Incidence and Age-Specific Presentation of Restrictive Eating Disorders in Children

A Canadian Paediatric Surveillance Program Study

Leora Pinhas, MD, FRCPC; Anne Morris, MBBS, MPH, FRACP; Ross D. Crosby, PhD; Debra K. Katzman, MD, FRCPC

Objectives: To document and describe the incidence and age-specific presentation of early-onset restrictive eating disorders in children across Canada.

Design: Surveillance study. Cases were ascertained through the Canadian Paediatric Surveillance Program by surveying approximately 2453 Canadian pediatricians (a 95% participation rate) monthly during a 2-year period.

Setting: Canadian pediatric practices.

Participants: Pediatricians and pediatric subspecialists.

Main Outcome Measures: A description of clinical presentations and characteristics of eating disorders in this population and the incidence of restrictive eating disorders in children.

Results: The incidence of early-onset restrictive eating disorders in children aged 5 to 12 years seen by pediatricians was 2.6 cases per 100,000 person-years. The ratio of girls to boys was 6:1, and 47.1% of girls and 54.5% of boys showed signs of growth delay. Forty-six percent of children were below the 10th percentile for body mass index, 34.2% were initially seen with unstable vital signs, and 47.2% required hospital admission. Only 62.1% of children met criteria for anorexia nervosa. Although children with anorexia nervosa were more likely to be medically compromised, some children who did not meet criteria for anorexia nervosa were equally medically unstable.

Conclusions: Young children are seen with clinically significant restrictive eating disorders, with the incidence exceeding that of type 2 diabetes mellitus. These eating disturbances can result in serious medical consequences, ranging from growth delay to unstable vital signs, which can occur in the absence of weight loss or other restrictive eating disorder symptoms.


Little information exists about restrictive eating disorders (EDs) in children and adolescents, despite onset occurring most commonly between the ages of 10 and 20 years1 and EDs reported in children as young as 5 years old.2 Subsyndromal presentations of anorexia nervosa (AN), typically referred to as EDs not otherwise specified, have higher rates of occurrence but often are underreported or misdiagnosed in children.3 Adequate data documenting the incidence and presentation of EDs among children in North America are lacking. Policy makers and health care professionals need epidemiologic information in children with EDs to improve treatment planning and resource allocation.4

The incidence and prevalence of mental health disorders are often estimated using large community surveys involving interviewing for specific diagnoses.5,6 Representative population-based studies yield more valid estimates of rates in the population than clinical case series or registries. However, the ability of a study to estimate incidence and prevalence is dependent on the number of cases detected. Less common or concealed disorders, such as EDs, can present particular challenges. Many population-based mental health surveys have failed to identify or report any child or adolescent cases of EDs; investigators typically have not attempted to estimate the occurrence of EDs.7,8

Therefore, North American data frequently originate in clinical registries from individual specialized ED treatment programs. These designs are challenged by selection bias, whereby nonidentification can result from failure to seek treatment. Regardless of method used, studies4,5,6,9,10 have found few cases of EDs in children; researchers using a clinical registry in a United Kingdom database of primary care settings reported in 1996 that the incidence of AN in girls younger than 10 years

Author Affiliations: Eating Disorders Program, Department of Psychiatry (Drs Pinhas) and Division of Adolescent Medicine, Department of Paediatrics (Dr Katzman), University of Toronto, The Hospital for Sick Children, Toronto, Ontario, Canada; Department of Pediatrics and Child Health, Children’s Hospital at Westmead, Westmead, Australia (Dr Morris); and Neuropsychiatric Research Institute, School of Medicine and Health Sciences, University of North Dakota, Fargo (Dr Crosby).
was 0.4 cases per 100,000 person-years. More recently, a prospective study in Australia documented the incidence of restrictive EDs as 1.4 cases per 100,000 children aged 5 to 13 years. Such data are unavailable for North America, and the only similar (although non-equivalent) information is provided by health services use hospitalization data in children with EDs. American data comparing estimates from 1999-2000 vs 2005-2006 indicate that 4% of admissions (n=11,26) for an ED (n=28,155) in 2005-2006 were among children younger than 12 years; compared with 1999-2000, this represented a 119% increase. In Canada, the hospitalization rate among girls aged 10 to 14 years with EDs was 22 admissions per 100,000 person-years. These numbers indicate that EDs exist among younger children.

From a diagnostic standpoint, the presentation of EDs among youth can differ significantly depending on age, and there is no clear picture of restrictive EDs in young children. Although some studies have described children with early AN, they represent small case series in single specialized treatment centers collected over a period of years. This method has limited generalizability of results and does not provide meaningful information on initial presentation of EDs. A recent retrospective study had a larger sample size and compared the presentation of EDs in young patients (<13 years) vs older adolescents (≥13 years). In that study, younger children were more likely to weigh less, be diagnosed as having EDs not otherwise specified, and have a shorter duration of disease. Children diagnosed as having AN were less likely to endorse cognitions related to weight and shape. As in the study from Australia, there was a large proportion of boys in the sample, as well as high rates of psychiatric comorbidity. Other studies have reported that children with EDs have a high incidence of comorbid psychiatric diagnoses.

The objectives of this study were to document and describe the incidence and age-specific clinical presentation of early-onset EDs in children (aged <13 years) with significant food restriction or weight loss seen in pediatric practices. This study was approved by the Research Ethics Board at The Hospital for Sick Children, Toronto, Ontario, Canada.

METHODS

Cases were ascertained between March 1, 2003, and February 28, 2005, through the Canadian Paediatric Surveillance Program (CPSP). Surveillance studies are used internationally to describe and track rare conditions, including EDs. The CPSP, a national initiative, is designed to collect data about rare conditions in pediatric populations. Approximately 2453 Canadian pediatricians (95%) in clinical practice participate in this program. Validation studies of the CPSP indicate an initial reporting rate of 82%, with a 96% response rate for detailed questionnaire completion. Pediatricians were surveyed monthly and were asked to report any new cases meeting criteria for this study.

CASE DEFINITION

Cases were defined as any child aged 5 to 12 years seen in the previous month with newly identified restrictive ED symp-

toms. In this study, the word restrictive refers to intentional limitation or avoidance of nutrition. A broad definition of EDs was used, which included any disordered eating behavior sufficient to cause a disruption, weight gain, or actual loss of weight. Obese children in a supervised program were excluded from the study.

PROTOCOL

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RESULTS

INCIDENCE OF EDs

The incidence of early-onset restrictive EDs in children aged 5 to 12 years seen by pediatricians was 2.6 (95% confidence interval [CI], 2.1-3.2) cases per 100,000 person-years. The lowest incidence was 0.4 (95% CI, 0.1-1.1) cases per 100,000 person-years, observed in boys aged 5 to 9 years, while the incidence in girls aged 5 to 9 years was 1.3 (0.7-2.3) cases per 100,000 person-years. The highest incidence was 9.4 (95% CI, 7.2-12.2) cases per 100,000 person-years, observed in girls aged 10 to 12 years, while the incidence in boys aged 10 to 12 years was 1.3 (0.5-2.5) cases per 100,000 person-years.

CHARACTERISTICS OF THE STUDY SAMPLE

In total, 161 children younger than 13 years from across Canada were included in the study. The ratio of girls to boys was 6.1 (138 girls and 22 boys) with 1 case not specifying sex. The mean (SD) age was 11.0 (1.5) years, and the mean (SD) duration of symptoms before ED identification was 28 (28) weeks. Most identified children of white race/ethnicity (91.2%), followed by Asian (4.4%); the remaining 4.4% of children were Latin American.
The mean (SD) weight loss among the children was 7.4 (10.0) kg, representing a mean loss of 20.9% in body mass. One boy (4.5%) and 26 girls (18.8%) had ED symptoms unaccompanied by weight loss. One hundred six girls (77.5%) had not reached menarche; among those who had, 14 of 27 (51.9%) had secondary amenorrhea (loss of menses for ≥3 months). Data were missing for 5 other girls' forms. Most girls (83.2%) were ineligible for the amenorrhea criterion, and 91.3% of the study sample did not or could not have secondary amenorrhea. Based on available growth curves, 33 of 70 girls (47.1%) and 6 of 11 boys (54.5%) had no growth in height during the previous 6 months. Among children who had not lost weight and for whom previous height was available, 6 of 20 (30.0%) had not grown in height in the previous 6 months. Seventy-four children (46.0%) were below the 10th percentile for body mass index, and 55 children (34.2%) had unstable vital signs.

All children had been seen by a pediatrician, and 89 children (55.3%) were seen by a psychiatrist, 92 (57.1%) by a psychologist, 128 (79.5%) by a dietician. Seventy-one children (44.1%) had at least 1 comorbid psychiatric diagnosis. Almost one-fifth (18.6%) had received a psychotropic medication, most commonly a selective serotonin reuptake inhibitor (54.8%) or an atypical antipsychotic (19.4%).

About half (47.2%) of the sample had been hospitalized, with a mean stay of 32.2 days (range, 2-109 days). Many children (61.0%) were admitted to a general pediatric unit, with the remaining admitted to a specialty ED unit (31.3%) or a child psychiatry unit (7.8%). Of those admitted, 18.4% were treated with a nasogastric tube, and 25.7% were treated with a psychotropic medication.

Unstable vital signs or body mass index below the 10th percentile was correlated with hospital admission, and children with both unstable vital signs and body mass index below the 10th percentile were most likely to be admitted. Nine children (16.4%) with unstable vital signs and 3 children (7.9%) with both unstable vital signs and body mass index below the 10th percentile were not admitted (Table 2).

One hundred children (62.1%) met criteria for AN. Forty-one children (25.5%) had EDs not otherwise specified. Data were unavailable for 20 children. Symptoms and associated characteristics of the 2 groups are given in Table 3. Children meeting criteria for AN were more likely to be hospitalized and to have unstable vital signs. Children who did not endorse a fear of getting fat or gaining weight, misperception of body size, or preoccupation with weight were equally likely to have lost weight and were more likely to endorse somatic complaints and to have a comorbid anxiety disorder.

To our knowledge, this is the first cross-country study in North America to describe the presentation and incidence of restrictive EDs among children. The incidence reported in this study reflects children identified by pediatricians but does not include cases that were not brought to medical attention or children who were seen by other physicians. Although the reported rates in this study are likely an underestimate of incidence, it represents one of few descriptions of this population in North America. There is no cost-effective way to screen the general population or family physicians to yield more comprehensive results. Extrapolating from the adult literature that suggests only 25% to 50% of patients with EDs access treatment, it is feasible that the true incidence in this population is 2 to 4 times greater than that reported herein. This study describes an incidence that is twice that of a similar study in Australia. Some of this difference can be explained by variation in study design. Rather than focusing on inpatients, the present study identified children who were admitted to the hospital and children who were treated as outpatients. The Australian study reported only on inpatients for the first 2 years of the study.

Comparing the incidence of restrictive EDs with the rate of other better-known disorders with potentially grave outcomes in morbidity and mortality, such as type 2 diabetes mellitus, helps contextualize the data. The American Diabetes Association has described type 2 diabetes mellitus in young people as a "new epidemic." Using the same study...

Table 1. Frequencies of Restrictive Eating Disorder Symptoms and Associated Characteristics

<table>
<thead>
<tr>
<th>Variable</th>
<th>No. (%) (n=161)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Food avoidance</td>
<td>156 (96.9)</td>
</tr>
<tr>
<td>Preoccupation with food</td>
<td>133 (82.6)</td>
</tr>
<tr>
<td>Fear of getting fat or gaining weight</td>
<td>118 (73.3)</td>
</tr>
<tr>
<td>Preoccupation with weight</td>
<td>115 (71.4)</td>
</tr>
<tr>
<td>Denial of symptom severity</td>
<td>100 (62.1)</td>
</tr>
<tr>
<td>Misperception that body is larger than it is</td>
<td>91 (56.5)</td>
</tr>
<tr>
<td>Overexercising</td>
<td>82 (50.9)</td>
</tr>
<tr>
<td>Family history of psychiatric disorder</td>
<td>59 (36.6)</td>
</tr>
<tr>
<td>Unstable vital signs</td>
<td>55 (34.2)</td>
</tr>
<tr>
<td>Somatic complaints</td>
<td>50 (31.1)</td>
</tr>
<tr>
<td>Comorbid anxiety disorder</td>
<td>44 (27.3)</td>
</tr>
<tr>
<td>Depression</td>
<td>25 (15.5)</td>
</tr>
<tr>
<td>Self-induced vomiting</td>
<td>18 (11.2)</td>
</tr>
<tr>
<td>Obsessive-compulsive disorder</td>
<td>14 (8.7)</td>
</tr>
<tr>
<td>Laxative or diuretic use</td>
<td>0</td>
</tr>
</tbody>
</table>

Table 2. Comparison Between Children Who Were Hospitalized vs Not Hospitalized

<table>
<thead>
<tr>
<th>Variable</th>
<th>Hospitalized</th>
<th>Not Hospitalized</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unstable vital signs (n=55)</td>
<td>46 (83.6)</td>
<td>9 (16.4)</td>
</tr>
<tr>
<td>BMI below 10th percentile (n=73)</td>
<td>50 (68.5)</td>
<td>23 (31.5)</td>
</tr>
<tr>
<td>Both unstable vital signs and BMI below 10th percentile (n=38)</td>
<td>35 (92.1)</td>
<td>3 (7.9)</td>
</tr>
</tbody>
</table>

Abbreviation: BMI, body mass index.

aTwo sided P<.001 by χ² analysis for all comparisons.
methods as herein, Canadian data on diabetes indicate an annual incidence of 1.54 cases per 100 000 person-years in those younger than 18 years and 0.27 cases per 100 000 person-years in children younger than 10 years. The incidence of restrictive EDs among children is 2 times greater than the incidence of type 2 diabetes mellitus among all children younger than 18 years.

In addition, this study confirms that children with clinically significant restrictive EDs are seen by pediatricians. Children in this study demonstrated food avoidance, and some showed signs of growth delay even without weight loss. They also had unstable vital signs and interruption of their normal growth trajectory. Almost half of the sample were hospitalized because of medical instability; however, a concerning finding is the number of underweight or medically unstable children who were not admitted to the hospital. Although EDs in children may seem mild, they can be as severe as in adolescents. Caution should be exercised when assessing a child with food avoidance of any kind, especially with associated weight loss or growth delay, regardless of whether he or she expresses the spectrum of typical psychological findings commonly seen in adolescents and adults. Pediatricians need to be vigilant about EDs, even if they seem minor, and respond accordingly.

Although most cases looked like typical AN, some children lacked cardinal AN symptoms and would typically be classified as having EDs not otherwise specified. The changes proposed for the Diagnostic and Statistical Manual of Mental Disorders (Fifth Edition) reflect recognition that the diagnostic categories for EDs are limited for early-onset EDs. Children identified in this study and others would likely meet criteria for the newly proposed category of food avoidant or restrictive disorder of childhood, which recognizes alternate underlying causes of food restriction other than weight and shape concerns.

The national sampling strategy used by the CPSP for this study is unique among pediatric EDs in North America and is a major strength. It allows for sampling of most clinical practices and is not limited to a single setting. A limitation of the study is the omission of bingeing as a symptom in the questionnaire. This was done purposefully to avoid confusion with bulimia nervosa, with the primary focus being on restrictive behaviors. As such, the study provides no information on bingeing behavior in this population. However, a current ongoing study on bingeing, using the same methods as those herein, has failed to identify this behavior in any children younger than 13 years, suggesting that bingeing is not prominent in this age group. Finally, previous literature has described additional eating disturbances of childhood. Cooper et al described other restrictive EDs unaccounted for by either of the 2 forms seen herein (AN and EDs not otherwise specified). The focus of the present study did not include questions that would allow for identification of these other diagnoses.

Restrictive EDs, although uncommon in children, occur more often than some other chronic illnesses and at presentation often require multidisciplinary treatment or hospitalization. The use of strict categories for diagnosis can limit true appreciation of the severity and differing manifestations of pathologic EDs in different populations. Current epidemiologic data on children with EDs are inconsistent and inadequate. It will be crucial for investigators to devise strategies that maximize case identification and to develop standardized means to capture and report data. This will improve comparisons across samples and enhance our understanding of EDs in children.

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Correspondence: Leora Pinhas, MD, FRCP, Eating Disorders Program, Department of Psychiatry, University of Toronto, The Hospital for Sick Children, 555 University Ave, Toronto, ON M5G 1X8, Canada (leora.pinhas@sickkids.ca).
Author Contributions: Study concept and design: Pinhas, Morris, and Katzman. Acquisition of data: Pinhas, Mor-

Table 3. Differences in Symptom Endorsement Between Children Who Met Criteria for Anorexia Nervosa (AN) vs Eating Disorders Not Otherwise Specified (EDs NOS)

<table>
<thead>
<tr>
<th>Variable</th>
<th>AN (n=100)</th>
<th>EDs NOS (n=41)</th>
<th>Two-Sided P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean (SD) [range], y</td>
<td>11.5 (1.4) [5-12]</td>
<td>10.9 (1.5) [5-12]</td>
<td>.046</td>
</tr>
<tr>
<td>Food avoidance, %</td>
<td>100.0</td>
<td>90.2</td>
<td>.01</td>
</tr>
<tr>
<td>Fear of getting fat or gaining weight, %</td>
<td>100.0</td>
<td>26.8</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Misperception that body is larger than it is, %</td>
<td>86.0</td>
<td>7.3</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Preoccupation with weight, %</td>
<td>92.0</td>
<td>31.7</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Preoccupation with food, %</td>
<td>90.0</td>
<td>61.0</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Overexercising, %</td>
<td>67.0</td>
<td>22.0</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Denial of symptom severity, %</td>
<td>77.0</td>
<td>39.0</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Self-induced vomiting, %</td>
<td>14.1</td>
<td>4.9</td>
<td>.15</td>
</tr>
<tr>
<td>Somatic complaints, %</td>
<td>22.2</td>
<td>43.9</td>
<td>&lt;.05</td>
</tr>
<tr>
<td>Comorbid anxiety disorder, %</td>
<td>41.5</td>
<td>25.0</td>
<td>.07</td>
</tr>
<tr>
<td>Weight loss, %</td>
<td>86.6</td>
<td>72.5</td>
<td>.08</td>
</tr>
<tr>
<td>Mean (SD), kg</td>
<td>7.9 (5.5)</td>
<td>5.6 (3.7)</td>
<td>.05</td>
</tr>
<tr>
<td>Unstable vital signs, %</td>
<td>43.2</td>
<td>22.0</td>
<td>&lt;.05</td>
</tr>
<tr>
<td>Hospitalized, %</td>
<td>56.0</td>
<td>31.7</td>
<td>&lt;.05</td>
</tr>
</tbody>
</table>

aData were unavailable for 20 children.

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REFERENCES


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