Avoidant/Restrictive Food Intake Disorder in Down Syndrome: A Case Report

Stephanie Kerswill, MD[1]; Jill Fodstad, PhD, BCBA-D[1,2]; Cassie Karlsson, MD[1,2]
[1]Department of Psychiatry, Indiana University School of Medicine; [2]Indiana University Health Physicians

Background

Avoidant/Restrictive Food Intake Disorder (ARFID)

- DSM-5 Criteria[1]
  - Feeding disturbance causing oral intake nutritional deficits associated with one or more of:
    1. Significant weight loss
    2. Significant nutritional deficiency
    3. Dependence on supplementary feeding
    4. Interference with psychosocial functioning
  - Not better explained by other circumstances or diagnoses
  - No evidence of concern over body image or weight
- Demographics:
  - Most commonly develops in childhood[1] and prevalence has been estimated at 0.3-3.2% in the literature[2]
  - ARFID often co-occurs with anxiety disorders, autism spectrum disorder, obsessive-compulsive disorder and attention-deficit/hyperactivity disorder.[3,5]
- The prevalence of ARFID in patients with Down Syndrome (DS) is unknown.

Case Description

Background:

- 24-year-old female with DS presenting with feeding disturbance.
- Two past choking-related traumas: 1) at 21 years old the patient choked and 2) around 23 years old, a friend with DS died from choking.
- Psychosocial changes at 22-24 years old: graduated high school, best friend got married/moved away, cousin died suddenly, started a job
- Past medical history: obstructive sleep apnea and tonsillectomy

History of present illness at intake:

- Feeding disturbance began over a year ago with:
  - Highly restricted food interests
  - Taking very small bites of food at a very slow pace
  - Became a messy eater
  - No concern over body image or weight
- Historically an over-indulger, but very good table manners.
- Developed significant anxiety about events where food might be served, began avoiding social events such as karaoke and dancing.
- Lost ~45 pounds in less than nine months.

Workup: Medical workup was unremarkable (see panel at right).

Diagnosis:

- See Table 1 for patient summary and alignment with ARFID criteria.
- Feeding behaviors beyond what would be expected in those with DS.

Case Description (continued)

Treatment:

- Nutritional standpoint:
  - Evaluated by an eating disorder specialist and started on supplementary oral nutrition and eventually had gastrostomy tube (g-tube) placed due to failure to maintain adequate nutrition.
- Behavioral/psychiatric standpoint:
  - Treated with Sertraline 100mg daily for comorbid anxiety.
  - Referred to a psychologist for modified cognitive behavioral therapy (CBT) to treat anxiety related to food intake.
- In active treatment: patient gaining weight, increasing interest in food, eating more in variety and quantity.

Table 1. Diagnostic Criteria for ARFID and Patient Symptom Description

Criterion	Patient Symptom Description
Weight loss	Lost 45 pounds in less than nine months
Nutritional deficiency	Low blood pressure and symptoms requiring IV hydration
Dependence on supplementary feeding	Initially started on oral supplemental shakes and eventual g-tube placement
Interference with psychosocial functioning	Began avoiding social events due to the presence of food

***Note**: Patient had no concerns with body weight or image. Symptoms were over and beyond what is expected in those with DS, and not better captured by another psychiatric condition.*

Medical Workup

Serology

- **Routine**: CBC, CMP, CRP, ESR, FLP - **Negative**
- **Nutrition**: prealbumin, Zinc, Mg, B12, folate, vitamin D - **Negative**
- **Endocrine**: TSH, FT4, TPO - **Negative**
- **Rheumatologic/autoimmune**: ANA, celiac panel - **Negative**

Urine:

- Urinalysis - **Negative**

Imaging/Radiologic studies:

- Abdominal x-ray: moderate fecal colonic burden, otherwise normal - **Negative**
- Swallow study: normal swallow study although limited bites/small food bolus - **Negative**
- EGD: normal - **Negative**

Acknowledgements

We would like to thank the patient and family for allowing us to share case details in pursuit of increasing recognition of ARFID in patients with DS.

Conflicts of interest: None.

Discussion

Recognizing and diagnosing ARFID:

- Consider in a patient with:
  - Severe or impairing avoidance/restriction of food that results in significant weight loss, health consequences, impaired psychosocial functioning, or requires nutritional supplementation
  - Absence of distress over body image/weight
- Diagnosing ARFID in DS: the eating disturbance should be out of proportion to what is expected in persons with DS.
- If ARFID is suspected, refer to behavioral health and an eating disorder specialist along with appropriate lab and medical workup to rule out organic causes of feeding disturbance.

Treatment:

- Eating disorders occur in DS, specifically anorexia nervosa.[4] Very limited literature on other eating disorders such as ARFID in patients with DS.
- Screen for other mental health disorders and refer to appropriate treatment if present (e.g., CBT and pharmacologic management).
- No literature exists on treatment of ARFID in patients with DS.
- Limited pharmacologic studies available for the specific treatment of ARFID.
- In non-DS populations, ARFID is treated using a tailored approach including:
  - Nutrition plans with gradual introduction of problematic foods[4]
  - Relaxation techniques and systematic desensitization if indicated[5]

Summary:

This case illustrates the importance of early identification and treatment of ARFID in patients with DS. When undiagnosed, invasive medical interventions may occur to maintain adequate nutrition. There is little existing literature about ARFID in DS, making this an area for future investigation.

References

1. American Psychiatric Association. (2013). Feeding and Eating Disorders. In *Diagnostic and statistical manual of mental disorders* (5th ed.). https://doi.org/10.1176/appi.books.9780890425596.dsm10
2. Brigham, K.S., Manzo, L.D., Eddy, K.T. *et al.* Evaluation and Treatment of Avoidant/Restrictive Food Intake Disorder (ARFID) in Adolescents. *Curr Pediatr Rep* **6,** 107–113 (2018). https://doi.org/10.1007/s40124-018-0162-y
3. Kambanis, PE, Kuhnle, MC, Wons, OB, et al. Prevalence and correlates of psychiatric comorbidities in children and adolescents with full and subthreshold avoidant/restrictive food intake disorder. *Int J Eat Disord*. 2020; 53: 256– 265. https://doi-org.proxy.ulib.uits.iu.edu/10.1002/eat.23191
4. Myers, B. A., & Pueschel, S. M. (1991). Psychiatric disorders in persons with Down syndrome. Journal of Mental and Nervous Disease, 179, 609-613.
5. Zimmerman J, Fisher M. Avoidant/restrictive food intake disorder (ARFID) Curr Probl Pediatr Adolesc Health Care. 2017;47(4):95–103. doi: 10.1016/j.cppeds.2017.02.005.