IC 14 – An Interdisciplinary Approach to Feeding Problems in Children with CP and other NDD

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Disclosure

We do not have any conflicts of interest or financial relationships with commercial interests relevant to this presentation.

There are no relationships to disclose.

Objectives

1. To review signs/symptoms of GI dysmotility and discuss management strategies.
2. To review oral-motor and sensory issues that contribute to feeding and problems and discuss approaches to therapy.
3. To review commonly used evidence-based behavioral techniques that can be applied to feeding problems in this population.
4. To describe a combined oral-motor and behavioral approach to treatment of feeding problems.
Feeding Problems are Common

- 25-40% of infants experience some difficulties with feeding
- Up to 80% of children with developmental disabilities have feeding problems
- Feeding problems include picky eaters, difficult mealtime behaviors (refusal and tantrums), delayed feeding skills, dysphagia


Prevalence of Feeding Problems in Children

- Prevalence among toddlers:
  - Not consistently hungry at mealtimes: 52%
  - End meals after a brief session: 42%
  - Picky eaters: 35%
  - Food selectivity: 33%

- Severe feeding problems are noted:
  - Children: 3-10%
  - Children with physical disabilities: 26-90%
  - Children with medical illness/prematurity: 10-49%

J Pediatr 1996;129:877-82
Arch Dis Child 1985;70:364-8

Defining a Pediatric Feeding Disorder

A child has a feeding disorder when he/she has significant difficulty consuming adequate nutrition by mouth.

- Feeding disorders are a heterogeneous group of disorders due to multiple factors including medical, developmental, psychosocial factors and environmental factors, often leading to maladaptive feeding/eating behaviors.

- Measures of severity might include:
  - Poor weight gain/height failure to thrive
  - Inadequate intake by mouth (tube fed or at risk for malnutrition
  - Severely limited variety of foods consumed (nutritional deficiency or at risk
  - Disruption to child/parent/family life (tantrums, excessive meal duration, etc.)
  - Significant difficulty advancing to normal (or developmentally appropriate) solid food textures

- We do not include children who eat non-food items (pica) or children with obesity/hyperphagia.
- Not to be confused with eating disorders, i.e. anorexia nervosa and bulimia.
Presentation of Feeding Disorders

- Underweight or malnourished
- Inappropriate mealtime behaviors
- Excessive meal duration
- Food refusal
- Food selectivity (restricted diet)
- Inadequate self-feeding
- Vomiting
- Gagging, choking, or coughing with feeds
- Respiratory problems due to aspiration


Classification of Underlying Mechanisms

- Behavioral issues 85%
- Neurologic conditions 73%
- Structural abnormalities 57%
- Cardiorespiratory problems 7%
- Metabolic dysfunction 5%

Inter-rater reliability for this classification was 88%


Underlying Factors

- Developmental Delays
  - Delayed feeding skills can be seen with other delays - consider whether feeding skills are commensurate with other abilities.
  - Can be associated with prematurity, birth defects, genetic syndromes, brain injury, etc.
  - Feeding problems common in Autism Spectrum Disorders and other NDD. Contributing factors include:
    - Hypersensitivity / hyposensitivity, oral aversion/defensiveness
    - Selectivity
    - Maladaptive behavior
- Dysphagia (difficulty swallowing)
  - Due to Cerebral Palsy or other neurological disorders (e.g. disorders affecting brainstem or cranial nerves, myopathies)
  - Can be seen in some children with central hypotonia and NDD.
Underlying Medical Factors

- **Structural Abnormalities**
  - Malocclusion, macroglossia, tracheo-esophageal fistula, esophageal atresia, intestinal atresias strictures, etc.
- **GI Motility Disorders**
  - Gastroesophageal reflux disease, impaired gastric emptying, functional constipation.
- **GI Diseases**
  - Reflux esophagitis, eosinophilic esophagitis, food allergy or intolerance, celiac disease, inflammatory bowel disease, cyclic vomiting syndrome

Hyman et al. Gastroenterology 2006; 130:1519-1526

Underlying Medical Factors

- **Other medical conditions**
  - Especially severe conditions in early life that limit ability to eat by mouth
  - Congenital heart disease, chronic lung disease, cancer/tumors, metabolic disorders
- **Other medical factors**
  - Prolonged illness / hospital stays (ICU)
  - Multiple medical procedures around face and mouth
  - Side effects of medications


Examples of Underlying Conditions of Children We Have Seen

- Complications of extreme prematurity (<28 wks)
- Congenital heart disease
- Diabetes insipidus (nephrogenic & central)
- Down Syndrome
- CHARGE Syndrome
- Williams Syndrome
- Noonan Syndrome
- Glycogen Storage Disease
- Hyperinsulinemia
- Mitochondrial disorders
- Birth defects
- Cerebral palsy
- Lots of autism spectrum disorders
- Other complex developmental disabilities
- Food allergies
- Eosinophilic esophagitis

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Other Factors Underlying Pediatric Feeding Disorders

- **Psychosocial Factors**
  - Limited family resources, parental conflict, divorce/separation, parental depression, incompetent parenting
  - Child may have phobias, anxiety, depression
- **Environmental Factors**
  - Setting in which child is fed, overstimulation or distractions, seating
- **Behavioral Factors**
  - All of the previously discussed influences can lead to maladaptive behaviors that affect feeding

Consequences of Pediatric Feeding Disorders

- Failure to thrive / poor growth
- Increased susceptibility to infection / illness
- Dehydration
- Less than optimal cognitive development
- Dependence on tube feeds
- Negative parent-child interactions in other areas
- Social impact on the child and family
- Economic impact

Pediatric Feeding Disorders: The Team Approach

- Most children have a behavioral component to their feeding problem, regardless of concurrent medical factors
- Pediatric feeding problems are biopsychosocial conditions in which biological and behavioral factors interact, and both need to be addressed to optimize feeding.
Pediatric Feeding Disorders: A Biopsychosocial Model

Child → Structural/Anatomical Abnormalities → Medical Issues

Medical Issues → Pediatric Feeding Disorder → Environmental Variables

Pediatric Feeding Disorders Program: The Interdisciplinary Team

- Medicine
  - Pediatrician & pediatric nurse practitioners
  - Nursing
- Nutrition
- Occupational Therapy
- Speech-Language Pathology
- Behavioral Psychology
- Social Work

Pediatric Feeding Disorders Program at Kennedy Krieger Institute

- Feeding Disorders Clinic
  - Interdisciplinary evaluation
  - Initial evaluation and follow-up visits
- Outpatient Treatment
  - Outpatient Behavioral Psychology
  - Outpatient OT and/or SLP
- Intensive Feeding Therapy Program
  - Day Treatment
  - Inpatient Treatment
Feeding Disorders Clinic

- Pediatrics (PNPs and MD)
- Peds GI
- Nutrition
- SLP (Tuesdays)
- OT (Thursdays)
- BP (specializing in feeding)

Medical Evaluation

- History
- Exam
- Observation
- Medical Testing as Indicated
  - Bloodwork to assess for effects of chronic disease or malnutrition
  - Allergy testing
  - Abdominal X-ray, Upper GI series, MBS
  - Endoscopy/Colonoscopy
  - pH/Impedance probe study
  - Motility tests

Nutritional Considerations

The ABC's

- Anthropometric Data
- Biochemical Data
- Clinical History
- Dietary History
- Eating habits
Meal Observation

• Done by OT/SLP and BP
• Sometimes others
• Fed by parent/guardian
• Many variables

Types of Recommendations in FDC

• Nutritional supplements & calorie boosters
  – Multivitamin
  – Calorie boosters: wheat germ, powdered milk, cheese, peanut butter, butter or oil
  – Formula
• Modifying schedule, portion sizes
• Modifying textures (often lower than given by parents)
• Presentation of food, i.e. spoon, cup, etc.
• Seating
• Simple behavioral strategies
  – Time limit to meals

Referral from FDC

• Additional medical evaluation
• Further clinical evaluation of feeding as outpatient (usually OT or SLP)
• Modified barium swallow study
• Outpatient BP
• Outpatient OT/SLP
• Combined BP and Oral-Motor
• Intensive treatment (Day or Inpatient)
Pediatric Feeding Disorders: Intensive Feeding Therapy Program

- Interdisciplinary feeding team
- Patients typically 2 to 12 years old
- About 10 kids in the program at a time
- Approximately 50 staff
- Typical length of program is ~ 6-8 weeks
- Treatment
  - 3 meals a day with behavioral feeding therapist
  - 3 to 4 sessions per week with OT and SLP to work on oral-motor and other skills
  - Monitoring by Medicine and Nutrition

Interdisciplinary Assessment

- Medical conditions
- Development
- Nutritional status and needs
- Oral motor skills
- Communication/language
- Appropriate and inappropriate mealtime behaviors
- Psychosocial assessment

Role of Nutritionist

Assist team and family in providing:
- Adequate kcalories to promote growth at expected rates and achieve IBW range (10-85th% for age)
- A varied, balanced diet to meet nutrient needs or prescribe appropriate supplements
- Adequate fluid to maintain hydration
- Feeding schedule and formula to optimize tolerance and intake
- Meeting special dietary needs, e.g. metabolic disorders, food allergies
- Education about portion sizes, meal planning, etc
Role of the Oral-Motor Specialist (OT and SLP)

- Assess oral-motor function and feeding skills
  - Assess child’s safety for eating and drinking by mouth
  - Recommend and perform modified barium swallow (MBS) studies
- Make recommendations about feeds to team/caregivers
  - Recommend appropriate liquid and solid texture consistencies
  - Recommend safe bolus size and drink presentation
  - Offer input about oral intake target, based on the child’s oral-motor status
- Recommend therapeutic feeding techniques
- Modify positioning during meals

Role of Speech and Language Pathologist vs Occupational Therapist

- Occupational Therapist:
  - Posture and Adaptive Seating
  - Self-feeding
  - Sensory aspects of Mealtime
  - Adaptive equipment
- Speech and Language Pathologist:
  - Overall communication during mealtime
  - Speech and language therapy
  - Functional communication

Normal Feeding Skill Development
Self Feeding and Oral Motor Skills 4-6 Months

Bottle/Breast
- Bottle or breast
- Efficient suck on bottle
- Spoon Feeding- AAP recommends exclusive breast feeding only to 6 months
- Drive for independence:
  - May begin to hold own bottle

Spoon
- Spoon Food
- Stage 1 baby food
- Thin puree
- Suckle pattern
Self-Feeding and Oral-Motor Skills
6-9 months

**Skills**
- Loses suckle on spoon, some lip closure over spoon emerges
- Sucks on rim of cup-news loss
- Gums food with a vertical pattern

**Texture**
- Spoon Foods:
  - Junior foods
  - Stage 2 and 3 fruits and vegetables (not dinners)
  - Table food blended to a thick puree
  - Evenly lumpy mashed foods

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Self-Feeding and Oral-Motor Skills 6-9 Months

**Skills**
- 6 months: gums baby biscuits/crackers
- 9 months: vertical chew with dissolvables
- Drive for independence:
  - 6 months: holds cracker
  - 9 months: finger feeds dissolvables with a pincer grasp

**Texture**
- 6 months: baby biscuit, frozen bagel
- 9 months: dissolvables and mashed foods
  - Dry cereal
  - Natures Promise Veggie Sticks
  - Gerber dissolvables
  - Cheese puffs

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Self-Feeding and Oral-Motor Skills 9-12 months

**Skills**
- Mixed: Vertical chew, diagonal jaw movements, lateral tongue movements
- Sustained bite on cracker
- More efficient with cup
- Drive for independence:
  - Plays with spoon
  - Begins to hold cup
  - Better voluntary release with finger food

**Textures**
- Spoon foods: junior foods, wet ground
- Soft dry foods that mash: dime size pieces of:
  - Toast
  - Cereal bars
  - Pancakes
  - French toast
- Wet foods that mash:
  - Bananas
  - Sweet and White potatoes
  - Cooked Carrot

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Self-Feeding and Oral-Motor Skills
12-18 months

**Skills**
- Diagonal chewing develops
- Transfers food from midline to sides
- Child is efficient with Sippy cup, inefficient with open cup
- Expands table foods
- Drive for independence: Hand to mouth movements with spoon: not efficient, prefers independent finger feeding

**Textures**
- Spoon food: Fork mashed/evenly lumpy purees
  - Grits
  - Hummus
  - Ground beef mixed with sauce and gravy
- Finger foods: Wet soft foods that require minimal chewing: Dime size pieces of:
  - Soft cold cuts
  - Noodles
  - Cauliflower
  - Peeled thin apples

18-24 Months: Oral-Motor Skills

- Emerging rotary chew
- Inconsistent close mouth chew
- Textures:
  - Spoon: Some soft mixed textures, e.g. casseroles, stew
  - Finger foods: Soft foods that require more complex chewing and limited strength, e.g. chicken nuggets, very soft shredded chicken, bologna, veggies with skin (corn), cubed apples/pears, meat loaf

18-24 months: Self-Feeding

- Independent self-feeding with spoon
- Cognitive ability to understand tool use
- Fine motor ability to scoop
- Persistence in self feeding: Bober, S.J., Humphry, ; Carswell; Core, A.J. (2001)
  - Association with persistence in fine motor play
  - Gross/Fine motor play groups
24-36 months: Oral-Motor Skills

- More frequent closed mouth chew
- Circular rotary chewing
- Transfers food from both sides of the mouth across the midline
- Increase in strength and endurance obtained
- Drive for independence: May use fork
- Cup drinking very efficient with covered cup; increases with open cup

24-36 months

Textures:
- Spoon food: soft mixed textures
  - Avoid mixed textures with tough food (stews, some soups)
- Finger food
  - Soft meats and harder cold cuts
  - Blanched carrots
  - Avoid large tough pieces of meat/veggies that need jaw strength and grinding:
    - Nuts, tough meats, raw carrots, hard candy
  - Avoid large slippery foods that will fit in the airway
    - Unmodified hot dogs, sausages
  - Supervision with some mixed textures:
    - Sandwiches, pizza, hamburgers

Addressing Oral-Motor Problems

- Oral-Motor Problems
  - Jaw Thrust
  - Tongue Thrust
  - Tonic Bite Reflex
  - Poor lip closure

- Tongue Thrust: Put spoon in straight, take it out straight, press down and back on the tongue

- Tonic Bite: Avoid metal or light plastic spoons
Oral-Motor Profiles

**Oral-Motor Deficits:**
- Delayed chewing skills
- Oral defensiveness
- Texture sensitivity
- Jaw weakness
- Weak suck
- Impaired swallowing
- Silent aspiration

**Possible results:**
- Cannot advance texture
- Food refusal
- Food selectivity
- Inadequate intake
- Lung disease

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**Dysphagia**

- Impaired swallowing during any stage
- Due to structural or neurological problems
- Aspiration: Secretions, food or foreign body entering below the true vocal folds vocal folds (Arvedson & Brodsky, 2002)

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**Indicators of Swallowing Disorders and Possible Aspiration**

- Frequent fever/respiratory infections
- Chronic lung disease
- Raspy breath sounds/congestion with oral feeds
- Coughing and choking on foods and liquids
- Tearing, gurgling after eating
- Food refusal or limited intake may be related to a swallowing disorder
- Children may show avoidance of foods or liquids that are difficult for them to swallow
Stages of Swallowing

Postural anticipation of feeding
Oral Preparation Phase: voluntary
Oral Stage: voluntary
Pharyngeal phase: voluntary/non-voluntary
Esophageal Phase: non-voluntary

Aspiration
Modified Barium Swallow Studies

- Determine if MBSS is needed based on medical history and clinical signs of aspiration
- Preparation for the study
  - Practice skills prior to the study to optimize results
  - Work up to volume needed in order to have a valid study
  - Work closely with Behavioral Psychology to promote compliance
- Considerations
  - Posture / positioning
  - Liquid bolus size
  - How are drinks presented, e.g. cup, spoon, straw
  - Fatigue study

Oral Motor/Feeding Therapy Goals

The child will:

- Maintain safety in swallowing as new skills are tested, taking into consideration the developmental sequence for:
  - Higher/mixed textures
  - Liquids by open cup
  - Self-feeding

Oral Motor/Feeding Therapy Goals

- Provide therapeutic opportunities to develop higher level oral-motor skills
- Provide caregiver training to maximize safety and skill development after discharge
Intervention for Swallowing Problems

- Alter texture
- Alter timing/pacing
- Adjust posture
- Improve oral-motor skills / promote chewing
- Alter bolus size
- Make utensil recommendations

Tools to Overcome Skill Deficits

- Infra-Trainer: Helps kids transition to regular cup
- Cut-out Cup: Allows for small amounts of liquid to be presented/supports coordination
- Chewy-tube: Practice chewing and build strength
- Nuk brush: Helps to increase oral-sensory awareness and provides oral stimulation

Promoting Chewing

**Spoon Food**
- Pure
- Junior Foods: Thickened puree
- Wet ground
- Fork Mashed
- Mixed Textures

**Finger Foods**
- Finger food that dissolves
- Dry soft foods
- Wet soft finger food
- Hard finger food
Strategies to Promote Chewing

- Sensory Strategies
  - Decreasing sensitivities (texture fading/crumbs)
  - Visual cues (modeling, mirror, iPad)
  - Increase sensory feedback
    - Texture: gritty textures, crumbs
    - Flavor: strong flavors, spicy foods
- Oral Motor Tools
  - Chewy tubes: easily places food between the molars

To Encourage Early Chewing

Place food in-between the lateral biting surfaces alternating sides

Foods that Encourage Early Chewing

- Foods that dissolve, form a cohesive bolus and offer sensory feedback
  - Cheese curls
  - Dehydrated foods
  - Pirates Booty
  - Baby finger food: puffs, wagon wheels
Promoting Cup Drinking

• Screen for safety
• Modify texture
• Modifying bolus sizes
• Increasing volume
• Backward chaining for self-feeding

Promoting Positive Mealtime Experiences

• Cooking Group
  – Exposes children to the tastes/smells and touch of food
  – Encourages age-appropriate mealtime prep (opening containers, cutting with a knife and fork, pouring, etc.)
  – Promotes social interaction
  – Peer Pressure!
  – Fun: this is important!

Pediatric Feeding Disorders: Why Don’t They Eat?

• Condition aversion
• Lack of experience
• Lack of appetite
• Hypersensitivity
• Reinforcement of inappropriate mealtime behavior
Behavioral Psychology:
Why Take Data?

• Anecdotal reports are subject to bias
• If procedures are not systematic they are often not easy to replicate
• Establish a baseline level to determine progress during treatment (ABAB design)
• Monitor behavior throughout treatment for trends
• Determine if fluctuations are due to behavioral, skill, physiological issues, or a combination

DATA, DATA, and more DATA!

• Rate of Acceptance
• Refusal Behavior
• Negative Vocalizations
• Expels
• Coughs/Gags
• Emesis
• Duration of Session
• Grams Consumed

The A, B, C's of Functional Assessment!

**Antecedent**
What happened just before the behavior occurred?

**Behavior**
Target Behavior—the behavior you are targeting for intervention

**Consequence**
What happened right after the behavior occurred?

One Behavior May Serve More Than One Function for the Same Individual

More Than One Behavior May Serve the Same Function for the Same Individual

Primary Outcomes of a Functional Assessment!

- A clear description of the problem behavior, including classes or sequences of behavior that occur together
- Identification of the events, times, and situations that predict when the problem behaviors will and will not occur
- Identification of the consequences that maintain the problem behaviors
- Development of summary statements or hypotheses that describe specific behaviors, the situation in which they occur, and the outcomes or reinforcers maintaining them in that situation
- Collection of direct observation data that support the summary statements that have been developed.
Three Strategies for Collecting FA Information

- **Informant Methods**: Talk to the individual and those who know the individual best.
- **Direct Observation**: Observe the person in natural conditions over an extended period of time.
- **Functional Analysis Manipulations**: Systematically manipulate potential controlling variables (consequence or structural variables) in analog or natural conditions and observe effects on person’s behavior.

Goals of Behavioral Psychology

- Improve acceptance of food.
- Decrease problematic mealtime behavior.
- Increase volume and texture.
- Maximize potential and enhance skill development.
- Training and support for parents and caregivers.

Behavioral Treatment: Antecedent Procedures

- Texture/Bite fading:
  - Bite Board, Response Effort.
- Modeling.
- Self-monitoring.
- Bite Rate/Pacing.

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Behavioral Treatment: Antecedent Procedures

• Bite or bolus placement (Girolami, Boscoe, & Roscoe, 2007)
• NUK
• Flipped spoon
• Finger Prompt

Fading Procedure

• Probed new food first
• Started with one preferred food—yogurt
• Mixed novel foods with preferred foods

<table>
<thead>
<tr>
<th>Ratio</th>
<th>50-50</th>
<th>75-25</th>
<th>100% new food</th>
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• Set criteria at 70% acc and CI under .5 per trial to move onto next ratio
• At the end of the admission, we probed new foods without fading

Behavioral Treatment: Consequence-based Procedures

• Non-removal of spoon (Escape Extinction/Prevention) (Ahearn et al., 1996)
• Physical guidance
• Reinforcement
• Re-presentation
• “Chasers”
• Response Cost