Helping Children with Autism and Restrictive Eating: An Interdisciplinary Approach to Improving Mealtimes

The Pediatric Feeding Program at Seattle Children’s Hospital
Danielle N. Dolezal Ph.D., BCBA-D, Cara Pierson, ARNP, Caryn Deskines CCC-SLP, and Barb York, MS, CD, RD
Common Problems in PFD’s
Field et al., 2003

Symptoms
• Total food refusal
• Food refusal by type
• Food refusal by texture
• Food refusal following small intake
• Difficulty transitioning to self-feeding
• Oral motor problems
  • Chewing, tongue movements, lip closure, etc
• Dysphagia
  • Difficulties swallowing/aspiration VFSS
• Sensory sensitivities
• Rigidity/anxiety

Food refusal looks like:
• Turning head, pushing food away, covering mouth
• Expelling food
• Packing food
• Gagging, coughing and vomiting
• Crying at meals
• Challenging behavior

Outcomes
• Chronic poor growth
• Compromised nutritional status or malnourishment
• Invasive medical procedures
• Tube/Liquid dependence
• Increased family stress
• Anxiety and learned behavioral challenges
• At-risk for poor outcomes due to variability in provider access, coordination and approaches
• Disrupted Hunger/Satiety
• Loss of developmental opportunities with feeding
Feeding Disorders and ASD

• Prevalence of feeding problems is estimated to be as high as 89% in children with ASD
  • Cermak et al 2010; Ledford & Gast, 2006; Matson & Fodstad 2009 for reviews

• Feeding problems are more common in children with ASD versus typically developing children (Schreck et al 2004)
  – Refused more food
  – Required more specific utensils to eat
  – Required food presented in specific ways
  – More likely to consume lower textured foods
  – Eat a narrower range of foods
**Multifactorial Influences to Feeding Disorders**

- Sensory processing differences (under and/or over Reactive)
- **Hunger/Satiety**
  - Inadequate nutrition
  - Supertasters
  - Sleep disruption
  - Anatomical differences
  - Stress (fight or flight)
- **Gastroenterology**
- **Food Allergy**
- **Obesity**
- **Prematurity**
- **Pulmonary**
- **Cardiac**
- **Poor growth**
- **Dysphagia**
- **Genetic syndromes**
- **Tube dependence**
- **Vomiting**

- **Physiologic**
- Dysfunctional swallow
- Delays in motor planning
- Delays in chewing
- Delays in coordination of gross and fine motor
- Limited practice at appropriate skill level

- **Psychological**
- Cognitive inflexibility/Rigidity
- **Fear and anxiety**
  - Learned avoidance through challenging behavior
  - Avoidance leads to lack of experience with eating
  - Parent and child stress
  - Lack of positive reinforcement
  - Punishment
  - Lack of independence

- **Oral-Motor**
- Gross-Motor
- Fine-Motor

- **Medical**

- **Psychologic**

- **Oral-Motor**
  - Dysfunctional swallow
  - Delays in motor planning
  - Delays in chewing
  - Delays in coordination of gross and fine motor
  - Limited practice at appropriate skill level

- **Physiologic**

- **Psychological**

- **Oral-Motor**

- **Medical**

**Often what sets the occasion for feeding difficulties is not what maintains the difficulty overtime**

Dolezal et al., 2016
The Pediatric Feeding Program at the Autism Center
Our Continuum of Care

The Pediatric Feeding Program

Intake Clinic (2 visits)
- ARNP/MD
- Ph.D., BCBA-D
- Dietitian
- SLP
- Ph.D.
- Follow Interns
- M.A. & BCBA
- BCaBA

Outpatient Therapy
- Clinic
- Co-treats
- Telehealth
- Rounds

Intensive Outpatient
- 2 week; 4 hrs daily
- Full Team
- Follow-up
- Rounds
- Goals
- Data driven

Consult
- Hospital

Parent Support and Education Groups
- Parent-to-Parent Partners
Medical Considerations
Head to Toe Screening and Evaluation
Pre-Treatment Medical Screening

- Hearing or vision impairment
- ADHD, anxiety, autism, speech delays, etc.
- Mouth problems (malocclusion, cleft palate, tongue-tie, cavities)
- Swallowing difficulty (dysphagia)
- Gastroesophageal reflux
- Cardiac or pulmonary issues
- Obstructions (cystic fibrosis, gallstones)
- Constipation

- Celiac or inflammatory bowel disease
- Allergies or intolerances
- Seizures
- Fine/gross motor dysfunction
- History of prematurity
- Surgical history
- Nutritional deficiencies
- Obesity or malnutrition
- Acute illness

Reference: Childhood Feeding Disorders (Kedesdy and Budd, 1998)
• Constipation is VERY common among our patient population.

• Signs and Symptoms: infrequent bowel movements, hard stools, large stools, straining with bowel movements, abdominal pain (can be severe), retentive posturing, encopresis (stool leakage), decreased appetite.

• Home Treatment: behavioral changes, dietary changes, PRN treatment with pear juice, apple sauce, prunes, or OTC laxatives.

• When home care isn’t enough: More aggressive treatment (which may include a “cleanout” phase) may be necessary.

Reference: Current Diagnosis & Treatment: Pediatrics, 20th ed. (Hay et al., 2011)
Medical Evaluation Goal: To maximize overall health and set the child up for a safe and successful feeding treatment.
Nutrition Considerations
Nutrient Intake
Hunger Regulation

Barb York, MS, RD, CD
Hunger and Satiety Regulation --
A Foundation for Larger Intervention Goals

• Interest in eating
• Focus on eating
• Engaged in feeding session
• Consistent intake (balance and quantity)
• Flexibility
• Interest in new foods (variety)
• GI function
• Tolerance of G-tube feedings
**Initial Hunger/Satiety Regulation Goal:**
Focus on Preferred Foods

<table>
<thead>
<tr>
<th>Preferred Foods</th>
<th>Moderately Preferred Foods</th>
<th>Novel Foods</th>
</tr>
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<tbody>
<tr>
<td>Potato Chips</td>
<td>Yogurt 2x per week</td>
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<tr>
<td>Goldfish</td>
<td>Applesauce</td>
<td></td>
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<tr>
<td>Pizza 3x per week</td>
<td>Carrots</td>
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<tr>
<td>Chocolate Milk</td>
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</table>
Presentation: Cater or Consider

Plate is served

I don’t like that

What do you like?

What do you want?

Apples

Not sliced like that!

Do you want apples or green beans

I don’t want fruit or veggies

If it’s hard for you to choose, I’ll choose for you
Our Continuum of Care

The Pediatric Feeding Program

Intake Clinic (2 visits) - ARNP/MD, Ph.D., BCBA-D, Fellow/Interns, M.A. & BCBA, BCaBA

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Consult - Hospital

Parent Support and Education Groups - Parent-to-Parent Partners
Education- Motivational Interviewing

- Feeding Relationships
- Eating patterns, hunger and satiety
- Food selection
- Target foods, behaviors
- Parenting skills, vocabulary
- Reading and responding to hunger
- Highly collaborative intervention process!!
What do Occupational Therapy (OT) and Speech-Language Pathology (SLP) Contribute?
Primary Factors Considered in Evaluation

• Swallowing Function/Aspiration Risk
• Oral-Motor Feeding Skills
• Sensory Awareness
• Gross and Fine Motor Skills
• Positioning and Environmental Factors

• OT and SLP can both address oral feeding. Each has different areas of focus/expertise.
  • OT often addresses gross and fine motor skills for self-feeding, equipment needs to maximize positioning, and sensory processing.
  • SLP tends to specialize in evaluation of swallowing, and may also address cognitive, speech, language, and social communication skills.
The Driving Questions:

• How do we help progress this child’s oral feeding in a way that is safe?

• What are the specific factors for this particular child that we will target in therapy and as a part of the team that will improve this child’s overall progress with eating/drinking?
Swallowing Function/Aspiration Risk

- Two types of Swallowing Evaluation
  - VFSS
    - Radiographic picture of swallowing
    - Must be able to sit in radiology booth
    - Must consume barium
  - Clinical Swallowing Evaluation
    - Evaluates for clinical signs/symptoms of aspiration
    - Can use real food/drink in a less threatening environment
    - Cannot rule out silent aspiration
    - Can also evaluate oral-motor feeding
Oral-Motor Skills

• Teeth, tongue, palate, lips, jaw, cheeks: Strength, range of motion, planning, and coordination? Are they symmetrical in form and movement?
• Ability to move bolus in an organized fashion to back of mouth to initiate swallow
• Lip seal, suck, liquid management within mouth, spoon clearance
• Stages of development of ability to move food bolus around within mouth (mashing, anterior-posterior tongue pump, lateralization, rotary chew)
Sensory Processing/Integration

• Sensory awareness and response to food/drink in the mouth
  
  • Hypo-sensitive (under-reactive): Child may stuff mouth with food in order to feel the food (over-stuffing/pocketing). May then hold food in mouth and cheeks and not swallow, or gag/vomit upon attempting to swallow.
  
  • Hyper-sensitive (over-reactive): Child may find common smells, tastes, textures, sounds, movements highly aversive. Gagging is a common response to this. As a result, may accept only a very restricted range of foods in order to avoid particular smells, tastes, or textures.

• OT may complete further evaluation of Sensory Processing using: parent report, clinical observations of mealtime and playtime, review of child’s food diary and accepted foods list, and the Sensory Profile questionnaire
Gross and Fine Motor Skills

Fine Motor Skills
• Pincer grasp for picking up small items
• Force gradation
• Utensil grip (power grip)
• Other hand skills: Rotation for opening containers, pronation/supination for positioning spoon correctly to get food to mouth, ability to bring cup to mouth.

Gross Motor Skills
• Posture, foot support, seating support
• Proximal stability (core strength) needed for distal mobility (arms and hands) and oral-motor ability
Psychological and Behavioral Considerations

Danielle Dolezal, Ph.D., BCBA-D
Clinical Supervisor of the Pediatric Feeding Program
Why Refuse to Eat?

- A child learned it was hurt or uncomfortable
  - Aversive conditioning and biologic complications
    - Food Allergies, Pain, difficulties integrating multisensory information, GERD, swallowing delay, constipation, child is NOT HUNGRY, Supertasters,
- A child feels like what you are asking is too hard
  - Response Effort and Skill Deficits (Chewing/volume/bite size)
- A child is scared even though they have the abilities
  - Anxiety/Phobia related to swallowing (choking episode)
  - Adults sneaking bites of new foods in thus refuse anything novel
  - A child vomited when tried something new
- A child has strong preferences for their favorites
  - Food jags, patterns of restricted interests, rigidity
- All lead to patterns of learning that don’t support feeding goals
  - A child developed avoidant behavior to gain access to favorite foods or escape eating all together (patterns of reinforcement)

Dolezal et al., 2015
What Maintains Anxiety?

removal from or avoidance of the feared situation

Anxiety

Time

Reinforced anxiety at its peak

Reinforced when anxiety is low
Variety of Approaches

- **Applied Behavior Analysis Methodology & Interventions**
  - Use of behavioral principles to improve mealtime and outside of mealtime behavior while also measuring child/parent change in response to these interventions
    - Interventions utilized include: positive reinforcement procedures, shaping, fading, and antecedent-based interventions (visual schedules, alterations in effort/quality of food types, bite size, utensil, choice, etc)

- **Cognitive Behavioral Therapy (CBT) Programs:**
  - For Child: *Facing Your Fears* and Exposure work
  - For Parents: *Optimistic Parenting* and Parenting Groups/Partners

- **Biobehavioral Interventions Combined with ABA**
  - **Hunger Regulation** to increase motivation and intrinsic positive reinforcement for eating coupled with ABA, sensory, and skill-based treatments. These might include systematic alterations in g-tube feeds or high-calorie beverage.
  - **Skill and Sensory-Based** to increase motivation and skills to be successful with eating targeting parent/child goals while also reducing a child’s desire to escape or avoid mealtimes coupled with ABA and other nutritional intervention.

Dolezal et al., 2015
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- Consult
  - Hospital

- Parent Support and Education Groups
  - Parent-to-Parent Partners
Intensive Outpatient Program

- Biopsychosocial Model
- Parents implement all assessment and treatment
- 2-3 weeks, M-F, 4-7 hours daily
- Interdisciplinary team involved throughout
- Goal setting and data-based evaluation and monitoring
- Family Satisfaction Measures

Dolezal et al., 2015
# The PFP Intensive Outpatient: Feeding Subtype

<table>
<thead>
<tr>
<th>Subtype of Feeding Difficulty</th>
<th>%</th>
<th>n</th>
</tr>
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<tbody>
<tr>
<td>Total Food Refusal</td>
<td>44%</td>
<td>11</td>
</tr>
<tr>
<td>90% g-tube or bottle dependence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Selectivity by Type</td>
<td>40%</td>
<td>10</td>
</tr>
<tr>
<td>Selectivity by Type and Texture</td>
<td>16%</td>
<td>4</td>
</tr>
<tr>
<td>G-tube Dependence</td>
<td>52%</td>
<td>13</td>
</tr>
<tr>
<td>Liquid Dependent</td>
<td>12%</td>
<td>3</td>
</tr>
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Dolezal et al., 2015

[Seattle Children's Hospital Research Foundation](https://www.seattlechildrens.org)
The PFP Intensive Outpatient: Medical and Developmental Concerns

<table>
<thead>
<tr>
<th>Medical and Developmental Concerns</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism</td>
<td>52%</td>
<td>13</td>
</tr>
<tr>
<td>Developmental Disability</td>
<td>68%</td>
<td>17</td>
</tr>
<tr>
<td>Genetic Syndrome</td>
<td>16%</td>
<td>5</td>
</tr>
<tr>
<td>Prematurity with NICU stay</td>
<td>40%</td>
<td>10</td>
</tr>
<tr>
<td>GERD</td>
<td>60%</td>
<td>15</td>
</tr>
<tr>
<td>Chronic Constipation</td>
<td>88%</td>
<td>22</td>
</tr>
<tr>
<td>Pulmonary disorder/dysfunction</td>
<td>48%</td>
<td>12</td>
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<tr>
<td>Food Allergy</td>
<td>32%</td>
<td>8</td>
</tr>
<tr>
<td>Cardiac Impairment</td>
<td>24%</td>
<td>6</td>
</tr>
<tr>
<td>Tube use prior to 1 year of age</td>
<td>81%</td>
<td>13</td>
</tr>
<tr>
<td>Disruptive Behavior Disorder</td>
<td>60%</td>
<td>15</td>
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</tbody>
</table>

Dolezal et al., 2015
# The PFP Intensive Outpatient: Behavioral Outcomes

<table>
<thead>
<tr>
<th>Type of Goal</th>
<th>Average at Baseline</th>
<th>Average at Discharge</th>
<th>Range at Discharge</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Food Refusal</strong> <em>(n=25)</em></td>
<td>73.5%</td>
<td>6.26%</td>
<td>(0-21%)</td>
</tr>
<tr>
<td><strong>Variety</strong> <em>(n=21)</em></td>
<td>5.76</td>
<td>26.88</td>
<td>(4-62)*</td>
</tr>
<tr>
<td><strong>Texture</strong> <em>(n=10)</em></td>
<td>40% 20% 40%</td>
<td>Puree to Junior Puree to Fork Mash Puree to Chopped Fine</td>
<td></td>
</tr>
<tr>
<td><strong>Goals Set</strong> <em>(n=25)</em></td>
<td>10.52</td>
<td>10.32</td>
<td>98% of goals achieved</td>
</tr>
<tr>
<td><strong>G-tube</strong> <em>(n=13)</em></td>
<td>90% of kcal</td>
<td>9.6% kcal</td>
<td></td>
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Dolezal et al., 2015
Conclusions

- Etiology of feeding disorders is complex and the initial factors that set the occasion for the difficulty don’t often explain its maintenance (e.g., GERD and respondent conditioning)
- Work with your team to isolate the functional factors for continued feeding difficulties to prioritize treatment
- Be systematic; ask questions, take data, one change at a time
- AutismPFP@seattlechildrens.org
Hope. Care. Cure.™