DEVELOPING A COMPREHENSIVE DYSPHAGIA PROGRAM FOR PATIENTS WITH COGNITIVE IMPAIRMENT

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Disclosures

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Introduction

• The incidence of dysphagia among the cognitively impaired population has been estimated to be high:
  • 80% or more among adults with developmental disabilities
  • 45% of patients with dementia who are institutionalized

Introduction

• Not only is the incidence of dysphagia high in this population, it often gets progressively worse rather than resolving.
Introduction

• Creating a program to manage patients with dysphagia and cognitive impairment creates a unique set of challenges, especially when your role in their care is more indirect.

In developing a dysphagia program in an institutional setting (nursing home/assisted living facility group home, etc.), your emphasis is upon three major groups:
• Clients
• Caregivers
• Facility Staff

Purpose

• Our purpose today is to discuss special considerations in assessing and treating individuals with dysphagia and cognitive impairment and in educating those individuals and their caregivers.

Learner Objectives

• Identify the components of a comprehensive dysphagia assessment for patients who have cognitive impairment.
• Identify the components of a comprehensive dysphagia treatment program for patients who have cognitive impairment.
• Identify factors that should be considered when educating the patient and his/her caregivers.
Components of a Comprehensive Dysphagia Program

• Assessment
• Treatment
• Education

ASSESSMENT

Goals of Assessment

• Determine the presence, nature, and cause of the swallowing impairment
• Examine the current level of function
• Develop strategies for dysphagia management
Patient-Specific Dysphagia Characteristics

- Dementia (in general)
- Alzheimer’s Disease
- Stroke/Vascular Dementia
- Frontotemporal Lobar Degeneration
- Lewy Body Dementia/PDD
- Down Syndrome
- Cerebral Palsy

Dementia

- Problems with the concept of mealtime
  - Confusion. Forget if/when they ate
  - Missed meals
- Nursing home residents with advanced dementia: 86% with “eating problems”
  - Nursing staff report there is a daily problem with feeding these patients

Alzheimer’s Disease

- Makes up 50% of all forms of dementia
- Progression of disease leads to dysphagia characterized by a sensory impairment due to dysfunction in the temporal-parietal areas
- Patient characteristics: memory loss, behavioral changes, apathy, irritability, delusions

Alzheimer’s Disease: Dysphagia Characteristics

- Early stages:
  - Delayed pharyngeal onset
  - Reduced lingual movement
Alzheimer’s Disease

- Feeding Behavior: Relies more heavily on cues and/or feeding assistance in self-feeding
- May benefit from finger foods to promote feeding independence as disease progresses (as swallowing and motor skills will allow)

Alzheimer’s Disease

- Focus on changing the environmental cues, such as the use of contrasting colors
  - Food vs. plate
  - Plate vs. tablecloth
  - Cup, utensils, napkin
- Watch for presence of distractions
  - Other residents
  - Environment

Alzheimer’s Disease: Dysphagia Characteristics

- Middle/moderate Alzheimer’s Disease:
  - Decreased oral prep (lingual coordination and bolus control)
  - Decreased HLE, pharyngeal constriction, decreased UES opening: ASPIRATION
  - Will forget they have eaten, demand more food but will lose weight (40% with reported weight loss)
  - Weight loss- predictor of mortality
  - Weight gain- can protect against decline associated with disease

Alzheimer’s Disease: Dysphagia Characteristics

- Severe Alzheimer’s Disease:
  - Latency of swallowing reflex is longer compared to mild/moderate stages, exacerbated by neuroleptics
  - Oral transit delay compared to individuals with vascular dementia
  - Therapy techniques:
    - Oral stage sensory stimulation (change textures, taste, temperature)
Stroke/Vascular Dementia: Dysphagia Characteristics
- Therapeutic suggestions (as based on cognitive status)
- Oromotor strengthening exercises for control
- Pharyngeal exercises including Mendelsohn, Shaker, CTAR, EMST

Stroke/Vascular Dementia: Dysphagia Characteristics
- Deficits in bolus formation, mastication of semi-solid foods, HLE
- Epiglottic inversion
- Silent aspiration secondary to impairment in corticobulbar tract

Frontotemporal Lobar Degeneration: Dysphagia Characteristics
- Characterized by alterations in food preferences (greater desire for sweet foods), changes in eating habits that correlate with degree of atrophy in orbitofrontal cortex and adjacent insula:
  - Gray matter loss in posterior location: hyperphagia
  - Gray matter loss is posterior location: sweet tooth

LBD and PDD Dementia: Dysphagia Characteristics
- Third most common form of dementia, making up approximately 15-20% of cases.
- Characterized by marked fluctuations in cognition, visual hallucinations, extrapyramidal symptoms (drug induced movement disorders - acute and tardive symptoms), and sensitivity to neuroleptics (antipsychotics).
- Higher incidence of dysphagia/anorexia than AD patients
### Down Syndrome: Dysphagia Characteristics
- Hypotonia of the lips, tongue, and pharynx
- Delayed development of oromotor function
- Poor lateral chewing movements due to hypoplastic maxilla and protruding mandible

### Down Syndrome: Dysphagia Characteristics
- Occlusal disturbances
- Upper airway obstruction
- Sleep apnea
- Oral stage problems such as biting on utensils, tongue thrust, change in taste, delayed or uncoordinated movements, emotional or behavioral problems

### Cerebral Palsy: Dysphagia Characteristics
- Abnormal muscle tone
- Persistence of primitive reflexes that interfere with eating and swallowing
- Drooling/poor saliva management
- Abnormal chewing and biting
- Silent aspiration, especially in non-ambulatory patients

### Cerebral Palsy: Dysphagia Characteristics
- Delayed swallow reflex
- Tongue thrust
- Poor head control
- Reduced strength
- Infrequent swallows
- Weak/absent protective reflexes
- Difficulties with peristalsis
Components of Assessment

A thorough assessment includes:
• Identification/Screening
• Case History/Caregiver Interview
• Instrumental Assessment

Identification/Screening

• In developing a dysphagia program for the cognitively impaired, the first step is to identify those with swallowing impairments.
• Best done through a bedside swallow screening (not always at bedside!).

Identification/Screening

• Include the caregiver in the screening process.
• Involve relevant team members: dietitian, PT, OT, Nursing.
• Observe the patient in his everyday setting.

Identification/Screening

• Give oral trials of various foods and liquids.
• Try adaptive utensils.
• Attempt compensatory strategies.
Identification/Screening

If the patient is fed by staff, observe during mealtime to assess:
• Rate of feeding
• Patient’s response to different foods and liquids (textures, temperatures, flavors)
• Patient’s behaviors during mealtime

Identification/Screening

• The accuracy of your bedside screening can be improved by including assessment of: dysphonia, dysarthria, abnormal volitional cough, abnormal gag reflex, cough after swallow, and voice change after swallow (Daniels, et al, 1997)

Caregiver Interview

• A critical component of your assessment is the caregiver interview.
• These individuals are invaluable in providing information that you may have missed during your screening process.
Caregiver Interview

- Caregivers may include CNA’s, facility managers, facility staff, family, and/or friends.
- A word of caution...the level of understanding with regard to dysphagia and feeding varies greatly among caregivers.
- Example

<table>
<thead>
<tr>
<th>Time of Day</th>
</tr>
</thead>
<tbody>
<tr>
<td>When does the swallowing impairment occur?</td>
</tr>
<tr>
<td>Is the disorder tied to caregiver behavior? For example:</td>
</tr>
<tr>
<td>Patient is tired in the morning and is “encouraged” to eat by caregiver, or</td>
</tr>
<tr>
<td>Patient may be fed at a rate that is not conducive to his optimum feeding behavior, or</td>
</tr>
<tr>
<td>A specific caregiver does not provide appropriate cues or techniques that other caregivers provide at different times of day.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Frequency of Occurrence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are there signs/symptoms of swallowing impairment every time the patient eats or drinks? Or, are the s/s infrequent?</td>
</tr>
<tr>
<td>A one-time occurrence of severe choking behavior can be scary and may trigger a referral, when it really is just a one-time occurrence.</td>
</tr>
</tbody>
</table>
Conditions

- Are there specific foods that trigger swallowing difficulty?
- It is essential to be aware of the foods that are allowed at the patient's facility as a part of his diet plan. For example:
  - Are high risk foods such as cornbread allowed?
  - How is mechanical soft defined?
  - Do pureed foods differ in viscosity?

Conditions

- Are there specific positions that trigger the swallowing difficulty? For example:
  - Does the patient eat better at the table or in his wheelchair?
  - Does adaptive equipment affect eating behaviors?

Instrumental Assessment

- Bedside screens do not identify the nature of the swallowing impairment, and silent aspiration may be missed.
- If indicated from the screening process, an instrumental assessment may be warranted.
Instrumental Assessment

- Caregivers are often in a position to indicate which type of assessment would be best tolerated by the patient...FEES or MBS.

Instrumental Assessment

In an instrumental assessment, the facility's diet plans and the patient's specific diet preferences must be communicated to the assessing SLP so that he/she can:

- Test specific consistencies and food preferences (that you send with the patient)
- Make appropriate dietary recommendations (based on the facility)
- Use any patient-specific utensils (cups, spoons, straws, etc).

Instrumental Assessment: Liquids

- Present thin, nectar-thickened, and honey-thickened as per usual in this type of assessment.
- In addition, assess:
  - Optimum “sip” size and presentation
  - Safety in isolation vs. with meal (as a liquid wash)
  - Safety may differ when used as a liquid wash based on size of sip and amount of residue

Instrumental Assessment: Solids

- Pureed (thinner and thicker viscosity): applesauce and pudding
- Mechanical soft (mixed and binding agent): peach cocktail and graham cracker with pudding vs. applesauce
- Regular: graham cracker- bite size matters!
**Instrumental Assessment: Other Considerations**

- Compensatory strategies: Which can the patient do and which will be most effective?
- Liquid wash vs. dry swallow:
  - The amount and location of residue. The strategy must work for all consistencies.
  - The difficulty in performing a dry swallow. Liquid wash may be more effective for patients who consistently tongue pump before the swallow.
- Other factors such as fluid restriction, fatigue, caloric intake

**Instrumental Assessment: Other Considerations**

- Timing of the oral and pharyngeal phases
- Does the specific consistency require more time and effort than a less complex consistency? Consider in regards to fatigue, expending of more calories than is consumed
- Piecemeal deglutition: Yes, it is a normal part of swallowing function, but how does it change how we feed patients?
- Time for additional swallows, bite size

**Treatment**

- Following the outcome of the assessment, an individualized management plan should be developed.
- This plan should be clear and caregiver-friendly.
Treatment

- The major goal of intervention is to insure safe and adequate nutrition and hydration.

Diet Modifications

- Diet modifications are the easiest changes to make, but they may influence the quality of life more than other changes. For example:
  - Caregivers may prefer to have a more restrictive diet with fewer compensatory strategies.
  - Facilities may push for a less restrictive diet due to cost associated with thickeners and preparation.
  - Family members may care more than the client.

Treatment

- Treatment targets three main areas:
  - Diet Modification
  - Compensatory Strategies
  - Exercise
  - The weight assigned to any of these areas differs based on the patient, the caregiver, and the facility.

Diet Modifications

- In this population, the goal is to help the patient continue an oral diet for as long as possible.
  - You must not only establish the safest and least restrictive diet, but to also train staff/caregivers to know when it is time to re-consult (more about this under education).
  - Generally speaking, when a diet has been established to be safe, your role is to verify (briefly), then turn patient care over to the caregivers.
Compensatory Strategies

- Patient strategies
- Adaptive equipment

Patient Strategies

- Chin tuck, head turn/tilt, super/supraglottic swallow, effortful swallow, Mendelsohn
- Don’t assume that the patient cannot complete these strategies due to their cognitive deficit
- Can often be trained with spaced retrieval—there’s an APP for that!
- Can be encouraged through the use of models, pictures, placement of spoon/straw

Patient Strategies

- Liquid wash and dry swallow
- To prompt a dry swallow, use a dipped spoon
Adaptive Equipment

- Spoons
- Plates
- Cups
- Table boxes
- Plate grippers
- Hand weights
Adaptive Equipment

Pros: can help patients be more independent in feeding, which can improve swallow function
Cons: Expensive, easily lost, issue with cleaning

Exercise
- Very rarely if ever used with this population due to:
  - Cognitive ability
  - Staff time
  - Lack of improvement

EDUCATION
Education

- Education is one of the most critical aspects of a successful dysphagia program.
- The patient, the caregiver, and the facility all must be educated for the program to run effectively.
- It is necessary to have an on-going in-service program for staff and caregivers.

Education Topics

- Dysphagia definition: general and patient specific
- Signs and symptoms of dysphagia
- Causes of dysphagia
- Aspiration pneumonia: causes and prevention
- Modifying diets: solids and liquids
- Feeding tubes: what they are and ARE NOT
- Feeding strategies
- Modifying mealtimes
- Adaptive equipment

Dysphagia Definition

- Discuss the process/phases of swallowing in laymen’s terms and explain the nature of the patient’s impairment
  - Pre-oral phase
  - Oral
  - Pharyngeal
  - Esophageal

General Signs and Symptoms of Dysphagia

- Coughing
- Drooling
- Food refusal
- Hoarseness/“gurgly voice”
- Poor weight gain/excessive weight loss
- Vomiting
- Pocketing food
### Causes of Dysphagia

In addition to diagnoses that impact sensory and/or motor function (e.g., neurodegenerative diseases) causes may include:
- Dental issues
- Medications
- GERD
- Positioning
- Intake method
- Food intolerance

### Aspiration and Aspiration Pneumonia

- Definitions:
  - Aspiration
  - Silent aspiration
  - Aspiration pneumonia
- Conditions that need to be present for aspiration pneumonia to develop
- Ways to prevent aspiration pneumonia

### Aspiration and Aspiration Pneumonia

- Factors that contribute: Smoking, dependence for feeding and oral care, more than one medical diagnosis, number of decayed teeth, presence of tube feeding, number of medications (Langmore, et al, 1998).
- Dysphagia alone does not predict aspiration pneumonia, but it does make it more likely to occur.

### Predictors of Aspiration Pneumonia in Cognitive Impairment

Hibberd and Taylor, 2009
- Concentrated bacteria due to dry mouth, mouth or dental disease, non-independent in oral care, multiple medications, feeding tubes
- Unintentional weight loss, urinary tract infections, older than 85 years, greater than 2 medical conditions
Predictors of Aspiration Pneumonia in Cognitive Impairment

• Pulmonary clearance impairment as a result of being confined to the bed, reduced activity levels, COPD, congestive heart failure, suctioning, and tracheostomy
• Additional factors such as lack of independence in oral feeding, dysphagia, consumption of a texture-modified diet, reduced awareness, non-medically controlled reflux disease

Cognition and Aspiration
Leder, Suiter, and Lisitano Warner (2009)

• Assessed orientation and ability to follow 1-part commands in patients with dementia and neurological injury
• Odds of liquid aspiration were 31% greater in individuals not oriented
• Patients who were not able to safely consume oral intake were 69% of those who were unable to follow 1-part commands
• Conclusion: cognition may be good screener for patients who are at-risk for aspiration

Diet Modification: Solids

• Define each consistency based on the characteristics.
• Discuss materials necessary to alter consistencies: kitchen shears, blender/food processor.
• Discuss ways to preserve food flavor while altering consistencies.
Diet Modification: Solids

- Discuss the impact of food temperature (stimulate receptors).
- Instruct on use of binding agents.
- Illustrate/give tips on preparing each consistency.

Diet Modification: Liquids

- Define each consistency based on the characteristics.
- Discuss materials necessary to alter: blender/food processor, thickener.
- Discuss naturally thickened liquids.

Diet Modification: Liquids

- Discuss different types of thickeners and their pros and cons.
- Discuss more controversial consistencies: ice cream, jello, alcoholic beverages, carbonated beverages.

Feeding Tubes

- What are they and what are the different types?
- Who is indicated for which type and when?
- How are they held in place?
- Types of feeding: bolus vs. continuous
- Pleasure feeds
Feeding Tubes

- Do they prevent aspiration pneumonia?
  - Tube feeding is associated with a higher rate of pneumonia than oral feeding
- Why?
  - Reflux
  - Oral bacterial that is aspirated in saliva

Feeding Tubes

Kuo, Rhodes, Mitchell, Mor, Teno (2009)

- Incidence of feeding tube placement in nursing home residents with advanced dementia over 12 months: 56/1000
- 2/3 inserted during acute hospitalization
- Inserted due to aspiration pneumonia, FTT, dysphagia
- Mortality rate in 12 months: 64.1%
- Mean survival rate: 56 days post tube insertion
- Repeat hospital admissions: 20%

Feeding Tubes

Peck, Cohen, Mulvihill (1990)

- Followed patients 6 months following tube placement:
- 58% nursing home residents with dementia developed aspiration pneumonia, but only 16% of those continued to be fed orally developed aspiration pneumonia at 6 months

Feeding Tubes

Sanders et al., (2000)

- Compared patients with dementia who received feeding tube and patients with head and neck Ca, CVA, and other neurological impairments
- 30 day mortality rate: 28% non-dementia group (NDG) vs. 54% dementia group (DG)
- 12 month mortality rate: 63% NDG and 90% DG
Feeding Strategies
- Typically best to feed in a calm environment that is free from distractions.
- Know the patient specific diet, strategies, adaptive equipment.
- Do not rush the patient, and be wary of feeding multiple patients simultaneously.

Feeding Strategies
- Feed from the front of patient at eye level.
- Place spoon in center of mouth and apply gentle pressure.
- Allow patient’s lips to scrape the food off the spoon.

Feeding Strategies
- Resource for teaching feeding techniques:
  - ASHA program
  - Silver Spoons Program – Miami VAMC

Modifying Mealtimes
Techniques to maximize nutrition and hydration for patients with dysphagia and cognitive impairment (Easterling and Robbins, 2008):
- Good oral hygiene
- Consistency in eating environment and seating
- Six small meals/hydration opportunities versus 3 large
Modifying Mealtimes
• Include spicy/sweet/sour foods/liquids
• Maximize calories at every opportunity
• Encourage self-feeding
• Eliminate staff disruptions during mealtime
• Remove non-food items from table

Modifying Mealtimes
• Increase visual appeal of foods
• Allow touching of foods
• Provide food choices
• Don’t make patients wait for meals

Final Considerations
• Be aware of how patient, caregiver, and facility factors may interact with one another and influence decisions.
• For example: Patient can safely take thin liquids if he uses a chin tuck. Without a chin tuck, patient must take nectar thickened liquids.

Final Considerations
• In this case, can the patient consistently perform a chin tuck independently?
• If not, are the caregivers trainable to make sure the chin tuck is completed consistently?
• Or, with the use of cognitive training, can the patient be taught to use a chin tuck independently?
• Answers to questions such as these can influence the program you ultimately create.
Case Study

- Patient at center for individuals with intellectual disabilities
- Male, 17 year old
- Resident at center, but often visited his mother and spent the night
- Recurrent aspiration pneumonia

Case Study

- Several Instrumental studies (MBSS and FEES) conducted with similar results found
- Pureed foods with nectar-thickened liquids
- Group meeting with patient and mother to discuss staff concerns
- Considering feeding tube to try to eliminate aspiration pneumonia

Case Study

- Staff trained and followed diet recommendations and strategies
- Mother promised she was following diet recommendations and strategies
- Decision to continue oral feeding status, wait and watch
- As mother was leading son out of meeting, she was heard to say..."We better hurry. I have your..."
- Two years later: Patient has both tube and trach