Beyond Aspiration Risk:
The Speech-Language Pathologist's Role in Palliative Dysphagia Management

MELANIE JOHNSON, MS, CCC-SLP

SAMANTHA WALCZAK, MA, CCC-SLP

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Disclosures

MELANIE JOHNSON, MS, CCC-SLP: NONE

SAMANTHA WALCZAK, MA, CCC-SLP: NONE

Objectives

- Discuss the relationship between speech therapy and palliative care
- Describe ways speech therapy can be included in advanced care planning discussions regarding oropharyngeal dysphagia
- Identify the methods speech therapy uses to assess and treat dysphagia
- Summarize the pros and cons of oral nutrition versus non-oral nutrition when aspiration risk is present

Dysphagia: Difficulty Swallowing

- Indicates there is a problem moving liquids and/or solids from the mouth to the stomach.
  - Red flags: coughing, choking, throat clearing or globus sensation
  - Patients can have silent aspiration which may not manifest with robust clinical symptoms until pulmonary decline occurs

- Four phases of the swallow
  - Oral prep
  - Oral
  - Pharyngeal
  - Esophageal

- SLP assessment focuses on oral and pharyngeal phases
  - If esophageal signs/symptoms are noted suggest a referral to GI

Prevalence of Dysphagia

- Dysphagia rates by settings:
  - Hospital setting: 36.5%
  - Rehabilitation setting: 42.5%
  - Nursing home setting: 50.2%

Dysphagia rates in palliative and end of life care may be as high as 79%

Etiologies

- Neurological
  - Stroke, TBI, ALS, Parkinson’s, Huntington's, Dementia, Multiple Sclerosis, spinal cord injury, prolonged use of antipsychotic medications leading to tardive dyskinesia
- Muscular/Neuromuscular disorders
  - Myasthenia gravis, Guillain-Barre Syndrome
- Structural
  - Head and neck cancer, prolonged intubation, vocal cord injury, cervical spinal surgeries, post radiation therapy fibrosis
- Physiological
  - Age related decline, general deconditioning, exacerbation of previous disease/disorder, Delirium/AMS, failure to thrive
- Developmental
  - Down’s syndrome, Cerebral Palsy

Why is Dysphagia a Big Deal?

- Dysphagia can cause immediate medical concerns such as choking, airway blockage and/or aspiration
- Healthcare workers are often concerned about dysphagia leading to aspiration pneumonia or aspiration pneumonitis
  - Frequently viewed as a problem to be addressed and fixed with diet modifications and/or therapy
- For patients and families, dysphagia includes concern for choking in a more general sense, but also the emotional aspect of distress over nutrition and the potential impact on quality of life that comes with eating
  - Patient and families have to ‘live with this problem’ for the duration of the concerning symptoms
- Symptoms of dysphagia noted by patients, family or medical personnel, or risk factors for dysphagia, often prompt a consult to the speech language pathologist

The Traditional Role of the SLP in Acute Care

- Assessment of swallowing - including clinical assessments and instrumental
- Determining most appropriate/least restrictive diet recommendations
- Establish a treatment plan for addressing dysphagia - if appropriate
- Education to patients and family
- Request appropriate referrals
- Make recommendations for next level of care if needed

The Swallow Assessment

Multidimensional approach

- Gather case history/review EMR
- Clinical swallow assessment
  - Social history, patient/family perspective/background, oral mechanism and oral trials
- Instrumental swallow assessment (as indicated)
  - Videofluoroscopic swallowing study (VFSS) vs. Fiberoptic endoscopic evaluation of swallowing (FEES)
    - Always discuss if an instrumental study will aid in informed decision making or is it an undue burden for the patient
    - VFSS results can be a catalyst to conversation regarding advanced decision making

VFSS - Videofluoroscopic Swallow Study

Real time diagnostic x-ray via video exam that directly visualizes anatomy and physiology of the mouth, throat, and esophagus while swallowing oral contrast (barium)

- Used to determine the WHY, HOW and WHAT NOW of a patient's dysphagia
- **Not a pass/fail examination**

Methods:

- Teaspoon, cup, straw of thin, mildly thick (nectar), moderately thick (honey), puree (extremely thick), regular and barium tablet
- Single and rapid consecutive sips
- Compensatory strategies: bolus hold, hard swallow, chin tuck, head turns, Supraglottic swallow, position changes

Modified Barium Swallow Impairment Profile (MBS-ImP)

- Evidence-based, standardization of the MBS study in the adult population
- Standardized protocol to profile the physiologic impairments of swallowing function and to communicate MBS study results in a manner that is accurate, specific, consistent, and objective
- Esophageal sweep as appropriate

After the Assessment

- Review results, recommendations, and plan of care with patient, including family whenever possible and/or appropriate
- This discussion may include:
  - Deficits noted on imaging and potential impact
  - Diet recommendations
  - Compensatory strategies
  - Modifications
  - Therapy POC
  - Prognosis
  - Needed referrals
    - SLP may be the one who opens the discussion of palliative care involvement and requests and consult for the palliative care team

The Role of the SLP in Palliative Care

Summary of ways in which SLP can assist in palliative care swallowing intervention

- Advocacy: Requesting palliative referral, notifying medical team of patient preferences for a certain diet after thorough discussion
- Identification: Determining patients that need to be seen, recognizing when to transition from rehab to comfort based approach
- Assessment: Trial strategies, provide a comfort focused diet recommendation that aligns with patients wishes/goals
- Intervention: Create oral care program, develop plan of care to support patient preferences while ensuring safeguards and strategies are in place
- Support: Participate in family meetings to advocate for further ST intervention as indicated.
  - Open discussion with medical team/MD about patient preferences, goals, desires and beliefs about eating
- Counsel: Prepare family/caregivers for expected changes in swallowing and secretion management with disease progression.
  - Suggest alternative bonding activities such as oral care or hand holding.
- Education: Train nursing staff on any strategies or positioning and discuss contraindications for TF in end stage dementia

The Role of the SLP in a Palliative Meeting

- General background of dysphagia
- Review assessment findings and their potential impact on the patient
- Recommendations
- Discuss oral intake goals
- Prognosis
- Field questions/supportive listening
  - Always keeping in mind that family likely has significant opinions and/or emotions pertaining to fear of choking, aspiration, malnutrition, or even denial of dysphagia or the severity

> The goal of the SLP mirrors that of the PC team: ensuring care is provided in alignment with patient values and preferences while avoiding unnecessary hardship for the individual and caregiver.
>
> (Yonan et al., 2025, p. 5)

Without SLP, management of dysphagia falls on the patient, family/caregivers and medical staff

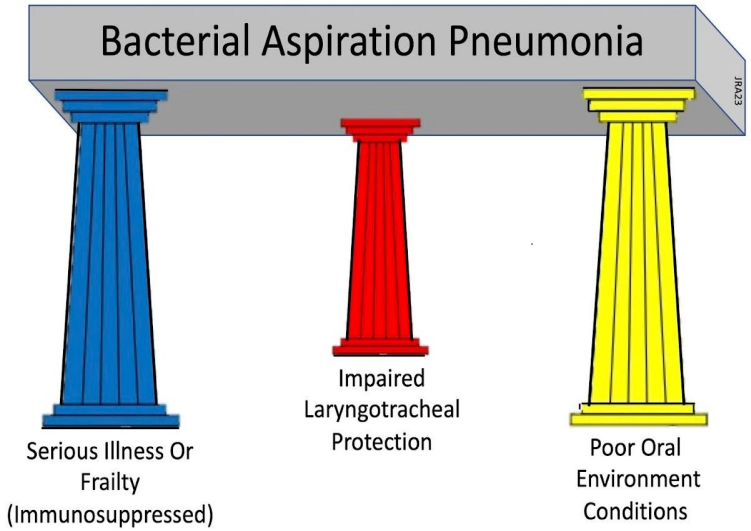
- SLP can assist in determining a middle ground and help determine patient priorities
- Diet plans in a palliative perspective should reflect patient wishes and align with goals of care

What Now?

Recommendations in Cases of Significant Dysphagia per instrumental assessment

1. NPO with further discussions regarding patient candidacy for alternative means of nutrition/hydration medication is indicated if goals of care are to minimize risk of airway invasion with oral intake and swallow inefficiency.
   - Benefits: Reduced aspiration of food/liquid, possible reduction of pneumonia/choking, possible reduction in cardiopulmonary decompensation
   - Disadvantages: Xerostomia, thirst/hunger, possible reduced quality of life, possible further decline in swallow function, possible need for physical or chemical restraints to prevent tube dislodgement
2. *** solids with *** liquids
   - Benefits: Potential avoidance of feeding tube, comfort from eating/drinking despite modified texture
   - Disadvantages: Potential aspiration/choking of food/liquid, Risk of dehydration/malnutrition
3. Regular solids and Thin liquids
   - Benefits: Potential avoidance of feeding tube, comfort from eating/drinking preferred food/liquid items
   - Disadvantages: Greater risk of aspiration/choking, possible cardiopulmonary decompensation

The Three Pillars of Aspiration Pneumonia



- To develop a true aspiration pneumonia, they must have more than just dysphagia
- Aspirating a foreign substance will result in pneumonia only if the aspirated material is pathogenic to the lungs and host resistance is compromised
- Aspiration is NOT synonymous with pneumonia
- Pneumonia is caused by pathogenic microorganisms colonizing in a *vulnerable* host, thus even with modified diets, thickened liquids, or tube feeding, aspiration of oral secretions may still occur and may lead to pneumonia

Pneumonia “Risk” Predictor

Scenario	Health/Immune System Status	+	Oral Health Status	+	Laryngeal Valve Protection Status	=	Predicted Outcome
1	Normal	+	Healthy	+	No Aspiration	=	No Pneumonia
2	Normal	+	Poor	+	No Aspiration	=	No Pneumonia
3	Normal	+	Poor	+	Aspiration	=	No Pneumonia
4	Normal	+	Healthy	+	Aspiration	=	No Pneumonia
5	Compromised	+	Healthy	+	No Aspiration	=	No Pneumonia
6	Compromised	+	Poor	+	No Aspiration	=	No Pneumonia
7	Compromised	+	Healthy	+	Aspiration	=	Lower Risk - Pneumonia
8	Compromised	+	Poor	+	Aspiration	=	High Risk - Pneumonia

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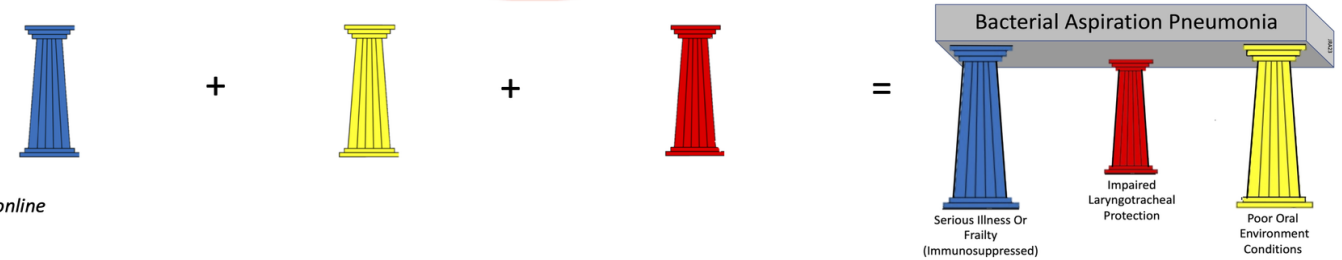

Risk factors for Aspiration PNA

- Advanced age
- Reduced mobility
- Dependence on others for oral cares and feeding
- Lung disease
- GI/GERD
- Dental disease/poor hygiene
- Immunocompromised or stroke induced immunosuppression
- Impaired mental status

Oral Hygiene

- Keeps mouth clean and moist, reducing risk of dry mouth, infection, and tooth decay
  - Dry mouth can make chewing, swallowing, and talking difficult, and can lead to infection and pain
- Reduces bacteria in our saliva, mouth, tongue, and teeth which further reduces the risk for aspiration pneumonia
- Mouth care improves our swallow and cough reflex
- Nocturnal denture wearing doubles risk of PNA
- Swabs alone are not oral care, however can help remove debris and secretions
  - Brush to clean, swab in-between
- It's still important to brush your mouth, gums and tongue with a toothbrush even if you don't have teeth
  - A majority of oral bacteria resides on the tongue
- Moisturize to improve lip and oral mucosa and prevent dry mouth

Frazier Free Water Protocol (FWP)

- Allows certain patients that are dysphagic access to thin liquid (ice chips or water only) in-between meals and/or 30 minutes after meals following rigorous oral cares and specific guidelines set by a SLP, with the approval of their medical team, despite being identified as an aspiration risk
- Can be implemented with patients who are on a modified/thickened liquid diet or NPO
- Water is pH-neutral, benign and to a degree can be absorbed by the lungs without causing significant harm if aspirated
- Benefits: improves hydration and fluid intake, improves oral mucosa, secretion management and saliva production, improves QOL, improves compliance of recommendations and improves swallow neuroplasticity
- Not all patients are appropriate for the FWP
  - Considerations: mentation, immunocompetence, oral hygiene, comfort
- Thickened liquid often results in decreased fluid intake and dehydration, which can further lead to other health complications

Thickened Liquids: Risks and Benefits

- Risks
  - Reduced quality of life/less palatable
  - Dehydration
  - May result in greater volume of residual material in pharynx after the swallow
  - More likely to lead to development of pneumonia if aspirated due to the presence of a thickening agent

- Benefits
  - Slows down liquid movement while swallowing
  - Easier to control
  - May allow more time to achieve airway closure during the act of swallowing
  - May improve comfort if patient has severe sensory response/discomfort secondary to aspiration

To Provide Enteral Nutrition or Not?

- Short term (NG/NJ) vs. Long term (PEG/GJ)
  - There are some circumstances where short term EN is beneficial (s/p prolonged/traumatic intubation, cervical spinal fusion complications, CVA w/ good rehab potential)
- NG/NJ is often used as temporary bridge to assess for recovery when the patient has medical needs to remain hospitalized
- Repeat VFSS is used to assess progress and guide overall treatment and/or discharge plan
- Patients are rarely able to discharge from the hospital with an NG tube
- When limited progress is noted or dysphagia is severe to profound, discussions may be opened regarding long term alternative feeding plans (PEG)
- Only 4 conditions have been proven to benefit from PEG insertion
  - Head and neck CA, acute CVA, neuromuscular dystrophy syndromes, gastric decompression
- PEG complication rates range from 17-32%
- Overall, 30-day mortality rates post PEG placement range from 16-30%
- PEG placement results in faster discharges from acute care and higher reimbursement for SNF

To Provide Enteral Nutrition or Not?

Some aggressive and invasive “life sustaining” measures, neither prolong nor sustain life in a meaningful way

In elderly populations a PEG….

- Does not prolong life
- Does not improve QOL
- Does not prevent aspiration PNA - some studies show an increased risk of aspiration
- Does not promote healing of pressure ulcers
- May require medicinal or physical restraints to prevent removal
- Can be burdensome to patients and/or caregivers
- Cause life threatening complications (infection, hemorrhage, gastric ulcerations, stoma, irritation, dislodging, clogging) requiring recurrent hospitalizations
- Can increase risk of aspiration of reflux
- May limit discharge locations or require patients to move to a different facility

Specific Case Study Examples

Clinical and ethical debates abound regarding PEG tube placement in elderly individuals with dementia

There were 3 most encountered populations of cognitively impaired older adults seen by geropyschiatrists either before or after PEG placement, characterized by 3 case studies discussing treatment issues (Detweiler et al., 2004)

- Ability to communicate with capacity: PEG placed secondary to aspiration. Demonstrated significant behaviors post PEG placement. Refused to abstain from PO. "He said he wanted to die if he could not eat." PEG was removed and patient resumed oral nutrition, gained weight and behaviors ceased.
- o Ability to communicate without capacity: Multiple bouts of aspiration pneumonia leading to PEG placement. Led to agitation and lengthy inpatient stays for medication management. Eventually, to manage behaviors, the patient was allowed to resume eating.
- o Severe verbal aphasia without capacity: Medication management required for behaviors at baseline. Fell and fractured his hip and became non-ambulatory. Gradually lost appetite and swallowing ability. Wife opted for PEG but he constantly pulled at the tube and then required restraints and special mittens to avoid self-extubation of his PEG.

Failure to Thrive

Failure to thrive encompasses four main syndromes

- Malnutrition/weight loss
- Impaired physical functioning
- Cognitive impairment
- Depression

Speech therapy may be consulted for patients who get admitted with refusal to eat or drink

- Need to determine if etiology is dysphagia, cognition, depression or a combination

Most patients who stop eating do not actively experience hunger

- The weight of the “need to eat” is often felt by the caregiver more than the patient

Terminal anorexia and dehydration may benefit dying patients

- Induces ketosis, uremia and endorphin release, and reduces burdensome secretions
- Near end of life, reduced hunger and thirst may be an adaptive mechanism rather than a maladaptation requiring treatment

Dementia

- Within 8 years of the diagnosis, approximately half of all patients with dementia will be unable to feed themselves
- 85% of institutionalized end stage dementia patients exhibit refusal to eat at some point

The American Geriatric Society, Alzheimer's Association, the ABIM Choosing Wisely campaign, Academy of Nutrition and Dietetics and American Society of Parenteral and Enteral Nutrition recommend against the use of feeding tubes in patients with advanced dementia, reporting there is no medical benefit from feeding tubes and that feeding tubes may actually cause harm

- Tube feeding placement in this population is associated with increased agitation, increased need for use of physical and chemical restraints, increased infections, frequent readmissions to the hospital, increased complication rates, and worsening pressure ulcers
- Tube feeding does not improve nutritional status in the setting of advanced dementia and does not result in better outcomes than oral feeding in regards to life expectancy, quality of life, patient comfort, functional status, and prevention of aspiration pneumonia

Careful hand feeding is the preferred approach to nutritional support in advanced dementia

Safe Feeding Strategies

- If patient is refusing food, try at another time
- Offer frequent verbal encouragement and one word cueing ("drink," "chew," "swallow") and gentle touch for stimulation
- Sit down and make eye contact
- Ask patient and patient's family about food preferences
- Do NOT force food into mouth
- Maintain a quiet environment and play relaxing music
- Remove distractions
- Allow patient to attempt to feed themselves
- Provide adequate time
- Offer finger foods
- Provide utensils that compensate for reduced motor ability

Body Autonomy

- Understanding patient's wishes of what they would have wanted BEFORE illness onset
- **Education to family is imperative**
  - May need to address emotionally driven fears such as starvation and choking, explore wishes of family and patient, and work to assist the patient in expressing their wishes in ways that their family can understand
- 1999 survey showed many Americans 65+ did not want any life-sustaining treatments after dementia diagnosis
  - 4% of those were agreeable to feeding tube if they progressed to the point they could not communicate and dependent on others
- “up to 40% of patient do not follow the recommendations of SLPs regarding dietary restrictions” (Horner et al, 2016)

SLP Support for the Comfort Patient

- Focus shifts from rehabilitation approach to a supportive approach
- Family education on safe feeding strategies
- Assessing for **comfort**
  - Ex: Patient is coughing and uncomfortable on thin liquids, but appears more comfortable on thickened liquids
  - The goal is not focused on swallow safety at this point
- The notion of starvation and dehydration often becomes the primary concern for family/caregiver
  - The reality of a naturally reduced drive to eat and diminished nutritional needs due to reduced mobility and muscle mass in end stages of dementia and illness are often overlooked
  - Death by dehydration may actually prevent a prolonged dying process and ease suffering in the last stages of life

SLP Support for the Comfort Patient

- Clinical teams often err between two extremes:
  - Overly restricted diets due to fear of dysphagia or full diet liberalization
- Compensatory techniques developed by the SLP may support and improve quality of life and make eating, regardless of the degree of dysphagia, more comfortable
- Thickened liquids should only be considered for reducing discomfort with swallowing at end of life
- Thickened liquids should be avoided when patients express that it negatively impacts their quality of life
- Instrumental assessments are important, but near end of life, the benefit vs the burden should be weighed
  - Ask - will the result of the study change wishes or goals of care? Would the patient be willing to consider a modified diet if that was recommended? Will the results aid in decision making?

Discussion of Case Examples

Questions?

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