**Pediatric Dysphagia: The Child with Medical Complexities**

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**Disclosures**

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**Learning Objectives**

- Participants will state three common characteristics (e.g., neurological, behavioral, respiratory issues) of medically complex children  
- Participants will identify two challenges and possible solutions, to traditional SLP assessment and treatment in medically complex children.  
- Participants will examine case studies and discuss a holistic model of management

**Presentation Overview**

- Review of the medically complex child:  
  - Etiologies (i.e., prematurity, syndromes, etc)  
  - Systems involved in feeding and swallowing (i.e., neurologic, respiratory, etc)  
- Assessment of feeding and swallowing in medically complex children  
- Considering the “whole” child  
- Case Studies

**The Medically Complex Child**

- Children with significant chronic conditions in two or more body systems  
- Children with a single dominant chronic condition

**The Medically Complex Child**

- **Neurologic issues**  
  - Respiratory concerns  
  - Gastrointestinal problems  
  - Cardiac compromise  
  - Anatomical abnormalities  
  - Multiple comorbidities - why?  
    - Prematurity  
    - Chronic conditions that affect multiple systems in the body  
    - Increasing survival rates of premature infants and children with disabilities
Neurologic disorders

- Grade 3 and 4 IVH (Intraventricular hemorrhage)
  - Often occurs with extreme prematurity or traumatic birth
  - Associated with spastic hemiplegia and impact cognitive function
- Congenital conditions
  - Gene or chromosome abnormalities (i.e., Down syndrome)
- TBI (traumatic brain injury)
- Infections (i.e., meningitis, encephalitis)
- Hypoxia/hypoxic ischemia

Neurologic disorders: Swallowing

- Abnormal tone (hyper or hypotonic)
  - Altering performance of swallowing muscles
- Developmental delay
  - Includes feeding skills
- Delayed swallow initiation
- Impaired sensation
  - Silent aspiration!
- Gastrointestinal issues
  - High rates of reflux and dysmotility

The Medically Complex Child

- Neurologic issues
- **Respiratory concerns**
- Gastrointestinal problems
- Cardiac compromise
- Anatomical abnormalities
- Multiple comorbidities

Respiratory Concerns

- Chronic Lung Disease (bronchopulmonary dysplasia)
- Ongoing O2 requirements
- Difficulty coordinating swallowing and breathing
  - Suck-swallow-breathe coordination during bottle/breast feeding
- Respiratory fatigue
- Which came first, the chicken or the egg?

The Medically Complex Child

- Neurologic issues
- Respiratory concerns
- Gastrointestinal problems
- Cardiac compromise
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Gastrointestinal problems

- Gastroesophageal reflux
- Delayed gastric emptying
- NEC (necrotizing enterocolitis)
  - Inflammatory disorder of GI tract
- Esophageal dysphagia/poor esophageal motility
- Constipation
- Food allergies/feeding intolerance
- Non oral feeds

Swallowing: food refusal, dysmotility, pressure changes in pharynx, decreased laryngeal/pharyngeal sensation
The Medically Complex Child
- Neurologic issues
- Respiratory concerns
- Gastrointestinal problems
- **Cardiac compromise**
- Anatomical abnormalities
- Multiple comorbidities

Cardiac conditions
- PDA (patent ductus arteriosus)
- Congenital heart disease
- Aortic valve stenosis
- Cardiomyopathy
- Tetralogy of Fallot

Swallowing: fatigue!

The Medically Complex Child
- Neurologic issues
- Respiratory concerns
- Gastrointestinal problems
- Cardiac compromise
- **Anatomical abnormalities**
- Multiple comorbidities

Anatomic Abnormalities
- Examples include, but are not limited to
  - Cleft lip/palate
  - Retrognathia
  - Laryngeal cleft

The Medically Complex Child
- Neurologic issues
- Respiratory concerns
- Gastrointestinal problems
- Cardiac compromise
- Anatomical abnormalities
- **Multiple comorbidities - why?**
  - Prematurity
  - Chronic conditions that affect multiple systems in the body
  - Increasing survival rates of premature infants and children with disabilities

Prematurity
- Estimated 15 million infants born preterm world wide
- 1 in 10 births
- Leading cause of death among children under 5 worldwide
- Higher rates of cerebral palsy, sensory deficits, learning disabilities, respiratory illnesses, GI difficulties, GERD, feeding difficulties, etc.
  - Issues are often chronic, lasting into adulthood (not just an issue in the NICU!)
Conditions with multiple components

- Down Syndrome
  - Cardiac (fatigue, poor tolerance aspiration)
  - Neurologic (delayed swallow, silent aspiration)
  - Tone (positioning challenges)
  - GI (reflux and constipation)
  - Anatomic and physiologic differences (large tongue, tongue thrusting)
- Many others exist and present with varied profiles

All this to say...

Assessing and treating dysphagia in medically complex children can be, well, complex!

As SLPs, it is crucial that we understand the effect of these key systems on feeding and swallowing.

Feeding in the Medically Complex Child

- Hayley (2016)
  - Pediatric feeding problems are complex and heterogeneous
  - In infants, feeding behaviors are considered appropriate functional responses to challenges of feeding
  - When older children present with feeding difficulties, they also often have complex medical history and yet are often not treated as such

Challenges and Solutions in Evaluating Dysphagia and Making Recommendations

Quick Reminder...

Instrumental assessment of the swallow is critical in this population:
- High risk of SILENT aspiration
- Risk of increased residue or poor clearance of thicker consistencies
- Risk of esophageal dysphagia
- Likely poor tolerance of aspiration
- Non verbal challenges

Challenges and Solutions in Evaluating Dysphagia and Making Recommendations

1. Behavior and refusal
2. Challenges in instrumental assessment of children
3. Thickening
4. Chronic aspiration
Food Refusal in Children

- Food refusal: “a child's refusal to eat all or most foods presented, resulting in the child either failing to meet caloric needs or dependent on supplemental nutrition”
  - 69% children with food refusal have reflux
  - 6% children with food refusal have delayed gastric emptying
  - 15% had food allergies
  - 25% had neurological conditions
  - 33% had cardiopulmonary conditions


69% children with food refusal have reflux
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Food Refusal in Children

- Williams, Reigel, & Kerwin (2009)
  - 85% children with food refusal had gastrointestinal abnormalities
  - Greer, Gulotta, Mader, & Lautd (2007)
  - 64% children with food refusal had cardiac, pulmonary, neurological, or genetic conditions
- Dellert, Hyams, Treem, and Geertsma (1993)
  - Typically developing infants with gastroesophageal reflux
  - Developed “feeding resistance” to the point of failure to thrive
  - Required supplemental tube feeds

Food Refusal in Children

  - Compared infants with GERD to infants without reflux
  - Infants with GERD had more food refusal and more swallowing problems
  - Some food refusal also found in children with anatomical abnormalities (ie. stenosis of trachea, cleft palate, etc.)
  - About 14% of children with food refusal had anatomical abnormality
  - Of 218 infants/children in this systematic review, 212 had medical issue, 116 (55%) had reflux or other GI issues, and 131 had some other non-GI related disorder (ie BPD, seizures, etc.)

So how does this change your evaluation of a “refuser”?

- History is crucial to problem solving
  - Chart Review
    - What systems could be impacting the child’s desire or ability to eat?
    - Neurologic > low tone > inability to clear residue or chronic aspiration events
    - GI > reflux esophagitis > discomfort with eating serial bites of solids?
  - Parent Interview
    - When did the refusal start?
    - Is it with specific consistencies?
    - Time of day?
    - Reflux and esophageal symptoms?
    - Always ask about bowel movements

- Instrumental assessment
  - Are they refusing as a protective mechanism (i.e. appropriate response) 2/2 aspiration or other dysphagia/discomfort?
  - Rule out any other cause before treating as “behavioral” or “sensory” feeding disorders

How does this alter your evaluation of a “refuser”?

- Don’t believe everything you see (or hear from parents)
  - Chewing issues vs esophageal or pharyngeal residue?
  - Absence of overt signs and symptoms of aspiration
  - Texture sensitivity

Case Study #1

- Instrumental assessment
  - Are they refusing as a protective mechanism (i.e. appropriate response) 2/2 aspiration or other dysphagia/discomfort?
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Challenges and Solutions in Evaluating Dysphagia and Making Recommendations

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Imaging Challenges

- Positioning
  - Hyper or hypotonia
  - Wheelchairs
  - Trying both positions
- Endurance (cardiac)
- Behavior/cooperation
  - Distraction
  - Preferred foods
- Materials/supplies

- Complete imaging on whatever they’re doing at home (or on the floors)
  - If variations, try them both/all
- Optimizing image
- Get creative with your set-up!
- What about trachs? One-way speaking valves?
  - Improve sensation, pressures, taste, secretion management
  - Can be a therapy goal prior to imaging!
  - Try your recommended consistency with valve on and off

Thickening

- Commercial thickeners
- Risk for infants and children with complex GI history
- Other thickening options
  - Cereal
    - Rice vs oatmeal?
  - Baby food
- Remember: thickening should be a LAST resort
  - Instrumental assessment of swallowing first, especially in medically complex population

Challenges and Solutions in Evaluating Dysphagia and Making Recommendations

1. Behavior and refusal
2. Challenges in instrumental assessment of children
3. Thickening
4. Chronic aspiration
What happens if they aspirate on EVERYTHING?

- What if no amount of thickening or strategies eliminates aspiration?
- Conversation with the family and the medical team
- What is the long term prognosis for this child?
- What are the families goals?
- What are the consequences of aspiration for this child?
- Provide multiple options for recommendations based on level of risk
  - Option 1 (most risk)
  - Option 2 (moderate risk)
  - Option 3 (least risk)

Case Study #2

The Whole Child: Interdisciplinary Collaboration

- Working with an Aerodigestive Team
  - ENT
  - GI
  - Neurology
  - Surgery
  - Pulmonology
  - SLP
  - Nutrition
  - Respiratory Therapy
  - Social Work

- If you suspect that a part of the child’s medical history is contributing to swallowing or feeding difficulties:
  - Ask primary care to consult that service
  - Ask specific questions—don’t be afraid to ask!
  - What testing would give you information that would guide your feeding plan?

Case Study #3

Team Approach

“All children need adequate nutrition provided in non stressful ways so they can maximize their learning potential in educational settings…collaboration between school – and medically based personnel is important to maximize the health and well-being for all children who need optimal nutrition and overall health for effective learning.”

(Arvedson, 2000)
References


