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Radcliffe ARFID Workgroup: Toward operationalization of research diagnostic criteria and directions for the field

Kamryn T. Eddy^{1,2}, Stephanie G. Harshman^{1,3,4}, Kendra R. Becker^{1,2}, Elana Bern⁵, Rachel Bryant-Waugh⁶, Anja Hilbert⁷, Debra K. Katzman⁸, Elizabeth A. Lawson^{3,4}, Laurie D. Manzo⁹, Jessie Menzel^{10,11}, Nadia Micali^{6,12,13}, Rollyn Ornstein¹⁴, Sarah Sally¹⁵, Sharon P. Serinsky¹⁶, William Sharp^{17,18}, Kathryn Stubbs¹⁸, B. Timothy Walsh^{19,20}, Hana Zickgraf²¹, Nancy Zucker²², and Jennifer J. Thomas^{1,2}

¹Eating Disorders Clinical and Research Program, Massachusetts General Hospital, Boston, Massachusetts. ²Department of Psychiatry, Harvard Medical School, Boston, Massachusetts. ³Neuroendocrine Unit, Massachusetts General Hospital, Boston, Massachusetts. ⁴Department of Medicine, Harvard Medical School, Boston, Massachusetts. ⁵Division of Gastroenterology, Hepatology and Nutrition, Boston Children's Hospital, Boston, Massachusetts. ⁶Great Ormond Street Institute of Child Health, University College London, London, United Kingdom. ⁷Integrated Research and Treatment Center Adiposity Diseases, Departments of Medical Psychology and Medical Sociology and Psychosomatic Medicine and Psychotherapy, University of Leipzig Medical Center, Leipzig, Germany. ⁸Division of Adolescent Medicine, Department of Pediatrics, Hospital for Sick Children, University of Toronto, Toronto, Canada. ⁹Division of Adolescent and Young Adult Medicine, MassGeneral Hospital for Children, Boston, Massachusetts. ¹⁰Department of Psychiatry, University of California, San Diego, California. ¹¹University of California San Diego Eating Disorder Center for Treatment and Research, San Diego, California. ¹²Department of Psychiatry, Faculty of Medicine, University of Geneva, Geneva, Switzerland. ¹³Department of Psychiatry, Icahn School of Medicine at Mount Sinai, New York, New York. ¹⁴Penn State College of Medicine, Hershey, Pennsylvania. ¹⁵Department of Speech, Language, and Swallowing Disorders, MassGeneral Hospital for Children, Boston, Massachusetts. ¹⁶Occupational Therapy Services, MassGeneral Hospital for Children, Boston, Massachusetts. ¹⁷Department of Pediatrics, Emory University School of Medicine, Atlanta, Georgia. ¹⁸Pediatric Psychology and Feeding Disorders Program, The Marcus Autism Center, Atlanta, Georgia. ¹⁹Columbia Center for Eating Disorders, Department of Psychiatry, Columbia University, New York, New York. ²⁰Eating Disorders Research Unit, New York State Psychiatric Institute, New York, New York. ²¹Department of Psychology, University of Pennsylvania, Philadelphia, Pennsylvania. ²²Department of Psychiatry and Behavioral Sciences, Duke University, Durham, North Carolina.

Abstract

Corresponding author: Kamryn T. Eddy, Ph.D., Eating Disorders Clinical and Research Program, Massachusetts General Hospital, 2 Longfellow Place, Suite 200, Boston, MA 02114, keddy@mgh.harvard.edu.

Conflicts of interest: Drs. Eddy and Thomas receive royalties from Cambridge University Press for their book *Cognitive-Behavioral Therapy for Avoidant/Restrictive Food Intake Disorder: Children, Adolescents, and Adults*.

Objective: Since its introduction to the psychiatric nomenclature in 2013, research on avoidant/restrictive food intake disorder (ARFID) has proliferated, highlighting lack of clarity in how ARFID is defined. Method: In September 2018, a small multi-disciplinary pool of international experts in feeding disorder and eating disorder clinical practice and research convened as the Radcliffe ARFID workgroup to consider operationalization of DSM-5 ARFID diagnostic criteria to guide research in this disorder.

Results: By consensus of the Radcliffe ARFID workgroup, ARFID eating is characterized by food avoidance and/or restriction, involving limited volume and/or variety associated with one or more of the following: weight loss or faltering growth (e.g., defined as in anorexia nervosa, or by crossing weight/growth percentiles); nutritional deficiencies (defined by laboratory assay or dietary recall); dependence on tube feeding or nutritional supplements (< 50% of daily caloric intake or any tube feeding not required by a concurrent medical condition); and/or psychosocial impairment.

Conclusions: This paper offers definitions on how best to operationalize ARFID criteria and assessment thereof to be tested in existing clinical populations and to guide future study to advance understanding and treatment of this heterogeneous disorder.

Keywords

ARFID; ARFID workgroup; DSM-5; diagnosis; research diagnostic criteria

In September 2018, we convened a small group of international experts in feeding disorder and eating disorder clinical practice and research to participate in a 2-day interdisciplinary discussion of avoidant/restrictive food intake disorder (ARFID). This meeting was supported by the Radcliffe Institute Exploratory Seminar Program (Radcliffe Institute for Advanced Study, Harvard University, 2018), which exists to promote intellectual risk-taking in new areas of scholarship (see <https://www.radcliffe.harvard.edu/academic-ventures/seminars-workshops/exploratory-seminars> for more information about program and guidelines). Our cohort included clinical psychologists, psychiatrists, pediatricians (including adolescent medicine specialists), dietitians, a gastroenterologist, an endocrinologist, a speech and language pathologist, and an occupational therapist who work at all levels of care and with patients of all ages. Invitees were a limited pool of experts in the field: researchers actively publishing ARFID findings or clinicians with active ARFID practices who were selected to represent multiple disciplines and a range of career stages from junior to senior investigators and clinicians. Due to budgetary constraints there was a larger representation from the Boston area, which was the location of the seminar; however, we made efforts to achieve geographical diversity and 20% of our attendees came from outside of the United States. Our objective was to consider operationalization of the ARFID diagnostic criteria and assessment thereof for research purposes and reach consensus through multi-disciplinary discussion whenever possible. We share the summary of this meeting to highlight discussion-based consensus operationalizations (i.e., agreed upon by the majority of attendees) and suggest key future directions to advance study of this heterogeneous disorder.

How do we define ARFID?

The *Diagnostic and Statistical Manual of Mental Disorders*, 5th edition (*DSM-5*; American Psychiatric Association [APA], 2013) Eating Disorders Workgroup created the first diagnostic criteria for ARFID based on evidence available at the time. However, five years later, the boundaries of the diagnosis and operationalization of the criteria remain imprecise. Although the eating disorders community—that is, individuals studying and treating those with anorexia nervosa, bulimia nervosa, binge eating disorder, and related presentations (to include restrictive eating disturbances described in childhood; see Bryant-Waugh & Lask, 2013)—has embraced ARFID as a diagnosis, the feeding disorders community—those treating ‘pediatric feeding disorder’ and adults with developmental and physical disabilities—has adopted it less widely (Goday et al., 2019). In fact, Goday and colleagues (2019) recently proposed new diagnostic criteria for ‘pediatric feeding disorder,’ which overlap substantially with *DSM-5* ARFID criteria. Our group had concerns that two sets of criteria to classify the same population would further bifurcate the field. In addition, our feeding disorder colleagues attending the Seminar recognized that a notable strength of ARFID is that the revised and expanded criteria provided a diagnostic home for patients who did not previously meet the DSM-IV diagnosis of feeding disorder of infancy or early childhood. This includes patients with feeding disorders without low-weight, such as cases involving food selectivity commonly observed in children with autism or patients where successful medical intervention (e.g., insertion of a feeding tube) results in improved weight status despite ongoing concerns with restricted oral intake. Research is needed to determine whether ARFID can fully encompass the pediatric feeding disorders, perhaps by the addition of a subtyping scheme, and if not, whether a second DSM diagnosis of ‘pediatric feeding disorder’ would be useful. This includes the challenge not only of differential diagnosis, but also highlights the need for further research to examine whether ARFID presents differently against diverse clinical backdrops (e.g., the presence of an autism diagnosis). The discussion highlighted a need to consider developmental stage and context of feeding or eating disturbance (e.g., birth history, medical complications, caretaker feeding dynamics, level of physical skills/functioning) when considering an ARFID diagnosis. Thus, consistent with revisions to other eating disorder diagnoses, diverse developmental manifestations of ARFID criteria may need to be added as we learn more about the disorder.

Diagnosis

The following questions arose regarding how to operationalize *DSM-5* criterion A, which describes four possible sequelae of avoidant (limited variety or avoidance of certain categories of food) and/or restrictive (limited volume or restriction of overall amount) eating:

What is *significant weight loss (or failure to achieve expected weight gain or faltering growth in children)* (criterion A1)? Experts defined this variably: for example, BMI < 18.5 kg/m² in adults or < 5th percentile in youth, as in the *DSM-5* guideline for significantly low weight in anorexia nervosa; weight loss greater than 10 lbs; crossing BMI or weight percentiles; or based on the *Journal of Adolescent Health* guidelines (Golden et al., 2015). The group agreed that any of these definitions may be acceptable but as variable definitions

may impact on case-ness and illness severity, researchers should test the impact and fit of these thresholds in existing clinical populations and take care to clarify definitions used in any published papers to maximize comparability across studies.

What is *significant nutritional deficiency* (criterion A2)? Among our group, expert perspectives varied on whether blood tests were always necessary, or whether assessment of intake via diarized daily logs may be sufficient to allow clinician estimation of deficiencies as manifestations of avoidant/restrictive eating. Reliance on laboratory data may not be feasible given that laboratory data do not necessarily always correlate with either clinical or dietary findings and the cost for many of these assays is high. Some individuals may be taking multivitamins and minerals prophylactically or relying on vitamin-fortified foods (e.g., breakfast cereals), which may be correcting for nutrients low or missing in the diet. Dietitians supported the use of prospective food records or dietary recall to identify deficiencies or insufficiencies in nutrient consumption that may increase the risk for deficiency. In fact, additional research is needed to identify crucial nutritional correlates and consequences of food avoidance and restriction patterns commonly observed in those with ARFID. Consensus was that either approach could be acceptable but requires validation in existing clinical populations. Operationalization used in research should be clearly specified in any published papers.

What is *dependence* on enteral feeding or oral nutritional supplements (criterion A3)? Operationalization of “dependence” varied with some using a threshold of 2 supplement drinks or any tube feeding, and another suggesting that the likely impact of *removing* supplements from diet on growth and development be considered as a measure of this criterion. However, the majority agreed on a definitional threshold of 50% or more of daily caloric intake via oral supplementation or *any* tube feeding that is not required by a concurrent medical condition to serve as a guideline for use in research. Future data collection will be needed to adjudicate this consensus definition.

Is *marked interference with psychosocial functioning* related to avoidant and/or restrictive eating (criterion A4) sufficient to meet criterion A in the absence of criteria A1–3? Although the stem criterion A includes the clause, “as manifested by persistent failure to meet appropriate nutritional and/or energy needs,” an individual need not have failure to meet nutritional/energy needs in order to have significant psychosocial interference. For example, expert clinicians in the room described individuals presenting for treatment with severely restricted diets due to sensory sensitivity are of normal weight with no nutrition deficiencies but unable to attend school, hold jobs, or establish romantic relationships due to inability to manage eating situations. While one Seminar member raised the risk of over-diagnosis, based on clinical evidence of over-reporting of impairment by some parents or caregivers on behalf of younger children, most experts in the Radcliffe group were already conferring diagnosis if criterion A4 alone was met. In fact at press-time the APA was actively considering a proposal to eliminate the above clause to clarify that A4 (in the absence of criteria A1–3) would satisfy criterion A.

Recovery

To complement the diagnostic criteria, our group discussed an operational definition of recovery, which was thought to be important to promote evaluation of the efficacy of new treatments. A consensus proposal for ARFID recovery included eating a diet that is adequate in volume and variety associated with the following: (1) eating foods from all the major food groups (fruits or vegetables, grains, protein foods, and dairy) regularly (e.g., having all food groups represented several days (e.g., 2–3) per week); (2) weight no longer in the underweight range (based on individualized clinical assessment), height growth and physical development (e.g., maturation) resumed; (3) no nutritional deficiencies; (4) no more than one nutritional supplement drink per day; (5) no longer avoiding, requiring major accommodation, or experiencing significant distress in social eating situations.

Next steps

Radcliffe experts proposed operationalizations—in some cases more than one possible such operationalization— of criterion A and of recovery, which all warrant testing in existing clinical populations. Validation within patient groups presenting across various settings can help to inform clinical utility of the possible thresholds. Ongoing and future data collection specifying operationalization of criteria will similarly allow for consideration and meta-analyses of the thresholds to guide revisions to *DSM* going forward.

How do we assess ARFID?

Screening

Individuals with ARFID often present to settings other than mental health clinics. The group achieved clear consensus (agreed upon by all attendees) that screening and identification of possible ARFID can be made by any healthcare professional including, but not limited to, a mental health provider, dietitian, pediatrician, family physician, internist, nurse practitioner, endocrinologist, gastroenterologist, speech and language pathologist, or occupational therapist. Generally, contact with a primary care physician can inform assessment of criteria A1–3 and whether there is any additional medical diagnosis that may contribute to eating or feeding difficulties, but when other psychiatric or medical morbidities or developmental concerns are present other specialties may also be needed for assessment and differential diagnosis.

Two new self-report screening tools include Eating Disorders in Youth-Questionnaire (EDY-Q; Kurz, van Dyck, Dremmel, Munsch, & Hilbert, 2015) for children and adolescents and Nine Item ARFID Screen (NIAS; Zickgraf & Ellis, 2018) for adults. These both yield dimensional symptom ratings rather than diagnoses. The EDY-Q in particular has a suggested cut-off score for possible ARFID. Applicability of these assessment tools in clinical versus non-clinical or research settings is variable. The experts identified a need for a screening tool with established sensitivity and specificity for the diagnosis of ARFID.

Evaluation and Diagnosis

A medical professional (e.g., primary care physician, pediatrician, nurse practitioner) is recommended to complete the medical and nutritional assessment of avoidant/restrictive

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eating. Such evaluation should include a physical assessment to ascertain growth, eating history, and the assessment of acute and potential long-term medical and nutritional complications of avoidant/restrictive eating such as sequelae of low weight (e.g., hypogonadism, bone loss) or obesity, as well as malnutrition (e.g., insufficient vitamin and mineral consumption), which can occur in individuals with ARFID across the weight spectrum. Medical assessment should also explore presence of underlying systemic or gastrointestinal disorders which may contribute to the onset or persistence of ARFID, such as celiac disease, peptic or allergic gastrointestinal disease (including eosinophilic esophagitis), Crohn's disease, and functional gastrointestinal disorders including constipation and irritable bowel syndrome. Nutritional/dietary assessment should determine the adequacy of dietary diversity, and caloric needs to maintain growth and development.

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A mental health clinician (e.g., psychologist, psychiatrist, social worker) should complete the diagnostic interviews and assessment of psychosocial impairment and functioning. Diagnostic tools that are available for use in research include the Eating Disorder Assessment for DSM-5 (EDA-5; Sysko et al., 2015), the new ARFID module of the Eating Disorder Examination (Schmidt, Kirsten, Hiemisch, Kiess, & Hilbert, in press), and the Pica, ARFID, Rumination Disorder Interview (PARDI) (Bryant-Waugh et al, in press). Preliminary reports on the EDE-ARFID module and the PARDI are included in the current *IJED* special issue, and larger-scale studies of the psychometric features of these measures for individuals across the lifespan are underway.

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Additional opinion and input from specialists may be needed for more complex ARFID presentations. For example, practitioners should consider investigation for underlying gastrointestinal pathology if feeding difficulties do not improve with standard care or if the following elements are noted on history or physical examination: presence of localized or nocturnal abdominal pain, recurrent diarrhea or vomiting, blood in the stool, dysphagia, or systemic symptoms (e.g., persistent fever, rash, oral ulcers, and joint pain). In addition, the presence of autoimmune disease and/or atopy in the individual or family members may serve as factors that can increase the likelihood that underlying GI pathology will be found. Referral for a clinical feeding/swallowing evaluation with a speech-language pathologist may be indicated if oral sensorimotor concerns are present, such as inadequate mastication, pocketing food in the oral cavity, lack of age-appropriate texture progression, and/or if oropharyngeal dysphagia concerns are present due to clinical signs of aspiration while eating or drinking (e.g., coughing, choking) or if there is respiratory compromise of undiagnosed etiology (e.g., pneumonia, recurrent upper respiratory infections, chronic cough). An occupational therapy assessment may be useful particularly for those patients who have difficulty processing sensory input during developmentally appropriate activities, consistent difficulty with self-care tasks (e.g., brushing their teeth, wiping their face), or ongoing difficulties with self-regulation. In addition, mealtime observations, commonly used in evaluation of feeding difficulties in younger individuals, were also acknowledged as forming a useful component of assessment to measure bites consumed, food selected, facial expressions, parent-child interactions, and more.

What areas of study are needed to advance understanding and treatment of ARFID?

Pathophysiology

Although researchers in the room were actively studying the neurobiology of ARFID, everyone acknowledged that research in this area is in its early stages. Some areas of importance for future studies included genetics, given clinical experience that ARFID runs in families; and examination of appetite-regulatory hormones and their contribution to eating behavior and clinical manifestations of ARFID (e.g., Thomas et al., 2017), which may guide development of pharmacological interventions. The group also discussed the roles of anxiety, avoidance learning, and cognitive features such as rigidity or detail orientation that may be transdiagnostic across psychiatric or neurodevelopmental disorders, and impact ARFID maintenance and outcomes. Additional applications discussed in our group included the development of a data repository of individuals with ARFID with the goal of genome-wide association studies (e.g., working toward an initial target of 2000–3000 cases) including collection of microbiome samples.

Treatment

As of yet, there are no well-established treatments for ARFID, with a limited number of randomized clinical trials among patients with pediatric feeding disorders (Sharp et al. 2017). Evidence to guide treatment for this heterogeneous population is needed. Our experts, representing several disciplines across different levels of care, all with diverse training backgrounds, agreed that not all individuals with ARFID would require a multidisciplinary treatment team. The expert consensus was that all patients generally require a minimum of a primary care practitioner and/or pediatrician to monitor physical health. The need for multidisciplinary involvement increases at younger ages and with higher levels of severity and medical complexity. Patients who are older or less severe may manage treatment with a single practitioner whose expertise is most relevant to the case. Furthermore, experts noted that ARFID is phenotypically heterogeneous and these variable presentations may in turn call for variable interventions, only some of which would be multidisciplinary.

Several novel treatments for ARFID were presented and are currently under study (e.g., Bryson et al., 2018; Lock et al., 2019; Ornstein et al., 2017; Thomas & Eddy, 2019; Zucker et al., in press). Across disciplines, levels of care, and developmental status of patient groups, significant themes were identified across existing psychosocial interventions including (1) psychoeducation about ARFID, nutrition, and principles of exposure and habituation; (2) caregiver or family involvement for support and to reinforce change, particularly for younger patients; (3) exposure therapy involving both in- and out- of session work; and (4) structured mealtimes. Other commonly implemented strategies included use of reinforcements to promote behavior change, sensory and self-regulation treatments, management of anxiety and other comorbidities, pharmacotherapy (e.g., cyproheptadine or mirtazapine to stimulate appetite), tube weaning, and other medical interventions, as needed. Given that community-based expertise in ARFID is limited, it was considered a strength that these competencies can be scaffolded based on existing expertise (e.g., with other eating disorders, anxiety disorders, developmental disorders). Furthermore, the experts highlighted

the often-protracted nature of treatment of feeding difficulties in the community and uniformly recommended that we work as one field—both individuals with expertise in eating and in feeding disorders—to advance time-limited and outcome-guided interventions, and to improve access to care and treatment efficacy.

Conclusions

The boundaries of ARFID require further study and input from investigators who bring varying developmental and clinical perspectives. The variable operationalization of the criteria contributes to the heterogeneity of the diagnosis and whether illness severity or trajectory varies in relation to these definitions is an open question that warrants testing in existing clinical populations. In this paper we have therefore proposed research diagnostic criteria for ARFID and criteria for recovery to guide the field in study of ARFID. To better treat ARFID, randomized controlled trials evaluating diverse treatment approaches and their application and fit across heterogeneous patient groups will eventually be necessary. Whether certain patient groups will respond to particular interventions requires study. Further medical complexities and co-morbidities associated with ARFID need to be evaluated to tailor interventions. Future studies involving cognitive testing and neuroimaging may help to capture the neurobiological underpinnings of ARFID.

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