



Avoidant/restrictive food intake disorder

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Background

Avoidant/restrictive food intake disorder (ARFID) is a complex and serious eating disorder. To date, very little is known about this disorder and its associated behaviours in Canadian children and adolescents. ARFID is a new diagnostic category in the DSM-5 that has replaced and expanded the DSM-IV diagnosis of feeding disorders of infancy or early childhood. The signature feature of ARFID is a disturbance in eating or feeding as exhibited by persistent failure to meet appropriate nutritional and/or energy needs leading to significant clinical consequences, such as weight loss, failure to achieve expected weight gain or faltering growth in children, nutritional deficiency, dependence on enteral feeding or oral nutritional supplements, or marked interference with psychosocial functioning.

Patients with ARFID are different from those with anorexia nervosa or bulimia nervosa in that they do not see themselves as overweight, are not preoccupied with body weight, shape or size, do not fear weight gain and do not have cognitive distortions. Children and adolescents with ARFID experience clinical impairment as evidenced by their significant degree of weight loss and/or growth interruption and, as a result, are at risk for severe acute and chronic medical complications. Although ARFID can occur in children, adolescents and adults, it is presumed to be more common in younger patients.

The depth of knowledge available concerning diagnostic features, clinical course, and outcomes associated with ARFID remains extremely limited. Preliminary data in North American studies suggests that the incidence of ARFID in children and adolescents



assessed for eating disorders at paediatric tertiary care eating disorder programs ranges between 6% and 14% (Fisher et al, 2013; Norris et al, 2013). Although the majority of these patients would have been referred from community settings, there are no studies that have looked at incidence rates of ARFID using community-based samples. Further, there is no information on the clinical presentation or characteristics of ARFID in Canadian children and adolescents. Much of what is known has been taken from a limited number of studies, which have drawn upon children and adolescents referred to paediatric eating disorder programs in tertiary care centres (Ornstein et al, 2013; Norris et al, 2013).

The proposed study will address an important and newly categorized paediatric health issue. There is a great need for data on ARFID and surveillance is an appropriate means of collecting these data. As outlined above, this disorder has significant scientific interest within Canada and internationally. Data collection nationally on ARFID will establish valuable information on incidence, provide important information on the spectrum of presentations in the paediatric population, establish the clinical impairment, medical complications and medical and psychiatric comorbidity, and will advance the knowledge of Canadian paediatricians who are most often the first health care professionals to evaluate these young people. This study is timely and has significant potential for educating paediatricians on this new DSM-5 eating disorder, which will ultimately facilitate early recognition and immediate treatment of children and adolescents. Study results will prompt further research into needed information on course, prognosis, and treatment approaches.

Methods

Through the CPSP, a survey will be sent to approximately 2,500 Canadian paediatricians and paediatric subspecialists each month asking them to report any new cases of ARFID. The CPSP is an ideal venue because it reaches paediatricians in a wide variety of community and academic health centres. Paediatricians who identify cases will be sent a questionnaire in order to provide detailed clinical information on the cases.

Objectives

Primary objective

To determine a conservative incidence rate of avoidant/restrictive food intake disorder (ARFID) in children and adolescents presenting to paediatricians in Canada.

Secondary objectives

- 1) To determine the clinical utility of the definition of ARFID and to determine whether or not the diagnostic criteria are correctly understood and interpreted by participants.
- 2) To describe the pathways of referral, patterns of presentation and clinical features (eating behaviours) associated with ARFID in children and adolescents presenting to paediatricians.
- 3) To examine duration of symptom onset prior to presentation to the paediatrician or child psychiatrist.
- 4) To identify comorbid psychiatric and medical disorders that co-occur with ARFID.
- 5) To describe the current treatment planned and/or offered to children and adolescents with ARFID, including regional differences in management.



Avoidant/restrictive food intake disorder (continued)

Case definition

Report any child or adolescent from age 5 up to the patient's 18th birthday, seen in the previous month with a newly diagnosed eating or feeding disturbance (e.g., 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.

Exclusion criteria

The feeding or eating disturbance is:

- a result of lack of available food
- a result of culturally sanctioned practice
- attributed to anorexia nervosa or bulimia nervosa
- associated with abnormalities in the way in which the young person perceives his/her body weight or shape
- explained by another medical or mental disorder, so that if treated, the feeding or eating disturbance will go away.

Duration

January 2016 to December 2017

Expected number of cases

A lack of prospective, longitudinal studies of ARFID onset in children and adolescents makes estimating the number of expected new cases per year (incidence rate) in Canada challenging. Based on available literature, it is estimated there will be approximately 300–350 newly reported cases per year in Canada.

Ethical approval

Research Ethics Committees of The Hospital for Sick Children, Toronto, and Children's Hospital of Eastern Ontario, Ottawa

Analysis and publication

Data will be analyzed using descriptive statistics. Descriptive summaries of demographic characteristics will be performed. Dichotomous variables will be summarized using percentages, normally distributed continuous variables will be summarized using means together with standard deviations, and continuous variables that are not normally distributed will be summarized using medians together with range.

Annual and final reports will be published in the *CPSP Results* and circulated to all participants. Completed study results will be presented at national and international scientific meetings and submitted for publication in scientific peer-reviewed journals.



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