

Early-onset eating disorders in Australian children: A national surveillance study showing increased incidence

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Abstract

Objective: The aim of this study was to collect prospective national data on early-onset eating disorders (EOEDs) in children in Australia to document changes in clinical presentations, medical complications, management, and incidence since initially described in 2002–2005.

Method: Each month pediatricians reported children aged 5–13 years newly diagnosed with an eating disorder to the Australian Paediatric Surveillance Unit and provided de-identified clinical data.

Results: Between 2016 and 2018, 184 children were confirmed with EOED with a minimum estimated national incidence of 2.79 per 100,000 children aged 5–13 years (95% confidence interval [CI] 2.40–3.23), nearly double the previously recorded incidence. The mean age at diagnosis was 12.2 years; 43(24%) were boys who were younger than girls (11.85 vs. 12.33 years; $p = .03$). All had food avoidance. Common symptoms included fear of weight gain 140 (76%), preoccupation with body weight 134 (73%), and misperception of body size 116 (63%). Bradycardia was present in 83 (45%) and 117 (64%) who required hospital admission. The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text Revision (DSM-5) criteria for anorexia nervosa were met for 144 (78%).

Discussion: Children with eating disorders continue to present with severe illness. Near doubling in incidence in just over a 10-year period highlights the need for increased clinical resourcing and comparable international data.

Public Significance: The incidence of new presentations of eating disorders in children aged 5–13 years has nearly doubled since a similar study was conducted over 10 years ago. Children were unwell for an average of 8 months before diagnosis; approximately 80% had a clear diagnosis of anorexia nervosa and 64% needed hospital admission due to medical complications. This highlights the need for improvements in education and clinical resources for this age group.

KEYWORDS

anorexia nervosa, children, early-onset, eating disorders, eating disorders, pediatric surveillance

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1 | INTRODUCTION

In Australia, the only data for early-onset eating disorders (EOEDs) are from 2009 and the estimated incidence was 1.4/100,000 children aged <14 years per annum using the Australian Paediatric Surveillance Unit (APSU) (Madden et al., 2009). Key findings were the high proportion of males (25%), high frequency of medical complications, hospitalizations, and psychological comorbidities, and limitations in applying the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) indicated by less than 37% of those requiring hospitalization meeting diagnostic criteria for anorexia nervosa (AN). Studies in the UK and Canada were conducted through national pediatric surveillance units using a similar methodology to the APSU estimated incidence of 3.0/100,000 and 2.6/100,000, respectively (Nicholls et al., 2011; Pinhas et al., 2011), but no recent data are available. AN has its peak onset in mid-adolescence but prevalence estimates of AN in children are difficult to interpret, with data for children and adolescents presented together, limitations in diagnostic criteria, and possible under-recognition (Herpertz-Dahlmann & Dahmen, 2019).

Diagnostic criteria for AN were revised in the fifth edition of the DSM (DSM-5) so that “low weight” was defined to include “weight less than minimally expected” (American Psychiatric Association, 2013). Amenorrhoea in post-menarchal females was removed and behaviors that interfere with weight gain were included as evidence of fear of weight gain, rather than an overt expression of this cognition. These changes allow for diagnosis in children where less weight loss or failure to grow may still cause serious medical complications and due to age, clear expression of psychological symptoms may be developmentally difficult.

Avoidant Restrictive Food Intake Disorder (ARFID) was included in DSM-5 and describes food avoidance with failure to meet nutritional and/or growth requirements in the absence of body image disturbance; however, epidemiological data in children are lacking (Bryant-Waugh, 2019).

Accurate, early diagnosis of EOED in children is important due to high rates of medical complications and hospital admission (Hudson et al., 2012). Psychological treatment includes family-based therapy (Couturier et al., 2013), with earlier treatment strongly predictive of improved outcomes (Treasure & Russell, 2018).

The aim of this study was to collect prospective national data on eating disorders in children aged 5–13 years (until 14th birthday) to describe clinical presentations, medical complications, management, and incidence and to document possible changes since 2009.

2 | METHOD

This active surveillance study was conducted by the APSU to identify newly diagnosed EOED between February 2016 and March 2018. The APSU has conducted active, national surveillance of rare conditions and rare complications of common diseases since 1993 using a well-described methodology (Teutsch et al., 2020). Monthly contributors to the APSU (1450 pediatricians and child psychiatrists) receive a report card, via email or post, listing current studies. For this study, clinicians (98.5%

pediatricians, 1.5% child psychiatrists) were asked if they had seen a child with a new diagnosis of EOED in the preceding month. Contributors received information (protocol and case report form [CRF]) prior to study commencement, informing them of the case definition and study objectives. Contributors who indicated that they had seen a child with EOED were asked to complete a CRF requesting de-identified demographic and clinical information on presentation, growth parameters, medical complications, psychiatric comorbidity, and management.

For this study, EOED was defined as “determined food avoidance in a child aged 5–13 years, where there is weight loss or a significantly low body weight (less than minimally normal) in the context of age, gender, developmental trajectory, and physical health”. Children with organic causes of weight loss were excluded. This definition was consistent with that used in the previous APSU EOED study (Madden et al., 2009). Data on additional diagnostic criteria for AN, including fear of weight gain or fatness, and abnormal body image were collected.

Frequency statistics were performed using SPSS version 25 and comparisons were reported as OR with 95% confidence intervals and were considered statistically significant at $p < .05$. Ethics approval was granted by the Sydney Children's Hospital Network Ethics committee (LNR/15/SCHN/476).

3 | RESULTS

Between February 2016 and March 2018, the return rate of the monthly report card was 91%. There were 214 notifications, for which 206 completed CRF were received (96% response rate). There were 184 confirmed cases, after the exclusion of six duplicate reports and 14 errors (diagnosis made outside reporting period, not meeting case criteria).

The minimum estimated incidence of EOED per 100,000 for children aged 5–13 years old was 2.79 per annum (95% confidence interval [CI] 2.40–3.23) (Australian Bureau of Statistics, 2020).

Of the confirmed cases, 141 were female (76%). The mean age at diagnosis was 12.2 years with boys younger than girls (11.85 vs. 12.33) years ($p = .03$). Cases were reported from all states and territories, most (53%) from New South Wales.

The frequency of symptoms at diagnosis is shown in Table 1 and compared with the 2009 study. Mean duration of symptoms prior to presentation was 8.2 months (SD 7.33; range .2–36.0 months). After food restriction, the most common additional weight controlling behavior was excessive exercise 117 (64%). Psychological symptoms consistent with AN diagnostic criteria were common, including preoccupation with food or food intake 155 (85%), fear of weight gain or fatness 140 (76%), preoccupation with body weight 134 (73%), and perception of body weight as larger than it is 116 (63%). Girls were more likely to have preoccupation with body weight (odds ratio [OR]: 2.26, 95% CI: 1.07–4.77, $p = .03$) and fear of weight gain (OR 2.32 95% CI 1.07–5.08). There were no other symptom differences between genders.

There had been weight loss or failure to gain any weight in the 6 months prior to completion of the CRF for 163 (88%). Weight loss

TABLE 1 Characteristics of children aged 5–13 with early-onset eating disorders 2016–2018

Demographics	2016–2018, n = 184 (%)
Sex (female)	141 (76)
Age at diagnosis in years (range)	12.2 (6.06–13.97), Mean
<i>Eating disorder symptoms</i>	
Preoccupation with food or eating	155 (85)
Fear of weight gain or fatness	140 (76)
Preoccupation with body weight	134 (73)
Denial of the severity of illness	121 (67)
Excessive exercise	117 (64)
Misperception of body size	116 (63)
Self-induced vomiting	24 (13)
Somatic complaints	56 (31)
Binge eating	12 (7)
Early feeding difficulties	22 (12)
Laxative use	2 (1)
Diuretic use	0
<i>Clinical findings</i>	
Bradycardia ^a	83 (45)
Hypotension ^b	16 (9)
Hypothermia ^c	22 (12)
Reached menarche (females only)	45 (32)
Secondary amenorrhoea	31 (69)
Lost or failed to gain weight over the last 6 months	163 (87)
<i>Psychological comorbidities</i>	
Anxiety	90 (49)
Depression	27 (15)
Obsessive–compulsive disorder	7 (4)
Family history of psychiatric illness	79 (43)

^aHR < 50 beats per minute.

^bBP < 80 mmHg.

^cTemperature < 35.5°C.

ranged from .25 kg to 30.0 kg with a median of 9 kg. Of the remaining 21, for whom the change in weight was not known or who had a small increase, all were at a low weight (<10th centile for age). All DSM-5 criteria for AN were met by 144/184 children (78%).

Somatic complaints were reported for 56 (31%). Significant early feeding difficulties or fussy eating was reported in 22 (12%) and food allergy in 4 (2%). Of the 45 girls who had reached menarche, 69% had secondary amenorrhoea. Anxiety was the most frequent comorbid psychiatric diagnosis in 90 children (49.5%), with 27(15%) diagnosed with depression and 7 (4%) with obsessive–compulsive disorder. Additional diagnoses included autistic spectrum disorder in seven children, post-traumatic stress disorder in three, fear of choking in two, and emetophobia in one. A family history of psychiatric illness was reported for 67 (36%) children and a probable or confirmed diagnosis of AN in a first-degree relative was reported for 12 children (15%).

Treatment by a specialist eating disorder service was provided for 138 (75%) children and 117 (64%) children were admitted to hospital,

TABLE 2 Clinical management of patients with early-onset eating disorders 2016–2018

Management	n = 184 (%)
Admitted to hospital	117 (64)
If discharged at the time of the report, the median number of days admitted (range)	14.5 (1–89)
Nasogastric tube feeding	87 (47)
Psychotropic medication	59 (32)
Specialist ED service involved	138 (75)
<i>Professionals required in the child's care</i>	
Pediatrician	177 (96)
Psychiatrist	127 (69)
Dietician	144 (78)
Psychologist	159 (86)

most frequently a specialist pediatric hospital 92 (78.6%). Medical instability (bradycardia [hazard ratio, HR < 50 bpm], hypothermia [<35.5 degrees] or hypotension [blood pressure, BP < 80/50]) was present in 92 children (50%). Of the 83 with bradycardia, 76 (92%) were admitted and 63 (83%) received nasogastric tube feeds

In addition to management by a pediatrician (96%), many children also received psychiatry or allied health care (Table 2). Psychotropic medication was prescribed for 59 (32%) children and in that group, fluoxetine was most prescribed (46%). Other medications included olanzapine (34%), quetiapine (7%) risperidone (3%), and lorazepam (3%).

4 | DISCUSSION

This is the first study to document an increase in the incidence of EOEDs over a period of more than 10 years with the minimum estimated incidence of EOED of 2.79 per 100,000 children under 14 years of age being close to twice that in 2009 (Madden et al., 2009). This is similar to estimates in Canada (Pinhas et al., 2011) and the UK (Nicholls et al., 2011) from 10 years ago, more recent data not being available to determine if there is a similar trend. The increased incidence in Australia has major implications for resourcing of clinical services and education of clinicians involved in EOED. This is consistent with reports of increased presentations of adolescent eating disorders during the coronavirus pandemic in Australia and internationally (Haripersad et al., 2021; Otto et al., 2021; Matthews et al., 2021). In Melbourne, Australia, there was an increase of 60% in medical admissions in a specialist child and adolescent eating disorder service during 2020 compared with the 2 years prior but the data do not provide sufficient detail to describe the change in incidence in children (Springall et al., 2021). Our study will therefore be important in informing future investigations of the potential impact of the coronavirus pandemic in children with eating disorders.

Boys accounted for 24% of cases, similar to previously in Australia (Madden et al., 2009) but higher than in the UK (18%) and Canada (13.6%; Pinhas et al., 2011; Nicholls et al., 2011). In adult community samples there is some evidence that eating disorders are increasing at a faster rate in males than females (Mitchison

et al., 2014). Children in the current study had clinical symptoms similar to those in the original study, with high rates of preoccupation with food and body weight, fear of weight gain, and misperception of body size. In addition to deliberate food restriction, two-thirds of children engaged in excessive exercise but other weight-controlling behaviors were less common. More than three-quarters of children met DSM-5 criteria for AN, whereas, in our previous study, only 37% of children with severe illnesses requiring hospitalization met DSM-IV criteria for AN (Madden et al., 2009). This suggests modifications in DSM-5 better reflect the pattern of illness in this younger cohort.

Children continue to present with severe illness, shown by significant weight loss (median 9 kg) and high rates of medical complications, hospitalization, and psychiatric comorbidities. The duration of symptoms prior to specialist medical review is over 8 months, consistent with the UK study (Nicholls et al., 2011) and suggests a delay in presentation for treatment and/or delay in recognition by health professionals.

Over half the children identified had one or more signs of medical compromise (bradycardia, hypotension, or hypothermia). Medical compromise is well recognized in AN and a key indicator for admission in national and international management guidelines (Hay et al., 2014; Hornberger et al., 2021). More than 90% of children with bradycardia were admitted to the hospital suggesting high compliance with published guidelines. The use of nasogastric tube feeding for early nutritional support varies nationally and internationally but is well tolerated and achieves more rapid weight gain without increased risk of refeeding syndrome, including in young adolescents (Rizzo et al., 2019). A higher proportion (82%) of children with bradycardia in this study received nasogastric tube feeds than in the 2009 study (58%; Madden et al., 2009). This may reflect increased awareness of treatment guidelines in the intervening period.

The longitudinal implications of the data are strengthened by using the same surveillance methodology (APSU) in the first national study (Madden et al., 2009) and the current study. The APSU has a consistently high participation rate from specialist pediatricians. Since 1993 the return rate of monthly report cards has remained more than 90% and the distribution of pediatricians is representative of the childhood population across Australia (Teutsch et al., 2020). Pediatric surveillance units are important for collecting epidemiological and clinical data on eating disorders and have promoted international collaboration (Katzman et al., 2017).

The risk of under-reporting of cases and hence underestimation of incidence is an acknowledged limitation of APSU surveillance, which relies on the voluntary participation of clinicians. Also, in this study most children had a severe illness and those with less severe presentations may have been managed by a general practitioner without a specialist pediatrician or psychiatrist referral and would therefore not be reported to the APSU. This reflects practice in Australia where we would expect most children with an eating disorder with medical complications or needing admission to be managed by a pediatrician. There may also have been underreporting of children with ARFID and other forms of disordered eating without sufficient dietary restriction to impair weight gain or growth. We suggest therefore that the incidence reported in this study is a minimum estimate of the full range of EOEDs in childhood.

This study does not provide information of why there appears to be an increase in frequency of EOED but does highlight the need for

comparable international data and appropriate increases in education and resourcing, particularly in light of current data on increasing rates of ED during the COVID-19 pandemic.

AUTHOR CONTRIBUTIONS

Anne Morris: Conceptualization; data curation; formal analysis; methodology; project administration; writing – original draft. **Elizabeth Elliott:** Conceptualization; data curation; methodology; supervision; writing – review and editing. **Sloane Madden:** Conceptualization; data curation; funding acquisition; methodology; project administration; supervision; writing – review and editing.

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CONFLICT OF INTEREST

All authors declare that they have no conflict of interest to disclose.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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