscles in the body
  - Disuse atrophy – lose up to 40% of muscle ability to generate force over 4-6 wk period.
- When a constant change in consistencies occur, this will change the physiology of the swallow.
- As we age, strength weakens and can decrease swallowing ability due to generalized weakness.
Dysphagia related health outcomes: pneumonia
- 5th leading cause of death in those aged 65 and older
- 3rd leading cause of death in those aged 85 and older
- Over the last decade Medicare beneficiaries admitted to the hospital with a diagnosis of aspiration pneumonia increased 93.8%.

Normal healthy older adults swallow more slowly and generate lower maximum lingual isometric pressures than younger counterparts.

Older patients were found to have a greater amount of food residual in the pharynx after swallowing, possibly indicating an increased risk for aspiration.

Coordination between swallowing and breathing pattern during eating of food decreases with aging, which may expose a risk of pre-swallow aspiration.
Sarcopenia

- The pervasive loss of muscle mass in normal aging that is associated with reduced muscle strength.

- Systemic decrease in skeletal muscle mass and skeletal muscle power, and is accompanied by physical impairment, deterioration of quality of life and death.

- Functional decline is the known result of sarcopenia in striated Type IIA musculature - swallowing musculature is not immune.

- Normal healthy older adults swallow more slowly and generate lower maximum lingual isometric pressures than younger counterparts. Indicating diminished reserve in older adults associated to sarcopenia of the head and neck musculature.
Clearly other conditions/comorbidities affect swallowing ability

- CVA
- Parkinson’s
- Dementia
- Other Neurological difficulties
- CHF
- DM
- General Frailty
Changes with disease process

- Swallowing difficulty includes:
  - refusal to accept food/liquids by mouth
  - decreased appetite can be common for an individual nearing the end of life.
  - Increased risk of aspiration due to decreased functional ability of the musculature

- Other factors that progress difficulties with swallowing:
  - Natural Process
  - Terminal Illness
  - Dementia
Speech Language Pathologist Rehabilitation Role

- Evaluating speech/language for communication abilities
- Evaluation swallowing abilities by MBS or FEES
  - Determine least restrictive diet
  - Determine strategies that increase safety of the swallow
  - Determine best therapy options for treating the swallowing disorder
- Initiate therapy
- Providing patient and family education regarding plan of care and exercises to be completed outside of therapy time.
Speech Language Pathologist Role in Palliative Care

- SLP can serve as a consultative resources for patients, caregivers, and members of supportive palliative care team by:
  - Evaluating effective strategies for communication
  - Evaluating swallow function by bedside evaluation, MBS or FEES and assisting in determining comfort, pleasure, satisfaction, and desired interactions
  - Evaluating positioning and use of different adaptive tools or equipment
  - Providing diet recommendations and swallowing guidelines to reduce risk of aspiration with a primary focus on patient’s comfort and pleasure
  - Providing education from results and recommendations

- Our palliative patients deserve the same attention to careful diagnosis and treatment possibilities as our rehab patients.
Recommendation Differences

- **Primary Recommendation**
  - Always the safest recommendation
  - This may mean altered diet recommendations such as thickened liquids
  - Occasionally this means that the recommendation is NPO with alternative nutrition and hydration
  - Treatment options

- **Secondary Recommendation**
  - Diet option of least risk with the understanding that aspiration is probable
  - This allows physicians, patient, and family to make the best decision for their care
Changes in appetite and food desires

- Desire decreases
  - This happens with decreased need and with difficulty swallowing
- Taste and appetite change because of:
  - Illness
  - Medications
  - Medical treatments (such as chemotherapy and radiation).
- Family and supportive loved ones often have a difficult time with this process
For many of us, sharing food and water seems to be a most basic way to show we care. It is difficult, but important, to remember that a person’s loss of interest in such basic needs are a normal part of the dying process and ARE NOT uncomfortable.

Families can offer small amounts of food and/or liquids, but try to not become upset if your loved one refuses. Some people will request old favorites or something new. Do not be surprised if they only want a taste or sip.

Comfort can be provided through talking, touch, music, prayer, or just being present in the room. These can be the most important ways to offer support during this difficult time.

Allowing the patient to eat and drink what he or she prefers despite the risk of aspiration. This continuum of care provides autonomy and promotes patient comfort. Let patients enjoy the last days of their lives with minimal to no restrictions; this enhances quality of life for patients and their family members.
Signs of Discomfort

- Administration of IV fluids or tube feedings may cause bloating, increased pain, shortness of breath, rattling of lung secretions and hiccups.

- Other signs may include constipation, nausea and/or vomiting. Patients who are forced to eat and drink may choke and draw food into their lungs (aspiration), leading to pneumonia.
A few things to remember

- It is important to realize that it is normal to refuse food and liquids as the terminal disease and the dying process advances. It is natural for the body to shut down many normal functions over time. In some individuals, this natural process may happen quickly.

- For majority of patients at the end of life, they do not feel hungry or thirsty. Often, they may want just a taste or a sip of something that sounds good to them. They are not starving or uncomfortable. This is a natural progression and provides support for the patient in a more comfortable way.

- As a patient slowly withdraws from eating and drinking, this is the most natural way to allow the body's own mechanisms to prepare for a comfortable death.
Ethical considerations

- **Beneficence** means to always act in the best interest of the patient.

- **Autonomy** is to respect the patient's self-determination. Autonomy recognizes the right of a patient with decision-making capacity to make decisions about treatments according to his or her beliefs.

- **Non-maleficence** is the principal of doing no harm.

Ethical principles should be embedded in our critical thinking processes when we assist the team in deciding when, if, how, and how much a patient can “eat, drink, and still be merry.”
Palliative care: is patient- and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering and burden of disease. Throughout the continuum of illness, palliative care involves addressing physical, intellectual, emotional, social, and spiritual needs, while facilitating patient autonomy, access to information, and support of choice.

Hospice: Our thinking shifts from the rehabilitative and curative perspective to quality of life care. During this stage of care, dysphagia clinicians allow patients to eat and drink what the patient would like, even those at risk for aspiration. There is no need to limit consistencies of foods or restrict thin fluids during this process.
FAQ: Will my loved one starve or feel hungry?

Many caregivers wonder about extra nutritional support such as IV fluids or tube feedings. Early in a terminal illness, these methods may help prolong life. Eventually, however, these artificial methods may actually cause discomfort and additional symptom burden for the individual who is dying.

- Depends on stage of dying process
- An individual actively dying will not feel hunger or thirst
- Patients typically DO NOT feel completely satisfied with tube feeds
- Decreased mental status can impact your loved one’s interest in food
- Terminally ill patients spend most of their time sleeping
- Medications may increase nausea
- Decreased body fluids can make respiration easier
- Decreased liquid intake can reduce pulmonary secretions which can eliminate need for suctioning
- Decrease in GI fluids can reduce nausea/vomiting
- Decreased intake = decreased urine output eliminating need to move your loved one
FAQ: Will a feeding tube change my loved one's outcome?

- In some cases, feeding tubes will not change the outcome, but will prolong the inevitable.
- In comparison with assisted oral feeding; long-term tube feeding has no advantages and a number of disadvantages.
- Discomfort of feeding tube can lead to your loved one pulling out the tube and with negative consequences.
- Tube feeding and intravenous (IV) fluids can cause fluid overload potentially resulting to peripheral edema and pulmonary congestion.
FAQ: How quickly will my loved one get sick if they are aspirating?

- VERY difficult to determine – every person is different and responds differently
- Contributing factors:
  - Oral care
  - Mobility level of patient
  - Amount aspirated
  - Material aspirated
  - Overall medical status
FAQ: If my loved one gets a feeding tube, will they get all the nutrition they need and avoid aspiration pneumonia?

- Nutritional state does not always improve with the use of a feeding tube
- Gastrostomy tubes do NOT prevent aspiration
  - Stomach content (Reflux)
  - Secretions
FAQ: Is it ethical to withhold nutrition/hydration?

Guidelines for the Treatment of Patients with Advanced Dementia states:

- “Severely and irreversibly demented patients need only care given to make them comfortable. If such a patient is unable to receive food and water by mouth, it is ethically permissible to choose to withhold nutrition and hydration artificially administered by vein or gastric tube. Spoon feeding should be continued if needed for comfort.”

- In 2000 - the Ethics Advisory Panel recommended that assisted oral feeding is a compassionate alternative to tube feedings, with hospice care, when needed.
We have a great responsibility to this specific group of patients. If we come together as a multidisciplinary team we can assist patients and family members through a very stressful and difficult time.


