



Early-onset eating disorders

Principal investigators

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Background

Incidence/prevalence

The term 'eating disorder', according to version IV of the Diagnostic and Statistical Manual (DSM-IV), includes anorexia nervosa, bulimia nervosa and eating disorders not otherwise specified (patients fulfilling some, but not all, of the diagnostic criteria for either anorexia nervosa or bulimia nervosa). While the issue of the most appropriate diagnostic criteria for eating disorders in children has been a matter of great debate, epidemiological studies suggest that the prevalence of anorexia nervosa (using DSM-IV criteria) in adolescents has been increasing over the last 50 years and document that it is now the third most common chronic illness affecting adolescent females. In fact, the age of onset of anorexia nervosa may be becoming even younger although very little incidence data is available for younger children with eating disorders (<13 years) and the few estimates that are available vary considerably. One retrospective population-based incidence study including patients up to 18 years of age found an incidence of anorexia nervosa of 25.7 per 100,000 girls aged 10–14 years and 3.7 per 100 000 boys in the same age group. In contrast, another study, again using the diagnostic criteria from the DSM-IV but with stricter weight-loss criteria, found an incidence of 9.2 per 100,000 girls aged 10–14 years.

Currently, there are no population-based studies specifically aimed at determining the incidence of eating disorders associated with weight loss in young children (<13 years). However, surveys of dieting and body dissatisfaction in children suggest that this is a problem in this age group. Depending on the study, between 20% and 42% of 9-year-old girls were trying to lose weight and 55% of girls between the ages of 8 and 10 were dissatisfied with their size. Of even greater importance, up to 21% of 5-year-old girls had weight concerns. Furthermore, it is possible that existing studies have underestimated the true incidence in younger children due to difficulties with the application of the current diagnostic criteria to children.



Although the exact cause of anorexia nervosa is unknown, the bio-psychosocial model of etiopathogenesis is widely accepted. Many researchers have hypothesized that the media may play a central role in creating and intensifying the phenomenon of body dissatisfaction and may even be associated with the development of specific weight-losing behaviours in children and adolescents.

The medical and psychological consequences of starvation, significant weight loss, lack of weight gain during a period of growth, and the use of dangerous methods of weight control are well documented. Acute complications include electrolyte disturbances, acid-base and fluid imbalances, as well as cardiac arrhythmia, hypotension, and hypothermia. Deliberately restricting food intake over long periods of time can lead to complications early in the illness and may have irreversible effects. These complications include growth failure, delayed sexual development and puberty, amenorrhea and delayed menarche and osteoporosis.

High rates of comorbid psychiatric illness are reported in studies of adolescents and adults. For example, a life-time diagnosis of anxiety disorders was reported in 56.4% of patients with adolescent-onset anorexia nervosa (mean age of 16.2 years at diagnosis), and major depressive disorder and dysthymic disorder occurred in 66% of female patients with a mean age of 14.5 years at diagnosis of eating disorder. However, no specific data on the rate of comorbid psychiatric illness is available for younger children. Clearly, it will be important to identify patterns of comorbid psychiatric illness in these children to provide recommendations for treatment.

Limitations of the current diagnostic criteria for eating disorders

Much of the dissatisfaction with the current diagnostic criteria for eating disorders in children and young adolescents stems from its obvious limitations. In one study, only 50% of referrals to a childhood-onset eating disorders clinic (age 7–15 years old) fit the current diagnostic criteria for anorexia nervosa or bulimia nervosa. Most papers reporting atypical eating disorders of childhood have been case studies or studies that contained cohorts of less than 10 children. The marked eating abnormalities described in these papers are qualitatively different from those seen using the strict DSM-IV criteria for anorexia nervosa, bulimia nervosa, and eating disorder not otherwise specified. As one study found, “it is inadequate to simply portray children’s cases that do not fit into a narrow adult standard as atypical.”

The **DSM-IV criteria** for eating disorders was developed by the Task Force on DSM-IV and its work group who conducted a three-stage empirical process. This process included (1) comprehensive and systematic reviews of the published literature, (2) reanalysis of already collected data sets, and (3) extensive issue-focused field trials. The majority of the best available clinical and research literature used to develop these criteria focused on older adolescents and adults. As such, there are some inherent limitations with these criteria when applied to children.



Early-onset eating disorders (continued)

The current DSM-IV criteria for anorexia nervosa requires that all of the following conditions be met:

- a) Refusal to maintain body weight greater than minimally normal (<85% for age and height)
- b) Intense fear of weight gain or becoming fat, even though underweight.
- c) Disturbance in the way in which body weight, size or shape is experienced.
- d) Undue influence of body weight or shape on self-evaluation.
- e) Amenorrhea for at least 3 consecutive cycles in post-menarchal females (secondary amenorrhoea).

Although weight loss is certainly present for some children, dietary restrictions and malnutrition in others may lead to weight maintenance when they should be growing and developing, rather than weight loss. The DSM-IV criteria, however, excludes children who have not yet reached the critical level of weight loss to represent <85% of expected weight but who may still have significantly abnormal eating or exercise behaviours. In addition, children with poor growth in height as a result of malnutrition may have an “expected” weight that is falsely low if the current growth restricted height is used in the estimate of “expected” weight. Thus, the use of “<85% of expected weight for age and height” may lead to an underestimation of the severity of low weight in younger children.

The DSM-IV criteria for eating disorders also include disturbance in the way in which body weight, size or shape is experienced, and undue influence of body weight or shape on self-evaluation. Some studies have shown that this may not be a developmentally appropriate measure for younger children. A recent study has demonstrated that even older adolescents have poor perception of their actual body size. Standardised self-report questionnaires, such as the Eating Disorder Inventory, may not detect these symptoms in children. Also, young children may not report fear of weight gain while at a low weight but may start to do so only when weight has been restored to a more healthy level. Children may also be unable to express distress in terms of body shape and self-perception but may instead experience and describe somatic symptoms, such as abdominal pain or discomfort, feelings of fullness, nausea, or loss of appetite.

Finally, while the presence of amenorrhoea is an important criterion for the diagnosis of anorexia nervosa in post-menarchal women (secondary amenorrhoea), obviously it is not relevant to the younger age group who are pre-menarchal. However, with early onset of weight loss or poor weight gain and growth restriction, there may be pubertal delay with accompanying failure to start menstruating (primary amenorrhoea). In fact, the value of amenorrhoea as a diagnostic criterion for adult patients has even been questioned. In summary, all of the diagnostic criteria for a diagnosis of anorexia nervosa according to DSM-IV have limitations when applied to younger children.



An alternative classification for the range of eating disorders of childhood proposed by Bryant-Waugh and Lask is the *Great Ormond Street (GOS) criteria*. The diagnoses within the classification are anorexia nervosa, food avoidant emotional disorder, selective eating, functional dysphagia, bulimia nervosa, and pervasive refusal syndrome. The overriding feature of all these diagnoses is the “excessive preoccupation with weight or shape and /or food intake which is accompanied by grossly inadequate, irregular or chaotic food intake.”

The definition of childhood anorexia nervosa according to the GOS classification includes:

- a) Determined weight loss (e.g., food avoidance, self-induced vomiting, excessive exercising, abuse of laxatives).
- b) Abnormal cognitions regarding weight and/or shape.
- c) Morbid preoccupation with weight and/or shape.

Again, this definition requires weight loss and does not explicitly allow for failure to gain weight or height as expected for the developmental or pubertal stage. Validation studies for this classification system are awaited. However, Nicholls et al have compared the reliability of the Great Ormond Street, DSM-IV and ICD 10 diagnostic criteria for eating disorders in a sample of 81 children aged 7 to 16 years. Inter-rater reliability was lowest for ICD10 (fair), substantial for DSM-IV and perfect for GOS criteria. The authors have suggested that while the classification of eating disorders in children still needs evaluation, the GOS criteria may be more reliable than existing criteria.

The purpose of this study is to determine the rate of new diagnoses of eating disorders in young children, providing otherwise unknown information. If the incidence of eating disorders is truly increasing, it is essential to determine the size of the problem in terms of resource allocation for diagnosis and management. This study will provide a range of descriptive data on the features present at the time of diagnosis, including some of the medical complications and concurrent psychiatric illness, which will contribute to the international debate on definition and classification and will inform the development of new diagnostic criteria. Without clear and appropriate diagnostic criteria, it is possible that children with significantly abnormal eating and other weight-related behaviours will continue to go unrecognized. A better understanding of the spectrum and presentation of this disorder will help promote the creation of developmentally appropriate management guidelines to provide improved outcomes for children and adolescents with this disorder. Further study, beyond the scope of this current proposal, will be required to describe the natural history and chronic complications of early-onset eating disorders.



Early-onset eating disorders (continued)

Methods

Paediatricians and child and adolescent psychiatrists will report cases through the CPSP monthly response survey. Reporting physicians will be asked to complete the clinical questionnaire, including information on:

- the presence of specific behaviours and cognitions related to food and weight;
- measurements of growth (weight and height) and pubertal status;
- the presence of acute medical compromise;
- family history of and/or concurrent psychiatric disease;
- types of therapeutic interventions and resource utilization, including hospitalisation.

This Canadian proposal has been developed to complement the study of early-onset eating disorders currently in progress through the Australian Paediatric Surveillance Unit (APSU).

Objectives

- To determine the minimum incidence of early-onset eating disorders in Canadian children as reported by paediatricians and child and adolescent psychiatrists.
- To obtain age and gender distribution of children reported with early-onset eating disorders.
- To describe the range of medical and psychiatric clinical features at the time of diagnosis.
- To compare the presentation of eating disorders in this population with existing diagnostic criteria for diagnosis of eating disorders.
- To describe the therapeutic interventions currently used in management.

Case definition

Excessive weight loss and underweight are usually defined as less than 85-90% of average weight for height. Standard growth charts are commonly used to determine this percentage. This method has significant limitations though, as it does not take into consideration different body types and muscle mass. Nevertheless, it remains the standard most often quoted. Childhood and early adolescence is a period where growth in weight, height and change in body composition is expected. The average expected weight gain in early adolescence is 2.0 kg per year. Failure to gain weight at this minimum rate or any weight loss should be a warning and requires investigation. This study aims to provide descriptive data about the range of clinical findings, the amount of weight loss, symptoms and behaviours in children with early-onset eating disorders.

A broad definition for “eating disorders” is proposed for this study to include the full spectrum of children with disordered eating sufficient to cause a disruption to weight



gain or actual loss of weight. Participants will report any child aged from 5 to 12 years of age inclusively, seen in the previous month, with newly diagnosed early-onset eating disorder,

where *eating disorder* is defined as:

- determined food avoidance
- and**
- weight loss or failure to gain weight during a period of expected growth, not due to any identifiable organic cause, such as celiac disease.

Exclusion criteria

Obese children in a supervised weight management program.

Duration

March 2003 to February 2005

Expected number of cases

Based on previous estimates of incidence and the current population of children in this age group in Canada, the expected number of cases would be up to 90-100 per year.

Ethical approval

The Research Ethics Board, The Hospital for Sick Children

Analysis and publication

The investigators will analyse data, and annual reports will be distributed to the CPSP participants.

Data will be published in a peer-reviewed journal on completion of the study period.

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(Other references are available from the investigators or the CPSP office.)