A Community Approach to Avoidant/Restrictive Food Intake Disorder

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Objectives

• Understand diagnostic criteria for ARFID
• Considerations for the community RD's care for kids with ARFID
  • What are the red flags?
  • When to suggest a referral for therapy or medical work up?
  • What is my role?
• Review of case studies
Diagnostic and Statistical Manual of Mental Disorders

- Published by American psychiatric association
- Gives common language and diagnostic criteria
- DSM-5 published in 2013
  - ARFID was defined and added for the first time.
DSM IV: Feeding disorder of infancy or early childhood

• Feeding disturbance manifested by persistent failure to eat adequately with significant failure to gain weight or significant loss of weight over 1 month

• The disturbance is not due to an associated gastrointestinal or other general medical condition

• The disturbance is not better accounted for by another mental disorder or lack of available food

• Onset < 6 years of age
DSM-V Avoidant/Restrictive Food Intake Disorder

• Eating/feeding disturbance as manifested by persistent failure to meet appropriate nutritional needs associated with one (or more) of the following:
  - Weight loss or unmet growth expectations
  - Nutritional deficiency
  - Dependence on nutritional supplements
  - Marked interference with psychosocial functioning

• Exclusionary criteria:
  - Not related to food scarcity or culturally sanctioned practice
  - Not related to body image or weight concerns
  - Not better explained by concurrent medical condition or another mental disorder
Pediatric Feeding Disorder (PFD)

A disturbance in oral intake of nutrients, inappropriate for age, >2 weeks + associated with 1 or more of the following:

1. Medical Dysfunction
   • Cardiorespiratory problems, aspiration sequelae, GI process

2. Nutritional dysfunction
   • Malnutrition, specific nutrient deficiency, reliance on nutritional supplements
Pediatric Feeding Disorder

3. Feeding skill dysfunction
   • Need for texture modification, modified feeding position or equipment, modified feeding strategies

4. Psychosocial dysfunction
   • Active or passive avoidance by child, inappropriate caregiver management, disrupted caregiver-child relationship

Absence of cognitive process consistent with eating disorders and oral intake is not due to lack of food or associated with cultural norms
Pediatric Feeding Disorder

• Used framework of the World Health Organization International Classification of Functioning, Disability and Health
  
  Acknowledges that this is more than a disease state, it is a disability impacting various aspects of life

• Unifies medical, nutritional, feeding skill and/or psychosocial concerns associated with feeding disorder
## ARFID vs PFD

<table>
<thead>
<tr>
<th></th>
<th>ARFID</th>
<th>PFD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disordered eating</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Avoids/restricts food</td>
<td>Yes</td>
<td>Possible</td>
</tr>
<tr>
<td>Poor appetite</td>
<td>Common</td>
<td>Possible</td>
</tr>
<tr>
<td>Malnutrition</td>
<td>Common</td>
<td>Possible</td>
</tr>
<tr>
<td>Traumatic or chronic experience</td>
<td>Possible</td>
<td>Possible</td>
</tr>
<tr>
<td>Comorbid anxiety or other MH disorder</td>
<td>Common</td>
<td>Possible</td>
</tr>
<tr>
<td>Frame as a disability</td>
<td>No</td>
<td>Yes</td>
</tr>
</tbody>
</table>
How does this happen?

• Medical problems, dysfunctional feeding relationship or other interruption promote conditioned food aversion
  Eating is associated with pain, nausea, fatigue, worry

• Once medical condition improves- aversion may not;
  Infants and children will have persistent disruptive mealtime behaviors trying to avoid contact with food.
How does this happen?

- Problem persist due to negative reinforcement
  - Parents remove feeding demand and end meal early
  - Behaviors shaped and strengthened over time

- Limited exposure $\rightarrow$ decreased sensory variability$\rightarrow$ developmental, physiological, social processes $\rightarrow$ more stress

$\rightarrow$ Ultimately, child needs major intervention or ongoing artificial support
Before ARFID is Diagnosed Consider:

Medical conditions:
- GI: Atopic history and risk for food allergy, GERD, EoE, Celiac Disease, IBD
- Cardiac: fatigue with feeds
- Genetic condition: delay in skills and other milestone. Often dysmorphic features
- Mental Health Condition

Skill based deficits:
- Choking, gagging, color changes with feeds, inability to handle own secretions
- Oral structures, tongue tie, dental alignment and health
- SLP and OT can help
- A modified barium swallow study may or may not be warranted.
Parental concern, aberrant feeding behavior, or inappropriate feeding

History
Systems review
Anthropometrics
Physical examination

Organic red flags
Behavioral red flags

Investigations as needed

Child
Limited Appetite
Misperceived
Energetic
Apathetic
Organic
Structural
Gastrointestinal
Cardiorespiratory
Neural
Metabolic
Selective Intake
Misperceived
Misperceived
Neophobia
Mildly selective
Highly selective
Autism
Organic
Delayed development
Dysphagia
Fear of Feeding
Misperceived pain
Colic
Infant pattern
Older child (choking)
Organic
Causes of pain
Esophagitis
Disordered motility
Visceral hyperalgesia
Feeding Styles
Responsive
Controlling
Indulgent
Neglectful
Feeder
Tube feeding
Approach:

The ARFID diagnosis is comes from the psychology and mental health arena

Pediatric Feeding Disorder is rooted in the medical and developmental realms

Even before medical work up is complete, behavioral and/or feeding therapy is recommended
  Beneficial whether or not ARIFD is ultimately diagnosed

Consider the impact of parenting and feeding styles
Management

• Priority is safe eating, proper nutrition, manageable behaviors

• No standard treatment for ARFID. Approach depends on setting/resources
  • Medical: labs, disease screening management. Possible appetite stimulation
  • RD: Supplements as able, may consider nutritional supplements and even tube feeding if weight has dropped.
  • OT/SLP: Assess structures and skill. Then work on behavior, interactions, sensroy properties.
  • PsyD: recognize and treat common co-morbid mental health conditions like anxiety or depression. Behavior modification and parent/child interaction

• Support/reinforce recommendation of mental health specialists and feeding therapists
Solving the Behavioral Mystery

...and Helping Skills to Build
Who is vulnerable?

• Flavor preferences are partly genetic.
• “Supertasters” can be born with a high concentration of taste buds on the tongue and may be more prone to disliking bitter foods (e.g. vegetables).
• There may have been an evolutionary advantage to food preferences. Foods like fruits, vegetables, and meats were more likely to be poisonous to our ancestors.

Plus...

• Eating the same foods all the time makes new foods taste more unusual.
• Certain nutrition deficiencies can change the way foods tastes.
• Opportunities to learn about new foods is limited, if it’s hard to eat around others.

A Differential Diagnosis Decision Tree
Picky Eating, PFD, or ARFID?

“When the eating disturbance occurs in the context of another (medical or mental) condition or disorder, the severity of the eating disturbance exceeds that routinely associated with the condition or disorder”

― Sensory Sensitivities
― Lack of Appetite
Important Questions That Give Us Behavioral Clues

1) How would you describe what happens during mealtimes?
2) What do you do when your child won’t eat?
3) How anxious (or stressed) are you about your child’s eating?

These Q’s can help to determine the parent’s “feeding style”: Controlling - *Responsive* - Indulgent - Neglectful
The Barriers that Keep Patients Stuck

Avoidant/Restrictive eating patterns are maintained by:

• Sensory Sensitivity (e.g. tastes, textures, smells, looks, sounds)
• Fear of aversive consequences (e.g. choking, vomiting, disgust)
• Lack of appetite or low interest in eating
Recent Findings for Patients with ARFID

- A retrospective chart review of patients with ARFID (N=59) found a co-occurrence of symptoms in over 50% of the sample. Patients with sensory sensitivities was the most common in the sample and frequently co-occurred with both lack of hunger and/or fear of negative consequences.

- Co-morbid conditions are often present... In reviewing these same Eating Disorders Day Treatment patients (N=59), it was found that:
  - 38.9% had Autism Spectrum Disorder
  - 10.17% had Attention-Deficit/Hyperactivity Disorder

(Reilly et. al., 2019)
Goals of Psychological Therapy for ARFID

1) Sensory Sensitivity:
   - Systematic desensitization following the “Steps to Eating”

2) Fear of Aversive Consequences:
   - Psychoeducation about how avoidance maintains anxiety and exposure decreases anxiety over time.
   - Development of fear hierarchy with graduated exposure to situations in which choking, vomiting, or other fears occur.

3) Lack of Interest in Food/Eating or Limited Appetite:
   - Interoceptive exposure to feelings of fullness or nausea (testing to see if negative predictions are really as bad as they seem – “We can do hard things!”).
Nutrition and ARFID
ARFID and Malnutrition

Nutritional Assessment in ARFID:

1. Description of mealtimes
2. Growth
3. Vitamin and mineral intake
4. Possible medical complications
5. Description of mealtimes
ARFID and Malnutrition:

Known:

- Diet quality is poor
  - Preference for refined carbohydrates, sugars, highly processed foods
  - Low or no consumption of meats, veggies, fruits
  - Major changes in dietary intake are very hard to achieve

Unknown:

- Which tools help us assess nutritional status in ARFID?
- How prevalent are complications related to poor nutrition in ARFID?
- Which nutrients should we be most worried about?
- Are their acceptable ways to fill these nutrient gaps?
ARFID and Malnutrition

Growth for people with ARFID looks like this:
ARFID and Malnutrition

- Variety restriction
  - Results in healthy weight or overweight status

- Volume and variety restriction
  - Low weight

- Post traumatic food restriction
  - Tends to result in rapid weight loss

A healthy BMI does not indicate whether or not feeding or behavioral supports will benefit a family.
ARFID and Malnutrition:

How does dietary intake in individuals with ARFID compare to same aged peers?
ARFID and Malnutrition:

Comparing Diets of Individuals with ARFID vs Controls

Population and Design:
• US, healthy weight individuals with ARFID, 52 4-day diet recalls compared to those of healthy controls

Findings:
Significant differences in intakes of:
- Vitamin K
- B12

Population and Design:
• Germany, low to normal weight individuals with ARFID seeking treatment. 20 3-day diet recalls and food preference lists compared to healthy controls

Findings:
Significant differences in intakes of:
- Calories
- B vitamins (Riboflavin, Thiamin)
- Vitamin C
- Vitamin K
- Zinc
- Iron
- Potassium


Considerations:

• Comparative studies. How great were were the diets of the controls?
ARFID and Malnutrition: Healthy Eating Index Score

- Data-driven assessment quantifying diet quality.

- Used to see how well the what we eat aligns with Dietary Guidelines.

- A score of 100 suggests *all* foods reported align with the Dietary Guidelines recommendations. A score of 0 indicates that none do.

Data source for Healthy Eating Index scores: What We Eat in America, National Health and Nutrition Examination Survey (undated data are from 2013-2014).
<table>
<thead>
<tr>
<th></th>
<th>Mean Intake a</th>
<th>% (n) Not Meeting Dietary Reference Intakes b</th>
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<tbody>
<tr>
<td></td>
<td>Full or Subthreshold ARFID</td>
<td>Healthy Controls</td>
</tr>
<tr>
<td></td>
<td>n = 52</td>
<td>n = 52</td>
</tr>
<tr>
<td>Vitamin A (mcg) c</td>
<td>699 ± 32.5</td>
<td>807 ± 32.3</td>
</tr>
<tr>
<td>Vitamin C (mg)</td>
<td>348 ± 88.3</td>
<td>904 ± 4.8</td>
</tr>
<tr>
<td>Vitamin D (mcg) d</td>
<td>5.4 ± 0.2</td>
<td>6.2 ± 0.3</td>
</tr>
<tr>
<td>Vitamin E (mg)</td>
<td>10.0 ± 0.4</td>
<td>9.8 ± 0.4</td>
</tr>
<tr>
<td>Vitamin K (mcg)</td>
<td>55.8 ± 1.9</td>
<td>162 ± 12.3</td>
</tr>
<tr>
<td>Vitamin B6 (mg) e</td>
<td>1.6 ± 0.04</td>
<td>1.9 ± 0.04</td>
</tr>
<tr>
<td>Folate (mcg) f</td>
<td>560 ± 17.2</td>
<td>569 ± 14.5</td>
</tr>
<tr>
<td>Vitamin B12 (cobalamin, mcg)</td>
<td>3.9 ± 0.1</td>
<td>4.7 ± 0.2</td>
</tr>
<tr>
<td>Calcium (mg)</td>
<td>1096 ± 29.1</td>
<td>1037 ± 26.7</td>
</tr>
<tr>
<td>Iron (mg)</td>
<td>14.5 ± 0.3</td>
<td>15.7 ± 0.4</td>
</tr>
<tr>
<td>Magnesium (mg)</td>
<td>248 ± 4.8</td>
<td>299 ± 6.6</td>
</tr>
<tr>
<td>Zinc (mg)</td>
<td>9.4 ± 0.2</td>
<td>11.0 ± 0.3</td>
</tr>
</tbody>
</table>
ARFID and Malnutrition: Comparing Diets of Individuals with ARFID vs Controls

Table 2. Achieved percentage of recommended vitamin and mineral intake in avoidant/restrictive food intake disorder (ARFID) and controls.

<table>
<thead>
<tr>
<th></th>
<th>Controls</th>
<th>ARFID</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M ± SD</td>
<td>Range</td>
</tr>
<tr>
<td>% of vitamin intake ¹</td>
<td></td>
<td></td>
</tr>
<tr>
<td>B1</td>
<td>60.9 ± 52.4</td>
<td>14.6–238.5</td>
</tr>
<tr>
<td>B2</td>
<td>41.5 ± 23.8</td>
<td>13.0–96.9</td>
</tr>
<tr>
<td>B6</td>
<td>61.2 ± 48.0</td>
<td>11.1–199.7</td>
</tr>
<tr>
<td>B12</td>
<td>42.7 ± 31.9</td>
<td>3.8–123.0</td>
</tr>
<tr>
<td>C</td>
<td>143.6 ± 138.1</td>
<td>21.1–491.4</td>
</tr>
<tr>
<td>D</td>
<td>5.3 ± 8.8</td>
<td>0.5–38.6</td>
</tr>
<tr>
<td>E</td>
<td>33.6 ± 23.0</td>
<td>8.7–94.5</td>
</tr>
<tr>
<td>K</td>
<td>64.5 ± 45.0</td>
<td>13.5–152.6</td>
</tr>
<tr>
<td>Folate</td>
<td>39.7 ± 21.7</td>
<td>13.0–95.9</td>
</tr>
<tr>
<td>% of mineral intake ¹</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Zinc</td>
<td>52.5 ± 28.7</td>
<td>11.4–122.6</td>
</tr>
<tr>
<td>Calcium</td>
<td>47.4 ± 32.2</td>
<td>13.1–116.6</td>
</tr>
<tr>
<td>Iron</td>
<td>30.6 ± 19.5</td>
<td>8.9–79.8</td>
</tr>
<tr>
<td>Magnesium</td>
<td>71.5 ± 38.8</td>
<td>22.1–154.9</td>
</tr>
<tr>
<td>Potassium</td>
<td>42.3 ± 24.3</td>
<td>13.1–115.6</td>
</tr>
</tbody>
</table>

¹ Reference values are based on German age- and sex-specific recommendations for energy and nutrient intake.
ARFID and Malnutrition

What is the prevalence of severe medical complications related to self restricted eating?
ARFID and Malnutrition:

– Systematic review of Case Reports and Case Series from 1957-2019
– 76 case studies from developed countries over 65 years
  The majority were from 2009-2019

ARFID and Malnutrition

ARFID and Malnutrition:

Considerations:

• Extreme cases involving hospitalization

• Remember common nutritional deficiencies:
  • Vitamin D
  • Iron
  • Calcium
  • Zinc
Interventions Nutrition and ARFID

What screws us up most in life is the picture in our head of how it is supposed to be.
Interventions Nutrition and ARFID
Interventions Nutrition and ARFID

Following *intensive* treatment findings include:

- Great parent satisfaction
- Improved behaviors and interactions at mealtimes
- Dietary changes: often none or very insignificant
  
  Occasionally increase ~20 foods, which must feel huge

Interventions Nutrition and ARFID

Labs
• Chemistry, CBC, Ferritin, 25(OH) Vitamin D
• Consider: Vitamin C, Vitamin A, Zinc, B12

Diet
• Provide reassurance
• Vitamin and mineral supplements, fortified foods
• Consider oral nutritional supplements if weight and micronutrient intake are poor

Goals
• Refer to therapy
• Provide reassurance
  – Nutritional intake will not improve until medical contributors to ARFID, stress and anxiety are addressed
Let’s go back to the beginning
Data from 2018 Hospital for Sick Children prospective study:

46% of children had been having a feeding disturbance for approximately 2 years before they received an evaluation.
Why does it take 2 years?

- Pediatricians hear about feeding concerns frequently.
- Growth may be ok.
- Developmental screening tools are not sensitive to feeding difficulties.
What does this waiting mean for the family of a child with PFD or ARFID?

- Family is having meal 3-6 (or more) times per day.
- They are experiencing stress 3-6 or more times a day or 2,190-4,380 times in the approximately 2 years while waiting for an evaluation.
- In trying to reduce the stress, they adapt and avoid.
What can you do?
ICFQ

- Free
- 36 months and under
- If over 36 months it will send families to another questionnaire
- Available online FeedingMatters.org
Consider:

- adequate weight gain and growth
- functional eating patterns and mealtime participation
Pay special attention to kids with:

- History of nursing difficulty
- Slow weight gain in infancy
- Difficulty making transitions –to purees, weaning from breast or bottle (over 18 months), solid food transitions
- Any other motor, language or social skill delays
Questions:

• Does the family have set meal and snack times?
• How long is mealtime lasting?
• Is it causing significant parent stress?
Refer to Community Feeding Therapy

Occupational Therapy

Speech Therapy
Feeding Therapy Evaluation

Medical history
Development
Oral motor
Dysphagia
Sensory processing

Mealtime participation
Behavior
Family-child interactions
Family stress
Family goals

Family + Child
Feeding Therapy

- Positioning
- Trust
- Practice
- Family
- Education
- Supportive Language
- Consent
- Play
- Behavior
- Support
- Respect
- Sensory Exploration
- Motor Skills
“You can’t go back and change the beginning, but you can start where you are and change the ending.” –C. S. Lewis
Thoughts Into Action...

*Best practices towards seeing improvements in our patients*
Case Study: 7-year-old Cisgender Male

History:
- He has been diagnosed with asthma, eczema, ADHD, sensory processing issues. More recently, anxiety and dysphagia have been occurring in the last 6 months.
- He has always been a picky eater, with preferred foods becoming more limited over the past year. Weight is stable (but lower with BMI at 5.24%), but he relies on significant nutritional supplementation.
- Patient is from a single-parent household and has two older siblings with significant neurodevelopmental and behavioral differences.

Clinical Findings:
- Normal EGD and MBSS
Approaches to Help: 7-year-old Cisgender Male

**Medical**-
- Evaluate for co-existing or underlying medical etiology of feeding difficulty and refer to appropriate specialty services.
- Support and reinforce recommendations of mental health providers and feeding therapists.

**Behavioral**-
- Increase meal/snack structure (3 meals and 2-3 snacks with the same time, place, and routine), Follow the “Rule of 3”, and Model pleasant/healthy eating behaviors.
- Establish a meaningful Positive Reinforcement system (consider the “Matching Law” in order to help their reason “why to” be higher than their “why not”). Also, help parents understand the importance of ignoring negative behaviors.
- Help the child to get involved with the selection and creation of family meals, even if they don’t taste the final product. Becoming a “food scientist” can facilitate systematic and low-stress exposures. Exposure is the key!
Approaches to Help: 7-year-old Cisgender Male

Nutrition-
• The growth chart isn’t a very effective tool in identifying PFD or chronic ARFID.
• Micronutrient deficiencies can happen, but serious consequences are fairly rare.
• Well-balanced vitamin and mineral supplements, along with fortified foods such as breakfast cereal and milk are great at combatting serious nutrient deficiencies.
• Food variety and nutrient intake will not improve until medical conditions and stress contributing to ARFID are managed.

Feeding Therapy-
• Evaluation of oral motor and oral sensory processing skills.
• Evaluation of mealtime participation.
• Treatment - Family coaching to reduce stress for mealtime participation.
• Treatment - Sensory and play-based exploration of food to reduce worry and increase practice.
References


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References


Thank You