

# Multidisciplinary Approach to Severe Avoidant Restrictive Food Intake Disorder: Two Cases Report

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## Abstract

Avoidant restrictive food intake disorder is an eating disturbance that causes many challenges for both parents and clinicians. This study describes the cases of two children with early onset of severe feeding problems related to sensory dysfunction and the need for enteral nutrition. A multimodal intervention was required with the involvement of pediatricians, gastroenterologists, and child psychiatrists. Some interventions included sensory integration, speech therapies, and individual and family-oriented psychotherapy. Moreover, avoidant restrictive food intake disorder can develop at a very early age, with great severity, and may have a huge impact on children and their families. It requires a multidisciplinary, longstanding, and individually tailored treatment approach.

**Keywords:** Adolescent; Avoidant Restrictive Food Intake Disorder/diagnosis; Avoidant Restrictive Food Intake Disorder/therapy; Avoidant Restrictive Food Intake Disorder/psychology; Child; Infant

## Keypoints

### What is known:

- Avoidant restrictive food intake disorder is an eating disturbance that can develop at an early age with great severity.
- Sensory dysfunction may be one of the underlying causes of the avoidant restrictive food intake disorder.

### What is added:

- A multidisciplinary and longstanding approach is required, and interventions may include sensory integration as well as individual and family emotional support.

## Introduction

Feeding problems in infants and toddlers are very often reported by caregivers. Even though most of these difficulties are temporary, some may persist, and we may be dealing with a feeding and eating disorder.<sup>1,2</sup> In terms of diagnostic nosology, clinical definitions have been in constant progress. Diagnostic and Statistical Manual of Mental Disorders (DSM-5) describes avoidant restrictive food intake disorder (ARFID) as an eating disturbance that leads to inadequate intake of a normal range of foods resulting in weight loss, nutritional deficiency, dependence on nutritional supplements and/or marked interference with psychosocial functioning. This disturbance can include an apparent lack of interest in eating or food, concern about aversive consequences of eating, or avoidance based on the sensory characteristics of the food.<sup>3</sup> The infant or child refusal to eat certain

foods with specific tastes, textures, temperatures, or smells was previously known as sensory food aversion.<sup>4,5</sup> To meet ARFID criteria, other psychiatric disorders and general medical conditions must be excluded.<sup>3</sup> In avoidant restrictive food intake disorder criteria, the age of onset, symptoms, severity and evolution are variable, which leads to the assumption that they will probably correspond to different disorders, each requiring their own therapeutic interventions. Due to the complexity and multifactorial etiology of feeding disorders in infants and toddlers, a multidisciplinary approach is frequently required.<sup>3,6</sup> A pediatric assessment should be considered to rule out possible medical conditions or provide support when nutritional intake is at risk.<sup>1</sup> The treatment of feeding disorders should be adapted to the child individual characteristics and may include interventions from multiple healthcare professionals,

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such as pediatricians, pediatric gastroenterologists, psychologists, child psychiatrists, and occupational and speech therapists. In severe cases, nasogastric or gastrostomy feedings have to be considered as a treatment option.<sup>6</sup>

In this report, we describe the cases of two children with early onset feeding problems related to sensory dysfunction and their follow-up to the present date.

## Case Report

### Case 1

#### Pediatric intervention

A 9-month-old girl was referred to the hospital due to feeding refusal and failure to thrive. She was a first-born child of healthy non-consanguineous parents, had no relevant past health issues, and was breastfed since birth. Even though she needed the mother insistence to eat, she had an appropriate weight progression. The feeding difficulties progressively worsened since the girl was five months old. She refused to breastfeed initially and later refused to take the bottle, spoon, or pacifier. It was easier to feed her when she was asleep.

She frequently and easily choked when forced to eat or when a lumpy texture was offered.

Growth was compromised at 8 months of age, crossing from percentile (P) 25-50 to below P5 for weight at 6 months, and from P25 percentile to below P5 in length. However, she was an active and curious baby with normal development, and the remaining physical examinations were unremarkable.

A thorough assessment was performed, including hemogram, ionogram, urea, glucose, total proteins and electrophoresis, hepatic and renal function, iron, ferritin and total iron binding capacity, cholesterol and triglycerides, capillary blood gas analysis, immunoglobulins, antigliadin, antireticulin, antiendomysium and antitransglutaminase antibodies - immunoglobulin (Ig) A and IgG -, thyroid function, radioallergosorbent test and specific IgE to cow milk protein. Other examinations included tests of sweat, fecal elastase, seric leptin, lactate and ammonia, plasma and urinary amino acids dosing, and chromatography of organic urinary acids. The results were all normal. The radiological esophago-gastro-duodenal study showed no anatomic or functional abnormalities. An upper gastrointestinal endoscopy with duodenal and gastric biopsies were performed with normal histology. Additional examinations included pHmetry, chest radiography, echocardiogram, electrocardiogram, abdominal and renopelvic ultrasound, and brain

magnetic resonance. The results of all examinations were normal.

Subsequently, the patient was referred for assessment by a child and adolescent psychiatrist to determine the behavioral etiology of the condition.

With the worsening of the nutritional status a nasogastric tube was placed. When she was 20 months old, she continued to refuse to be fed and a percutaneous endoscopic gastrostomy (PEG) was performed. However, she was eating progressively increasing amounts of food at 6 years old, which led to removing the PEG.

At the age of 17, she keeps a healthy diet, although she still shows some food selectivity. She weighs 48.8 kg and her height is 153.5 cm (in the context of a short family stature) with a body mass index (BMI) of 20.5 kg/m<sup>2</sup> (P43). No nutritional deficits were found at this time, and she presents good school performance and has regular physical activity.

#### Child psychiatric intervention

The intervention started at 11 months old, during hospital admission. A detailed feeding history was collected while observing mother-child feeding interaction. The girl had a nasogastric tube placed and she allowed her mother to feed her with some soup spoons, but she dropped some soup or actively avoided the spoon. Apart from the feeding moments, the baby presented good interaction with her mother and she was interested in exploring the environment. The mother described her lack of appetite and several used strategies to deal with her increasing feeding difficulties, such as walking around with the baby on her lap, using the feeding bottle, feeding her while she was asleep, or forcing the spoon inside her mouth and immediately covering it with the pacifier. Food refusal and intolerance to food textures were observed in all contexts (house, kindergarten, hospital) and with different caregivers.

The intervention consisted in providing emotional support to the mother and establishing a behavioral approach with the child that focused on reducing stress, eliminating all coercive actions, and helping her to experience pleasure during mealtimes. Unfortunately, although some improvement occurred, it was not enough to prevent the need for a gastrostomy.

She started speech therapy and an oral desensitization promoting program was implemented at kindergarten. A positive evolution was achieved and, by the age of 6, the gastrostomy was removed. Nevertheless, meals were time-consuming and food selectivity persisted. She described her feelings towards food as "it strikes me... when I have food in my mouth". Due to this

oral hypersensitivity, she started sessions of sensory integration therapy, followed by another period of sensory integration to improve her chewing and swallowing skills.

Despite all the therapies, the evolution in food diversification was slow, and she still complained about the texture or flavor of food. For example, she used to swallow small pieces of food with water without chewing them.

As an adolescent, she avoided some social situations due to her persistent eating problems. However, she was supported to develop healthier coping skills with a positive impact on her emotional and social interaction status.

## Case 2

### Pediatric intervention

A 2-month-old boy was admitted to the hospital due to persistent vomiting. He was born at term after an uneventful pregnancy and delivery. There were no hypoglycemia or feeding disturbances during the neonatal period. He was exclusively breastfed for 10 days and afterward with formula, and then he started pouring his milk and vomiting.

At hospital admission, he had a normal physical exam and no evidence of cow milk allergy (nor response to extensive-hydrolyzed formula after a four-weeks trial). The radiologic esophago-gastro-duodenal study revealed reflux, for which he was given esomeprazole and domperidone without improvement. Metabolic work-up showed high lactate (3.40-4.11 mol/L) and high pyruvate (lactate to pyruvate ratio ~30) in the glucose overload test, with normal ammonia, acylcarnitines, plasma and urinary amino acids and urinary organic acids with Krebs cycle metabolites and ketonuria.

Six months later, due to food refusal, the boy was fed by nasogastric tube, with persisting vomiting. An upper gastrointestinal endoscopy was performed which was normal. Despite unsatisfactory weight evolution, height or cephalic perimeter was not affected. Another upper gastrointestinal endoscopy (9 months of age) showed discrete congestion of the distal esophagus and small duodenal erosions, with discrete and nonspecific duodenal inflammatory process, without identification of microbial agents or esophageal mucosa damage.

At 20 months of age, he still refused eating, and a percutaneous endoscopic gastrostomy was performed, which was later removed at the age of 5.

Due to persistent hyperlacticaemia he underwent a muscle biopsy that showed variable size fibers with atrophy, ultrastructure with increased mitochondria,

and distorted matrix structure with mitochondrial inclusions and other fibers with lipidic inclusions, without respiratory chain complex deficiency. Brain magnetic resonance was normal, and the genetic studies did not confirm a primary mitochondrial disease or any other cause for his mitochondrial dysfunction.

### Child psychiatric intervention

When the boy was 7 months old, he was referred to a child psychiatrist to evaluate the possibility that parental anxiety or a previous bad experience with feeding could explain his eating behavior. He was a happy baby and easily engaged in interaction with his parents. No relationship disturbance between the child and his parents was found. Even so, the parents were very focused in the feeding moments and had both interrupted their jobs to stay home with the baby. They were offered psychotherapeutic sessions with the child to help them manage their feelings and anxiety and provide moments of shared pleasure with the child.

At 12 months old, the boy showed a global developmental delay, with higher negative impact in the language / listening, eye and hand coordination and gross motor skills. The infant / toddler sensory profile showed impairments in multiple sensory areas (textures, strong smells, relevant oral hypersensitivity). Around 33 months old, the patient showed excessive motor activity and could persist in tasks only for a short time, which led to the diagnosis of a sensory processing disorder. At this point, the vomiting episodes diminished, he went to kindergarten and started speech therapy and sensory integration therapy.

At this point, the boy started showing oppositional behavior towards his parents. He began to show greater interest in food and had less frequent episodes of vomiting, despite some occasions of food refusal. He stopped using the PEG at dinner and lunch. Nonetheless, he swallowed his food without chewing and used to eat very slowly. At 4.5 years old, he threw up only the food that was introduced through the PEG. Therefore, at 5 years old, it was decided to remove it. He started to eat solid foods when he was 7 years old.

Later he was diagnosed with attention deficit hyperactivity disorder and his parents complained of his dysregulated behavior and anxiety at school. Considering the comorbidity with anxiety disorder he started atomoxetine with positive results and was referred for psychological intervention. The eating behavior was no longer an issue.

## Discussion

The clinical cases described above are severe presentations of avoidant restrictive food intake disorder with a potentially fatal outcome. Both children showed an apparent lack of interest in eating, feeding refusal and avoidance based on the sensory characteristics of the food, in the absence of severe medical conditions. Frequent vomiting aggravated oral discomfort and contributed to the refusal to eat as a form of precluding contact with food. At the time they were evaluated, they met sensory food aversion criteria, which is a recent and broad category that captures a large range of clinical presentations.

When a sensory-based feeding problem is identified, sensory integration therapy should be the treatment of choice to promote sensory modulation, which involves modification of the child sensory diet.<sup>7</sup> However, the simultaneous application of sensory integration with other strategies makes it difficult to evaluate its real efficacy.<sup>8</sup> Although used in both cases, sensory integration therapy may have been initiated too late and affected the outcome in both patients negatively. However, a greater impact was observed in the first case.

Both children needed enteral nutrition at a sensitive period for developing feeding skills, which could lead to difficulties in the transition to normal oral feeding and risk of tube dependency.<sup>9</sup> For these reasons, this nutritional mode must be administered only for the shortest possible period. For some caregivers the use of enteral nutrition may result in an improvement in the quality of life. However, it can cause intense grief, frustration, and high levels of stress in many individuals.<sup>10,11</sup> This was the case in both studied children, and there was a need for additional support from the mental health team.

Based on the evidence, a big percentage of children with severe feeding problems may continue to show them later in life and experience emotional and behavioral difficulties with the eviction of social activities. In another study, 71% of children at four years and even more at eight years of age still had feeding problems.<sup>12,13</sup> In our first case, progress was very gradual, and the food selectivity was never resolved. However, in the second case, the child eating symptoms resolved favorably.

Both children benefited from mental health interventions that aimed to help them deal with several developmental challenges, oppositional problems, peer interaction difficulties, embarrassment, low self-esteem, and anxiety.

A severe feeding disorder can also greatly impact parent-child relationship because parents may feel responsible

for their child problem, and the inability to provide physical nourishment can diminish self-confidence in their parenting skills.<sup>14</sup> That is why parents were given emotional support and help to cope with their anxiety and improve their parenting skills, considering a coercion pattern during mealtimes in the first case and a permissive style that became more evident over time, in the second one.

There is still much to know about the different clinical presentations of ARFID, including the role of the various etiological factors and risk factors. The filling of these knowledge gaps will help provide better treatment to very young children with this diagnosis, especially those with severe symptoms and little verbal capacity to explain their difficulties. Considering the important role of sensory difficulties in the etiology of some presentations of avoidant restrictive food intake disorder, we also highlight the importance of providing manual-based treatments based on sensory integration therapy.<sup>15</sup> Until then, treatment approaches have to be focused on mitigation of symptoms, use of nutritional supplements, and provision of emotional support to both parents and children.

In summary, it is relevant to underline that avoidant restrictive food intake disorder can develop at a very early age, with great severity, and requires a multidisciplinary, longstanding, and individually tailored treatment approach.

### Author Contributions

MF, AFL, VM and MSC participated in the study conception or design. MF, AFL, HM, MC, FP, VM and MCS participated in acquisition of data. MF, HM, MC, FP, VM and MCS participated in the analysis or interpretation of data. MF, AFL, VM and MCS participated in the drafting of the manuscript. MF, HM, MC, FP, VM and MCS participated in the critical revision of the manuscript. All authors approved the final manuscript and are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

### Conflicts of Interest

The authors declare that there were no conflicts of interest in conducting this work.

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### Protection of human and animal subjects

The authors declare that the procedures followed were in accordance with the regulations of the relevant clinical research ethics committee and with those of the Code of Ethics of the World Medical Association (Declaration of Helsinki 2013).

### Provenance and peer review

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**Confidentiality of data**

The authors declare that they have followed the protocols of

their work centre on the publication of patient data.

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### Abordagem Multidisciplinar de Perturbação de Ingestão Alimentar Evitante Restritiva Grave: Relato de Dois Casos

A perturbação de ingestão alimentar evitante restritiva é uma perturbação da alimentação que traz vários desafios aos pais e aos médicos. Os autores descrevem dois casos de crianças com problemas alimentares graves e de início precoce, relacionados com disfunção sensorial e com necessidade de nutrição entérica. Foi necessária uma intervenção multimodal com pediatras, gastroenterologistas e pedopsiquiatras. Algumas das intervenções incluíram terapias de integração sensorial e terapias da fala, bem como psicoterapia individual e de intervenção familiar. A perturbação de ingestão alimentar evitante restritiva pode

ter apresentações graves e desenvolver-se em idades muito precoces, condicionando um grande impacto nas crianças e suas famílias. Requer uma abordagem individualizada, duradoura e multidisciplinar.

**Palavras-Chave:** Adolescente; Alteração da Evitação ou Restrição da Ingestão de Alimentos/diagnóstico; Alteração da Evitação ou Restrição da Ingestão de Alimentos/psicologia; Alteração da Evitação ou Restrição da Ingestão de Alimentos/tratamento; Criança; Lactente