4TH PEDIATRIC FEEDING CONFERENCE

It Takes a Village

Syllabus

Saturday, February 28, 2015
Combined Aerodigestive Evaluation for Feeding Struggles and Dysphagia

Feeding Matters 2015

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Disclosure

In the past 12 months, I (we) have had no relevant financial relationships with the manufacturer(s) of any commercial product(s) and/or provider(s) of commercial services discussed in this CME activity.

Aerodigestive disease

• What is it?
• How does it relate to feeding problems?
• Two topics:
  ◦ Gastroesophageal reflux in the aerodigestive patient
  ◦ Dysphagia in the aerodigestive patient
WHAT IS AERODIGESTIVE DISEASE?

Aerodigestive disease
- Problems with the airway, breathing, or swallowing associated with problems in the airway, lungs, and/or upper GI tract
- Overlaps across disciplines
  - ENT
  - Pulmonary medicine
  - Gastroenterology
  - General surgery
  - Speech-language pathology
  - Occupational therapy
  - Nutrition
  - Behavioral sciences

Who has aerodigestive problems?
- Medically complicated children
  - H/O Prematurity BPD, chronic lung disease Subglottic stenosis CP
  - Congenital anomalies Heart disease Esophageal atresia Pulmonary hypoplasia Diaphragmatic hernia Omphalocele Cleft lip and/or palate Cystic adenomatoid malformation (CCAM)
  - Genetic syndromes Trisomy 21 William’s syndrome VCPS 22q11 deletions Pierre Robin syndrome
  - Other Unexplained cough Recurrent pneumonia Caustic ingestion Asthma with GERD
- Children who are otherwise well
HOW DO AERODIGESTIVE PROBLEMS RELATE TO FEEDING?

Feeding → Airway

Upper GI Tract

TOPIC 1: GASTROESOPHAGEAL REFLUX IN THE AERODIGESTIVE PATIENT
Adapted from Nelson et al, Arch Pediatr Adolesc Med 1997

Benign regurgitation resolves over infancy

<table>
<thead>
<tr>
<th>Age (months)</th>
<th>0-2</th>
<th>4-6</th>
<th>7-9</th>
<th>10-12</th>
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<tbody>
<tr>
<td>Percentage of Infants</td>
<td>0-5</td>
<td>10-20</td>
<td>30-50</td>
<td>70-80</td>
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GE Reflux and Aerodigestive Disease (Extra-Esophageal Reflux Disease)

Does reflux cause pneumonia?

10-year record review from The Hospital for Sick Children, Toronto, Canada

2952 children hospitalized with pneumonia

298 (8%) with recurrent pneumonia

220 (72%) of recurrent disease had an identifiable associated process:

- GER 5%
- Pulmonary abnormalities 5%
- Asthma 9%
- Cardiac defect 15%
- Immunodeficiency 11%
- Aspiration 12%
- Sickle cell disease 4%

Isolated reflux probably does not cause pulmonary disease…

34 children with neuro-disability screened with VFSS and 24-hour pH probe

Morton et al, Dev Med and Child Neu, 42, 1999

Elements of Causality

- Temporal relationship
- Strength of association
- Dose-response relationship of findings
- Replication of findings
- Biological plausibility
- Consideration of alternate explanations
- Cessation of exposure
- Consistency with other knowledge
- Specificity of association
Elements of Causality

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- Cessation of exposure
- Consistency with other knowledge
- Specificity of association

Is gastric reflux a cause of otitis media in children?
Tasker et al., Laryngoscope, 2002
- Middle ear fluid collected during myringotomy
- 91% positive for antipepsin antibody and pepsinogen
- Levels of pepsin/pepsinogen up to 1000 times higher than serum levels

Association of Reflux with Otitis Media in Children
Lieu et al., Otolaryngology-Head and Neck Surgery, 2005
- 73-77% positive for pepsin and/or pepsinogen
- Did not correlate with reflux symptoms

Role of Pepsin and Pepsinogen: Linking LPR with otitis media with effusion in children
Luo et al., The Laryngoscope, 2013
- Pepsinogen mRNA and protein levels assayed in adenoid tissue
- Pepsin and pepsinogen assayed in middle ear fluid
- Elevated pepsin/pepsinogen in middle ear fluid in children with OM
- Concentration of pepsinogen correlated with expression of pepsinogen protein in adenoid tissue

Hypopharyngeal pepsin and Sep70 as diagnostic markers of laryngopharyngeal reflux: preliminary study
Komatsu et al., Surg Endosc, 2014
- Tissue samples of hypopharynx, distal esophagus, and gastric cardia from adults with LPR symptoms
- Sep70 depletion noted in distal esophagus and hypopharynx in patients with reflux to proximal esophagus
Simulated reflux and laryngotracheal reconstruction: a rabbit model
Carron et al., Arch Otolaryngol and Head Neck Surg, 2001
- Anterior cartilage laryngotracheoplasty performed in rabbits
- Repair exposed to pH 1.5 with pepsin or pH 4 with pepsin to simulate reflux
- Necrosis and inflammation markedly increased with acid exposure

Failed laryngotracheoplasty

Reflux disease identified as a contributor to failed airway reconstruction
- Cincinnati: Boseley et al., J Ped Otorhinolaryngol, 2001

Prevalence of Pediatric Aspiration-Associated Extraesophageal Reflux Disease
Kelly et al., JAMA Otolaryngol, 2013
- 65 children with chronic respiratory symptoms undergo bronchoscopy with BAL
- Pepsin-positive BAL identified in 74%; all controls negative
- Lipid-laden macrophages identified in 91% of cases and 64% of controls

The presence of pepsin in the lung and its relationship to gastro-esophageal reflux
Rosen et al., Neurogastroenterol Motil, 2012
- 50 patients recruited; undergo aerodigestive testing with measurement of lower airway pepsin from BAL
- Reflux profiles compared between pepsin-positive and pepsin-negative subjects
- Pepsin may be an important biomarker for GERD-related lung disease; its presence does not predict pathologic reflux in the esophagus, but correlates with increased inflammatory cells in the lower-airway

Efficacy of Esomeprazole for the Treatment of Poorly Controlled Asthma
American Lung Association, NEJM, 2009
- 412 adults with inadequately-controlled asthma
- Treated with 40 mg of esomeprazole BID or placebo
- Despite high prevalence of asymptomatic reflux among patients, treatment with PPI does not improve asthma control

Lansoprazole for children with poorly controlled asthma: a randomized controlled trial
American Lung Association, JAMA, 2012
- 306 children with poor asthma control randomized to lansoprazole or placebo
- Addition of lansoprazole in children with poorly-controlled asthma did not result in any benefit over placebo
The apparent verdict…

- Reflux alone probably does not cause major airway disease in otherwise healthy children.
- When coupled to other problems, particularly in medically-complex children, reflux can contribute to significant airway disease.

GE Reflux and Aerodigestive Disease
(Extra-Esophageal Reflux Disease)

GERD with erosive esophagitis
Measuring esophageal acid

- 1960-1964
  - primitive measurement with indwelling pH probe; research tool
- 1974
  - first practical 24-hour indwelling pH probe developed by Johnson & DeMeester
  - Development of pH probes with multichannel intraluminal impedance testing (pH/MII) supersedes standard pH probe
  - Obituary for pH probe written
    - (Putnam, J Peds, 2010)

pH / impedance testing

- Combined pH and multichannel intraluminal impedance testing (pH-MII)
- Impedance (Z)
  - measure of the opposition a circuit presents to a current when voltage is applied
  - Utilized to differentiate liquid and air in the esophagus
  - Can detect non-acid reflux

112 children with unexplained cough or wheezing
- All undergo aerodigestive evaluation including pH/impedance testing
- 32% endoscopic abnormalities (GERD, EoE, Candida)
- 58% abnormal reflux testing
- 60% bronchoscopic abnormalities

But...
- No correlation between reflux symptoms and lipid-laden macrophages on BAL
- No correlation between reflux events and lipid-laden macrophages on BAL

Aerodigestive testing with reflux testing in patients with chronic cough is considered “high yield”; however, the findings may come short of assigning causality for the symptoms.

Rosen et al, Pediatric Pulmonology, 2013

High Rate of Bronchoalveolar Lavage Culture Positivity in Children with Nonacid Reflux and Respiratory Disorders
- 46 children underwent aerodigestive and reflux testing
- Patients with positive culture on BAL specimens had statistically more nonacid reflux
- After controlling for PPI use, total time of nonacid reflux and full-column GER were independent predictors of a positive culture

Rosen et al, J Peds, 2011
Eosinophilic esophagitis (EoE)
- Chronic, immune-mediated inflammatory process
- Associated with atopic disease
- Can present with airway symptoms
- Frequent mimic of GERD

Presenting signs of EoE vary by age

Noel et al., NEJM 2004

Normal Esophagus
EoE Presenting as Aerodigestive Disease

- EoE can present initially to ENT with aerodigestive symptoms
- Review from CHOP pediatric ENT

657 EoE patients
144 (20%) seen by ENT
79 previously Dx with EoE
65 not Dx with EoE
21 referred to GI for EoE evaluation
44 not referred to GI and remained undiagnosed

Smith et al. JPO, 2009
EoE impact on airway

- EoE may be associated with subglottic and tracheal inflammatory changes that impact decannulation of tracheostomy patients.
- EoE should be considered in the diagnosis of unexplained airway findings refractory to reflux treatment.

Brigger et al, Arch Oto Head Neck Surg, 2009

EoE has an impact on feeding

- In population-based epidemiologic study, youngest EoE patients presented with feeding disorder.
  - Noel et al, NEJM, 2004
- Young infants and toddlers with EoE can develop feeding disorders with dysfunction that persists beyond the resolution of EoE.
  - Pentiuk et al, Dysphagia, 2007
- Children with EoE commonly have feeding disorders with that may persist beyond resolution of esophageal inflammation.
  - Mukkada et al, Pediatrics, 2010

To summarize...

- GERD’s contribution to aerodigestive disease is complex
  - Probably not the primary driver of airway disease in otherwise healthy children
  - Studies implicate a clear association
  - Linear causality cannot always be established
  - Operative treatment is not benign; aerodigestive evaluation can be helpful patient assessment
- Always consider EoE as a mimic of GERD
  - Impact on aerodigestive and feeding problems more severe that that of GERD
TOPIC II: DYSPHAGIA IN THE AERODIGESTIVE PATIENT

Pediatric Dysphagia

- Prevalence not well known
  - 13.4% of full-term infants with history of emesis or respiratory symptoms (Mercado-Dean MG et al. 2001)

- Well-established:
  - Increased incidence in premature infant
  - 26% of premies have feeding problems
  - 3.5% of all newborns with feeding issues, 3-fold more if born <37 weeks, and 7-fold more if VLBW

- Premature births continue to rise
  - 2003 rate 16% higher than 1990 and 30% higher than 1981 (Martin et al. 2005)
  - Majority of healthy premies achieved oral feeding skills by 38 weeks PMA

Causes of Dysphagia

- Anatomic
  - Laryngeal Cleft
  - Tracheoesophageal fistula
  - Esophageal abnormality – stricture, achalasia
  - Tracheostomy
  - Gastric outlet obstruction
  - Cardiac abnormalities – vascular ring
  - Micrognathia

- Physiologic
  - Eosinophilic Esophagitis

- Functional
  - Dysfunctional swallow - ?
  - Neurologic or developmental

- Neurologic
  - Cranial nerve deficit: IX, X, XII
  - Altered mental status
  - Syndrome
**Swallowing Dysfunction**

- Mercado-Deane et al 2001
  - Premature infants 25.7%
  - X-preme/BPD 30.7%
  - CHD 37%
  - Syndromes 46.9%
  - Neurologic 55.3%
  - Esophageal atresia 24.8%
  - General population 13.4%

**High Risk**

- 80% with developmental disabilities have feeding problems
- 3 Major High Risk Conditions for Dysphagia
  - Cerebral Palsy, Down Syndrome and Prematurity
- GERD is the most prevalent disorder associated with these conditions
  - High correlation of dysphagia and food refusal in setting of GERD

**High Risk**

- Cerebral Palsy
  - Most common neurologic etiology of dysphagia
  - 85-90% have swallowing disorder at some point
  - By age 1, 57% have problems sucking, 38% have swallowing problem, 33% malnutrition (Reilly, Skuse, & Poblete 1996)
- Down Syndrome
  - > 80% have oral motor delays (Field D et al.)
  - Very selective to texture: macroglossia, tongue thrusting, poor chewing
Dysphagia – Other Sources

- Tracheostomy Tube
  - Tracheostomy prevents rise in subglottic pressure and laryngeal elevation.
  - Passe-Muir valve has been shown to improve swallowing function in adults and children by improving oropharyngeal sensation and increasing subglottic pressure during swallow.

Pediatric Dysphagia

- Feeding problems complex interaction of biology and environment
  - Babbitt et al. classify feeding problems into Motivational or Skill-based
    - Motivational: maintained by child's environment
    - Skill: lacking necessary skills for eating - sucking, chewing, swallowing

Swallowing: Complex Interaction!
Dysphagia and Infants

- Infant swallow begins to resemble adult swallow - 5 months of age.
- Mechanoreceptors and chemoreceptors in pharynx, epiglottis, arytenoid cartilages and vocal cords.
  - Stimulation of laryngeal chemoreceptors can lead to prolonged apnea
  - Chemoreceptors activated by water, salts, sugars and acid.
  - Mechanoreceptors in pharynx stimulate swallowing at all ages.
- Gastric in lower esophagus may still may elicit cough as well as apnea and bronchoconstriction. (Randolph CD, 1995)(Herbst et al 1979)(Boyle et al 1985)

Anatomical Differences between Infants and Adolescents

- **Infants**
  - Smaller Oral Cavity
  - Tongue entirely in OC
  - 1/3 size of Adult Larynx
  - Epiglottic tip at C2
- **Adolescents**
  - Larger Oral Cavity
  - Base of Tongue in Oropharynx
  - Adult size larynx
  - Epiglottic tip at C5-C7

Infant Anatomy

- Oral cavity occupied by tongue
  - Apposes hard and soft palate
- Pharynx small
- Epiglottis can usually be seen
- Anatomy ideal for suckle feeding allowing nasal breathing during feeding
  - 2 or more sucks per swallow
  - Closure of airway during sucking
  - Larynx elevates during swallow to prevent aspiration
- Suckle reflex feeding regulated at brainstem
  - Probably not fully developed in premature baby
Infant Swallow

- Pharyngeal phase of swallow
  - Similar to adults but posterior OP apposes base of tongue causing strong posterior pharyngeal wave
  - Noisy breathing during feeds most likely due to nasopharyngeal reflex

- Vigorous feeding
  - Several swallows rapidly before breathing...last swallow may be incomplete/abnormal leading to aspiration

- Laryngeal penetration
  - Occurs during pharyngeal contraction

- Aspiration
  - Occurs during breathing phase
  - Can be a result of premature pharyngeal “leak”, poor pharyngeal clearance, delayed drainage from nasopharynx
  - Neonatal response to aspiration is to stop breathing. Cough not always present (may be absent due to immaturity or desensitized (chronic aspiration))

Swallowing

- LEFT: Oral or preparatory phase.
- RIGHT: Transport to pharynx and subsequent triggering of the actual swallowing reflex.

- LEFT: Pharyngeal constrictors push the bolus down.
- RIGHT: Together with the contraction of the inferior constrictor, the cricopharyngeus relaxes.

Dysphagia in Infants

- Coordination of swallow improves with age

- Reasons for dysphagia
  - Uncoordinated swallow and breathing
  - Feeding too fast – “guzzler”
  - Immaturity of neuromuscular swallow system
  - Anatomic abnormalities
Dysphagia in Infants

- Numerous studies demonstrate consistent findings on normal swallow studies
  - No material seen in piriform sinus area before initiating pharyngeal swallow
  - No penetration of material into supraglottic area or or below the vocal folds
- Strong relationship between laryngeal penetration/aspiration and pneumonia
- Nasopharyngeal reflux associated with apnea, choking and pneumonia

What is the significance of Laryngeal Penetration?

- Aspiration
  - Clinically significant
    - Pneumonia, etc
- Laryngeal Penetration
  - Is there clinical significance?

Dysphagia – Signs and Symptoms

- Signs of oropharyngeal dysphagia:
  - Abnormal or disorganized sucking patterns
  - Failure to thrive
  - Drooling
  - Apnea
  - Desaturations
  - Wheezing
  - Stridor
  - Bradycardia
  - Congestion
- Also as infant grows... difficulty transitioning to solids, increased gagging, coughing, oral aversion.
Dysphagia Complications

- Aspiration
  - Recurrent pneumonia
  - Extensive work up and testing
  - Chronic lung disease
- Failure-to-Thrive
  - Feeding tube
  - Growth Delay
- Quality of life
  - Thickeners
  - Feeding Tube
  - Constant monitoring

Aspiration*

There are three instances when aspiration can occur: before, during or after the actual swallow.

- Aspiration before swallowing is either the result of insufficient closure of the oral cavity during the preparatory phase or inability to start the swallow reflex when contrast enters the pharynx.
- Aspiration during swallowing is due to insufficient closure of the larynx.
- Aspiration after swallowing is the result of stasis of contrast in the pharynx - when the larynx opens the contrast leaks into the trachea.

*Swallowing disorders - interpretation of radiographic studies
Robin Smithuis, Radiology department of the Rijnland Hospital in Leiderdorp, the Netherlands

Aspiration

- Radiotracer studies in adults has shown physiologic aspiration during sleep. No such studies in children.
- Barbiera et al. reviewed video fluoroscopic swallow studies on 220 NORMAL ADULTS
  - 38% had some alteration of oral and/or pharyngeal swallowing.
  - 28% had subepiglottic laryngeal penetration
  - 8% had gross aspiration.
- Increased incidence of aspiration in CF patients.
Aspiration and Pneumonia

- RSV infections have been shown to influence VFSS with transient abnormalities. 
  *Recommendation not to perform VFSS on children with URI.*

- Increased incidence (over 5x) of pneumonia in patients aspirating thicker consistencies
  - Lung injury when aspirated contents have pH < 2.5 with maximal lung injury at pH 1.5 (Teabeut RJ 1952)

Dysphagia Work-up

- Patient history
- Medical status
- Developmental skills
- Oral-motor function

- Bedside Swallow - unreliable

Bedside Swallow

- Suiter et al:
- 3-ounce water challenge in evaluating risk for aspiration
  - Concluded it was not the best screening tool for identifying at risk children for aspiration of thin liquids
    - high false positive rate and low specificity of the test.
Evaluation of Dysphagia

- Video Fluoroscopic Swallow Study (VFSS)/Modified Barium Swallow (MBS)
- Fiberoptic Endoscopic Evaluation of Swallowing (FEES)
- Lipid-laden Macrophage Index (LLMI)
- Salivagram (radionucleotide study)
- Blue dye tests (tracheostomy patients)

NO VALID DATA FOR EVALUATING ASPIRATION IN CHILDREN

VFSS/MBS

- Dynamic view of all stages of swallow
  - Oral preparatory
  - Oral
  - Pharyngeal
  - Upper Esophageal
- Disadvantages
  - Radiation
  - Time limited
  - Need for patient cooperation
  - Patient medical status
  - Hospital anxiety
  - Interobserver reliability: Variable
  - Individual reads vs reads with group discussion

VFSS VS FEES

- VFSS
  - Images oral cavity, pharynx, larynx, trachea, and upper esophagus during all 4 stages of swallow
  - Barium liquids and coated semi-solids and solids
  - Limited to 2-4 minutes due to use of fluoroscopy
  - Non-invasive
  - Poor Anatomy
  - Radiation

- FEES
  - Visualizes pharynx and larynx before and after swallow
  - Real food with color enhancement
  - Good for examination of entire meal
  - "White Out" phase
  - Optimal age for FEES 3-12 months and > 4 years old
VFSS/MBS vs FEES

*MBS and FEES can be normal in aspiring patient and doesn’t rule out cleft...complementary tests*

- FEES vs VFSS: Rao et al found higher sensitivity in FEES but higher specificity with VFSS,
- CURRENT DATA ON ADULTS ONLY

Diagnostic Testing – Beware!

- Result of MBS should be interpreted in context of patient.
- No gold standard for diagnosing aspiration. All current tests have limitations.
- Workup needs multidisciplinary approach, ENT, pulm, GI, Speech, OT.

Laryngeal Clefts

- Incidence of Type 1 cleft:
  - Chien W et al: 7.6%
  - Watters and Russell: 7.1%
  - Parsons et al: 6.2%
- Most common symptom:
  - Chien et al: Aspiration to thin liquid 90%, recurrent pneumonia (50%) and chronic cough (35%).
  - Watters and Russell: 75% presented with aspiration pneumonia, 42% choking with feeds, 25% chronic cough
Development of Cleft

- Cleft develops in 5th-7th week gestation due to arrest in fusion of the tracheoesophageal folds or failure of cricoid ring to close

![Diagram of normal and cleft larynx]

Clefts and Other Abnormalities

- Up to 50% of patients with laryngeal clefts have associated congenital abnormalities (Brown et al., Management of posterior laryngeal and laryngotracheoesophageal clefts, 1995)
- Cleft and TEF as high as 27% (Cohen SR, 1975 and Lim TA et al., 1979)
- Other risk factors: maternal drug and alcohol abuse, polyhydramnios (Tucker and Matteo, 1987)
- TEF
- Tracheomalacia
- Cleft lip and palate
- Anomalus right subclavian artery
- Pyloric atresia
- Imperforate anus
- Pancreatic ectopia
- Congenital heart disease
- Subglottic stenosis

Deep Interarytenoid Notch

- Much more common than true cleft
- Management options
  - Feeding therapy
  - Injection laryngoplasty
  - Repair – rarely

Most children with DIN outgrow dysphagia by 3 years of age

Need to buy time ⇒ injection
Management of “Clefts”
- Conservative: Thickened liquids, feeding maneuvers, feeding therapy
- Injection Laryngoplasty
  - Gel foam
  - Hydroxyapatite
  - Temporary
- Endoscopic Cleft Closure
- Open Closure
  - Anterior laryngofissure
  - Lateral pharyngotomy

Injection Laryngoplasty

Cleft Repair
Management of Patient with Dysphagia and “Cleft”

- No consensus on management
- Most attempt conservative therapy before surgery
  - Reflux medication, thickened feeds and feeding maneuvers
  - MBS and/or FEES to assess presence, severity and mechanism of aspiration

Studies

- Chien et al.: 20% (4 patients) treated successfully with conservative therapy
  - 80% required surgical repair of cleft after failing medical therapy.
    - Surgical success rate 94% (15/16)
  - 75% failed conservative measures in study by Watters and Parsons (2003)
    - Surgical success rate 100% (9 patients who failed conservative management)
  - Parsons series (1998): 41 children all managed conservatively

Results of Cleft Repair

- Injection laryngoplasty - shown to improve pharyngeal dysphagia, but not oral-phase dysphagia

  - 81 patients
  - 49 required surgical intervention due to failed medical management. Mean age 1.5 years.
  - Most common complaint dysphagia with cough with thin liquids.
  - 85% taking GERD medication, 86% had aspiration on MBS
  - Type I clefts: 71% success rate, 29% had persistent aspiration
  - Type II clefts: 21 patients, 86% success rate
Pitfalls of Cleft Repair

- Injection Laryngoplasty
  - Temporary
- Endoscopic Cleft Closure
  - Wound dehiscence
  - Deepening of Cleft
  - Granulation tissue
  - Supraglottic stenosis
- Open Cleft Closure
  - Dysphonia
  - RLN injury

Treatment for Dysphagia

- Compensatory Mechanisms:
  - positioning,
  - changing bottles/nipples/utensils,
  - exercises and maneuvers,
  - thickening feeds.
  - Vital Stimulation: neuromuscular electrical stimulation to engage cranial nerves to improve swallow. Lack of data demonstrating efficacy

Treatment for Dysphagia

- Treat Reflux
  - Antihistamine – Ranitidine
  - Proton Pump inhibitor
  - Promotility
  - Fundoplication: 5-34% will require fundo to control symptomatic reflux disease
- Treat EE
  - Diet change
  - Steroids
- Repair Cleft
- Speech and Feeding Therapy
Management of the Dysphagia Patient

- Swallowing is a complicated task
  - Normally it is an unconscious task
- Multisystem problem
  - Mouth, pharynx, larynx, esophagus, stomach
- Multidisciplinary Approach
  - ENT, Pulmonary and GI

Aerodigestive Clinic at PCH

- Multidisciplinary Clinic
  - ENT, Pulmonary, GI
- Coordinated Care
  - One clinic appointment for families
  - One anesthetic for 3 procedures
  - Coordinate ancillary tests – MRI, MBS, FEES

Select References

Instrumental Swallow Studies & Thickened Fluids: What, When, & Why?

Pediatric Feeding Conference
It Takes a Village
February 28, 2015

Joan C. Arvedson, PhD, CCC-SLP, BCS-S
Pamela Dodrill, PhD, CCC-SLP

Arvedson Disclosure
- Financial relationships relevant to content:
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  - Salary from Children’s Hospital of Wisconsin-Milwaukee
  - Travel expenses from Feeding Matters
- Non-financial relationship: Board member Feeding Matters

Education is the greatest need of the people, but first they must be fed
(Danton’s Memorial, Paris)

Instrumental Swallow Studies (FEES & VFSS)
- WHAT?
  - Criteria for exams
  - Signs/symptoms reported by caregivers
- WHY?
  - Define oropharyngeal physiology
  - Trial possible therapeutic interventions
- WHEN?

State of Art & Science for Evaluation of Infants & Children with Signs/Symptoms of Dysphagia
- Clinical feeding evaluation
- FEES (often when upper airway & swallowing concerns are noted)
- VFSS
  - Stand alone examination
  - Combined with esophageal manometry
Introduction

- Predictability: the only predictable aspect for infants & young children is unpredictability
- Systematic decision making is important, with individual variability always in mind
- Sensori-motor learning & neural plasticity: useful considerations for management plans
- What else?

Criteria for Instrumental Evaluation

- Risk for aspiration by history or observation
- Prior aspiration pneumonia
- Suspicion of pharyngeal/laryngeal problem on basis of etiology
- Gurgly voice quality
- Need to define oral, pharyngeal, & upper esophageal components for management

Signs That Caregivers May Report

- Frequent coughing during oral feeding
- Wet/gurgly voice quality
- Increased congestion during feeding
- Wheezing or “rattling” chest sounds
- Color changes
- Reduced oxygen saturation levels
- What else?

Flexible Endoscopic Evaluation of Swallowing (FEES)

- No radiation – minimally invasive
- Bedside exam possible
- Defines some aspects of pharyngeal physiology
- White out at pharyngeal swallow initiation – cannot define aspiration precisely
- Can evaluate handling of secretions
- Sensory testing possible

Videofluoroscopic Swallow Study (VFSS)

- Defines oral & pharyngeal phases
- Defines esophageal transit & basic motility
- Delineates aspiration related factors
  - Before, during, &/or after swallows
  - Texture specificity
  - Physiologic reasons for aspiration
  - Estimate of risk

What VFSS is NOT

- Pass/fail test
- To rule out aspiration or determine if child aspirates with oral feeding (important finding but not reason for exam)
- Simulation of a real meal
- Evaluation of oral skills for bolus formation
- Chewing evaluation
- Esophageal function (only upper esophagus)
VFSS Aims
- Define anatomy & physiology of oropharyngeal swallow
- Measure efficiency of swallow
- Define movement patterns of structures in oral cavity, pharynx, & larynx
- If aspiration occurs, determine when, why, & how much

VFSS Aims (continued)
- Examine intervention possibilities
  - Postural changes
  - Sensory enhancement
  - Maneuvers (not infants & young children)
  - Diet modifications (texture changes) – thickening covered by Dr. Dodrill

Major Unanswered Question:
How much aspiration of what can a system tolerate before chronic lung disease becomes a problem?

Patient Considerations
- Diagnostic & management needs
  - Define nature of swallow impairment
  - Determine ability to feed safely
  - Develop management plans
- Ability or readiness to participate
  - Medical stability
  - Ability/willingness to cooperate
  - Age, cognitive, & developmental status

Preparation of PO Feeders
- Hungry, but not starving
- Schedule close to feeding time if possible
- Normalize the situation as much as possible
  - Child’s own utensils
  - Video/music as needed
- GT + PO: same guidelines as for total PO, unless child gets slow, continuous tube feeds

Preparation of Tube Feeder: NPO
- Child should demonstrate some level of oral intake, at least for therapeutic “taste trials”
  - NG tube – no difference (Alnassar et al 2011)
  - Amount per bolus: 2 to 3 cc
  - Total of 10-15 cc preferred, but not necessary, for validity & reliability
- Medication schedules maintained, or in some cases, adjustments needed
### Child’s “State”
- Typical feeding status
- Increased risks for aspiration
  - Lethargy
  - Agitation (fussing & crying)
- Cooperative child: interpretation possible in reliable & valid ways
- Always remember: Just a brief window in time, not a typical meal

### VF Procedure Considerations
- Real time (30 frames/second), not pulsed
- Radiation exposure set by radiologist
  - Need adequate clarity
- Minimal radiation dose (Decreasing fluoroscopic pulse rate cannot be used to decrease radiation dose – miss events)
  - Coning – avoid orbits of eyes – cannot eliminate the thyroid gland

### Radiation Safety Considerations
- Patient
  - Collimate x-ray field
  - Use magnification judiciously
  - Limit “fluoro-on” time (ex., 1-3 min)
  - Lead protection
- Personnel
  - Use shielding (e.g., lead apron, thyroid collar, lead gloves, protective glasses)
  - Radiation monitor badges; keep distance

### Important Considerations in High Risk Pediatric Patients
- Radiologist or PA must be present
- Well formulated questions
- Lateral view standard, A-P selective
  - Enlarged tonsils?
  - Oral & pharyngeal asymmetry?
- Audio
  - Fluoroscopy time shortest possible while obtaining needed information

### Feeding Supplies & Recipes
- Readily available when caregivers are asked to bring food samples
- Textures & barium recipes need to be standardized (products are available)
- Data lacking, especially in children
- Poor relationship between viscosity of dysphagia diet foods & swallow barium test feeds of different viscosities (Strowd et al., 2008)

### Procedural Decisions
- No fixed order for presentations in pediatrics
- Preferable to start with thinnest liquid
  - Controlled bolus size to start, e.g., spoon before going to bottle or cup drinking
- Work toward thicker as needed
  - Not want residue in pharynx that may complicate interpretation with thinner later
- Exceptions: parents tell us that child will not accept anything else if he gets liquid first
Reasons to Start with Thin Liquid

- If aspirated
  - More easily expectorated – but remember young infants & those with neurologic impairment are not likely to cough
  - Small amounts of thin liquid may be absorbed by “stable” lungs (more research needed – we don’t know how much, how long)
  - Cannot block the airway

Lateral & Antero-Posterior Views

- Lateral showing lips, soft palate, posterior pharyngeal wall, fifth to seventh cervical vertebrae, varying with age of child
- Simultaneous view of oral, pharyngeal & upper esophagus before food is presented
- PA when asymmetry is known or suspected (e.g., unilateral VF paralysis)

VFSS Procedural Considerations

- Positioning/seating: typical & optimal
- Cooperative patient imperative
- Caregivers included, findings reviewed
- Findings interpreted & used as part of total team approach: maximize safety
- Review in slow motion, frame-by-frame

Modifications In Radiology to Determine Possible Interventions

- Position/posture (chin tuck - not for infants)
- Bolus changes
  - Texture & order of textures
  - Temperature
  - Taste
  - Size

Modifications (continued)

- Utensils (nipples, spoons, cups)
- Placement in mouth
- Rate of presentation
- Maneuvers (older children who can follow directions usually)

Findings by Phase of Swallowing

- Oral preparation (bolus formation)
- Oral phase/transit
- Initiation of pharyngeal phase
- Pharyngeal phase
- Upper esophageal phase
### Pharyngeal Swallow Problems
- Tongue base retraction reduced
  - Residue in valleculae or tonsils
- Pharyngeal contraction reduced
  - Residue in pyriform sinuses
- Pharyngeal motility reduced
- Vocal fold paralysis/paresis
- Reduced velopharyngeal closure
- Incoordination

### If Aspiration Occurs
- Causes must be described in relation to
  - Timing (before, during, after swallows)
  - Muscle strength (where residue is seen provides clues to reasons)
  - Structural anomalies (e.g., laryngeal cleft)

### Interpretation of VFSS Findings
- SLP reviews with caregivers & therapists or others involved in care
  - Findings by phase of swallow
  - Timing of laryngeal penetration/aspiration related to physiologic processes
  - Slow motion & frame-by-frame review

### Problem Areas from VFSS
- Oral phase
- Initiating pharyngeal swallow
- Pharyngeal phase
  - Esophageal phase (upper)
    - Esophagram or UGI may be needed to define esophageal function
    - Impedance, manometry, or pH probe

### Management Recommendations
- Route for nutrition/hydration
- Feeding suggestions
- Therapy recommendations
- Additional suggestions
- Plans for follow-up or re-evaluation

### Principles for Repeat VFSS
- Same as for initial VFSS
- Information needed for
  - Definition of etiology or diagnosis
  - Guide for management decisions
- NOT some arbitrary time interval
- Inadequate information from prior study
- Child should be at baseline
**Instrumental Evaluation Summary**

- Purpose & questions must be well defined
- Keep in mind: children with complex health & developmental issues may have many radiology studies throughout their lifetimes
- How will findings impact management decisions?
- A cooperative child is needed for reliable & valid interpretation of findings

**Instrumental Evaluation Summary**

- Remember: Study samples a brief window in time while the child is in an atypical eating situation
- Strive for development of noninvasive measures that can infer pharyngeal physiology so accurately that radiologic studies will not be needed. Children (& parents) will be happy....

---

**Dr. Dodrill:**

**Thickening Considerations**
VIDEOFLUOROSCOPIC SWALLOW STUDIES AND THICKENED FLUIDS: WHAT, WHEN, AND WHY

Dr Pamela Dodrill, PhD, CCC-SLP
Boston Children’s Hospital

No financial or other conflicts of interest
Board Member of Feeding Matters
POOR SSB COORDINATION

CONTROL FLOW
- Stop sucking
- Slower sucking
- Weaker sucking

CAN'T CONTROL FLOW

PROTECT AIRWAY
- Apnea

CAN'T PROTECT AIRWAY
- Aspiration

FEEDER HELPS CONTROL FLOW

PROTECT AIRWAY
- Apnea

CAN'T PROTECT AIRWAY
- Aspiration
LEARNING OBJECTIVES
THIS SECTION WILL COVER:

- Factors that need to be considered when prescribing thickened liquids
- Possible alternatives to thickening liquids for children with swallowing difficulties
THICKENED FLUIDS: FACTORS TO CONSIDER

- Rationale behind thickening drinks:
  - Slow the rate of flow of the fluid, thereby allowing more time for the entrance to the airway to close over prior to the swallow
  - Reduce penetration into airway via any gaps in entrance during or after the swallow

- The effectiveness of thickened fluids in preventing airway penetration/aspiration can be evaluated objectively during instrumental assessment

THICKENED FLUIDS: FACTORS TO CONSIDER

- Depending on the severity of their dysphagia, patients may require fluids to be thickened to different degrees in order to be able to swallow safely, without primary aspiration

- Standard terminology is generally used by feeding therapists and dietitians to assist in communication regarding the level of thickening a patient requires for safe swallowing
  - Nectar thick, honey thick, pudding thick
  - Mildly thick, moderately thick, extremely thick
  - 1/4 thick, 1/2 thick, full thick

THICKENED FLUIDS: FACTORS TO CONSIDER

It is important that thickened fluids are prepared correctly.
- If thickened fluids are too thin, they may not assist in managing the underlying problem (i.e. aspiration during swallowing)
- If thickened fluids are too thick, they may cause additional problems (e.g. increased work of breathing, reduced intake due to fatigue)
THICKENED FLUIDS: FACTORS TO CONSIDER

- For bottle-fed infants, their bottle feed provides them with both nutrition and hydration.

- Infants should be able to suck the feed through a teat/nipple on a bottle in 20-30 minutes, in order to meet their nutritional and fluid requirements without expending excess energy.
  - May need to switch to a faster flowing nipple to accommodate the thicker fluid.
  - Need to be aware of temperature.
    - Thickened bottle feeds are generally served heated, but will cool over the duration of a feed, and will likely get thicker.
    - If the feed is re-heated, it may get somewhat thinner.

THICKENED FLUIDS: FACTORS TO CONSIDER

FLUID REQUIREMENTS ARE HIGH IN CHILDREN

- Thickness of thickened fluids can be affected by:
  - Type of base fluid: More of less thickening agent may be required when thickening different fluids (milk, juice, water, soda).
  - Amount of base fluid: The relationship between amount of base fluid and amount of thickening agent may not be linear (e.g. the amount of thickening agent that needs to be added to thicken 200mL may be more or less than 2x the amount that needs to be added to thicken 100mL).
  - Temperature: Fluids generally get thicker when cooler and thinner when warmer.
  - Standing time: Fluids generally get thicker with time.
THICKENED FLUIDS: FACTORS TO CONSIDER

- Thickness of thickened fluids can be affected by:
  - Type of thickening agent: Thickening agents are generally starch-based, gum-based, or a combination of starch- and gum-based
  - Thickeners are not all consistent in how they react to different types of fluids:
    - Smaller or larger amounts of different thickening agents may be required to produce the same level of thickness for a particular fluid
    - Companies that manufacture thickening agents may change their recipes in their thickening products and/or may change the provided measuring utensil. These changes can impact the recipe you use for preparing thickened fluids.

OTHER FACTORS THAT NEED TO BE CONSIDERED WHEN PRESCRIBING THICKENED LIQUIDS

- Check fluids in diet match thickness of test fluids (i.e. barium samples used in VFSS)
  - Check terminology
  - Check recipes
  - Check understanding
  - Provide practical demonstrations

THICKNESS OF THICKENED FLUIDS

- Expected line spread test measurements for thickened fluids of different degrees of thickness (50mL)

<table>
<thead>
<tr>
<th>Thickened fluids</th>
<th>Radius (mean)</th>
<th>Radius (range)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Extremely thick</td>
<td>2.2 cm</td>
<td>1.50- 2.89 cm</td>
</tr>
<tr>
<td>Moderately thick</td>
<td>3.2 cm</td>
<td>2.90- 3.89 cm</td>
</tr>
<tr>
<td>Mildly thick</td>
<td>4.2 cm</td>
<td>3.90- 5.00 cm</td>
</tr>
<tr>
<td>Infant thick (AR)</td>
<td>6.0 cm</td>
<td></td>
</tr>
<tr>
<td>Infant formula</td>
<td>9.7 cm</td>
<td></td>
</tr>
</tbody>
</table>

Queensland Health
CLINICAL INDICATORS SUGGESTIVE OF AIRWAY COMPROMISE/ASPIRATION

- Wet voice/coughing/rattly chest during feeds
- Unexplained pneumonia
- Increased work of breathing
  - (Thoyre et al 2003)
- Desaturation events/color change during feeds

OTHER FACTORS THAT NEED TO BE CONSIDERED WHEN PRESCRIBING THICKENED LIQUIDS

- Consider child’s age
  - Especially if preterm
  - <12 months
  - <3 years
  - Others at risk of gut complications
    - GI malabsorption or motility issues
    - Cardiac disease
- NEC concerns
  - FDA
  - Beal et al (2012)

OTHER FACTORS THAT NEED TO BE CONSIDERED WHEN PRESCRIBING THICKENED LIQUIDS

- Consider allergies (especially wheat, corn, soy, milk)

<table>
<thead>
<tr>
<th>Product</th>
<th>Ingredients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Simply Thick</td>
<td>Xanthan gum, citric acid, potassium sorbate</td>
</tr>
<tr>
<td>Thick &amp; Easy</td>
<td>Modified maize starch, maltodextrin</td>
</tr>
<tr>
<td>GelMix</td>
<td>Maltodextrin, Organic Carob Bean Gum, Calcium Lactate</td>
</tr>
<tr>
<td>Rice Cereal</td>
<td>Rice flour, tri- and di-calcium phosphate, soybean oil, mixed tocopherols,</td>
</tr>
<tr>
<td></td>
<td>electrolytic iron sulphate, alpha tocopheryl acetate (vitamin A), pyridoxine</td>
</tr>
<tr>
<td></td>
<td>hydrochloride (vitamin B6), thiamin mononitrate (vitamin B1), folic acid</td>
</tr>
<tr>
<td></td>
<td>cyanocobalamin (vitamin B12)</td>
</tr>
<tr>
<td>Enfamil AR</td>
<td>Rice starch, maltodextrin</td>
</tr>
<tr>
<td>Similac Sensitive AR</td>
<td>Potato starch, maltodextrin</td>
</tr>
<tr>
<td>Nan AR</td>
<td>Potato starch, maltodextrin</td>
</tr>
</tbody>
</table>
OTHER FACTORS THAT NEED TO BE CONSIDERED WHEN PRESCRIBING THICKENED LIQUIDS

- Consider energy content of thickening agent
  + Especially infant cereal
    - Adding 1 teaspoon of rice/oat cereal adds 5 cal
    - Adding 1 Tablespoon adds 15 cal
  + Standard formula = 20 cal/oz
    - Adding 1 ½ teaspoons of cereal (nectar-thick) increases energy content from 20 to 27.5 cal/oz (1.4x)

AAP and WHO recommend introduction of solids >16 weeks (4-6 mths)

OTHER FACTORS THAT NEED TO BE CONSIDERED WHEN PRESCRIBING THICKENED LIQUIDS

- Thickening agents used for children with dysphagia should be labelled as suitable for use with patients with dysphagia
- The packaging should contain clear instructions on how much thickening agent is required to prepare fluids that are consistent with the levels set out in the National Dysphagia Standards and/or to thicken infant bottle feeds
- In addition to feeding therapy staff, dietetic, pharmacy, and medical staff should be involved in deciding which types of thickening agents are suitable for use with children

OTHER FACTORS THAT NEED TO BE CONSIDERED WHEN PRESCRIBING THICKENED LIQUIDS

- Consider financial costs
  + Thickeners may or may not be covered by insurance
  + Can cost $10 - $50 per week
- Consider burden
  + Infants drink approx. 8 bottles a day
  + Measuring and mixing
  + Standing time
  + Needs to be available for all oral intake (home, while away from home, at school etc)
CONCERNS REGARDING USE OF THICKENING LIQUIDS FOR CHILDREN WITH SWALLOWING DIFFICULTIES

- Delayed transit time, increased residue
  - Gosa et al (2012)
  - Steele et al (2014)

POSSIBLE ALTERNATIVES TO THICKENING LIQUIDS FOR CHILDREN WITH SWALLOWING DIFFICULTIES

- Modified utensils
  - Slow flow bottle nipple
  - Chang et al (1997)
- Modified positioning
  - Side-lying
  - Dawson et al (2013)
  - Thoyre et al (2013)
- Modified feeding strategy
  - Pacing
  - Thoyre et al (2013)

POSSIBLE ALTERNATIVES TO THICKENING LIQUIDS FOR CHILDREN WITH SWALLOWING DIFFICULTIES

- Reducing volume &/or duration of feed
  - Avoid fatigue
- Tube feeding
  - Supplemental
  - Total (i.e. NPO)
IF THICKENING...
- Consider is it needed
- Consider logistics
- Consider alternatives
- Don’t thicken for longer than they need it
  - Consider when you will review need for thickening
  - Consider how you will wean

REFERENCES
- Goss MB. Videofluoroscopic analysis to determine the effects of thickened liquids on oropharyngeal swallowing function in infants with respiratory compromise. Communication Sciences and Disorders. Memphis: University of Memphis; 2012.

REFERENCES
- Goss MB. Videofluoroscopic analysis to determine the effects of thickened liquids on oropharyngeal swallowing function in infants with respiratory compromise. Communication Sciences and Disorders. Memphis: University of Memphis; 2012.
PARENT EXPERIENCES AND REFLECTIONS ON FEEDING THEIR CHILDREN: WHAT WE ALL SHOULD KNOW
JOY V. BROWNE, PHD, PCNS-BC, IMH-E AND PARENT PANEL

NO SYLLABUS
Risks and Benefits of Blenderized Tube Feeding

I have no financial disclosures

Blenderized tube feeding

- What is it?
- Why might I want to use it?
- Who is a good candidate?
- Frequently asked questions
What is homemade tube feeding?

- Definition:
  Liquefied food given through a feeding tube

What is homemade tube feeding?

COMMERCIAL FORMULAS

BLENDED FOODS

Why might I want to use homemade tube feeding (HTF)?

- Potential benefits include:
  - Improved tolerance
    - Constipation
    - Reflux
  - May cost less than commercial formula
Why might I want to use HTF?

Potential benefits include:

- Psychosocial benefits to child and family
  - Help children feel more included in family meals
  - Help parents feel more involved in feeding their child

What does the evidence say?

- There is little research currently available on HTF
- There are published case reports\(^1,2\) of HTF leading to
  - Improved feeding tolerance
  - Improved interest in food
  - Improved intake of essential fatty acids

What does the evidence say?

- Pasadena Child Development Feeding Team published their experiences with HTF\(^3\)
  - Greater volume tolerance
  - Improvements in reflux and constipation
  - Improved nutrient composition of the diet
  - Greater inclusion of the child in family meals
  - "Normalization" of enteral feedings
  - Facilitating transition to oral feeding
What does the evidence say?

- Cincinnati Children’s Hospital has documented success with pureed-by-gastrostomy-tube (PBGT) diet\textsuperscript{4,5}
  - 73\% of patients had >50\% decrease in gagging and retching
  - 57\% of patients increased their oral intake
  - Parent satisfaction was extremely high
  - Reports of decreased constipation

Things to remember with HTF

- HTF requires extra planning and time from the caregiver

- There are some risks with HTF that you do not have with commercial formula

Things to remember with HTF

- Potential risks include:
  - Increased wear on tube
  - Clogged tube

- Can be prevented by:
  - Blending food well and straining
  - Flushing tube with water after every feeding
Things to remember with HTF

- Potential risks include:
  - Food-borne illness

- Can be prevented by:
  - Food safety in formula preparation and administration

Things to remember with HTF

- Potential risks include:
  - Inadequate nutrient intake

- Can be prevented by:
  - Working with a skilled dietitian for growth monitoring and nutrient analysis

Commerically available blended foods
Who is a good candidate for HTF?

- Consider:
  - Child's medical and nutritional status
    - Medically stable
    - Appropriate growth
  - Type and size of tube
    - G-tube, at least 14 French in size

Who is a good candidate for HTF?

- Consider:
  - Continuous vs bolus feeding
    - Bolus feeds necessary for HTF
  - Family resources
    - Motivated care providers
    - Appropriate kitchen facilities

The best candidate for HTF

is a child whose family:
- has carefully considered the pros and cons of HTF
- is willing to commit the time for instruction and for preparation of HTF
- is willing to work with a diettian to provide the best and safest nutrition for their child
Who is not a good candidate for HTF?

- Someone with:
  - A weakened immune system
  - A J tube or NG tube
  - Continuous drip feedings
  - The need to avoid many foods, due to food allergies or another reason

Frequently Asked Questions
About Homemade Tube Feeding

FAQ: how do I support a family considering HTF?

- Be realistic but keep an open mind
- Know your role
- Seek others’ expertise as needed
  - A dietitian working together with the prescribing provider is essential
Resources

- Refer to a registered dietitian
- Homemade Blended Formula Handbook
- Websites / social media

Resources

- Oley Foundation
  - www.oley.org
- Feeding Tube Awareness Foundation
  - www.feedingtubeawareness.com
- Real Food for Real People
  - www.foodfortubies.org
- Choosemyplate.gov

FAQ: what if my doctor is not supportive of HTF?

- Listen carefully to your doctor’s concerns
- Share helpful resources you have found
- If you cannot come to an agreement, seek a second opinion
- Do not attempt HTF without medical supervision and collaboration
FAQ: how should I get started with HTF?

- Work together with your doctor and dietitian
- It is often easiest to start by blending strained baby food into current formula
- Start slowly
  - Add one new food at a time
  - Try a new food every few days

FAQ: HTF in the hospital?

- Many hospitals do not allow HTF
- Ask:
  - Can you make and bring in your own HTF?
  - If you provide the recipe, can they prepare your HTF in their kitchen or formula room?
  - Can you use a commercially prepared blended food product?

Questions?


Special Thanks to:

- The Homemade Tube Feeding Committee at Children's Hospital of Wisconsin
- Members
  - Angie Edlbeck, MS, RD, CSP, CD
  - Mary Beth Feuling, MS, RD, CSP, CD
  - Megan Van Hoorn, RD, CD, CNSC
  - Cassandra Walia, MS, RD, CD, CNSC
Oral Feeding Skills and Pediatric Approaches to Address Chewing Deficits

AMY L. DELANEY, PHD, CCC-SLP
AND
CAROL ELLIOTT, BS, OTR/L

Disclosures

Amy Delaney and Carol Elliott have no financial disclosures

Prevalence of feeding problems

Feeding problems occur in 5-10% of typically developing children (Transient and do not cause acute nutritional risk)

Up to 80% of children with developmental disabilities have feeding problems (Persistent and cause acute nutritional risk in 40% (Ahearn et al., 2001; Matson & Kuhn, 2001))

Oral feeding skill deficits contribute to more than half of the children (427/700) diagnosed with a feeding problem with 66% of those children under 2 years of age (Rommel et al., 2003)
Transitional feeding period

- Transition through all textures from 6 to 12 months, adult-fed to self-feeding, breast-bottle to cup
- Intake of advanced textures requires complex oral-motor control and coordination
- Refinement of skills continue into childhood

*Children are particularly vulnerable to these demands!

Chewing Function

- Food placed into mouth
- Stage 1 transport: tongue transports food from front of mouth to occlusal surfaces of post-canine teeth (*lateral movement*)
- Processing Stage: food is reduced in size by chewing and softened by saliva until appropriate size for swallowing (*chewing*)
- Stage 2 transport: food propelled posteriorly into oropharynx (*swallow*)

*(von der Bilt, 2011; Matsuo & Palmer, 2012)*
Stage 1 Transport

- Mouth opens
- Tongue carries food to molar surfaces
- Tongue rotates laterally
- Food placed on molar surface

[Video example](van der Bilt, 2011; Matsuo & Palmer, 2012)

Food Processing: Jaw movement

- Two phases of jaw closing:
  - Fast closure: directly after start of jaw closure until teeth contact food
  - Slow closure: lower jaw slows due to resistance of food and jaw closure muscles increase activity — food in compressed and sheared
- Rhythmic jaw movements
  - Coordinated with tongue, cheek, soft palate

[Video example](van der Bilt, 2011; Matsuo & Palmer, 2012)

Food Processing: Tongue movement

- Moves forward as jaw opens
- Moves backwards as jaw closes
- Rotates along a-p axis
- Food squeezed off molars during jaw closing
- Tongue and cheek push against medial and lateral surfaces of food during jaw opening pushing food back onto molar surfaces
- Repeated until ready for Stage 2

[Video example](van der Bilt, 2011; Matsuo & Palmer, 2012)
Factors that influence chewing

- Dentition
- Jaw muscle and bite force
- Food properties
- Saliva

- 50% of performance correlated with dentition in adults
- More muscle activity needed for harder foods
- Number of chewing cycles and duration increased with hardness and bolus size
- Lubricates food and assists in bolus formation and perception of taste and flavor

(van der Bilt, 2011; Matsum & Palmer, 2014)

Oral-motor skill development

- Rapid acquisition occurs in first year of life (Delaney, 2010; Morris, 1982; Stovall & Gisel, 1991)
- Variability of strength, timing, and movement patterns decrease with age (Chigira et al., 1994; Potter & Short, 2009; Gisel, 1991)
- Typically developing children 8 to 12 months mastered 50% of examined skills (21 of 52) regardless of age, experience, or texture (Delaney, 2010)

<table>
<thead>
<tr>
<th>Recommended Age of Introduction</th>
<th>Food Textures</th>
<th>Example within textures</th>
<th>Oral feeding skills</th>
</tr>
</thead>
<tbody>
<tr>
<td>6 and 7 months: Smooth puree</td>
<td>Smooth and thin puree (no lumps)</td>
<td>Infant rice cereal, Stage 1 baby foods, Homemade blended foods</td>
<td>Efficiently open mouth for spoon; attempt to close lips on spoon</td>
</tr>
<tr>
<td>8 and 9 months: Easily dissolvable solids (early finger foods)</td>
<td>Smooth and thicker puree (no lumps)</td>
<td>Stage 2 baby foods; increased volume and variety of flavors in purees</td>
<td>More consistent mouth opening and lip closure on spoon</td>
</tr>
<tr>
<td>10 and 11 months: Textured puree and Diced solids</td>
<td>Textured puree (with lumps)</td>
<td>Stage 3 baby foods; yogurt with fruit purees, cottage cheese</td>
<td>Efficient skills for spoon feeding; tongue mashing pieces</td>
</tr>
<tr>
<td>12 to 18 months: Toddler foods</td>
<td>Diced solids</td>
<td>Canned fruit; cooked vegetables; soft cheese; deli meat</td>
<td>Improved chewing; more food to side with tongue</td>
</tr>
<tr>
<td></td>
<td>Toddler foods</td>
<td>Soft table foods in bite-sized pieces</td>
<td>Biting and chewing skills more efficient</td>
</tr>
</tbody>
</table>
Oral Feeding Skill Milestones: 6 months

- Insert video

**Biting**
- Tastes/Licks
- No sustained bite
- Does not bite through cracker in one motion

**Chewing**
- No lateralization of food
- Vertical jaw movements
- Tongue moves up and down
- Lateral shift of tongue

(Delaney, 2010; Stolovitz & Gisel, 1991; Morris, 1982)

Oral Feeding Skill Milestones: 9 months

- Insert video

**Biting**
- Lips touch solid during biting
- Attempts to bite
- Bites in front of mouth
- Inconsistently bites through early solids

**Chewing**
- Initiates chewing
- Lips open during chewing
- Jaw moves in varied directions
- Initiation of lateral tongue movement

(Delaney, 2010; Stolovitz & Gisel, 1991; Morris, 1982)

Oral Feeding Skill Milestones: 12 months

- Insert video

**Biting**
- Lips touch solid during biting
- Attempts to bite
- Bites in front of mouth
- Consistently bites through early solids

**Chewing**
- Active jaw movements in chewing
- Jaw moves in varied directions
- Consistent lateralization of food
- Tongue tip lateralization and sweeping

(Delaney, 2010; Stolovitz & Gisel, 1991; Morris, 1982)
Oral Feeding Skill Milestones: 18 to 24 months

- Bites through hard solid in one motion
- Fewer chewing cycles needed
- Jaw movements adjust to texture
- Transfer solid across midline
- Can keep lips closed during chewing

(DeLucia, 2010; Stolovitz & Gisel, 1990; Morris, 1982)

Chewing Gum Analysis

- Central placement, lateral shift
- Identify dominant chewing side
- Observe & feel for cheek activation with different chewing patterns
- Analyze tongue movements used to move the bolus
- Analyze cheek, jaw and tongue coordination while chewing
- Identify “anxiety” with poor control of the bolus
- Identify compensatory techniques used with poor oral motor skills

Identifying The Cause of Poor Chewing skills

- Some children with chewing deficits are easy to spot, others are a bit harder to identify.
- Poor chewing skills are typically a result of 1 or more of the following issues:
  - Medical issues
  - Oral-motor skill issues
  - Sensory issues
- Negative behavior looks like “misbehavior”.
- Assessment and identification of the root causes will help to set up an appropriate and successful treatment plan
Medical Issues that Impact Chewing

Medical issues can delay and interfere with the child learning to chew at the appropriate age. Medical issues may include some of the following:

- Neurologic Disorders
- Genetic Disorders
- Prematurity
- Developmental Delay
- GI issues
- Allergies

Poor Chewing: Signs of oral-motor skill issues

- Use immature chewing patterns or compensatory techniques to break down food
- Chewing with the front teeth
- Lips are closed and pursed when "chewing"
- Using vertical patterns and munching only – not appropriate for age
- Swallowing food whole
- Tongue mashing
- Will not open mouth when asked to "show"
- Difficulty clearing mouth of chewed food
- Look confused

Video Example: Using Compensatory Techniques

- (poor oral motor, using compensatory techniques)
Poor chewing: Signs of Sensory Issues

- Can be over or under responsive to sensory feedback. Over responsive is more frequent.
  - Fight or Flight response
  - Gagging, retching
  - Raking food out of the mouth or spitting
  - Looking fearful
  - Crying

Video example: Sensory Issues Impacting Oral-motor Skills

- (poor skills, sensory responses)

Poor Chewing: “Behavioral” issues

- Avoidance and Fighting
  - Pushing away the feeder
  - Food refusals
  - “Picky” eater – selective about types of food
  - Crying
- Not eating appropriate volume or variety of table food
  (age >2 y/o)
Addressing the Problem: Feeding Therapy

- Takes a long time!
  - Medical management
  - Missed developmental window
  - Age
  - Oral-motor, sensory, behavior

Addressing the Problem: Feeding Therapy

- Parent Education:
  - Setting goals
  - Understanding underlying problem
  - Recognizing oral-motor “age” of the child
  - Understanding and supporting that you may need to take a step back to move forward

Addressing the Problem: Feeding Therapy

- Oral-motor work:
  - Tongue
  - Jaw
  - Cheek
- Systematic desensitization to address sensory deficits:
  - Trials with mesh
  - Analysis of food trials to meet oral-motor skills
  - Food fading new foods
Addressing the Problem: Feeding Therapy

- Diet adjustments:
  - Eliminate trials and exposure to foods the child is using inappropriate skills to consume.
  - Match current diet to "oral-motor" skill age, not chronological age.
  - Use pureed foods to meet nutritional needs.
  - Once skills are sufficient, target foods that maximize calories and volume; supplement with higher calorie drink (consult dietitian).
  - Use a mix of chewable food and "non–chewable" food in the meal; rotating to minimize fatigue.

- Behavioral/Psychosocial Interventions:
  - Create positive experiences that foster confidence and learning
    - Appropriate challenges
    - Understanding and acknowledgement of the problem areas
    - Providing a structured plan/routine
  - Positive reinforcement to enhance skills building
  - Practice
  - Patience

Contact Information

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804-691-4526
NEURODEVELOPMENTAL ORGANIZATION
OF EATING IN EARLY INFANCY: WHAT
HAPPENS LONG TERM WHEN THINGS
DON’T GO RIGHT IN THE BEGINNING

Dr. Erin Sundseth Ross, PhD, CCC-SLP
and
Dr. Pamela Dodrill, PhD, CCC-SLP

OBJECTIVES

- Identify four types of pediatric feeding struggles that can delay discharge past term age.
- List three factors that can contribute to growth faltering in premature infants post-discharge and across the first five years of life.
- Discuss three factors that can contribute to alterations in family functioning during mealtimes in the first five years of life.
PREMATURITY
- Neonates born before 37;0 weeks gestation
- >12% of infants in the US, 540,000 infants per year
- >8% of infants in Australia, 20,000 infants per year

GROWTH AND FEEDING
- Feeding skills impact ability to ingest calories and grow
- Growth influences feeding skill development
- Maturity influences ability to utilize calories consumed
- Appropriate growth is difficult to achieve in the NICU
  - Nutrient absorption
  - Gut intolerance
- Much of growth faltering occurs in the initial hospitalization

FACTORS THAT CAN CONTRIBUTE TO GROWTH FALTERING
**FACTORS THAT CAN CONTRIBUTE TO GROWTH FALTERING**

- Increased energy requirements
- Increased energy losses
- Reduced energy intake
- Feeding/swallowing problems
- Reduced efficiency of feeding
- Physiological stress
- Immature gut
- Gastro-oesophageal reflux
- Illness

**HOW ARE WE DOING?**

- Approximately 50% of infants have a negative change in weight-for-age z-scores from birth to discharge from the NICU.
- Approximately 30% of infants continue to be identified as underweight across the early years of childhood

Ross & Browne, 2013

**RAW MEASUREMENTS**

- Weight and length measurements

<table>
<thead>
<tr>
<th>Group</th>
<th>Term (6m CA)</th>
<th>Mean (SD)</th>
<th>4m CA</th>
<th>Mean (SD)</th>
<th>8m CA</th>
<th>Mean (SD)</th>
<th>12m CA</th>
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<td>Weight</td>
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<td>3.41 (0.26)</td>
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<th>Group</th>
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<th>Mean (SD)</th>
<th>12m CA</th>
<th>Mean (SD)</th>
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<tr>
<td>Length</td>
<td>FT-AGA, 64</td>
<td>51.1 (1.5)</td>
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<td>71.2 (2.9)</td>
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<td>68.7 (2.3)</td>
<td>73.8 (1.8)</td>
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</table>

0.5-1kg lighter, 2-3cm shorter  Dodrill, et al., 2008
**STANDARDISED MEASUREMENTS**

- Weight and length Z scores

---

**FEEDING DIFFICULTIES IN PRETERM NEONATES**

Developmental delays & impairments
Interruptions to family mealtime functioning

---

**DEGREE OF PREMATURITY AFFECTS FEEDING OUTCOMES**

Dodrill et al (2008)
DEGREE OF MORBIDITY AFFECTS FEEDING OUTCOMES

Dodrill et al (2008)

BREAST FEEDING OR BREAST MILK?

- Current breastfeeding definitions focus on what the infant receives and do not encompass how a baby is fed.
- It seems the breastfeeding relationship is not considered in the definition.

Noel-Weiss, et al., 2012

SHORT-TERM BREASTFEEDING

- Mamemoto, et al. (2013) Japan
  - 22.6% exclusively breastfeeding at discharge
  - 15.7% exclusively breastfeeding at start of complementary feeds
  - 57% of those exclusively breastfeeding at discharge were exclusively breastfeeding at start of complementary feeds
- Dowling, et al. (2012) US
  - 71.8% providing some breast milk at discharge
  - 44.7% exclusive breast milk
- Pineda (2011) US
  - 78% of mothers initiate breastmilk feeds
  - 52% of the infants ever breastfeeding in the NICU
Statistically significantly fewer preterm infants received only breast milk feeds or any breast milk feeds than full-term infants (p<0.01)

Fewer infants breastfeeding

BREASTFEEDING PATTERNS

- Prevalence of feeding problems delaying discharge from the NICU past 36 weeks gestational age
  - 44% had difficulty latching
  - 89% fatigued during feeding
  - 22% had liquid loss
  - 56% demonstrated short sucking bursts
  - 22% demonstrated suction and compression components not fully integrated
  - 44% had unusual swallowing noises
  - 44% had feeding intolerance/reflux/vomiting

FEEDING PROBLEMS DELAYING DISCHARGE FROM THE NICU

- Kirkby et al. (2007)
  - 0.8% of their large cohort of infants [n=4932] born between 32 and 36 weeks GA were discharged with the need of a supplemental tube

- Jadcherla et al. (2010)
  - 79% discharged to home fully nipple feeding
  - 16.6% discharged home on oral plus gavage feeds
  - 8.6% on gastrostomy-tube feedings
FEEDING SKILLS AFTER DISCHARGE

- DeMauro et al. (2011)
  - Feeding problems were prevalent in both the early born (25 to 33.6 weeks GA) and later born (34 to 36.6 weeks GA) groups evaluated at 3, 6 and 12 months
  - Diminished for both groups over time

<table>
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<tr>
<th></th>
<th>1 Mo GA (0%)</th>
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<th>6 Mo GA (0%)</th>
<th>12 Mo GA (0%)</th>
<th>1 Yo GA (0%)</th>
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<td>13</td>
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<td>10*</td>
<td>4*</td>
<td>3</td>
<td>2</td>
<td>1*</td>
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<tr>
<td>Dysfunction</td>
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<td></td>
<td></td>
<td></td>
<td>0*</td>
</tr>
<tr>
<td>High Assistant</td>
<td>7*</td>
<td>3*</td>
<td>3</td>
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<td>3</td>
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*p<0.05

FEEDING SKILLS AFTER DISCHARGE

- Den Boer and Schipper (2013)
  - Delays across gross motor and eating skills in preterm infants
- Pridham et al. (2007)
  - Preterm infants lagged behind expected skill acquisition at every one of the 4 time periods evaluated, even after correcting for prematurity
- Davis et al. (2003)
  - Total feeding scores on a standardized feeding assessment were significantly lower compared to normative data

SOLID FEEDING PATTERNS

- Preterm infants began beginner (pureed) solids statistically significantly earlier (p<0.01)

[Graph showing feeding patterns]
Preterm infants began beginner (pureed) solids statistically significantly earlier (p<0.01).

Preterm infants took statistically significantly longer to transition onto textured solids (p<0.01).

Consistent with oral motor delay and altered oral sensitivity.
QUALITY OF FEEDING SKILLS

- N=20 (BW<1000 grams; mean GA 27 weeks)
- 17 RDS, 4 BPD, 3 birth asphyxia, 6 PVL, 13 IVH (1 Grade 3, 1 Grade 4)
- Feedings are prolonged and messy
- Much of food drops out of mouth
- Pace of feeding is rapid
- Increased sensitivity to texture, temperature and tastes
- Both infant and feeder become impatient
- Feeding problems in preterm infants create a risk for early interaction and communication

Torola, et al., 2012

FEEDING PATTERNS

In the first month post-term age:
- Term neonates feed for approx. 3 hours per day, 23 mins per feed x 8
- Preterm neonates feed for approx. 4.5 hrs per day, 34 mins per feed x 8

Dodrill et al (2008)

LAYING A FOUNDATION

- Infant brain development, as well as later developmental trajectories, are influenced by:
  - the quality of care given during the NICU
  - parent empowerment
- Interventions to support infant regulation and parent involvement, empowerment, and knowledge have been shown to improve infant functioning in both the short- and long-term.

Achenbach, et al., 1993
Als, et al., 2003; 2004
Peters, et al., 2009
NEONATES AND YOUNG INFANTS FEED DIFFERENTLY TO ADULTS

Development of:
- Cognition
- Gross motor skills
- Fine motor skills
- Fully dependent > semi-dependent > fully independent
- Reflexive vs. voluntary oral phase
  - Adaptive reflexes (suckling, rooting)
  - Protective reflexes (tongue protrusion, tongue lateralisation, phasic bite, gag, cough)
- Different type of intake (milk vs food) and method of delivery (suckling feeding vs eating)

EARLY FEEDING DEVELOPMENT

- Early suckling (feeding)
  - Oral phase is reflexive
  - Plane of movement in uni-directional
  - Brainstem mediated
  - Central pattern generator
- Later transition to solids (eating)
  - Oral phase is volitional
  - Plane of movement in multi-directional
  - Greater cortical input is required

FEEDING ISSUES THAT CAN PERSIST THROUGHOUT CHILDHOOD

- Delayed oral motor skills
- Altered sensory sensitivity
- Inefficient eating skills
- Feed aversion
- Reduced parent confidence in feeding child
EARLY INTERVENTION FOR FEEDING DIFFICULTIES

- Neonates and young infants:
  - There is never a time when nutrition is more important
  - There is never a time when the brain is more plastic
  - There is never a time when the individual is more dependent on others

MAIN CAUSE OF FEEDING DIFFICULTIES IN PRETERM NEONATES?

- Weak suck?
- Poor suck-swallow-breath coordination?

SURVEY OF NICU PRACTICE DOESN’T MATCH CLINICAL ISSUES

- Interventions aimed at assisting oral feeding:
  - strategies aimed at supporting the neonate’s sucking skills during feeds (e.g. chin/cheek support during oral feeds)
  - strategies aimed at preparing the neonate’s sensory-motor system for feeding (e.g. NNS during tube feeds or prior to oral feeds, oral stimulation programs, suck training)
  - feeding the neonate based on hunger cues (i.e. demand feeding)
  - interventions aimed at assisting respiratory support for feeding (e.g. actively pacing feeds, reduced milk flow)
  - Dodrill et al (2008)
WELL INTENTIONED INTERVENTIONS DON'T ALWAYS HELP, AND MAY HINDER

Techniques aimed at compensating for weak suck can make coordination of suck-swallow-breath more difficult and can encourage feeding practices that are not cue-based.

TO SUPPORT POSITIVE EXPERIENCES WITH FEEDING

- Support SKILL (coordination) first!
  - Look to stability signs to determine readiness for and influence of feeding
- Implement feeding supports to facilitate skill development
- Focus on experience – volume is a natural outcome of experiences that improve skill, efficiency and endurance

EXPERIENCE

"Practice is everything. This is often misquoted as Practice makes perfect."

Periander
665-580 BC
THEORY OF NEURONAL GROUP SELECTION (TNGS)

- The brain is a selective system
- The brain is strongly influenced by signals, provided by the infant’s body and the infant’s interactions with the environment
- The brain is continually changing, in response to these signals

(Edelman, 1987; Sweeney, et al., 2010)

EXPERIENTIAL SELECTION

- After birth, infant interacts with environment (distal and proximal)
- Environment provides experiences that drive changes in development
- Synaptic connections are either strengthened through repetitive activation, or weakened through “disuse”

(Edelman, 1987; Sweeney, et al., 2010)

REENTRANT MAPPING

- Neural maps are selected through past and present experiences, and link to form integrated connections
- Global mappings are created that involve motor and sensory systems
- Experiences do not happen in isolation – every experience matters!
- Negative experiences also create neural maps (but for NOT wanting to eat!)

(Edelman, 1987; Sweeney, et al., 2010)
WHAT WE KNOW

- Infant feeding is a function of both maturation and experience
- Primitive mechanisms (CPG) support early feedings, but are integrated and feeding is solely a learned skill beginning at 4 mos.
- Immaturity and medical instability increase likelihood of aversive feeding experiences
- Experience directly builds brain pathways
- Children learn to NOT EAT if the experience of eating is repeatedly aversive

Delaney & Arvedson, 2008; Ross, 2014

FACTORS THAT CAN CONTRIBUTE TO ALTERATIONS IN FAMILY FUNCTIONING DURING MEALTIMES

- Feeding difficulties
- Concerns regarding weight gain
- Learned practices from the NICU

WHAT ARE THESE INFANTS EXPERIENCING?
WHAT ARE THESE FAMILIES EXPERIENCING?
VIDEOS OF POOR AND GOOD EATERS HERE

THEY’RE HOME!
- Discharge criteria focus on weight gain – not on feeding skill
- Frequently feedings are arduous for both infant and family in the first weeks after discharge
- Feeding behaviors often develop that interfere with both the child’s eating as well as the family functioning
- Feeding is fundamental to being a parent
- Focus should be on enjoyable mealtimes – not just volume or weight gain.

Ross & Philbin, 2011

FEEDING AND THE FAMILY
“…Infant feeding is a matter of infant-mother relationship, a putting into practice of a love relationship between two human beings.”

Winnicott, 1987

“The feeding relationship is important because it supports the infant’s development… (and) because parents frequently evaluate their premature infant’s health and their competency as parents by the infant’s feeding success and weight gain before and after discharge.”

Deloian, 1998

“A baby’s ability to eat and a mother’s ability to feed her baby are at the heart of who she is as a mother. A majority of the time together in the first year is spent feeding. It is a powerful social and emotional learning experience and, if positive, they develop synchrony.”

Thomas, 1995
PARENTAL EXPERIENCE OF HAVING A CHILD WITH FEEDING PROBLEMS

- All encompassing fear
- Concerns that are often not heard
- Guilt and a feeling that they are blamed for their children's growth failure
- Isolation and helplessness
- Validation when included as members of team
- Pride in their expertise and capability in providing care
- Adaptation and Perseverance in pursuit of answers
- Value for those professionals who trust and respect the role of the family

Thomlinson, E. 2002

INFLUENCE OF CONGENITAL HEART DEFECTS ON FEEDING AND FAMILY

- After survival, feeding issues are the number one stressor for parents as they try to assist their infant in gaining adequate weight.
- Concerns include
  - Adequate weight gain
  - NG tube placement (after infant pulls it out)
  - Managing schedule
  - Managing tube feedings
  - Poor recognition of/signaling of hunger, fullness

Hartman & Medoff-Cooper, 2012

PARENTS OFTEN FOCUS ON THE VOLUME, NOT THE EXPERIENCE

- Videotapes of 10 mother-infant dyads, across the time periods of discharge, 1 and 4 months corrected age
- Mother’s on average talked to their infants only 10% of the feeding time across all 3 time periods
- Infants generally had eyes closed for entire first feeding (discharge), but fed with eyes open for 59% of the feeding at 4 months corrected age.

Reyna, et al., 2012
ALTERATIONS IN FAMILY FUNCTIONING
- Cerro et al. (2002)
  - 51% of parents use food rewards
  - 69% use coaxing during mealtimes
  - 78% of parents identified as the most important issue the quality of the foods eaten by the toddler

HELPING FAMILIES COPE
- 35 caregivers of children with chronic feeding problems
- The mothers/caregivers in this study were most likely to cope with their child's feeding problems by making active attempts to understand the problems
- It is beneficial for these families to acquire a thorough understanding of their child's medical situation
- It is important to provide a variety of resources, including access to support and information groups.

PARENTS NEED SUPPORT
- Study of mother’s with children with chronic feeding and swallowing disorders
- Mothers’ experiences can be understood as two continuing journeys that are not mutually exclusive
- "Deconstruction: A journey of loss and disempowerment,"
- "Reconstruction: Getting through the brokenness"

DECONSTRUCTION

- Losing the mother dream
- Everything changes: living life on the margins
- Disempowered: from mother to onlooker


RECONSTRUCTION

- Letting go of the dream and valuing the real
- Self-empowered: becoming the enabler
- Facilitating the journey
- The continuing journey: negotiating balance.


FOCUS ON QUALITY OVER QUANTITY CAN HELP

- Improved feeding outcomes at 3-5 months corrected age, after discharge from the hospital, when ALL caregivers focus on enjoyable, comfortable feedings
  - Decreased need for feeding therapy
  - Decreased gagging, discomfort
- Preliminary evidence that parents had enough confidence and competence to support earlier transition off supplemental tube feedings.

Horner, et al., 2013;
Horner, et al., 2014
It is universally accepted that a wide range of dietary intake is essential for optimal growth and development. It is widely reported that many children aren’t meeting their nutritional requirements. Parents report feeding difficulties as one of their biggest concerns. Parents want guidance on how to get their children to eat a wide range of foods. There is currently wide variation in practice related to managing children with feeding difficulties.

Focusing on weight and not nutrition can promote a diet high in energy and low in nutrients. If children do not learn the physical skills and cognitive behaviors to eat a wide variety of food, it will be difficult for them to meet their nutritional requirements through their diet.

Important life events are celebrated with meals.
REFERENCES


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The Infant and Child Feeding Questionnaire©: Its Role as an Engagement Tool and as a Potential Tool for Screening

Alan Silverman, Ph.D.
Associate Professor of Pediatrics
Medical College of Wisconsin

Julie Barkmeier-Kraemer, Ph.D., CCC-SLP
Professor, Otolaryngology
University of Utah

Speaker Disclosures

• Financial
  – Feeding Matters® waived registration and supported travel costs associated with this invited presentation
  – Both speakers were funded by Feeding Matters® and Del E. Webb Foundation to complete research discussed in this presentation
  – Both speakers are financially supported by Feeding Matters® for continuation of relevant research to this presentation
  – Dr. Silverman is an Educational Consultant and Speaker for Mead Johnson Nutrition
• Nonfinancial
  – Both speakers conduct research in the area of pediatric feeding and swallowing disorders
  – Both speakers have professional expertise related to the topic of this presentation

What is a feeding problem?

When eating has an adverse effect on health or functioning
• Food refusal?
• Failure to advance diet?
• Limited variety of foods?
• Disruptive mealtime behaviors?
• Undernutrition?
• No consensus on definition makes diagnosis and treatment referrals difficult!
Feeding Problems

• 25% to 45% of the general population
• Up to 80% of children with developmental disabilities
• 40% to 70% of children with chronic medical conditions
• Severe feeding disorders, characterized by long term growth and nutrition problems, affect 3-5% of children

No Two Feeding Problems Are the Same

What’s on the mind of a caregiver of a child with feeding difficulties?

• Is my child growing?
• Is my child healthy?
• Is my child developing?
• Does my child have adequate nutrition?
• Am I worried about NOTHING?!
• I just need some answers!!
What’s on your pediatricians mind at the 15-20 min well-child visit?

Physician Needs to Assess...
- Medical
- Developmental
- Behavioral
- Social

Plan for...
- Consultation
- Education
- Immunization
- Further assessment
- Reassurance

Pediatric Feeding and Swallowing Disorders

- There are approximately 1,000,000 families throughout the nation that have children with severe feeding difficulties.
- Many children with such struggles are not identified at well-child visits.

Pediatric Feeding and Swallowing Disorders

- Parents recognize when their child is struggling to eat; HOWEVER...
  - May have difficulties effectively describing the issue to their child’s primary care provider (PCP).
  - PCPs often lack the time and education to make informed feeding and swallowing assessments.
Pediatric Feeding and Swallowing Disorders

• Delays in treating feeding and swallowing struggles negatively impact:
  – Child cognitive,
  – Physical,
  – Respiratory,
  – Gastro-intestinal,
  – Emotional,
  – Social development, and
  – Adversely affect parent-child relationships.

This Seems Complicated
What’s a Family To Do?

• Where do I go for evaluation?
• Who can provide care if my child DOES have a feeding disorder?
• How do I get a referral?
• Are some models of care better than others?
• What are appropriate goals and outcomes?

This Seems Complicated
What’s a Provider To Do?

• Where do I send them for evaluation?
• Who can provide care if this child DOES have a feeding disorder?
• How do I make a referral?
• Are some models of care better than others?
• What are appropriate goals and outcomes?
Feeding Matters’ Infant & Child Feeding Questionnaire© (ICFQ©)

- The ICFQ was created to improve PCP early identification and referral of children at risk for feeding/swallowing problems and appropriate intervention:
  - Web-based questionnaire
    - [http://www.feedingmatters.org/questionnaire](http://www.feedingmatters.org/questionnaire)
  - Created by nationally-recognized pediatric feeding and swallowing experts from multiple disciplines in partnership with Feeding Matters®

ICFQ© Features

- Automatically calculates a child’s adjusted age if born prematurely (Less than 37 weeks gestation).
- Eleven age-adjusted versions of the ICFQ each presenting 12-core questions aligned with well check visit milestones for the parent’s child’s age.
- Free and accessible online and can be completed within 10-15 minutes.
- Provides a printable summary of results to be further discussed between the caregiver and the child’s medical professional team.

Example Online View of part of 2-3 mo. ICFQ©
ICFQ© Example Summary Printout

Potential Feeding Concerns

Does your child like to eat?
You answered: No
Children this age let their parents know that they enjoy eating in many ways. They may ask for food or reach for the cup, spoon or fork. Many want to be independent and do not like to be fed by someone else. Some parents still prefer to feed their child all of their meals. If they are still being fed by their parents, they will often open their mouth and move toward the food when they are ready for the next bite of food. If you feel your child does not seem to like eating, talk with his or her doctor.

Suggests Normal Feeding Development

Does your child let you know when he is hungry?
You answered: Yes
Children this age show that they are hungry in many ways. They may still fuss as they did when they were younger. But, they also use hand, eye, and body movements that are easy to understand. For example, they turn adults to the refrigerator and point to the food they want. They also reach for the water faucet or try to climb in their high chair if they have one. Some say words such as “up”, “eat”, “more”, or the name of a favorite food such as “juice”. If you feel that your child does not let you know that he is hungry or if you have to initiate feeding your child all the time, talk to your child’s doctor. You can work together to find ways to best feed your child.

The ICFQ© as an Engagement Tool

• Preliminary pre- and post-questionnaire survey responses from families indicated that the ICFQ© – was easy to use, – informative, and – useful in facilitating parent communication with physicians.
• Currently gathering post-wellness visit parent surveys via web-based administration.

Web-Based Parent Survey

YES NO The information provided by the check list and its summary provided understandable and useful information.

YES NO The information on the printed check list summary sheet gave me reason to believe my child may have a feeding or swallowing problem.

YES NO I shared the printed checklist summary sheet with my child’s physician.

If you answered NO to the last question, do not respond to the questions below, otherwise continue.

YES NO The physician discussed the information on the printed check list summary sheet.

YES NO The check list summary sheet helped me discuss concerns about my child with my child’s physician.

YES NO My physician made a treatment recommendation for my child related to the information shared from the printed check list summary sheet.

YES NO My physician will contact a pediatric feeding/swallowing healthcare professional to address problems discussed with my child’s physician.

YES NO (parent) will contact a pediatric feeding/swallowing healthcare professional to address problems discussed with my child’s physician.
The ICFQ© as a Potential Screening Tool

- Preliminary investigation was completed to determine which items, or set of items, from the Feeding Matters® ICFQ© might distinguish children with and without feeding/swallowing problems.
- Funded by Del E. Webb Foundation
- Two participating research sites
  - Children’s Hospital of Wisconsin, Milwaukee (MCW)
  - University of California, Davis (UCD)

The ICFQ© as a Potential Screening Tool

- Parents or caretakers of children aged 36 months or younger were recruited to participate:
  - 64 parents of children with *known* feeding/swallowing problems were recruited from the MCW.
  - A total of 56 parents of children *without known* feeding/swallowing problems were recruited from UCD Pediatric Outpatient Clinics.
  - Two Pediatric medical experts excluded 3 of the UCD respondents as not meeting inclusion criteria based on medical record review.

The ICFQ© as a Potential Screening Tool

**DATA COLLECTION**

- Participants completed the online ICFQ© and associated demographic questions.
- Data from research participants at UCD and MCW were anonymous, but tracked via the Feeding Matters® web site.
The ICFQ© as a Potential Screening Tool

ANALYSIS OF DATA

• Demographic information was compared between parents from each testing site.
• Statistical comparison of the 12 core questions common across the 11 age-based questionnaires was completed to determine:
  – Odds Ratios for feeding behaviors as a sign of problems
  – Multivariable Stepwise Logistical Regression Analysis to determine the optimum cluster of behavior distinguishing groups
  – Sensitivity and Specificity was determined for each question and clusters of questions

The ICFQ© as a Potential Screening Tool

COMMON CORE QUESTIONS:

1. Does your baby like to be fed?
2. Do you feed your baby (Does your baby eat) more often than every 2 hours?
3. Does your baby/child let you know when he is hungry?
4. Do you think your baby/child eats enough?
5. How long does it usually take to feed your baby/child?
6. Do you often have to do anything special to help your baby/child eat?
7. Does your child let you know when he is full?
8. Do you have concerns about your baby’s/child’s weight?
9. Most of the time, does you child seem content after eating?
10. Do you enjoy feeding time with your baby/child?
11. Does your child often do any of the following when you feed him (he eats)?
    [check all that apply]
12. Based on the questions you have answered, do you have concerns about feeding your baby/child?

The ICFQ© as a Potential Screening Tool: RESULTS

<table>
<thead>
<tr>
<th>PARENT GROUP</th>
<th>Age of Child Level</th>
<th>Relationship to Child</th>
<th>Marital Status</th>
<th>Feed Child</th>
<th>Rate of Education</th>
<th>Ethnicity</th>
<th>Employment</th>
</tr>
</thead>
<tbody>
<tr>
<td>FEEDING PROBLEMS</td>
<td>Mother 80%</td>
<td>Father 10%</td>
<td>Both 10%</td>
<td>Single 15%</td>
<td>Married 49%</td>
<td>High School 10%</td>
<td>Caucasian 70%</td>
</tr>
<tr>
<td>NO FEEDING PROBLEMS</td>
<td>Mother 80%</td>
<td>Father 10%</td>
<td>Both 10%</td>
<td>Single 15%</td>
<td>Married 49%</td>
<td>High School 10%</td>
<td>Caucasian 70%</td>
</tr>
</tbody>
</table>

COMPARISON OF GROUPS

• On average, the parent responses from older children predominated the MCW population compared to UCD.
• The UCD population represented greater ethnic diversity than did MCW’s population.
The ICFQ® as a Potential Screening Tool: RESULTS

**ODDS RATIOS FOR FEEDING BEHAVIOR PROBLEMS**
1. Coughs (OR=25.2)
2. Falls asleep before the end of feedings (OR=23.8)
3. Chokes (OR=20.5)
4. Refuses to eat (OR=18.6)
5. Does not swallow (OR=10.8)
6. Makes loud breathing noises (OR=9.49)
7. Gags (OR=6.7)
8. Turns away from the breast or bottle or cup (OR=5.33)
9. Arches his body (OR=2.59)

R² = 62.7% for presence of feeding/swallowing problems for the combined presence of the bold and underlined items above.

**MULTIVARIABLE ANALYSIS**
Stepwise logistic regression analysis gave the area under the ROC curve = .974 for this cluster of questions:

- Q12: Based on the questions you have answered, do you have concerns about feeding your baby?
- Q4: Do you think your baby eats enough?
- Q1: Does your baby like to be fed?
- Q6: Do you often have to do anything special to help your baby eat?

The ICFQ® as a Potential Screening Tool: CONCLUSIONS

- Comparison of parent responses to 12 core questions on the ICFQ® from those with children having known versus absent feeding and swallowing problems identified:
  - Feeding behaviors differentiating children from each group.
  - A cluster of 4 questions that highly distinguished those with and without feeding/swallowing problems.
- Future research will:
  - Compare age-related differences across questionnaires
  - Recruit additional research sites for multi-site testing
The ICFQ© as a Potential Screening Tool
ACKNOWLEDGEMENTS

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  - Elizabeth Fischer, PhD
  - Andrea Begotka, PhD

DISCUSSION
Head, Shoulders, Knees, and Toes: Implementing the Critical Role of Nutrition Assessment in the Diagnosis and Treatment of Pediatric Feeding Struggles

Presented By:
Sarah Vermilyea, MS, RD, CSP, LD, CNSC

Objectives

• Identify the benefit of a comprehensive nutrition assessment as well as ongoing reassessment.
• Describe how nutrition status impacts treatment decisions for a child with feeding struggles.
• Implement evidence-based nutrition interventions

Where does nutrition fit in?
Why does nutrition matter with feeding difficulties?
Not getting enough calories, protein, or micronutrients such as vitamin C, vitamin B12, iron, zinc, etc. can result in problems such as:

- Decreased appetite
- Weakness
- Fatigue
- Irritability
- Difficulty concentrating
- Insomnia
- Mouth pain
- Constipation
- Inability to progress beyond feeding problems
- Hallucinations
- Weakened immune system
- Growth failure
- Short adult height
- In extreme circumstances, irreversible nerve damage, vision problems, and decreased intellectual ability can result

Not getting enough calories, protein, or micronutrients such as vitamin C, vitamin B12, iron, zinc, etc. can result in problems such as:

What is dietitian’s role in feeding?

- Assess
- Intervene if needed
- Support

Assess Nutrition Status

### Nourished
- Goal weight
- Goal height
- Goal fluid/hydration
- Goal micronutrients
- Good appetite
- Adequate age-appropriate physical strength
- Maximum development potential

### Undernourished
- Underweight
- Slunted height
- Inadequate fluid intake
- Physical signs of micronutrient deficiency
- Suspicion for micronutrient deficiency based on history of food/fluid intake
Physical Assessment

- “Sunken” eyes
- Indented temples
- Prominent clavicle
- Rib cage wider than stomach
- See each rib on back
- Hanging skin folds
- Unexpectedly short for age
Physical Assessment

• Nails (finger or toes): abnormalities in shape, color, lack of color, lack of ‘crescent moons’ at base
• Hair: texture, color, integrity, length, loss
• Skin: color (pale, red, blue, yellow, darker, lighter), spots, small bumps, rashes, bruises, wounds, moisture
• Eyes: color, moisture
• Mouth: bleeding, open sores inside or around lips, cracks around outside of corner of lips, pain/redness/enlarged tongue,

Why does nutrition matter with feeding difficulties?
Not getting enough calories, protein, or micronutrients such as vitamin C, vitamin B12, iron, zinc, etc. can result in problems such as:
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I think I found…

• If you recognize signs that might indicate a nutrition deficit, assist the person in accessing the following assistance:
  - primary care physician for rule out of non-nutritive causes
  - dietitian for assessment and intervention of nutrient imbalance
<table>
<thead>
<tr>
<th>Possible Dietitian-Led Interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Calories</strong></td>
</tr>
<tr>
<td>– Education</td>
</tr>
<tr>
<td>– Ensure all food items are full calorie</td>
</tr>
<tr>
<td>– Add high calorie additives to foods the child will already eat</td>
</tr>
<tr>
<td>– Consider more intensive methods if undernutrition is severe and intractable to other interventions</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Possible Dietitian-Led Interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Protein</strong></td>
</tr>
<tr>
<td>– Education</td>
</tr>
<tr>
<td>– If there is a high protein food the child will already eat, offer that item more frequently</td>
</tr>
<tr>
<td><strong>Fluid</strong></td>
</tr>
<tr>
<td>– Education</td>
</tr>
<tr>
<td>– Adjust volume, flushes, and/or schedule</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Possible Dietitian-Led Interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Micronutrients</strong></td>
</tr>
<tr>
<td>– Education</td>
</tr>
<tr>
<td>– Increase offerings of foods high in the deficient nutrients</td>
</tr>
<tr>
<td>– Attempt supplementation if within the child’s tolerance</td>
</tr>
<tr>
<td>• Beverages</td>
</tr>
<tr>
<td>• Liquid/pill/crushed nutrient medications</td>
</tr>
</tbody>
</table>
Possible Dietitian-Led Interventions

• Feeding schedule
  – Adjust to maximize oral intake
  – Transition from drip to bolus

• Formula regimen
  – Transition from 1.0 to 1.5 to condense volume of feedings to improve schedule

Support

• Communication with medical and allied health providers
• Communication with family
• Adjustments to plan to meet overall goals

Ongoing

• As the oral intake of a child changes, the dietitian will recommend changing interventions as well. Being open to change, but resistant to moving the plan too fast, is important for success!
• Reassessment by the dietitian and other team members is needed to continue to provide the best plan for each individual
• Frequency of follow-up is typically based on clinical judgment
Post-test question

• True/false: nutrition-based physical assessment can help to identify deficits that if treated can lead to better success with oral feeding therapies

• Answer: True
The Role of Psychologists and Behavior Analysts in Helping to Enhance Feeding Therapy, Parent/Child Feeding Relationships, and Home Feeding Environments

Amy Kenzer, PhD, BCBA-D, Elizabeth Clawson, MS, PhD, LCQ, HSPP
Elizabeth Fischer, PhD
Kay A. Toomey, PhD, Shannon Goldwater, Feeding Matters Board Chair and Founder

Why is it important for a Psychologist/Behaviorist to be part of the feeding treatment team?

Learning Objectives

- Explain the role of psychologists and behavior analysts in feeding therapy and why their inclusion is important to the treatment plan
- Describe strategies that families can implement to make feeding therapy successful at home
- Discuss how the needs, desires and past experiences of parents and children impact feeding relationships, and how the parent/child feeding relationship can be improved
What are some strategies that parents can implement in their homes to help make feeding therapy successful at home/outside of the therapy environment?

What can parents and other professionals consider/do when the parent’s “agenda” (to nurture and feed their child which gets translated into to a focus on volume and calories) is different than the child’s “agenda” (to have a pleasant/enjoyable/ painless experience that is easily/skillfully completed and makes them feel good)?

What can parents/caregivers and other members of the feeding treatment team do if a psychologist and/or behaviorist is not available in their community?
Q & A
Routine to Family Meals

**Step 1** = 5 minute *Warning*

**Step 2** = *Transition Activity* (= hand washing)

**Step 3** = Sit at the table with an empty plate at their spot

**Step 4** = *Family Style Serving*
  - everyone gets a little of EVERY food served at the meal
  - use a “Learning Plate”

**Step 5** = start with what your child can do, then consider Parent intervention if needed, (OR may start with Parent assistance first then allow your child to independently eat/explore)

**Step 6** = *Clean Up* = throw or blow one piece of every food served at that meal into trash or scraps bowl

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**Why do the CLEAN UP?**

- **Reason #1** = helps a child to stay in their chair by giving them a clear concrete cue about when this meal will end
- **Reason #2** = often first time a child will taste or touch a food is when it’s going in the trash
- **Reason #3** = tests whether a child is done eating or not
- **Reason #4** = can provide additional calories
- **Reason #5** = helps speed up a child’s eating

---

**Why match the foods chosen at a meal/snack to the skill your child has currently**

1. If a child needs to consume some volume at a meal, or the meal is structured that a child has to consume some volume at the meal, choosing a “challenging” food is a set-up for a power struggle
   - a. Challenging = from a sensory, oral-motor or preference standpoint
   - b. Hard, raw fruits or vegetables and meat are most difficult oral-motor wise
   - c. Mixed textures and bitter or cooked vegetables are hardest sensory-wise
   - d. For some children, wet/slimy/squishy foods are most challenging

2. When children are stressed at a meal because the task is too hard, their Adrenalin increases and their appetite decreases

3. Children need to feel that they can be and are successful at mealtimes so eating becomes a more enjoyable activity for them
How to tell what your child’s skill level is

1. Ideally, receive an assessment with a Feeding Specialist of where your child’s oral-motor and sensory skills are at currently

2. Make a list of foods your child likes to eat regularly and look for texture similarities. What texture of foods does your child eat readily most often?
   I.E. dry, meltable foods (e.g. puffed Cheetos), hard crunchy (e.g. kettle potato chips), soft cubes (e.g. mandarin oranges), soft chewy (e.g. pancakes), pre-chewed (e.g. chicken nuggets), hard chewy (e.g. licorice), hard-to-chew (e.g. celery), smooth pureed (e.g. yogurt),

3. Review this list for flavors that your child gravitates to (e.g sour, sweet, salty, savory, spicy, bready, tangy etc.)

4. Make a list of fluids your child prefers to drink most frequently. Are there flavor (or texture) similarities?

Ideas for Matching Foods to Your Child’s Skill Level

• Make sure at least one food presented at every meal is a very preferred food to set them up for at least one success at a meal.

• Don’t give your children their hardest-to-manage foods at their worst times of the day. Given them their “easy” foods at their harder times of the day.

• Food is “just food”. There is no such thing as breakfast, lunch, snack or dinner foods. Don’t get caught up in your child having to eat certain categories of food, other than nutrition categories (proteins, starches, fruits, vegetables, fats).

• Identify foods with higher nutrition that are the same textures or flavors that your child is most accepting of
   (e.g. prefers dry, meltable puffed Cheetos => Calbee Snap Pea Crisps; e.g. likes spicy => Boond; e.g. likes licorice-type chewy foods => dried fruits; e.g. likes pureed foods => puree the family’s spaghetti; e.g. likes hard/crunchy foods => dehydrated/freeze dried versions of fruits and vegetables; e.g. likes juice flavors => Vruit or V8 Fusion)

• Make the harder-to-manage foods from a sensory standpoint easier to manage
   (I.E. separate mixed textured foods into separate components; e.g. buy very smooth hummus versus the grittier kind; e.g. make pancakes with pureed cottage cheese; e.g. let them eat dry cereal rather than in milk; e.g. let them eat raw or frozen peas, or frozen blueberries; e.g. use dried meats - jerky or salami)

• Add preferred flavors into less preferred foods
   (e.g add lemon juice or cinnamon sugar onto cooked carrots; e.g. add a ramen noodle spice packette into your meatball recipe; e.g add blue raspberry icee syrup into milk; e.g add coffee/mocha flavoring into oatmeal; e.g. add pizza sauce into a fish dish)

• Change the texture of harder-to-chew foods
   (e.g. chop crunchy carbohydrates with meats; e.g. make cracker sandwiches versus bread sandwiches; e.g. microwaved pepperoni versus cold pepperoni)

• Add easier-to-chew or blander flavored foods for nutrition/calories
   (e.g. hemp seeds; e.g. powdered milk; e.g. use breading on meats/fish; e.g. canola oil or extra, extra virgin olive oil)