

CASE REPORT

Delayed diagnosis of avoidant/restrictive food intake disorder and autism spectrum disorder in a 14-year-old boy

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Abstract

Psychiatric comorbidities are common among individuals with ARFID and may contribute to a failure to establish an accurate diagnosis, delayed diagnosis, and poor long-term prognosis, especially among children and adolescents.

KEYWORDS

autism spectrum disorder, avoidant restrictive food intake disorder, diagnostic error, eating disorder

1 | INTRODUCTION

Avoidant/Restrictive Food Intake Disorder (ARFID) in pediatrics is a condition that can be often characterized by extreme picky eating and subsequent weight loss and/or failure to grow. This type of disordered eating pattern may also be observed in other conditions such as generalized anxiety disorder, autism spectrum disorder, sensory integration disorder, communication, and other learning disorders. This report illustrates the case of a 14-year-old boy with ARFID who, because of diagnostic uncertainty, had a delayed presentation to medical care and treatment. This paper intends to better inform the reader on recognizing ARFID among a number of possible diagnoses, especially when growth stunting is present in children. The report highlights that ARFID is still a relatively new diagnosis and more research is needed around understanding the various clinical subtypes and approach to management.

Picky eating is a common problem with up to 50% of caregivers reporting this behavior in their children by age 2.¹ Persistent, extreme picky eating associated with impairment in functioning, however, may go on to meet diagnostic criteria for a more serious eating disorder such as Avoidant/Restrictive Food Intake Disorder (ARFID). ARFID is a

condition that results in either weight loss or failure to gain weight as expected for developmental age, nutritional deficiency, and/or psychosocial interference.² Three distinct presentations have been described for ARFID including sensory sensitivity due to aversions to specific tastes or textures, lack of interest in eating, or avoidance of specific foods following a traumatic experience.³ Other conditions with overlapping eating patterns and behaviors, such as autism spectrum disorder, sensory integration disorder, communication, and other learning disorders, may further complicate diagnoses, especially when comorbidities exist. We present a case highlighting the phenotypic overlap between these conditions, and the resulting diagnostic uncertainty, which in this case, led to delayed access to treatment and significantly impacted the young person's growth and development trajectory.

2 | CASE

A 14-year-old boy with a history of failure to gain weight and restrictive eating behaviors since early childhood was referred by his pediatrician to an outpatient eating disorders program for assessment. After initial review of the referral, the family was immediately instructed to bring their child

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to the emergency department for an urgent assessment due to extreme low weight and possible growth stunting. Upon review of his case, it appeared that diagnostic uncertainty may have resulted in a delay to access care. He was subsequently admitted to an eating disorders unit for further diagnostic clarification, nutritional rehabilitation, and weight restoration.

In terms of history, parents reported longstanding difficulties with feeding including early breastfeeding concerns and challenges with certain textures and smells as an infant and toddler. These symptoms persisted up until his acute presentation. He showed a strong preference for very plain meals (eg, burgers with no toppings) and those with a smooth texture (eg, purees). He had a very limited repertoire of food (eg, cheerios, chicken nuggets, chocolate chip granola bars). He also demonstrated rigidity in other domains of his life, such as insisting on consistency in certain routines. At dinnertime, he preferred sitting in the same exact place each time and he folded his clothes a particular way. There was marked distress associated with moments where this insistence on sameness and routine was not upheld or possible. He was also noted to be an anxious child; his anxiety was described as having been significantly exacerbated after his parents separated at age 5. His mother was also concerned about difficulties with inattention, which were causing impairment at school and at home. Psychosocial stressors related to family dynamics and conflict were also felt to be contributing to his clinical presentation.

Historically, his weight had tracked along the 3rd percentile until age 5. At that time, he was experiencing significant stressors at home including his parents' separation and a grandmother living in the home with serious mental health challenges. In terms of follow-up, he was followed only briefly by a psychologist for anxiety and there were long intervals between his primary care visits. Unfortunately, his restrictive eating behaviors worsened, and his growth plateaued for the ensuing 8 years. He was eventually assessed by a community pediatric endocrinologist 2 months prior to his presentation with no clear endocrine diagnosis to explain his failure to thrive. A radiographic assessment of his bone age revealed a one-year delay in bone development as compared to chronologic age. He had also been seen by a psychiatrist 1 month prior to admission whose formulation included a broad differential, including sensory integration disorder, communication and other learning disorders, eating disorder, and autism spectrum disorder. Occupational therapy and psychoeducational assessments were recommended to clarify the diagnosis, none of which had been completed.

On admission, his weight was 24.4 kg (<0.01%ile), and his height was 143.5cm (0.39%ile), with an associated BMI of 11.8 kg/m². We estimated his weight to be approximately 68% of an ideal healthy weight of approximately 33 kg based

on his age and developmental stage, body composition, and pattern of growth since early childhood. Weight restoration began promptly with the introduction of a structured and normalized nutrition plan with close monitoring of macronutrients and caloric intake. Laboratory investigations were performed to monitor for refeeding syndrome and showed no electrolyte abnormalities. He was noted to have transaminitis, thought to be related to refeeding. The gastroenterology service was consulted and did not feel that his longstanding failure to thrive was organic in nature.

Throughout the admission, he required significant amounts of support around meal completion and distress tolerance with nutrition. He frequently became visibly anxious when faced with larger portions, as well as certain types of foods, commenting on aspects of the food that made them particularly difficult to ingest such as shape and texture. Lorazepam was trialed as a way of minimizing his anxiety prior to eating, and it was not found to be helpful. Neither were trials of nasogastric tube feedings.

Diagnostic clarification became a paramount goal of admission as it appeared to the multidisciplinary team that diagnostic error may have harmed this patient both psychologically and physically. A psychoeducational assessment was performed and confirmed a diagnosis of learning disability with strengths in fluid reasoning and visual-spatial skills, and challenges in verbal comprehension and written expression. Educational supports were recommended at discharge to address these concerns. A preliminary diagnosis of autism spectrum disorder (ASD) was also made after the administration of a complete Autism Diagnostic Observation Schedule (ADOS). The diagnosis was labeled as preliminary given that the ADOS was done while the patient was still at only 75% of his determined ideal healthy weight. No accompanying intellectual or language impairment was noted on this assessment, but support was recommended for deficits in social communication and restricted and repetitive behaviors. An assessment by an occupational therapist did not reveal any primary oral-motor or pharyngeal swallowing dysfunction with either liquid or solid food textures, but did suggest that the oral sensory aversion was fitting of a diagnosis of ASD. A behavioral therapist was consulted for support with distraction and reward strategies around completion of nutrition and made recommendations upon discharge. From an eating and feeding disorder perspective, the patient met criteria for avoidant restrictive food intake disorder (ARFID). As per DSM-5 criteria, he presented with a persistent failure to meet appropriate nutritional needs which were associated with marked failure to achieve expected weight gain and faltering growth, as well as marked interference with psychosocial functioning. In this case, it was also felt that the severity of the eating disturbance exceeded that routinely associated with the diagnosis of ASD, thus fulfilling the final DSM-5 criterion for ARFID (Box 1, Criteria 4).

BOX 1 ARFID DSM-5 Diagnostic Criteria

- 1) An eating or feeding disturbance (eg, apparent lack of interest in eating or food; avoidance based on the sensory characteristics of food; concern about aversive consequences of eating) as manifested by persistent failure to meet appropriate nutritional and/or energy needs associated with one (or more) of the following:
 - Significant weight loss (or failure to achieve expected weight gain or faltering growth in children).
 - Significant nutritional deficiency.
 - Dependence on enteral feeding or oral nutritional supplements.
 - Marked interference with psychosocial functioning.
- 2) The disturbance is not better explained by lack of available food or by an associated culturally sanctioned practice.
- 3) The eating disturbance does not occur exclusively during the course of anorexia nervosa or bulimia nervosa, and there is no evidence of a disturbance in the way in which one's body weight or shape is experienced.
- 4) The eating disturbance is not attributable to a concurrent medical condition or not better explained by another mental disorder. When the eating disturbance occurs in the context of another condition or disorder, the severity of the eating disturbance exceeds that routinely associated with the condition or disorder and warrants additional clinical attention.

He was ultimately discharged after a 2-month hospitalization on olanzapine 2.5mg, which seemed to allow for greater cognitive flexibility and distress tolerance when it came to nutritional intake. At discharge, his weight was 30.7 kg (85% of his determined ideal healthy weight), and he was eating 3 meals and 3 snacks of approximately 2500 calories. The patient was again subsequently assessed at a tertiary care-level psychiatric institution and confirmed to meet criteria for autism spectrum disorder, with difficulties in social communication and repetitive, restricted, and stereotyped interests and behaviors. He was also found to continue to meet criteria for Avoidant Restrictive Food Intake Disorder. Additionally, he was diagnosed with learning disabilities in reading, writing, and math. He equally demonstrated areas of superior to very superior IQ, working memory, and nonverbal IQ. Unfortunately, the family has since reported that the diagnosis of autism spectrum disorder has impeded their ability to access care for the eating disorder.

3 | DISCUSSION

Our case highlights an example of a diagnostic error, defined as the failure to a) establish an accurate and timely

explanation of the patient's health problem(s) or b) communicate that explanation to the patient.⁴ Our patient experienced a significant delay in an accurate diagnosis. In childhood, failure to thrive should routinely include a rapid assessment of both biological and psychosocial etiologies as insufficient nutrition is associated with poor physical and neurodevelopmental outcomes that can have lasting consequences. In our case, the delayed diagnosis very likely contributed negatively to the patient's physical and emotional development.

Contrary to older populations where the hallmark of many eating disorders is significant weight loss, one must assign greater clinical importance in pediatrics to growth stunting, as well as developmental and pubertal delay, that can result from chronic inadequate nutritional intake and failure to gain weight.⁵ We can hypothesize that the novelty of the ARFID diagnosis, having only made its first appearance in the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5),² also renders it a diagnosis that may not always be on many clinicians' differential diagnoses.

The clinical heterogeneity associated with the ARFID diagnosis also makes the diagnosis challenging and requires further study.⁶ Research around determining the various clinical presentations of ARFID is ongoing.⁷ While some patients may present with acute changes in intake secondary to an event such as choking, others present after a much more chronic and insidious history, such as the patient in this case, which arguably resulted in a more delayed presentation.

Our assessment was further challenged by the fact that prolonged disturbances in nutrition may have conferred harmful physiological and psychological consequences, including significant effects on cognitive function and mental health, coined the "starved brain".⁵ Psychiatric comorbidities, including anxiety disorders, autism spectrum disorder, and attention deficit hyperactivity disorder are common among individuals with ARFID.⁸ In our case, it was difficult to ascertain what degree of the patient's presentation, such as his difficulties concentrating and rigidity around routine, might have resulted from the potential cognitive effects of malnutrition. In this case, subsequent assessment at a tertiary psychiatric institution, at a time where the patient's weight was closer to ideal healthy weight, confirmed the ASD diagnosis.

It is important to note that feeding difficulties are common in children with ASD and estimated in the literature to be as high as 90%.⁹ As per the DSM-5, a secondary diagnosis such as an eating disorder is not warranted if subsidiary to a mental condition such as ASD, except in certain circumstances where outcomes are "sufficiently severe".² Recent research has shown that children with ASD and eating problems are more likely to also have externalizing behavioral problems such as conduct issues or hyperactivity, which may be a helpful distinguishing factor for clinicians.¹⁰ Nevertheless, diagnosis and management of patients with co-occurring ASD and ARFID are

challenging and often require highly specialized interdisciplinary teams with expertise in both eating and developmental disorders.

4 | CONCLUSION

This case report highlights diagnostic error in the form of delayed diagnosis of an adolescent with ASD and comorbid ARFID, and the subsequent treatment challenges. ARFID is a relatively new diagnosis and more research is needed around understanding the various clinical presentations and approaches to management. Increased awareness of ARFID, the various subtypes, and associated comorbidities are important for early diagnosis and treatment. Furthermore, it is important to recognize that growth failure may be an important and early sign of an eating disorder in children and adolescents. In our patient, earlier diagnosis may have resulted in improved physical and psychosocial development as well as school performance and achievement.

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CONFLICT OF INTEREST

None of the authors have any conflicts of interest with this case report.

AUTHOR CONTRIBUTIONS

Rageen Rajendram: is the primary author on this article and was involved in data collection, synthesis, and editing of the report. Maria Psihogios: is second author and was involved in data collection, synthesis, and editing of the report. Alene Toulany: is the principal investigator for this report and was involved in data collection, synthesis, and editing of the report.

ETHICAL STATEMENT

Informed consent was obtained from parents of the patient regarding the report of his clinical information in an anonymized way.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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