Pediatric Feeding/Swallowing Problems
Purdue University: Crossroad Conference
October 24, 2016

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Financial
- NIH/NIDCD, R01. Standardization of videofluoroscopic swallow studies for bottle-fed children
- Ataxia-Telangiectasia Children’s Project
- Speaker Honorarium: Purdue University

Non-Financial
- None
- Not now, nor have ever been an expert in all the dimensions of feeding swallowing / development and disorders

Past
At one time, dysphagia was recognized solely in children with cerebral palsy, other high risk conditions, and developmental delays
Normal feeding and swallowing development is 'biopsychosocial' process that involves children, their caregivers, and a host of other factors (e.g., culture, professionals). Stevenson & Allaire, 1991

Feeding
- Any aspect of eating or drinking, including swallowing
- Provides children & caregivers w/ communication and social experiences that form basis for many future interactions

Swallowing
- Process of deglutition that occurs after liquids or foods enter the mouth
- Involves any or all phases of deglutition

Disruptions that occur early in life may result in long-term feeding problems or exacerbate pre-existing swallowing problems.

Increasing Incidence of Feeding / Swallowing Disorders in Children
- Better diagnostic tools and improved recognition of potential problems associated w/ wide range of diagnostic conditions and presentations (medically complex → typically developing children)¹ ²
- Improved survival rates of children with complex and medically fragile conditions¹
- Increased longevity of persons with childhood dysphagia

Prevalence
- > 115,000 infants discharged from short stay hospitals with diagnosis of feeding problems¹
  ICD 9 = 779.3
  ICD 10 = P92 series or R63.3 in children over 28 days old
- 569 ±63,000 children (3-17 years old) diagnosed with dysphagia in US in 2012
  ≈ 1% of children annually

¹ Newman et al, 2001
² Lefton-Greif et al, 2000; Lefton-Greif, 2008
³ National Hospital Discharge Survey, CDC 2013
⁴ Bhattacharyya, N. Laryngoscope 2014
The “desirable” goals for children with feeding/swallowing disorders can only be accomplished by a team

Barriers to Understanding & Managing Dysphagia in Children

- Growth and development are dynamic processes with changing anatomy and physiology
  - What is normal?
  - What is normal variability?
- Patient cooperation may be suboptimal during exams, investigations and therapies
- Reliability of results?
- Same behaviors for different reasons (e.g., child who won’t vs. can’t)

Adapted from Kaul, 2008

Frequency of Common Feeding Problems in Typically Developing Children (n = 281)

<table>
<thead>
<tr>
<th>Feeding Problems (≥ 1): Reported by 62% Caregivers</th>
<th>Toddler n = 151</th>
<th>Infant n = 130</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not always hungry at mealtimes</td>
<td>54%</td>
<td>33%</td>
</tr>
<tr>
<td>Tries to end meals after a few bites</td>
<td>42%</td>
<td></td>
</tr>
<tr>
<td>Picky eating</td>
<td>36%</td>
<td></td>
</tr>
<tr>
<td>Does not always enjoy feeding</td>
<td>33%</td>
<td>9%</td>
</tr>
<tr>
<td>Has strong food preferences</td>
<td>34%</td>
<td>12%</td>
</tr>
<tr>
<td>Refusal to eat a meal</td>
<td>26%</td>
<td></td>
</tr>
</tbody>
</table>


Barriers to Understanding & Managing Dysphagia in Children

“At different ages, different functions require prioritization:”

- the neonate must suckle milk from the breast while maintaining regular nasal breathing in a semisupine position;
- the toddler must cope with the formation of a food bolus from solid foods and swallow precise manageable portions while seated;
- the schoolchild must breathe through his/her nose and swallow secretions while dealing with upper respiratory tract infections during sleep;
- the adolescent must learn to speak garrulously and simultaneously eat voraciously with friends, yet remain monosyllabic and slouched when dining with immediate family.

Walls & Ryan 2012
Swallowing and Swallowing Development

Fetal Swallowing
- Fetal swallowing motions reported as early as 11 wks GA
- Frequency increases as infant approaches term
- Essential for normal growth and structural maturation of the fetal lung
- Thought to influence timing of labor

Doppler sonogram of fetus (26 wks gest.)
- Fluid oral cavity (arrow)
- Distention of hypopharynx (arrowheads)


Fetal Swallowing

<table>
<thead>
<tr>
<th>Gestational Period</th>
<th>Median Duration (sec)</th>
<th>Median Number of Swallows/Min</th>
</tr>
</thead>
<tbody>
<tr>
<td>Week 16-18</td>
<td>30-95</td>
<td>16-17</td>
</tr>
<tr>
<td>Week 22-26</td>
<td>48-52</td>
<td>22-52</td>
</tr>
<tr>
<td>Week 26-30</td>
<td>49-59</td>
<td>43-59</td>
</tr>
</tbody>
</table>

Attainment of oral feeding does not depend on the present of a fully mature suck-swallow pattern—suggesting that as with acquisition of other motor milestone, learning continues to occur.

Bingham. J Child Neurol, 2009

Post-Natal Swallowing
- One component of feeding development
  - “Simple”
  - Involves 26 muscles in the mouth, throat, and esophagus
  - Involves multiple cranial nerves
  - Is coordinated with breathing
  - 600 - 900 times daily

One component of feeding development

Attainment of oral feeding does not depend on the present of a fully mature suck-swallow pattern—suggesting that as with acquisition of other motor milestone, learning continues to occur.

Post-Natal Swallowing
- May be a “global” red-flag for communication problems
- Components of sucking development (e.g., sucking) may signal future neurodevelopmental problems

Stages of Sucking Development

\[1\text{ Malas et al., 2015, }\]
\[2\text{ Wolthuis-Stigter et al., 2015, }\]
Levels of Airway Protection

1. Swallow
   - Cough
   - Mucociliary action
   - Immune system

Swallow = Primary means of airway protection

Four Phases of Swallowing

- Oral preparatory
- Oral
- Pharyngeal
- Esophageal

Oral Preparatory Phase

- Bolus preparation
- Variable length
- Voluntary
- Airway is open

Oral Phase

- Transport bolus to back of oral cavity
- Duration ≥ 1 sec. regardless of texture
- Voluntary
- Airway is open

Pharyngeal Phase

- Transport thru pharynx / protected airway
- Duration
  - Adults ≥ 1.0 second
  - Infants ≥ 0.6 ± 0.10 seconds
- Voluntary & involuntary
- Airway closed
Esophageal Phase

- Transport bolus into stomach
- Duration ≈ 6 - 10 seconds
- Involuntary
- Airway open

Throughout life the primary functions of swallowing are to:

- Direct food, liquid & saliva from the mouth to the stomach while keeping airway protected
- Provide enough of the right types of liquids & foods for:
  - adults to stay healthy
  - children to grow and develop

Swallowing Function Must Adapt to:

- Alterations in anatomic relationships of pharyngeal structures due to
  - Normal developmental changes, including aging
  - Changes in head & neck posture → alterations in anatomic relationships of pharynx
- Developmentally appropriate changes in nutritional intake
  - e.g., Changes in liquid/food characteristics, volume & temperature

Feeding/Swallowing Must Adapt to:

- Demands of typical oral motor skill development (in context of overall development)
- External and social demands
  - Infant/young child - caregiver interactions
  - Older children - environments outside of the house

### Normal Infant Swallow

- Infant suckle feeding

### Development & Oral-Motor Skills Associated with Feeding Progression: Birth to 24 Months

<table>
<thead>
<tr>
<th>Age (months)</th>
<th>Progression of Oral-Motor Skills</th>
<th>Developmental Milestones</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 - 4</td>
<td>Liquid</td>
<td>Sitting balance</td>
</tr>
<tr>
<td>4 - 6</td>
<td>Purees</td>
<td>Suck off spoon at first</td>
</tr>
<tr>
<td></td>
<td>Soft chewables</td>
<td>Suckie → suck</td>
</tr>
<tr>
<td>6 - 9</td>
<td>Purees</td>
<td>Cup drinking</td>
</tr>
<tr>
<td></td>
<td>Soft chewables</td>
<td>Vertical chewing</td>
</tr>
<tr>
<td></td>
<td>Limped lateral movements</td>
<td>Assists with spoon</td>
</tr>
<tr>
<td>9 - 12</td>
<td>Ground</td>
<td>Cup drinking independent</td>
</tr>
<tr>
<td></td>
<td>Lumpy purees</td>
<td>Finger feeding</td>
</tr>
<tr>
<td>12 - 16</td>
<td>All textures</td>
<td>Grasps spoon w/ whole hand</td>
</tr>
<tr>
<td>18 - 24</td>
<td>More chewable food</td>
<td>Total self-feeding</td>
</tr>
<tr>
<td></td>
<td>Rotary chewing</td>
<td>1 use of fork</td>
</tr>
<tr>
<td></td>
<td>More food</td>
<td>Cup drinking, open cup, no spilling</td>
</tr>
</tbody>
</table>

Arvedson & Lefton-Greif, 1998
Throughout life: Feeding /Swallowing must be:

- Safe
- Enough / Adequate (hydration & nutrition)
- Enjoyable (socially functional) vs. Stressful

Must Be Enjoyable...: Consistent w/ Developmental Skills & Child/Caregiver Interactions (Satter, 1999)

0 - 2 or 3 mos. Homeostasis
Regulation of sleep & wake states

2 - 6 mos. Attachment
“Learning to love”

6+ mos. Separation / Individuation
Discovery of autonomy

Post-natal Feeding / Swallowing Development

Family / Caregiver Factors

Other Factors

Interaction of Multiple Factors

Feeding / Swallowing Behaviors

Child/Host Factors

Review of Neurobiology of Swallowing and Oral Feeding

Swallowing Dysfunction or Oropharyngeal Dysphagia
dysphagia (dīs-fā’ jē-ā)

[G. dys, difficult + G. phagein, to eat]

Inability to swallow or difficulty swallowing
Dysphagia is not a disease. Rather it is a symptom of a disease that may be affecting any part of the swallowing tract from the mouth to the stomach.” Donner, 1986

Potential Causes
- Anatomic anomalies
- Neurologic conditions
- Complex medical conditions
- Lack of or delayed introduction of feeding

Potential Consequences
- Aspiration/Resp. Problems
- Nutrition Compromise
- Altered family/social interactions

Factors that Determine/Modify the Impact of the Swallowing Dysfunction

Host Characteristics:
- Diagnostic condition(s)
- Co-morbidities
- Severity of dysphagia

Host Characteristics: Diagnostic Conditions
- Direct causes of dysphagia
  - Anatomic or structural anomalies
  - Neurologic conditions
- Indirect causes of dysphagia
  - Cardiac – fatigue
  - Direct and indirect
    - Cardiac – fatigue
    - Vocal fold paralysis
Severity of the Dysphagia

- Phases
- Prognosis dependent upon underlying diagnostic condition
- Repair or treatment related changes
- Ability to compensate

Beyond Swallowing: Host Conditions that May Modify Impact of Dysphagia

- Medical or Surgical Needs/Interventions
  - May influence child’s ability to tolerate the respiratory or nutritional consequences of the dysphagia
  - e.g., Critical time for child to stay healthy and grow

Beyond Swallowing: Host Conditions that May Modify Impact of Dysphagia

- Some children may not be able to tolerate:
  - even “normal” aspiration because of their fragile cardiopulmonary status or
  - fluctuations in oral intake because of their nutrition needs

Factors that Determine / Modify the Impact of the Swallowing Dysfunction

- Host Characteristics
  - Diagnostic condition(s)
  - Co-morbidities
  - Severity of dysphagia
- Age / Timing of Exposure
  - Growth and development
  - Susceptibility to injury

Dangerous Periods for Aspiration

- Brief period just before and immediately after birth
- Neonatal aspiration syndromes associated with significant morbidity and mortality

Adapted: Lefton-Greif + McGrath-Morrow 2007

Thach, 2001
**Meconium Aspiration**

**Post-Natal Levels of Airway Protection**

1. Swallow
   - Cough
   - Mucociliary action
   - Immune system

Swallow = Primary means of airway protection

**Dangerous Periods for Aspiration**

- Brief period just before and immediately after birth
- Neonatal aspiration syndromes associated with significant morbidity and mortality
- Recurrent aspiration during first two years of life

Thach, 2001

**Oropharyngeal Dysphagia: Potential Impact on Developing Lung**

- aspiration → possible lung injury
- in turn, injury to developing lung → may be associated with long-term pulmonary sequalea

**Anatomic & Physiologic Changes: Post-Natal Human Lung Growth**

**Aspiration: “Normal” Adults Average During Sleep = 0.1- 0.2 mL**

**Assumptions about Aspiration due to Dysphagia vs. Normal Aspiration**
- Occurs more frequently
- Occurs in greater volumes
- Occurs with more than just saliva
  - Liquids
  - Foods
  - Secondary to GER

**Factors Influencing Variability in Pulmonary Manifestations of Aspiration**
- Aspiration occurs normally, including during sleep
  - Intact defenses mechanisms protect lung from damage
- Blunted host response → pulm manifestations
  - Populations at risk for blunted response: neurodisability w/ ineffective cough protection, primary ciliary dyskinesia, CF (abn. mucociliary clearance), immunodeficiency, and prematurity

**Factors Influencing Variability in Pulmonary Manifestations of Aspiration**
- **Volume of aspiration**
  - Large (>0.08ml/kg) associated w/ rapid + acute hypoxia
  - Small → chronic, insidious, and greater impact on more distal lung structures

**Factors Influencing Variability in Pulmonary Manifestations of Aspiration**
- **Structure of aspirated material**
  - Solid matter → acute hypoxia with airway obstruction that will cause sudden death, partial lung collapse (if obstruction complete or ball-valve effect with distal air trapping)
  - Finely aerosolized liquid particles hypoxic response or generate a chronic inflammatory reaction as far distally as the terminal airways with reduction in surfactant protein levels

**Throughout life: Feeding /Swallowing must be:**
- Safe
- **Enough/Adequate** (hydration & nutrition)
- Enjoyable (socially functional) vs. Stressful

**Nutrition: Support Brain Growth & Development**
- Most sensitive period: mid-gest. - 2 yrs
- Malnourished children have smaller brains due to
  - reduced dendritic growth
  - reduced myelination
  - production of fewer glia which are responsible for the production of mylin
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WHO Child Growth Standards: Growth Charts

SOURCE: http://www.who.int/childgrowth/standards/en/

Childhood Growth

<table>
<thead>
<tr>
<th>Age</th>
<th>Weight</th>
<th>Height</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth</td>
<td>6 - 10 lbs</td>
<td>18 - 22 ins</td>
</tr>
<tr>
<td>4-5 mos</td>
<td>BW x 2</td>
<td></td>
</tr>
<tr>
<td>1 yr</td>
<td>BW x 3</td>
<td>BH + 50%</td>
</tr>
<tr>
<td>2 yrs +</td>
<td>7 lbs / yr</td>
<td>2.5 ins / yr</td>
</tr>
</tbody>
</table>

Nutrition: Support Brain Growth & Development

- Brain size
  - Newborn = 25% adult brain
  - 3 year old = 80% adult brain
  - 5 year old = 90% adult brain
- Speed of neural processing
  - Increases due to myelination

Poor Nutrition

- Adverse development
- Compromised CNS development

Potential Impact of Fetal and Infant Malnourishment ...

- Behavioral and cognitive deficits
- Slower language development
- Slower gross & fine motor development
- Lower IQ's
- Poorer school performance

Impact of Under Nutrition

Potential Impact of Fetal and Infant Malnourishment ...
Age and Development

- Sensitive or critical times for learning...
  - Bonding
  - Communication re: mealtimes

Factors that Determine / Modify the Impact of the Swallowing Dysfunction

- **Host Characteristics**
  - Diagnostic condition(s)
  - Co-morbidities
  - Severity of dysphagia

- **Age / Timing of Exposure**
  - Growth and development
  - Susceptibility to injury

- **Environmental / Social Factors**
  - Feeding techniques
  - Health care access and management
  - Exposure to environmental stressors

Adapted: Lefton-Greif + McGrath-Morrow 2007

Environmental / Social Factors

- **Environmental Exposures**
  - Weather
  - Secondhand smoke
  - Illness (e.g., RSV)
  - Daycare

Environmental / Social Consequences

Disruptions in feeding / swallowing development may:

- Be multi-factorial in nature
- Alter child’s interest and ability to feed
- Cause or escalate behavioral problems
- Cause sensory issues
- Cause stressful child-caregiver interactions
- Impact the caregivers

**Environmental / Social Factors**

- Disruptions in feeding / swallowing development may:
  - Impact work and socio-economic factors
  - Change family dynamics
Summary of Findings

- Using census data, 122 (76%) families were above the mean (SD) median US household income of $72,608 (± $27,317)
- All FS-IS subscales and composite score were significantly associated with PEDS-QL™
- Presence of a feeding tube interfered with daily activities

Lefton-Greif et al, 2014

Type of Scale is Important because....

Understanding caregiver’s concerns in the outpatient setting is particularly important given that:

- Recent health care cost containment measures have shifted services from in-pt to ambulatory care settings
- Increasing the burdens placed upon the caregivers

Lefton-Greif et al, 2014

Type of Scale is Important because....

- QoL has been implicated in noncompliance to recommendations of caregivers for adults with dysphagia
- Lower HRQoL has been reported for caregivers of children with other conditions

Lefton-Greif et al, 2014

Type of Scale is Important because....

- Health-Related Quality of Life (HRQoL) has been established as an important gauge of patient-based health outcomes and a recommended endpoint in all clinical trials

Lefton-Greif et al, 2014
Ethical Decision-Making

- Each time we make decisions that are based upon judgments or factors that are outside the realm of factual knowledge
- Cues may be signaled by statements including terms such as "should", "ought", "good", or "better"

Potential Ethical Challenges

- Treating or "not treating" the child who you feel is unsafe to treat
- Balancing ethics, knowledge, and the unknowns

Caregivers and Team Do Not Agree About Placement of a Feeding Tube

- Limited evidence-based guidelines to help determine the risk-benefit ratio of non-oral vs. oral feeding
- Unknowns
  - Natural history of respiratory disease in children with aspiration
  - Risk factors for and predictors of pulmonary damage in children with documented aspiration

Ethical Goal: Balance

- Caregiver autonomy
- .... in the child's best interest

Today → Future

- Diagnostics / Interventions
- Genetics and epigenetics
Genetics and Epigenetics

- **Genetics**: the study of heredity and variation of inherited characteristics (aka DNA)
- **Epigenetics**: all heritable changes in gene expression and chromatin organization that are independent of the DNA sequence itself

It has become apparent that environmental factors during prenatal and postnatal life can have profound effects on the programming of intracellular signals, cell-to-cell interactions and metabolic pathways.

In the future medicine will be directed toward treating individuals, not diseases.

Health will be defined as a function of gene-environmental homeostasis.

Dysphagia or Swallowing and Children with 286 listings (9/29/16)
Epigenetics is about:

- Turning genes on and off
- Stability - a leopard does not change its spots even if it sheds its fur each year
- Cellular memory that persists after cell division and reproduction
- Mechanisms that make organisms or parts of organisms look different, despite the fact they have the same genes and are in the same environment

Epigenetics: Trait or Fate

Postnatal exposures

Mounting evidence suggests that fetuses are surprisingly susceptible to outside influences such as environmental pollutants, pesticides, and other toxins.