Burden of eating disorders in 5–13-year-old children in Australia

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Lifetime prevalence rates in women are 4.3% for anorexia nervosa and partial syndrome anorexia nervosa,[1] and 4%–7% for bulimia nervosa.[2] Onset is primarily during adolescence,[3] when eating disorders are the third most common chronic illness in women.[4] Eating disorders have the highest lifetime mortality rate of any psychiatric disorder (up to 20%),[5] and mortality rates are 12 times higher for women with eating disorders than for unaffected women.[6] In adults, outcomes are poor: less than 50% of adults recover within 5 years of diagnosis. In children, evidence-based treatments, including Maudsley family therapy, have improved recovery rates to 70% after 12 months and 90% after 5 years.[7] Early diagnosis improves outcomes and reduces complications such as growth retardation, impaired bone health, cognitive impairment, disruption of pubertal development, infertility, depression, anxiety and death.[8]

No national data have been published to date about early-onset eating disorders (EOEDs) in children younger than 14 years. Although some epidemiological studies include EOEDs, children comprise a small proportion of samples, and results for children have not been analysed separately.[9-11] Most studies that include EOEDs focus on anorexia nervosa exclusively. Few data about incidence, age of onset, diagnostic characteristics, severity and outcomes of early onset anorexia nervosa are available, and almost nothing is known about the spectrum of EOEDs.[11,12] Incidence rates for anorexia nervosa in 10–14-year-olds, based on data from population-wide studies of eating disorders, have been estimated to be 4.2–26.3 per 100 000 girls and 3.3–3.7 per 100 000 boys.[13-16] Lack of data makes it difficult to quantify the problem of EOEDs or allocate resources. A need for early identification is now evident because anorexia nervosa prevalence in adolescents has increased over the past 50 years,[14] and the age of onset has decreased.[12]

Our objective was to prospectively collect nationally representative epidemiological data on EOEDs in Australia, to document disease rates, morbidity and comorbidity, and concordance of clinical features with the *Diagnostic and statistical manual of mental disorders*, fourth edition

ABSTRACT

Objective: To collect nationally representative epidemiological data on early-onset eating disorders (EOEDs) in children.

Design: Prospective, active surveillance using the Australian Paediatric Surveillance Unit with key informant design.

Setting: Child health specialists in Australia (July 2002 to June 2005).

Patients: Incident cases of EOEDs in children aged 5–13 years.

Main outcome measures: Disease rates, demographic characteristics, clinical features and complications, hospitalisation, psychological comorbidity, and concordance of clinical features with *Diagnostic and statistical manual of mental disorders*, fourth edition (DSM-IV) criteria.

Results: We identified 101 children aged 5–13 years with EOEDs (median age, 12.2 years; range, 5.5–13.9 years), of whom one in four were boys. Most were hospitalised (78%), and the mean duration of hospitalisation was 24.7 days (range, 1–75 days). More than 70% of inpatients were admitted to specialised eating disorder units in paediatric teaching hospitals. Among inpatients, 37% met DSM-IV diagnostic criteria for anorexia nervosa; although 61% had life-threatening complications of malnutrition, only 51% met weight criteria. Psychological symptoms were similar to those in adults with anorexia nervosa: 67% of inpatients met both psychological diagnostic criteria for anorexia nervosa (fear of weight gain/fatness and misperception of body shape). Of 19 postmenarchal girls, 18 had secondary amenorrhoea. Nasogastric feeding was used in 58% of inpatients, and 34% received psychotropic medications.

Conclusions: This is the first prospective national study of EOEDs. It demonstrates the limitations of applying DSM-IV diagnostic criteria for anorexia nervosa to young children; the high proportion of boys affected by EOEDs; and the significant psychological comorbidity and high frequency of hospitalisation associated with EOEDs. Potentially life-threatening medical complications are common at presentation, suggesting possible missed diagnoses and a need for education of health professionals. The study underlines the severity of EOEDs and the need for joint medical and psychiatric specialist management.

(DSM-IV) criteria.[17] National data are essential to underpin clinical care, service planning and policy development.

METHODS

Between July 2002 and June 2005, the national surveillance system of the Australian Paediatric Surveillance Unit (APSU) undertook a study to identify EOEDs.[18] During the study, about 1100 child health specialists received a monthly APSU report card via email (68%) or post (32%). Each month, clinicians indicated whether or not they had seen any newly diagnosed patients with EOEDs (incident cases). Those who reported an incident case received a two-page questionnaire requesting de-identified information about diagnosis, management and short-term outcomes. Reporting clini-

cians were predominantly paediatric Fellows of the Royal Australasian College of Physicians, but also included child psychiatrists (2%). In 2007, 92% of Fellows in clinical practice participated in APSU surveillance.[19]

Case definition

Clinicians were asked to report any child aged 5–13 years who was newly diagnosed with an EOED, defined as determined food avoidance plus weight loss or a failure to gain weight during a period of growth, in the absence of any identifiable organic cause. This definition, developed in consultation with paediatric EOED specialists, was based on existing diagnostic criteria from the DSM-IV;[17] the International classification of diseases, 10th revision (ICD-10);[20] and the Great Ormond Street Hospital for

Children Feeding and Eating Disorders Service.[12] The definition was broad to enable full characterisation of abnormal eating behaviours associated with childhood weight loss.

The first study year included only inpatients ($n = 23$). The final 2 years also included outpatients, as many clinicians indicated that they managed most children with EOEDs as outpatients (inpatients, $n = 56$; outpatients, $n = 22$).

Ethics approval was obtained from the Human Research Ethics Committee of the Children's Hospital at Westmead.

RESULTS

Questionnaires were obtained for 163 of 183 notifications (89%). Of these, 14 were duplicates and 48 did not meet the case definition, leaving a sample of 101 children with EOEDs. There were 74 girls and 25 boys (sex was not specified for two children); the median age was 12.2 years (range, 5.5–13.9 years). There were no significant differences between boys and girls in terms of age, presenting symptoms, psychological comorbidities, family history or outcome. Patients were identified from all Australian jurisdictions except the Northern Territory and the Australian Capital Territory (Box 1).

Most children were hospitalised (79, 78%), the median age of inpatients was the same as the median age for all identified cases, and 86% of inpatients were aged over 10 years. Data from inpatients and outpatients are separated in Box 2. The annual estimated incidence for EOEDs was 1.4 per 100 000 children aged 5–13 years (95% CI, 1.1–1.7). For inpatients only, this rate was 1.1 per 100 000 (95% CI, 0.9–1.3). These rates varied by state, and were highest in New South Wales: 2.1 per 100 000 children (95% CI, 1.5–2.9) for inpatients only, and 2.8 per 100 000 children (95% CI, 2.1–3.4) for inpatients and outpatients. Inpatients were more likely than outpatients to have severe medical complications, including hypothermia ($\chi^2 = 6.0$; $P < 0.05$), hypotension ($\chi^2 = 6.5$; $P < 0.05$) and bradycardia ($\chi^2 = 6.5$; $P < 0.05$).

In the 6 months before presentation, 85% of inpatients had lost weight and 8% failed to gain weight as would be expected during normal growth. Weight loss ranged from 1.5 kg to 16.0 kg (median, 7.0 kg). Forty inpatients (51%) weighed less than 85% of their ideal body weight according to height. Common presenting symptoms were food avoidance, preoccupation with food and fear of weight gain, and 68% of inpatients

demonstrated misperception of body shape. No child reported laxative or diuretic misuse, but 13% of inpatients reported self-induced vomiting. One or more life-threatening complications of malnutrition (hypothermia, hypotension or bradycardia) occurred in 61% of inpatients, psychological comorbidities were seen in 62%, and 39% had a family history of psychiatric illness. Only 37% of inpatients met all DSM-IV criteria for anorexia nervosa (Box 2). Most (67%) met both psychological criteria (abnormal body image and fear of weight gain), whereas about half (51%) met the weight criterion.

Among the inpatients, 19 girls (32%) had reached menarche, of whom 18 had secondary amenorrhoea. Girls who had reached menarche were older than those who had not (median, 13.5 years v 11.9 years; Mann–Whitney $U = 106.5$; $P < 0.001$). There were no significant differences in presenting symptoms, psychological comorbidities, family history or outcome between the premenarchal and postmenarchal female inpatients.

Sixty-eight per cent of the inpatients were admitted to a paediatric teaching hospital, 27% to a metropolitan general or rural hospital, and 5% to a child psychiatric unit, with 71% of all inpatients admitted to a specialised eating disorders unit. Children were treated mainly by paediatricians, psychiatrists and dietitians (Box 3).

Nasogastric feeding was used in 58% of inpatients, and 34% were administered psychotropic medications — mainly antidepressants and atypical antipsychotics (Box 3). The mean duration of hospitalisation was 24.7 days (SD = 17.4; range, 1–75 days). There were no deaths and, according to the treating doctors, treatment resulted in improvement of the patient's condition in 56 patients (71%), no change in 17 patients

(22%), and deterioration in two patients (3%). Information on outcome was not provided for four patients.

DISCUSSION

In children aged 5–13 years, we estimated the annual national incidence for EOEDs requiring hospitalisation to be 1.1 per 100 000 children, and the total annual national incidence to be 1.4 per 100 000 children. There was an excess of cases from NSW (56% of total cases versus 33% of the national population aged 5–13 years who reside in NSW), which may reflect underreporting in some states. In support of this is the total incidence for EOEDs in NSW (2.8/ 100 000 children), which closely resembles rates reported by the British Paediatric Surveillance Unit (3.28/100 000 children) and the Canadian Paediatric Surveillance Program (2.6/100 000 children).[22,23] Alternatively, the differences between states may reflect differences in service availability, with specialist services concentrated in the larger states, or the work location of study investigators. We also found that about a quarter of the patients were boys. The reason for this high proportion of boys is not known, but these data are consistent with other studies.[13-16]

When DSM-IV diagnostic criteria for eating disorders were applied to children hospitalised with EOEDs, only 38% met the criteria for anorexia nervosa. Although 67% met both psychological criteria, only 51% met weight criteria, despite 61% having potentially life-threatening complications of malnutrition. This highlights the limitations of a criterion that requires a body weight less than 85% of ideal weight (or expected weight during a time of predicted growth). This problem was also identified in a recent

1 Numbers of early-onset eating disorder (EOED) incident cases and inpatients, and population of children aged 5–13 years, by state or territory

	Incident cases	Inpatients	Population of children aged 5–13 years[21]
New South Wales	57 (56%)	43 (54%)	808 330 (33.1%)
Victoria	21 (21%)	18 (23%)	586 936 (24.1%)
Queensland	14 (14%)	11 (14%)	493 206 (20.2%)
Western Australia	2 (2%)	2 (3%)	246 081 (10.1%)
South Australia	5 (5%)	3 (4%)	176 081 (7.2%)
Tasmania	2 (2%)	2 (3%)	60 042 (2.5%)
Australian Capital Territory	0	0	38 554 (1.6%)
Northern Territory	0	0	29 849 (1.2%)
Total for Australia	101 (100%)	79 (100%)	2 439 079 (100%)

2 Characteristics of patients aged 5–13 years with early-onset eating disorders*

	Inpatients (n = 79)	Outpatients (n = 22)	Total (n = 101)
Demographics			
Sex (female)	59 (75%)	15 (68%)	74 (73%)
Median age in years (range)	12.2 (5.5–13.9)	11.8 (7.2–13.8)	12.2 (5.5–13.9)
Aged less than 10 years	11 (14%)	4 (18%)	15 (15%)
Medical symptoms			
Weight loss[†]	67 (85%)	8 (36%)	76 (75%)
Failure to gain weight[††‡]	6 (8%)	1 (5%)	7 (7%)
Weight <85% of ideal[§]	40 (51%)	5 (23%)	45 (45%)
Potentially life-threatening[¶]	48 (61%)	3 (14%)	51 (50%)
Hypothermia**	31 (39%)	2 (9%)	33 (33%)
Hypotension[††]	20 (25%)	0	20 (20%)
Bradycardia[‡‡]	37 (47%)	3 (14%)	40 (40%)
Presenting psychological symptoms			
Food avoidance	78 (99%)	21 (95%)	99 (98%)
Preoccupation with food	73 (92%)	18 (82%)	91 (90%)
Fear of weight gain/fatness	60 (76%)	15 (68%)	75 (74%)
Preoccupation with weight	58 (73%)	16 (73%)	74 (73%)
Misperception of body shape	54 (68%)	13 (59%)	67 (66%)
Excessive exercise	47 (59%)	8 (36%)	55 (54%)
Self-induced vomiting	10 (13%)	1 (5%)	11 (11%)
Psychological comorbidities			
At least one comorbidity	49 (62%)	14 (64%)	63 (62%)
Depression	20 (25%)	4 (18%)	24 (24%)
Obsessive compulsive disorder	10 (13%)	2 (9%)	12 (12%)
Anxiety	28 (35%)	12 (55%)	40 (40%)
Other psychiatric illness	12 (15%)	2 (9%)	14 (14%)
Family history of psychiatric illness	31 (39%)	3 (14%)	34 (34%)
DSM-IV criteria for anorexia nervosa			
Weight <85% of ideal[§]	40 (51%)	5 (23%)	45 (45%)
Fear of weight gain/fatness	60 (76%)	15 (68%)	75 (74%)
Misperception of body shape	54 (68%)	13 (59%)	67 (66%)
Fear of weight gain/fatness + misperception of body shape	53 (67%)	12 (55%)	65 (64%)
Amenorrhoea[§§]	72 (91%)	17 (77%)	89 (88%)
All four DSM-IV criteria	29 (37%)	3 (14%)	32 (32%)

DSM-IV = *Diagnostic and statistical manual of mental disorders*, fourth edition. * Data represent numbers (percentages) of children unless otherwise specified. † In the 6 months before presentation. ‡ As expected during normal growth. § Ideal body weight calculated according to height. ¶ Complications of malnutrition including one or more of hypothermia, hypotension or bradycardia. ** Body temperature < 35.5° C. †† Systolic blood pressure < 80 mmHg. ‡‡ Heart rate < 50 beats/min. §§ Children were deemed to have met the criterion for amenorrhoea if either primary or secondary amenorrhoea was present in girls or the child was a boy. ◆

position paper on eating disorder classification in children.[24] Specifically, it is difficult to determine a cut-point for ideal weight when age at onset and normal growth during puberty must be considered. Our study also highlights the absence of a threshold body weight or body mass index in children below which medical compromise occurs, with rapid weight loss more likely to result in life-threatening complications.

The high proportion of inpatients with potentially life-threatening medical complications indicates that young children are presenting with severe disease and physio-logically significant weight loss, or failure to thrive. Additionally, 14% of outpatients (3/22) had hypothermia and/or bradycardia. Current treatment guidelines recommend inpatient management for such children,[25,26] though it is possible that these children were hospitalised after initial presentation and reporting to the APSU.

Rates of psychological symptoms were similar for inpatient and outpatient groups. Of the inpatients, 62% were reported to have at least one comorbid psychological illness and 39% were reported as having a family history of psychiatric illness, which is consistent with previous studies.[27-29] It also underlines the complexity of the aetiology and treatment of eating disorders, and the need for joint medical and psychiatric management. More than 30% of children in our study received one or more psychotropic medications, of which selective serotonin reuptake inhibitors (SSRIs) were most common. Published studies show no benefit from SSRIs for comorbid or EOED symptoms.[30]

Inpatients represented 78% of all reported incident cases of EOEDs, and 72% of cases reported during the final 2 years of the study. Several possibilities could account for the high rate of hospitalisation. Perhaps young children present to paediatricians or child psychiatrists late, once there is a significant physical compromise, or perhaps the psychological disturbance is not recognised early in young children. It is possible that some children are managed as outpatients by general practitioners alone, particularly in locations where access to specialist services is limited and cases would not be reported to this study. Early identification and treatment leads to reduced morbidity and mortality.[7] Additionally, reduced hospitalisation would dramatically reduce costs associated with initial management. Of note, admission rates in comparable studies in the United Kingdom and Canada were 44% and 50%, respectively;[22,23] however, admission criteria were not recorded in these studies, making direct comparison with our study complex.

Nasogastric feeding in severe eating disorders is controversial. It was used to treat 58% of inpatients in our study, most of whom were reported from one institution in NSW, possibly reflecting the practices of this institution rather than a national management philosophy. Few published data document the efficacy of nasogastric feeding in anorexia nervosa. Two retrospective studies demonstrated a greater rate of weight gain

3 Management of patients aged 5–13 years with early-onset eating disorders

	Inpatients (n = 79)	Outpatients (n = 22)	Total (n = 101)
Management			
Nasogastric feeding	46 (58%)	1 (5%)	47 (47%)
Psychotropic medications	27 (34%)	5 (23%)	32 (32%)
Antidepressants	18 (23%)	3 (14%)	21 (21%)
Antipsychotic agents	12 (15%)	1 (5%)	13 (13%)
Typical antipsychotics	2 (3%)	0	2 (2%)
Atypical antipsychotics	10 (13%)	1 (5%)	11 (11%)
Professionals involved in care of affected child			
Paediatrician	78 (99%)	16 (73%)	94 (93%)
Psychiatrist	70 (89%)	7 (32%)	77 (76%)
Psychologist	49 (62%)	20 (91%)	69 (68%)
Dietitian	74 (94%)	11 (50%)	85 (84%)
Specialised eating disorders unit	56 (71%)	2 (9%)	58 (57%)

with no differences in psychological recovery or patient satisfaction.[31,32] Current treatment guidelines provide little advice, although there is growing acceptance of nasogastric feeding in the management of medical instability in eating disorders.[33]

APSU surveillance for child mental health research has strengths: 92% of practising paediatricians participated,[19] of whom 92% returned monthly report cards during this study. However, complete case ascertainment is unlikely, reflecting the lack of specialist services in rural settings. Of significance for this study is that only 2% of reporting clinicians were child psychiatrists, and most were hospital based. Although we consider it likely that most patients hospitalised for EOEDs have seen a paediatrician, outpatients may be managed by GPs and psychiatrists who do not report to the APSU.

This is the first prospective national study of EOEDs. It provides estimates of incidence, and indicates the need for services for the 5–13-years age group. However, differences between the states and territories suggest that regional differences exist in diagnosis and resource provision. Our data confirm that psychological symptoms in children with EOEDs are similar to those in adults with anorexia nervosa, but highlight limitations in the current diagnostic criteria for use in young children. The high rates of potentially life-threatening medical complications at presentation underline the severity of EOEDs and raise the possibility of missed or incorrect diagnoses. High rates of comorbidity reiterate the need for specialist medical and psychiatric management. Management of most children in paediatric teaching hospitals highlights the need for education of paediatricians and appropriate health resource allocation.

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