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COMMENTARY

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Avoidant Restrictive Food Intake Disorder (ARFID)—Looking beyond the eating disorder lens?

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Abstract

Avoidant Restrictive Food Intake Disorder (ARFID) was first included as a diagnostic category in 2013, and over the past 10 years has been adopted by the international eating disorder community. While greater awareness of these difficulties has increased identification, demand and enabled advocacy for clinical services, the heterogeneous nature of ARFID poses unique challenges for eating disorder clinicians and researchers. This commentary aims to reflect on some of these challenges, focussing specifically on the risk of viewing ARFID through an eating disorder lens. This includes potential biases in the literature as most recent research has been conducted in specialist child and adolescent eating disorder clinic settings, bringing in to question the generalisability of findings to the broad spectrum of individuals affected by ARFID. We also consider whether viewing ARFID predominantly through an eating disorder lens risks us as a field being blinkered to the range of effective skills our multi-disciplinary feeding colleagues may bring. There are opportunities that may come with the eating disorder field navigating treatment pathways for ARFID, including more joined up working with multi-disciplinary colleagues, the ability to transfer skills used in ARFID treatment to individuals with eating disorder presentations, and most notably an opportunity to provide more effective treatment and service pathways for individuals with ARFID and their families. However, these opportunities will only be realised if eating disorder clinicians and researchers step out of their current silos.

KEYWORDS
classification, clinical, treatment

Highlights

- Avoidant Restrictive Food Intake Disorder (ARFID) has been adopted by the eating disorder community, leading to expectations of existing services

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providing effective care and treatment in the context of a limited evidence-base and the absence of robust clinical guidelines.
- By viewing and researching ARFID predominantly via an eating disorder lens, we are potentially creating biases in the literature, limiting generalisability of findings to the broad spectrum of individuals affected by ARFID and not considering the range of effective skills our colleagues may bring to treatment.
- Navigating the development of ARFID pathways brings with it significant opportunities but these are dependent on the eating disorder community looking beyond the eating disorder lens.

Avoidant Restrictive Food Intake Disorder (ARFID) was first included in a diagnostic manual as part of the Feeding and Eating Disorder category in DSM-V in 2013, followed by ICD-11 in 2019. Avoidant restrictive food intake disorder is characterised by avoidance or restriction of food intake resulting in insufficient quantity or variety of food to provide adequate energy or nutritional requirements. This results in one or more of: significant weight loss, clinically significant nutritional deficiencies, dependence on oral nutritional supplements or tube feeding; and this can significantly impact on functioning. These difficulties are not driven by shape or weight concerns and therefore by definition, according to ICD-11, ARFID would be considered a feeding disorder.

Despite this, ARFID appears to have been embraced by parts of the eating disorder community with it frequently being referred to as a "*new eating disorder*". A search of four major eating disorder journals, including European Eating Disorder Review, using the keywords of ARFID and/or ARFID, revealed 19 publications between 2013 and 2018. In the following five years this increased to 60 publications, representing a threefold increase. Avoidant restrictive food intake disorder is frequently represented at international eating disorder conferences and was the theme of the UK's Eating Disorder Awareness Week in 2024. Positively, this increases awareness of this presentation and enables advocacy for more research and the development of treatments in the field. However, this stance also leads to expectations of existing eating disorder services providing effective care and treatment in the context of, at present, a vastly heterogeneous and weak evidence-base regarding possible treatments (Willmott, et al., 2024) and a lack of clear care pathways in the absence of robust clinical guidelines.

One of the difficulties services now face in designing appropriate clinical pathways lies in the heterogeneous nature of ARFID as a broad "umbrella term". It is a construct based on observable behaviour (avoidant or restrictive eating) rather than a common underlying mechanism. One of the purposes of diagnosis is to support our understanding of the cause, prognosis, and treatment of specific difficulties, yet this is problematic with ARFID where there are such broad diagnostic criteria. A 40-year-old woman with no early history of feeding difficulties could be diagnosed with ARFID following a traumatic choking incident leading to significant avoidance of food through fear of aversive consequences. Equally an Autistic three-year-old with historical feeding difficulties from weaning due to hypersensitivity to specific smells, tastes and textures of food could also meet criteria for ARFID. Both DSM-5 and ICD-11 have attempted to address this heterogeneity by describing underpinning drivers for ARFID; specifically sensory sensitivity (e.g., smell, taste, texture, appearance, colour, temperature), lack of interest (chronically low appetite, a poor ability to recognise hunger or low interest in food or eating), and fear of aversive consequences (avoiding foods because of fear of choking, vomiting, or other adverse outcome). This has been referred to in some of the ARFID literature as "*subtypes*" (despite diagnostic criteria not using this terminology) to support differentiation of presentations. However empirical data challenges the presence of distinct subtypes with a high proportion of individuals exhibiting a mixed presentation, which is the most frequent presentation for young people attending secondary care with ARFID in the UK (Kurz, et al., 2015; Sanchez-Cerezo, et al., 2024). Furthermore, diverse characteristics are aligned with differing presentations including gender, co-morbid anxiety, intellectual disabilities and being Autistic, highlighting the need for research to further explore aetiology and refine characteristics of ARFID presentations (Sanchez-Cerezo, et al., 2024). These findings are more aligned with Thomas et al. (2017) proposal of a dimensional model of ARFID where the three proposed underpinning drivers vary in severity and are not mutually exclusive, leading to highly individualised formulation driven care. Therefore practically, due to the broad differences in age, developmental stage, underpinning mechanisms, and clinical presentation; individuals with

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ARFID will require very different specialist skills and interventions from a range of clinical services and professions. The expectation that the diverse needs of all individuals with ARFID can be met by one specialist eating disorder service is perhaps unrealistic. However, the current situation of a range of disconnected services that individuals and families find themselves being passed between, or indeed a complete lack of any service at all, is clearly not acceptable.

Individuals with ARFID have always presented to eating disorder services (potentially previously being diagnosed with eating disorder not otherwise specified), however they also presented to a range of other services including medical paediatrics, occupational therapy, speech and language therapy, dietetics, and general mental health services. By viewing ARFID predominantly through an eating disorder lens and positioning ARFID in eating disorder services, we are potentially ignoring the range of skills that many of our multi-disciplinary colleagues use to effectively work with this population. For example, the skills of paediatric Speech and Language Therapists in the assessment and intervention for oral motor skills; our community Occupational Therapy colleagues in consideration of postural stability when feeding, our neurodevelopmental specialist colleagues to support effective communication and adaptations to the environment. We should be aiming to incorporate the skills of health visitors and child development centres to support prevention, identification, and early intervention for ARFID and developing joint pathways with our paediatric and medical colleagues to ensure effective assessment and treatment of common physical health comorbidities, such as gastrointestinal difficulties.

Clinicians and services have been presented with a diagnosis but are waiting for research and robust clinical guidelines to inform care, treatment, and service pathways. For example, Healthcare Improvement Scotland's SIGN Guidelines for Eating Disorders (2022) attempted to include ARFID within their evidence review as "*people with ARFID can be seen in a range of services, including eating disorder services*", however was unable to find any robust evidence that could be used to inform clinical guidance. There is a significant risk of viewing ARFID as a new disorder and the potential of dismissing 25 years of research and clinical experience of paediatric feeding disorders and associated interventions (Sharp & Stubbs, 2019) which could also inform clinical guidelines. We need to consider how to integrate this wealth of knowledge into our current understanding, care, and treatment of ARFID.

Positively, we are beginning to see some development of treatment protocols in the field. However, there is risk of ARFID research being led by eating disorder research groups and the potential bias this may bring. A recent systematic review on the prevalence of ARFID led to varying estimates of between 0.3% and 84% due to such variations in the sample populations, with a lack of large-scale epidemiological studies on incidence and prevalence (Sanchez-Cerezo, et al., 2023). The majority of studies in this review recruited from specialist eating disorder services. Similarly, in a recent scoping review of psychological interventions for ARFID, 28 out of 50 studies were delivered in day treatment/partial hospitalisation settings or on an inpatient basis, often as part of specialist eating disorder clinics (Willmott, et al., 2023), suggesting an overrepresentation of literature reporting on ARFID interventions from specialist eating disorder services and settings.

While it is positive that interventions are being considered for those with ARFID presenting to eating disorder clinics, this creates some difficulties in generalisation of the research findings to the broader ARFID population. This includes a weight bias where underweight individuals are overrepresented within eating disorder services, meaning people with ARFID who are nutritionally deficient and of a higher weight may be under researched. Feeding problems are found to effect up to 97% of children with intellectual disability (Gal Hardal-Nasser et al., 2011) yet a high proportion of novel interventions being developed exclude individuals with developmental delay. Avoidant restrictive food intake disorder is more common in Autistic individuals with high levels of sensory sensitivities and there is a need to consider whether outcomes based on neurotypical eating patterns are acceptable for this population, rather than neurodiversity-affirming care. Additionally, adults were significantly underrepresented in ARFID intervention studies (Willmott et al., 2023) and recruitment from community eating disorder services naturally omits infant and child populations who are more likely to present to child development services. Where research is conducted with populations presenting to specialist eating disorder clinics, it may not be appropriate to generalise findings to the full spectrum of individuals experiencing ARFID. This is in addition to the grouping of diverse phenotypes under an broad ARFID diagnostic umbrella, which already limits our capacity to meaningfully integrate research findings into clinical practice. This highlights the need to accurately define the role of ED clinicians and services in ARFID pathways, the skills eating disorder clinicians can bring, and to acknowledge the absence of specific skills that may need to be sought elsewhere to be able to provide effective care.

The potential of developing ARFID pathways also brings significant opportunities for the eating disorder field. We have an opportunity to work more productively

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with a range of colleagues and skill-mixes outwith the traditional eating disorder team, enhancing joined up care provision. In turn, this could have an impact on the generalisation and consideration of ARFID specific skills for eating disorder populations, for example, greater understanding of sensory and interoceptive difficulties in Autistic individuals with anorexia nervosa, bulimia nervosa and binge eating disorder. We have a significant opportunity to provide more effective treatment and care for individuals with ARFID and their families who frequently find themselves passed between services; being "held" with little effective intervention or with no service support at all. This would include the opportunities for co-production, developing interventions in partnership with individuals with ARFID that meet their needs. However, these opportunities are dependent on the eating disorder community looking beyond its silo. We need to explore partnerships between research and clinical communities, including our paediatric feeding colleagues, and look beyond the eating disorder lens.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no new data were created or analyzed in this study.

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