**National Eating Disorder Information Centre** 

## BULLETIN



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# **Understanding ARFID: A Developmental and Relational Perspective**

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The current DSM-5 diagnoses of "Feeding and Eating Disorders" reflect a broad range of eating disturbances across the developmental spectrum with a lifespan approach. In particular, Avoidant/Restrictive Food Intake Disorder (ARFID) is a new diagnosis, more commonly seen in childhood, acknowledging significant eating disturbances not characterized by concerns about body weight or size.

As more children and youth are diagnosed with ARFID, families are seeking help from eating disorders professionals. Many children have undergone therapies to address their eating in early childhood with varied results. Unresolved childhood feeding disturbances can persist into adolescence and adulthood. These diverse and complex presentations challenge us to broaden our understanding of eating behaviours and consider the origins of eating challenges. This article is the first of a two-part series providing an overview of ARFID and reviewing current treatment options.

#### **NOMENCLATURE**

Feeding and eating problems are acknowledged as complex, involving a multitude of factors including medical/physiology, development, family systems and feeding/eating behaviours. Clinicians from different disciplines use different classification systems<sup>1</sup>, which likely has slowed collaboration and progress in treatment. Several classification systems of clinically significant eating disturbances (now under the "new" ARFID diagnostic label) are listed here to include knowledge and perspectives that predate "ARFID" and to stress the developmental and relational process of early eating relevant to ARFID cases.

Avoidant/Restrictive Food Intake Disorder (ARFID) is a new diagnosis, more commonly seen in childhood, acknowledging significant eating disturbances not characterized by concerns about body weight or size.

## Feeding Disorders in Infants, Toddlers and Young Children (Chatoor)

Chatoor describes six subtypes of feeding disorders in infants and young children, four of which are specific to developmental stages: feeding disorder of state regulation, feeding disorder of caregiver-infant reciprocity, infantile anorexia, and sensory food aversions. The other subtypes, post-traumatic feeding disorder and feeding disorder associated with a concurrent medical condition, are not age-specific.<sup>2</sup> Identification of when and why eating diverges from typical patterns, inseparable from the feeding relationship, guides treatment for each subtype.

#### Feeding Disorders as a Relational Disorder (Davies et al.)

Feeding disorders involve both parental factors such as feeding styles and parental limitations (such as depression, addiction, eating disorders – essentially any factors that interfere with sensitive parental response to the child's needs), as well as child factors such as medical issues and temperament<sup>3,4</sup>. Davies et al. proposed a multiaxial system diagnosis to capture the relational and multisystemic nature of feeding disorders.<sup>3</sup>



### Pyramidal Representation of Feeding Behaviours (Kerzner et al.)

Kerzner et al.<sup>5</sup> use a pyramid to illustrate the spectrum of feeding challenges. The bottom of the pyramid represents typical eating in ~75% of children. Three layers of feeding problems are represented at the top: feeding disorders, milder feeding difficulties, and misperceived feeding problems. Feeding disorders, at the apex, represent severe difficulties. The proposed management algorithm considers both feeder (feeding styles) and child (limited appetite, selective intake, and fear of feeding) factors.<sup>5</sup>

## Eating Disorders in Childhood and Adolescence (Bryant-Waugh & Lask)

Bryant-Waugh & Lask described eight types of eating difficulties and disorders occurring in childhood along with working definitions including: anorexia nervosa (AN), bulimia nervosa (BN), food avoidance emotional disorder, selective eating, restrictive eating, food refusal, functional dysphagia, and other phobic conditions and pervasive refusal syndrome.<sup>6</sup>

These classification systems all strive to understand why a child is reluctant to eat. We trust that children do their best. Eating behaviours provide clues – anything that makes chewing, swallowing or digesting difficult or uncomfortable, an aversive eating experience, or unsupportive feeding can play a role.

## DSM-5 & CHALLENGES WITH THE CURRENT DIAGNOSTIC CRITERIA

Feeding and eating disturbances range from mild to severe.<sup>5,7</sup> ARFID is intended to identify individuals "with truly limited intake, in both type and range of foods, and an intense fear of novel foods and eating behaviors that impair development".<sup>8</sup> The diagnostic criteria of ARFID are:

- 1. significant weight loss (or failure to achieve expected weight gain or faltering growth in children),
- 2. significant nutritional deficiency,
- 3. dependence on enteral or oral nutritional supplements, and
- 4. marked interference with psychosocial functioning. (Refer to DSM-5 for diagnostic and exclusion criteria.)

A broad range of eating behaviours can be considered normal or typical, and 'normal' can vary more dramatically among children with special needs who are at higher risk of eating challenges. While current criteria identify more children with eating difficulties, there is potential for

over-identification. Clinicians need to exercise discretion in identifying the more extreme presentations of weight/growth, nutrition, and psychosocial concerns. In particular, the following questions should be noted.<sup>7</sup>

- What is considered a "significant" weight loss or failure to maintain "adequate" growth without weight loss?
- What constitutes a nutritional deficiency? When is a deficiency considered significant: by energy deficits, specific nutrients, lab abnormalities or clinical symptoms? How to determine if oral supplement use is "dependence"?
- How to define "marked interference" with psychosocial functioning?

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#### CONSIDERING ARFID SUBTYPES

Similar clinical presentations of eating disturbance may have very different etiologies and therefore require different interventions. 1 Eating disorder professionals likewise provide treatment for AN and BN based on individual factors such as age, comorbidity, psychosocial contexts, and the course of illness. Three categories were proposed based on subtypes described in DSM-5: 1) ARFID-limited intake, 2) ARFID-limited variety, and 3) ARFID-aversive.9 (ARFID due to choking or traumatic event has relevant research under "phagophobia", "psychogenic dysphagia" or "emetophobia".) All patients in Norris et al's study<sup>9</sup> diagnosed with ARFID could be assigned to one of the three subtypes; 22% had mixed presentations. The clinical picture is further complicated if maladaptive strategies or ineffective treatment have been applied. 10,11 For instance, children with inflexible food selections may develop an aversion towards eating if they are coerced to eat "nonpreferred" foods.

Clinicians should strive to assess the full clinical picture, including the history of growth, feeding, and eating, ideally from birth, and identify the etiologies as well as the nature of the eating disturbance (subtypes) to inform treatment<sup>9</sup>.

## THE DEVELOPMENT OF EATING/FEEDING DIFFICULTIES

Severe feeding and eating problems are often outcomes of dynamic interactions between factors accounting for the onset of feeding difficulties and maladaptive coping strategies.<sup>3,5</sup> Early childhood feeding problems may develop from food refusal and subsequent attempts to circumvent the presenting problems, such as distracted or forced feeding, that become an intrusive cycle. 10,11 Segal et al. 11 identified "pathological" feeding in 100% of children presenting with infantile feeding disorders. This view is also supported by recent ARFID literature. Approximately 25% of children experience feeding problems, with 1-5% meeting feeding disorder criteria.5 Lukens & Silverman (2014) reported chronic feeding problems are unresolved in 3-10% of children, which may cause functional impairment.<sup>12</sup> Patients with ARFID in Fisher et al.'s study<sup>13</sup> were younger, with a significantly longer history of eating disturbance. Among youth diagnosed with ARFID, 28.7% had experienced selective eating since early childhood, whereas early childhood eating issues were not identified among those diagnosed with AN and BN.13

It is noteworthy that many children evaluated for ARFID had previously been treated unsuccessfully for feeding problems. While treatment is usually focused on the child or youth having difficulties with eating, family context and maladaptive feeding must be considered and addressed.

Rarely, ARFID-consistent presentation is related to Group A Strep infections, known as pediatric acute-onset neuropsychiatric disorder associated with streptococcal infections (PANDAS). The defining characteristic is sudden onset, typically before puberty, "...in the context of obsessional fears about contamination, as well as in the context of the sudden onset of fears of swallowing, choking, or vomiting that are often associated with sensory phenomena".<sup>14</sup>

#### TREATMENT OPTIONS

Evaluation of ARFID-specific interventions is scant at present, and interventions have not considered subtypes. This section discusses common treatment options along with precautions we consider important. With significant overlap between ARFID and feeding problems, relevant interventions for pediatric feeding are included. It is critical to understand the treatment history of anyone presenting with ARFID.

#### **Family-Based Treatment for ARFID**

Family-based treatment (FBT) is a manualized approach developed to treat AN in children and adolescents, where parents take charge of what and how much is eaten. It has also been modified to treat BN. FBT is being used to treat ARFID, with no standard at this time. This approach is based on framing ARFID as a restrictive eating disorder. Some protocols resemble FBT-AN, where parents prompt children to eat more volume and/or to try new foods, and may include weight restoration goals as in FBT-AN. Fitzpatrick et al.<sup>3</sup> described a different approach in which parents encourage food intake in a less directive way. Families are provided with skills to cope with food-related experiences and consequently build competence and mastery. Novel food is introduced through gradual exposure.

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A review of 14 adolescent eating disorder programs (eight extensively using FBT) found that ARFID patients had higher drop-out rates (59.8%) and were less likely to achieve weight recovery compared to AN.<sup>15</sup> The authors suggested that "(d)ifferent approaches may be needed to help these patients overcome their eating difficulties, which were of longer duration before presentation."<sup>15</sup> Directive eating protocols with or without explicit weight gain expectations similar to FBT-AN may not be the best approach for the subgroup of ARFID patients where coercive feeding may have played a role in exacerbating or maintaining feeding and eating challenges.

#### Other Types of Psychotherapy

Anxiety is common with ARFID (notably higher than with AN).<sup>13,16</sup> Eating disorders professionals do not yet have a standard approach in treating concurrent anxiety. Based on information we have gathered from current literature<sup>17,18</sup>, discussions with colleagues, and ARFID presentations, various ways being used to address anxiety include: cognitive behavioural therapy (CBT), dialectical behavioural therapy (DBT), Unified Protocol, biofeedback, massage,

yoga, meditation and aromatherapy. ARFID- aversive subtype seems to favour treatment with CBT, involving family as appropriate.

#### **Behavioural Feeding Interventions**

Behavioural feeding interventions draw from applied behavioural analysis (ABA) principles, with the goal of reducing and eliminating negative "behaviours" (including crying, gagging and vomiting) and increasing desired behaviours (greater food intake).<sup>19</sup> Intensive behavioural feeding therapies generally include multi-disciplinary teams, for infants and young children. Treatments are often several hours a day for two or more months, provided mostly by ABA technicians. While there is research supporting strategies that increase desired outcomes (bites taken, decreased negative vocalizations), there is little research looking at eating and attitudes over time (a concern with most feeding therapy research).20 A 2017 review concluded "(g)iven the need for better patient characterization, more uniformity in outcome measurement and unanswered questions on the necessary components of treatment, these 11 studies prohibit definitive conclusions regarding optimal models of care."21 Further, ABA protocols are often difficult for parents to follow at home and to transition to typical eating, as demonstrated in this case – "Maria responded to her mother's feeding attempts by whining, crying, arching her back and vomiting... Maria's mother reported that trying to force Maria to eat was too stressful for her and that she could not continue."22

"Behavioural" strategies such as rewards and negative consequences are often used with other therapies. Some children respond to incentives such as stickers or screen time. For others, it leads to increased anxiety and become counterproductive. As a mother of Dr Rowell's client described, "Video game time works for everything but getting him to eat."

#### **Sensory-Motor Therapies**

Sensory-motor therapies are generally provided by speech and occupational therapists. The SOS (sequential-oral-sensory) approach developed by Dr. Kay Toomey involves desensitizing children through "play with a purpose". <sup>23</sup> The child is moved up a hierarchy of comfort from tolerating food on the table, to touching with an item, to touching skin, mouth, lips, etc., until the food is eaten. Though a popular approach, there is little data on outcomes. <sup>24</sup>

Food chaining and fading are techniques incorporated into other therapies whereby accepted foods are "chained" to

novel foods by introducing foods with similar or linked sensory properties (crunch, shape, colour, etc.) to previously accepted foods; or accepted foods are changed slightly (fading) as tolerated.<sup>5</sup>

#### **Relational Approaches to Optimize Feeding**

As feeding and eating disturbances always involve a relational dynamic between a child/youth and caregivers, relational approaches intervene primarily through establishing best-practice feeding. Segal et al.<sup>11</sup> implemented the "role reversal" parent intervention to replace intrusive with responsive feeding for "infantile feeding disorders" before age six (now within the ARFID diagnosis). Outcomes were positive with over 70% resolution of growth and pathological feeding patterns after three and six months.<sup>11</sup>

Some children respond to incentives such as stickers or screen time. For others, it leads to increased anxiety and become counterproductive.

Ellyn Satter's Division of Responsibility (sDOR) is a relational approach: at its core, parents are responsible for what, when, and where of feeding, and the child decides how much to eat from what is provided.<sup>5,25</sup> sDOR is recognized as the best practice in child feeding.<sup>26</sup> Some therapeutic strategies are compatible with sDOR, others, such as ABA, are not.

Evidence and lessons learned from relational feeding approaches form the foundation of "responsive feeding". Examples of responsive therapies include the 'Get Permission' approach (Marsha Dunn Klein)<sup>27</sup>, Mealtime Partners Program (Suzanne Evans Morris)<sup>28</sup>, AEIOU integrative approach (Nina Johanson)<sup>29</sup>, and STEPS program (Jenny McGlothlin)<sup>30</sup>. All exemplify combined normalization of the child's response to sensation and the development of oral-motor skills for eating and drinking as needed within a relational and child-led approach, compared to being adult-directed as in conventional behavioural programs. As with other therapies, there is little data on outcomes. The principles and rationale of responsive interventions (structure, facilitation, non-pressured exposure, responding to child's feeding cues, and modeling) will be explored in the next article.

#### **Pharmacotherapy**

Pharmacotherapy may be considered as an adjunct intervention if weight restoration is a primary concern. However, medications do not address food acceptance and feeding skills. Quality clinical trials are lacking to guide the use of appetite stimulants, anti-emetics, pro-motility agents, and anxiolytics in addressing eating disturbances.

The above interventions are not necessarily distinct categories. CBT for children often includes families. Fitzpatrick et al.'s FBT-ARFID protocol utilizes desensitization strategies, and this protocol's focus on mastery resembles child-led interventions emphasized in relational approaches. Of note, theoretically similar therapies may be conducted differently between practitioners. Therefore, it is important to clarify how interventions were implemented for each client. Individual reaction to treatment and efficacy over time provide important information.

#### CONCLUDING THOUGHTS

Diverse clinical presentations are folded into ARFID, with the apparent majority dealing with anxiety and eating that grow out of childhood challenges and their often maladaptive responses. It is unlikely that one standardized intervention will emerge. As pointed out by Bryant-Waugh, "(t) reatment needs are likely to vary across individuals and, as a rule of thumb, are generally informed by the main areas of impact of the avoidance or restriction of food intake."17 Currently, common treatment options focus on 'correcting' behaviours to match 'typical expectations' lacking coherent theoretical foundations of eating and feeding behaviours. We advocate that it is critical to thoroughly assess individuals' history of feeding and eating difficulties, as well as any therapies undertaken in order to provide informed individualized interventions. Professionals from both pediatric feeding and eating disorder fields can advance ARFID treatment by collaborating and developing a toolkit of treatment options to support individuals and families from early childhood through adolescence and adulthood. In the next issue, we will further discuss the intervention process along with case studies.



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