Childhood eating disorders: British national surveillance study*
Dasha E. Nicholls, Richard Lynn and Russell M. Viner

Background
The incidence of eating disorders appears stable overall, but may be increasing in younger age groups. Data on incidence, clinical features and outcome of eating disorders are sparse.

Aims
To identify new cases of early-onset eating disorders (<13 years) presenting to secondary care over 1 year and to describe clinical features, management and 1-year outcomes.

Method
Surveillance over 14 months through the established British Paediatric Surveillance System, and a novel child and adolescent psychiatry surveillance system set up for this purpose.

Results
Overall incidence was 3.01/100,000 (208 individuals). In total, 37% met criteria for anorexia nervosa; 1.4% for bulimia nervosa; and 43% for eating disorder not otherwise specified. Nineteen per cent showed determined food avoidance and underweight without weight/shape concerns. Rates of comorbidity were 41%; family history of psychiatric disorder 44%; and early feeding difficulties 21%. Time to presentation was >8 months. A total of 50% were admitted to hospital, typically soon after diagnosis. Outcome data were available for 76% of individuals. At 1 year, 73% were reported improved, 6% worse and 10% unchanged (11% unknown). Most were still in treatment, and seven were hospital in-patients for most of the year.

Conclusions
Childhood eating disorders represent a significant clinical burden to paediatric and mental health services. Efforts to improve early detection are needed. These data provide a baseline to monitor changing trends in incidence.

Declaration of interest
None.

Epidemiological studies suggest that although the incidence of eating disorders has been fairly static over the last few decades,1,2 individuals with anorexia nervosa are presenting at an earlier age.3,4 Current knowledge about childhood or early-onset eating disorders (defined here as onset before 13 years of age) has been largely derived from clinical case series from specialised settings.5–11 Accurate estimates of case numbers and information about natural history and prognosis is needed to plan and coordinate developmentally appropriate services for this patient group, as advocated in clinical guidelines.12 General mental health screening is generally poor at picking up eating disorders,13 the diagnosis of which require self-report of highly specific cognitions and behaviours, corroborated by physical findings and, in children, by parental report.14 In addition, incomplete involvement of those with eating disorders in population-based research is difficult to interpret.15 General practitioner (GP) registers are commonly used to identify cases,1,4 but the recognition of eating disorders in children by GPs can be poor.16 Eating disorders in prepubertal and peripubertal children frequently require paediatric admission and long-term medical monitoring as well as psychiatric management. In the UK they are likely to present to paediatricians as well as to child psychiatrists.6 Surveillance is well established as an effective methodology for the identification of rare disorders or events of clinical significance,17 and does not rely on patient consent for case ascertainment.

Our objectives in this study were to estimate the incidence of early-onset eating disorders in children presenting to secondary care in the British Isles; describe the age, gender and family history, clinical features at presentation including psychiatric comorbidity and identify aspects of current management, including hospitalisation; explore the validity of current diagnostic groupings for childhood eating disorders and to assess outcome at 1 year.

Method
Individuals with early-onset eating disorders were notified for a period of 14 months (March 2005 and May 2006), through two linked surveillance systems. The British Paediatric Surveillance Unit (BPSU) inquiry system is well accepted for the study of rare conditions. Consultant paediatricians throughout the British Isles (United Kingdom (UK) and Republic of Ireland (ROI)) return monthly notification cards for a series of rare conditions; approximately 93% of paediatricians respond each month (see http://bpsu.inopsu.com/). For this study, a separate system for surveillance of notification by psychiatrists, the Child and Adolescent Psychiatric Surveillance System, was established using similar methodology.

In each system, details of cases were obtained from a questionnaire completed by the notifying paediatrician or child and adolescent psychiatrist. Follow-up data were obtained from clinicians at 1 year. The case definition was designed to encourage over- rather than underreporting, and duplicate case reporting was encouraged. The response rate for paediatricians was 93% and for child and adolescent psychiatrists was 85%.

The study was approved by the BPSU Executive and the National Research Ethics System. Patient Information Advisory Group Section 60 exemption approval for this study was obtained.

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(PIAG/BPSU 2-10(H)/2005) for notification without the need for consent from children or families.

Case definition

The case definition was based on modified DSM–IV and ICD–10 criteria for eating disorders, and approved by the BPSU Executive Committee. Developmental considerations in the case definition and questionnaire included: a focus on behaviours and preoccupations rather than specific cognitions; omission of amenorrhoea, since most would be premenarcheal; recognition that weight loss may manifest as failure in weight gain in this age group; and no binge frequency was specified or operational definition of bingeing used, since access to food can limit bingeing in this age group. The instruction used for notification was:

Please report any child aged 5 to 12 years inclusive seen in the last month, with two or more of the following:
- weight loss or failure to gain weight during a period of expected growth, not due to any identifiable organic cause
- determined food avoidance
- fear of weight gain
- preoccupation with body weight or energy intake
- self induced vomiting
- excessive exercising
- recurrent episodes of binge eating or abuse of laxatives

*Exercise may be considered to be excessive when it significantly interferes with important activities, when it occurs at inappropriate times or in inappropriate settings, or when the individual continues to exercise despite injury or other medical complications.*

Consultants who notified potential cases were then asked to complete a data form from which the authors identified eligible individuals and their diagnoses. Confirmed cases meeting the case definition were grouped by eating disorder subtype using operational criteria based on symptoms reported in the questionnaire (Appendix). Clinician report of comorbidity was noted.

Follow-up took the form of data collection at 12 months after notification through a questionnaire mailed to reporting clinicians.

Analysis

Analyses were primarily descriptive. Where duplicates were reported, data were used from the most complete data-set, or the data-set closest to the reporting date. Incidence was calculated as number of cases/total children of that age in the population (UK plus ROI) expressed as per 100 000 population, using data for the total population of children for 2005 aged 5–13 obtained from the Office of National Statistics (UK) and the Central Statistics Office (Ireland). Nutritional status was determined by calculating body mass index (BMI) from weight and height, then converting to % of median BMI for age and gender using UK BMI reference data. Underweight was defined as < 85% BMI for age and gender, based on the criteria used for diagnosis of anorexia nervosa and the World Health Organization definition of malnutrition.

To investigate the validity of eating disorder diagnoses in this age group, principal-components analysis was used to identify clusters of symptoms, using eigen values greater than one as a threshold. Analyses were performed using Microsoft Excel and SPSS version 15 on Windows.

Results

Figure 1 shows a flow diagram of case reporting. Of 505 suspected cases, 380 (75%) were reported by psychiatrists and 125 (25%) by paediatricians. A total of 78 (15%) potential cases had to be excluded as insufficient data were obtained to judge eligibility. For 427 suspected cases with sufficient data, 124 (29%) were judged to be reporting errors. The majority of these were for individuals where the age was outside the reporting range or that presented prior to the reporting period, making them prevalent rather than incident cases. Of 303 notifications that met inclusion criteria, 95 (31%) were duplicate notifications, leaving 208 early-onset eating disorder cases as the sample for analysis.

Incidence

Notification of 208 cases during the study period provides an overall incidence estimate of 3.01/100 000 (95% CI 2.6–3.5). Figure 2 shows incidence by age for the overall group and for each eating disorder category. There was a clear relationship between incidence and increasing age. There were no cases identified for individuals aged 5 years. The overall incidence age 6–7 years was 0.21/100 000 (95% CI 0.01–0.88); at age 7–8 years was 0.21/100 000 (95% CI 0.01–0.89); at 8–9 years was 0.92/100 000 (95% CI 0.28–1.66); at 9–10 years was 1.64/100 000 (95% CI 0.89–2.84); at 10–11 years was 3.56/100 000 (95% CI 2.34–4.99); at 11–12 years was 4.46/100 000 (95% CI 3.12–6.17); and at 12–13 years was 9.51/100 000 (95% CI 7.5–11.9).

Using the operational definitions in the Appendix, 76 individuals were classified as having anorexia nervosa (overall incidence 1.09/100 000); 3 with bulimia nervosa (incidence 0.04/100 000); and 89 with eating disorder not otherwise specified (EDNOS) (incidence 1.22/100 000), of which 6 showed binge eating but no compensatory behaviours, hereafter called binge eating disorder (incidence 0.09/100 000) (Fig. 2). Forty individuals met the case definition, but did not have weight and shape concerns or fear of weight gain (defined as ‘other’; incidence 0.58/100 000).

Demographics and medical status

Of the 208 individuals identified, 171 (82%) were female and 37 (18%) male. Of the anorexia nervosa group 12% were boys, rising to 18% of the EDNOS group and to 33% of the ‘other’ group. In total, 86% were White British, 2.5% Irish, 5% Asian/Asian mixed ethnicity and 1% Black/Black mixed ethnicity. The mean age was 11.5 years (s.d. = 1.3), with a reported mean duration of illness of 8.3 months prior to presentation.

Of all the boys and girls, 59% were fully prepubertal, 27% in early/mid-puberty, 8% were in late puberty and 6% unknown. Menarcheal status was known in 161 of 171 girls; 123 (76%) were premenarcheal. Of the 38 girls known to be postmenarcheal, 23
had amenorrhea, 8 did not and the remainder was unknown or not reported.

By definition, individuals with anorexia nervosa were underweight (mean 77% BMI for age), but % BMI in this group was not lower than for the ‘other’ group, whose mean % BMI was 79%. The six individuals classified with binge eating disorder were overweight, with a mean % BMI of 144%.

Family and early history

For 44% of individuals there was a close family member with a history of psychiatric disorder and for 12% more than one family member was affected. The proportion did not vary across diagnostic groups. Anxiety and depression accounted for almost 70% of the family history of mental health problems. Obsessive–compulsive disorder (OCD), anxiety disorder, psychosis, substance misuse and neurodevelopmental disorders were also represented.

Of 186 individuals in whom gestation was reported, only 2 were less than 36 weeks premature. A history of early feeding problems was reported in around 21% (66% none, 13% unknown), across all diagnoses (range 17–26%). The majority of feeding difficulties reported (as free text) were picky, fussy or faddy eating, and restrictive eating (eating small quantities). Comments were made highlighting specific features or severity (for example ‘fussy to 9 years’; ‘milk only until age 3’; ‘at 3–4 still eating liquids, could not tolerate lumps, not aware of hunger’).

Symptom profiles

Determined food avoidance was the most common symptom, occurring in 96% of all individuals. Other symptoms were morbid preoccupation with food (84%), fear of weight gain (71%), preoccupation with body weight (67%), preoccupation with body shape (51%), excessive exercising (43%), somatic complaints (31%), self-induced vomiting (19%), binge eating (5%) and laxative or diuretic use (1%). There was 71% concordance in preoccupation with body weight and with body shape. Weight concerns were more common in the absence of shape concerns than vice versa.

Principal-components analysis of the nine key symptoms found three components with an eigen value of over one, together accounting for 60% of the variance (30% for component one; 18% component two; 12% component three). Figure 3 shows the symptoms weighting each component. Component one was distinguished by fear of weight gain, preoccupation with body weight and shape and excessive exercise. Component two comprised underweight and somatic complaints but not weight and shape concerns and negatively for binge eating. Component three comprised self-induced vomiting and binge eating and was negative for underweight.

Comorbidity and medication

The three main comorbidities (depression, anxiety and OCD) were reported as possible or definite in 86 (41%) individuals, absent in 98 (47%) and the remainder unknown. Comorbidity was fairly evenly distributed across diagnoses, anxiety being the most common. For 13 individuals comorbid autism-spectrum or other pervasive developmental disorder was mentioned, as were a number of other neurodevelopmental problems such as tic disorders and attention-deficit hyperactivity disorder. Other comorbidities noted included trauma and grief reactions (n = 7), chronic fatigue syndrome and other somatoform disorders (n = 3), psychosis (n = 2) and learning disability (n = 2).

Management

In total, 104 (50%) were admitted to hospital (71% of those with anorexia nervosa). Most admissions were to paediatric wards for

**Fig. 2** Incidence by age at onset and diagnosis.

Other eating disorders include all other eating disorders (bulimia nervosa, eating disorder not otherwise specified, binge eating disorder); ‘other’ category includes individuals meeting definition for clinically significant eating difficulty, not currently classifiable as an eating disorder.
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Comorbidity at follow-up was almost identical to that at school, with 16 attending part time and 8 not in school. Most children were in follow-up. By 1 year only six children had been readmitted or had been in hospital for more than 200 days by the time of reporting. Only 4% were identified with bulimia nervosa or other binge eating, which is likely to be an underestimate. Almost 20% met the case definition but did not have the weight and shape concern, and are thus not classifiable by current DSM–IV criteria. Admission to hospital was required for 50% of individuals, typically shortly after presentation.

Incidence

Direct comparison with previous UK data is limited because of differences in the age bands used and methodology. The 1999 Office for National Statistics study reported a prevalence of 0.3% for eating disorders in 11- to 15-year-olds, based on a single screening question, with no one in the 5- to 10-year-old age group.7

Incidence data from a general practice registry study in the early 1990s found an incidence estimate for anorexia nervosa of 0.3/100 000 in 0- to 9-year-olds and 17.5/100 000 in the 10- to 19-year-olds. For bulimia nervosa the rates were 0/100 000 and 20.5/100 000 respectively.27 Our data for 0- to 9-year-olds was two and a half times higher (7.5/100 000). Retrospective studies from the USA and Denmark have suggested higher figures for anorexia nervosa, for example 9–27 per 100 000 for 10- to 14-year-old girls and 3.7 per 100 000 for boys.25,26 Previous studies have been limited to anorexia nervosa and bulimia nervosa, and excluded EDNOS and other atypical presentations, which together accounted for 62% of our sample.

Two surveillance studies have used similar methodology to ours. Madden et al27 reported an annual incidence of 1.4 per 100 000 children in Australia, half that of this UK/ROI study. The Australian study was confined to in-patients for 1 of 3 study years, and included few child and adolescent psychiatrists (2% of respondents). Our study used a dedicated child and adolescent psychiatric surveillance system. Unpublished data from the Canadian Paediatric Surveillance Program report 2.6/100 000, similar to our study.28

Importantly, our data provide a baseline from which to measure whether the incidence of eating disorders in children are really increasing as Van Son et al8 suggest, but do not at this point provide evidence for a true rise in incidence in children.

Demographics and medical status

As expected, the majority of individuals with eating disorders were female. Boys made up 18% of the overall sample, increasing to 33% of the ‘other’ category. This compares with 27% males overall in the Australian study.27 This may be as a result of the broader case definition used in the Australian study, resulting in a higher proportion of atypical cases. Atypical presentations and lack of awareness that these conditions can arise in young children and boys can lead to delay in referral, diagnosis and treatment.6,29 Three-quarters of girls were premenarcheal, similar to findings among in-patients in the Australian Paediatric Surveillance Unit study.27

We found that around 50% of individuals needed to be admitted to hospital. This contrasts with hospitalisation rates of over 70% in the Australian study, a sample biased towards in-patients. Our study provides a more representative picture in terms of the burden on hospital resources for younger individuals with eating disorders. The majority (73%) of those admitted in...
our study were admitted to paediatric units rather than psychiatric or specialist eating disorders units. The National Inpatient Child & Adolescent Psychiatric Survey showed that eating disorders were the most common diagnosis among child and adolescent psychiatric in-patients in England and Wales, 9.2% of whom were <13 years. The National Inpatient Child & Adolescent Psychiatric Survey did not include children on paediatric wards. Ours are the first published data on the scale of paediatric resource used by this patient group in the British Isles. Clinical experience suggests wide variation in the confidence among paediatricians over the management of these cases. This study provides the baseline figures needed to determine whether increases in hospitalisation rates are real or perceived, and can aid planning of age-appropriate services. Furthermore, there are currently no national paediatric guidelines for the care of individuals with eating disorders.

Diagnostic categories
Diagnosis and nosology are the subject of much discussion and debate, with revisions to DSM-IV and ICD–10 pending. In particular, the category of EDNOS has been widely criticised for being too heterogeneous, accounting for 77.4% of all individuals diagnosed with adolescent eating disorders in the community compared with only 13% for anorexia nervosa and 10% for bulimia nervosa. Particular problems with the application of current diagnostic criteria for children and adolescents have also been highlighted. This study provided an opportunity to explore the nosology of early-onset cases using a symptom-based approach. Principal-components analysis, based on nine key symptoms, found that three main clinical profiles in this age group in our study accounted for 60% of the variance. Our findings support those who argue that weight status is a continuum and does not distinguish between clinical cases on other criteria. This is particularly so in children; weight status is often a reflection of adult interventions (i.e. whether the child had been fed) rather than a measure of severity of illness. Those individuals who present with determined food avoidance in the absence of weight and shape concerns, 20% of our sample, are of less clear nosological status. Variously described as food avoidance emotional disorder or non-fat phobic anorexia nervosa, these cases might possibly be classified as anorexia nervosa on GP registers. Identification of these individuals has important implications for the development of clinical approaches to intervention, currently lacking, and for the scope of eating disorders provision.

Management
Of the total sample, 11% (22% of in-patients) were fed via nasogastric tube, compared with 58% of in-patients in the Australian study. Furthermore, 34% were prescribed psychotropic medication in the Australian sample, compared with only 13% in our sample. The mean duration of admission in the Australian study was only 24.7 days, compared with 76 days overall and 32 days for paediatric admissions in our sample. These differences may reflect cultural differences in treatment approach and/or differences in health service organisation, as well as the bias towards studying in-patients in the Australian study. Further research is needed to understand the implications for outcome of different approaches.

Risk factors and early intervention: psychiatric comorbidity
This study enabled examination of the first phases of an eating disorder in young children, before it has become compounded by chronicity. Increasing recognition of the neurodevelopmental contributions to risk for anorexia nervosa are reflected in the proportion of individuals in our study with comorbid autism-spectrum, psychotic and other developmental disorders. Prepubertal cases provide an opportunity to explore neurobiological risk factors before they are overshadowed by the major role that puberty plays.

In over 40% there was a family history of mental illness, most commonly anxiety or depression. In addition, a history of early feeding problems was reported in over 20% of individuals, across the diagnostic groups. Our study supports others that highlight the importance of family history and of early feeding problems, particularly fussy or picky eating, as risk factors for the development of early-onset eating disorders.

One of the most concerning findings from this study was that the mean time between onset of symptoms and presentation to secondary care was 8.3 months. The follow-up data show that most hospitalisations occur in the period immediately after presentation, with very few once treatment is established. The length of illness prior to presentation and the severity of illness at presentation suggest an urgent need to improve early detection and management of these individuals. Lask et al found that a single GP consultation about eating behaviour or weight and shape concerns is a strong predictor of the subsequent emergence of anorexia nervosa.

1-year outcome
Our study is the first to report the short-term outcome in a large representative sample of individuals with childhood-onset eating disorders. Although outcome was reported as good for the majority, a significant minority (16%) were reported as worse or unchanged at 1 year. Almost two-thirds of individuals were still in treatment, with a small number (seven) in hospital for most of the year. These data confirm that the healthcare burden of childhood eating disorders is not solely attributable to in-patient admission, and reinforces the needs to plan for long-term out-patient care. Our data suggest that the National Institute for Health and Clinical Excellence (NICE) guideline recommendation that out-patient treatment be offered typically for 6 months in the first instance and for a year after hospitalisation can reasonably be applied to children with eating disorders as well as adolescents and adults.

Strengths and limitations
The main strengths of our study are the national representative sample, and consequently adequate cases for descriptive analysis. With the high response rate from clinicians, the inclusion of cases presenting both to paediatricians and child psychiatrists, and the encouragement of dual reporting, we are confident that we have identified over 80% of restrictive eating disorders in those under 13 presenting to secondary care in the UK and ROI in the reporting year in both the National Health Services (NHS) and independent sector.

This methodology is limited to cases seen by consultant paediatricians and child psychiatrists. Those managed by GPs, in mental health services that do not have paediatric or psychiatric involvement, by training grade or career grade clinicians, receiving alternative healthcare or those receiving purely dietetic/nutritional care would not be identified by this methodology.

Case ascertainment in surveillance studies relies on clinician judgement and accuracy of clinician reporting. This will be more important for some data, for example binge eating and comorbidity, than for others such as weight. Binge, or loss of
control eating is likely to be particularly underrepresented, since this would require systematic screening and clear operational criteria to detect. Data were checked for internal consistency, especially when duplicate reports were available. For example, individuals reported as both in early puberty and as postmenarcheal were reassigned to mid-late puberty.

**Implications**

The 2004 NICE guidelines on the treatment of eating disorders highlight the need for developmentally appropriate care for young people with eating disorders, and the importance of coordination between professionals involved in their care. Many eating disorder services are specifically aimed at adolescents. Our study reaffirms the importance of considering the needs of children with eating disorders, in addition to and separately from those of adolescents, rather than simply lowering the age range of adolescent services. In particular, the role of paediatic services needs clarification and coordination between professionals in the management of these individuals, for example through the use of care protocols. Childhood eating disorders are not quick to diagnose and require systematic screening, and clear operational criteria to detect. Data were checked for internal consistency, with the expectation that this will improve prognosis.37

**References**


**Eating disorder not otherwise specified (EDNOS)**

(a) Binge eating (binge eating disorder)

Bingeing but no compensatory behaviours or food avoidance.

Weight and shape concerns present.

(b) EDNOS

All other cases not meeting criteria above but with the presence of weight and shape concerns.

**Operational criteria for diagnostic grouping for cases meeting the case definition**

**Anorexia nervosa**

- Weight <85% median body mass index/age.
- Determined food avoidance.
- Weight and shape concerns.

**Bulimia nervosa**

- >85% ideal body weight.
- Bingeing.
- One or more compensatory behaviour.
- Weight and shape concerns.

**Appendix**

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Invasion of the Body Snatchers (Don Siegel, 1955)

Trevor Turner

‘A strange neurosis . . . evidently contagious . . . people worrying about what’s going on in the world’, that is how the contented, pipe-smoking, 1950s Californian small town psychiatrist explains what is happening in Santa Mira. Ten or more patients referred complaining of their relatives somehow being changed – and the hero, a local doctor/GP played by the strong-faced actor Kevin McCarthy (a great name for a McCarthy era paranoid thriller) cannot work out what is going on. He is first seen at the city emergency hospital, as a screaming, dishevelled paranoid psychotic (‘you fools I’m not crazy . . . I’m a doctor too . . . you must understand me . . . I’m not crazy’). He recounts the story in a prolonged voice-over flashback. The audience is a sceptical emergency clinic physician, a policeman, and ‘Dr Hill from the state mental hospital’. Is Kevin mad, even though he starts to talk quite calmly, or are there really large leafy pods turning into people and replacing them with emotionless automatons, looking like people but with ‘something missing’?

Given the liberal way our doctor hero hands out tablets, some sleeping meds to young Jimmy who has ‘got the crazy idea his mother isn’t his mother’, as well as things to keep awake on, for him and his beautifully coutured girlfriend (her strapless dress looks extremely expensive), Given the liberal way our doctor hero hands out tablets, some sleeping meds to young Jimmy who has ‘got the crazy idea his mother isn’t his mother’, as well as things to keep awake on, for him and his beautifully coutured girlfriend (her strapless dress looks extremely expensive), Given the liberal way our doctor hero hands out tablets, some sleeping meds to young Jimmy who has ‘got the crazy idea his mother isn’t his mother’, as well as things to keep awake on, for him and his beautifully coutured girlfriend (her strapless dress looks extremely expensive),

Fast-paced, economical, black and white, a mere 80 minutes long, Invasion is not just a classic paranoid thriller, it is also an accidental archive of the 1950s medical practice and a brilliant exposition of the Capgras syndrome, en masse. Most viewers read it as either a trumpet call to the dangers of a communist takeover (‘there’s no emotion, just the pretence of it’) or a coded warning of the dangers of McCarthyite witch-hunts (‘is he Uncle Ira or isn’t he Uncle Ira?’). Not overtly a film about psychiatry or its practices, like so many police and sci-fi melodramas it uses a psychiatric condition as the framework for plot, character and exposition. As writers became more confident with this kind of material, drawn from our very own casebooks, they no longer needed a doctor or psychiatrist actually in the picture. The investigating cop, for example Jack Nicholson in Roman Polanski’s Chinatown (1974), unravels the history and diagnosis thanks to his intuition and police know-how, but he was just dealing with child abuse.

However you take Invasion, it is not only fine entertainment, but also great fun for psychiatrists to watch. Its implicit assurance that psychiatrists probably know much more than anyone else about how the world works and why people do certain things is also rather refreshing. After all, ‘Dr Hill from the state mental hospital’ does let our hero have his say.


