


## ORIGINAL ARTICLE

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# Recognition and duration of illness in adolescent eating disorders: Parental perceptions of symptom onset

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## Abstract

**Aim:** To understand the earliest parent reported signs suggesting their child may have an eating disorder (ED), and to quantify time from symptom onset to specialist assessment.

**Methods:** This is a secondary analysis of data derived from parents of 78 young people presenting to a British community ED service who completed a questionnaire asking when they first noticed their child displaying (a) a change in eating pattern, (b) weight concerns, (c) shape concerns. Parents were also asked to describe the first thing they noticed in terms of possible ED symptoms.

**Results:** Mean age was 14.9 (SD: 1.58), 94% were female with diagnoses of anorexia nervosa ( $n = 50$ ), bulimia nervosa ( $n = 10$ ) and atypical anorexia nervosa ( $n = 18$ ). Weight and shape concerns were most often noticed over a year prior to assessment (mean 12.7 months [SD: 12.8] and 13.3 months [SD: 13.2], respectively), with eating pattern change observed a mean of 9.7 months (SD: 7.6) before referral to specialist care. Seven main themes were developed from parents' descriptions of their child's symptoms: (1) eating pattern change, (2) shape concern, (3) weight concern, (4) observed weight loss, (5) binge eating/compensatory behaviours, (6) other mental health concerns and (7) physical symptoms.

**Conclusions:** The most common parental concerns were eating pattern change, specifically their child becoming more rigid/rule-bound with regard to eating and dietary restraint. Such external changes are likely observed before physical changes such as weight loss, offering potential for early identification by parents, primary care and other professionals, with implications for improved prognosis.

## KEYWORDS

early intervention, early signs, eating disorders, first symptoms, parent report

## 1 | INTRODUCTION

Eating disorders (EDs) are serious psychiatric disorders, which may carry physical, social and psychological consequences (Klump et al., 2009). The estimated incidence for anorexia nervosa (AN) in 8–17 years old from the UK and Ireland is approximately 14 per 100 000, with a recent increase in children under 13 (Petkova et al., 2019).

Early identification of EDs is important; longer duration of untreated illness can lead to poorer outcomes, including lengthy hospitalization and lower rates of recovery (Herpertz-Dahlman et al., 2018). Children and young people with an ED often first present to primary care services, although typically a general practitioner (GP) will only see about two incident cases of EDs in young people per year (Demmler et al., 2020). A single GP consultation for changes

in eating behaviour or shape and weight concerns has been shown to be a significant predictor for the later development of AN (Lask & Bryant-Waugh, 2005). However, early recognition and diagnosis is often challenging. Help seeking may be for reasons not directly related to eating behaviour (e.g. amenorrhoea or stomach pains) or for anxiety and mood problems, with concerns about eating not immediately forthcoming. Even when ED symptoms are apparent, young people with an emerging ED tend to show a lack of insight into their difficulties (Ali et al., 2017), and it is often parents who initiate consultations with primary care. Parents want information and guidance on how to address their eating concerns and some caregivers describe primary care clinicians as lacking sufficient understanding and knowledge to meet these diagnostic and management needs (Johns et al., 2019). A number of parents feel their concerns are dismissed by health care professionals (Ciao et al., 2020). In turn, GPs report insufficient training, competence and resources with regard to screening for ED symptoms, which may impede prompt referral to specialist services (Reid et al., 2010). A recent cohort study, which included patients, aged between 10 and 65 attending primary care revealed increased psychiatric diagnoses in the 2 years before identification of an ED as well as excess prescriptions for gastrointestinal medications, neuropsychiatric medications and dietetic medications in this period. Whilst data for children and adolescents were not analysed separately, this prescribing behaviour could represent efforts by GPs to treat a broad range of symptoms, which could in fact be indicative of an early ED, with these patients presenting with higher rates of gastrointestinal, dietetic and psychological symptoms (Demmler et al., 2020). Parents are usually the first to express concern about their child's potential ED symptoms, with mothers normally being more aware of these difficulties than fathers, and the full extent of symptoms often concealed by the young person (Laporta & Latorre, 2020). Both adolescent males and females with EDs report body image and weight concerns as key symptoms, with boys more likely to link these issues to external factors such as a desire to build more muscle bulk or life transitions (Arnow et al., 2017). However, these symptoms may only be elicited through direct questioning.

To our knowledge, no previous study has explored parent reports of the early symptoms and signs of their child's ED. The primary aim of this study was to understand the first symptoms of potential EDs in young people as noticed by parents. This understanding may be helpful in contributing to the early identification of EDs by parents and by clinicians, particularly in the primary care setting, and help to facilitate prompt access to staged treatment. The secondary aim was to describe the time from symptom onset to referral for specialist ED assessment.

## 2 | METHODS

### 2.1 | Participants

Participants were recruited from cases newly presenting to the Surrey Child and Adolescent ED Service (June 2012–December 2014). The

sample included caregivers and their children (aged 8–18) with any ICD-10 (World Health Organization, 1992) ED diagnosis, and who had not been previously diagnosed or treated for an ED.

This is a secondary analysis of data from a preliminary study evaluating a parenting intervention for ED (Nicholls & Yi, 2012; Rosello et al., 2020) for which ethics approval was obtained from the Bloomsbury Ethics Committee (REC reference 12/LO/0921).

### 2.2 | Data collection

A questionnaire was developed by the study team, which requested information from parents about their child's early ED symptoms. This was completed at the time of recruitment, shortly after initial assessment. Parents were asked when they first noticed their child displaying (a) a change in their eating pattern, (b) concerns about their weight and (c) concerns about their shape. Parents were also asked to describe the first thing they noticed in terms of possible ED symptoms.

Demographic information was collected for all participants and included age, gender, family structure and information about any history of ED or other mental health problems in the immediate family. ED psychopathology was assessed using the Eating Disorders Examination Questionnaire (EDE-Q 4.0), (Fairburn & Beglin, 2008) which measures patient's attitudes and behaviour towards food and weight over the previous 28 days. It is comprised of four subscales (restraint, eating concerns, shape concerns and weight concerns), including a global score for overall severity. Most responses are quantified using a Likert scale to indicate symptom frequency and ranging from 0 (never) to 6 (everyday). Higher scores on the global scale and subscales indicate more problematic behaviours and attitudes with a cut-point of three or more indicative of clinical significance (Carter et al., 2001). At the time of this study, the EDE-Q was validated for self-report from age 12.

Patients' percentage median body mass index (%BMI) was calculated based on normative data of weight for height for age and gender (Van Wieringen & Roede, 1985), with the formula: BMI/50th percentile BMI for age and height  $\times 100$ .

### 2.3 | Data analysis

- a) Demographic details and ED symptoms were described.
- b) Quantitative Data.

The mean time between parental perception of symptom onset and referral was analysed for the key symptom domains (change in eating pattern, concerns about weight and concerns about shape) across all diagnostic groups and for each ED diagnosis separately.

- c) Qualitative data.

A qualitative approach was used to analyse parents' responses to the questions about early ED symptoms. These responses were analysed by researchers who were entirely independent of the clinical team and of the data collection process, using a reflective thematic

framework approach to generate themes and subthemes from the data (Braun & Clarke, 2006; Clarke & Braun, 2018). Parent questionnaires were analysed by the first author (RR) and read a number of times to immerse the researcher in the data. Directed by existing concepts and ideas on EDs (a deductive form of thematic analysis), all the responses were collated verbatim into meaningful symptom clusters from which themes and subthemes were derived. These were shaped and reshaped through in-depth discussion with a co-author (JG) and the principal investigator (DN). Disagreements such as coding differences were resolved by consensus in regular research meetings held to evaluate and monitor the process.

### 3 | RESULTS

#### 3.1 | Participants

Seventy-eight young people (and their families) took part; they had diagnoses of anorexia nervosa (AN;  $n = 50$ ), bulimia nervosa (BN;  $n = 10$ ) or atypical anorexia nervosa (AAN;  $n = 18$ ), according to ICD-10 (World Health Organization, 1992) criteria. Mean age was 14.9 (SD: 1.58) and 94% were female.

Fifteen percent of the participants were reported by parents as having been overweight in the past. The majority of young people lived with both biological parents (83.2%), 43.4% had a close relative with a MH problem under specialist care and about a quarter had a family history of an ED.

Clinical characteristics of the patients can be found in Table 1.

#### 3.2 | Temporal onset of symptoms

Concerns about weight and shape were most often noticed just over a year prior to the initial assessment (mean 12.7 months [SD: 12.8] and mean 13.3 months [SD 13.2], respectively), with changes in eating pattern observed at a mean of 9.7 months (SD: 7.6) before referral to specialist care. A minority of parents (about 8%) recalled symptoms over 3 years prior to specialist assessment.

The full chronology of initial difficulties (eating patterns and concerns about weight and shape) observed by parents is represented in Figure 1 with respect to the whole sample and each diagnostic group.

#### 3.3 | Qualitative results of the parent questionnaire

Responses to the open-ended question about early symptoms were between two to six sentences long. Seven main themes were identified from parents' descriptions of their child's initial ED symptoms: (1) changes in eating pattern (frequency/type/quantity of food consumed in meals/snacks), (2) shape concern (preoccupation with appearance or efforts to conceal body shape), (3) weight concern (preoccupation with weight, excessive control over weight, extreme desire to reach a specific weight), (4) observed weight loss, (5) binge eating/compensatory behaviours (eating large amounts of food, experiencing loss of control, using compensatory behaviours to avoid weight gain), (6) emotional and other mental health concerns and (7) physical symptoms.

The themes and subthemes are described in detail in Figure 2, including examples of participants' quotes.

### 4 | DISCUSSION

As far as we aware, this study is the first to document responses to an open question asking parents about the signs and symptoms they first noticed which made them think their child might be developing an ED.

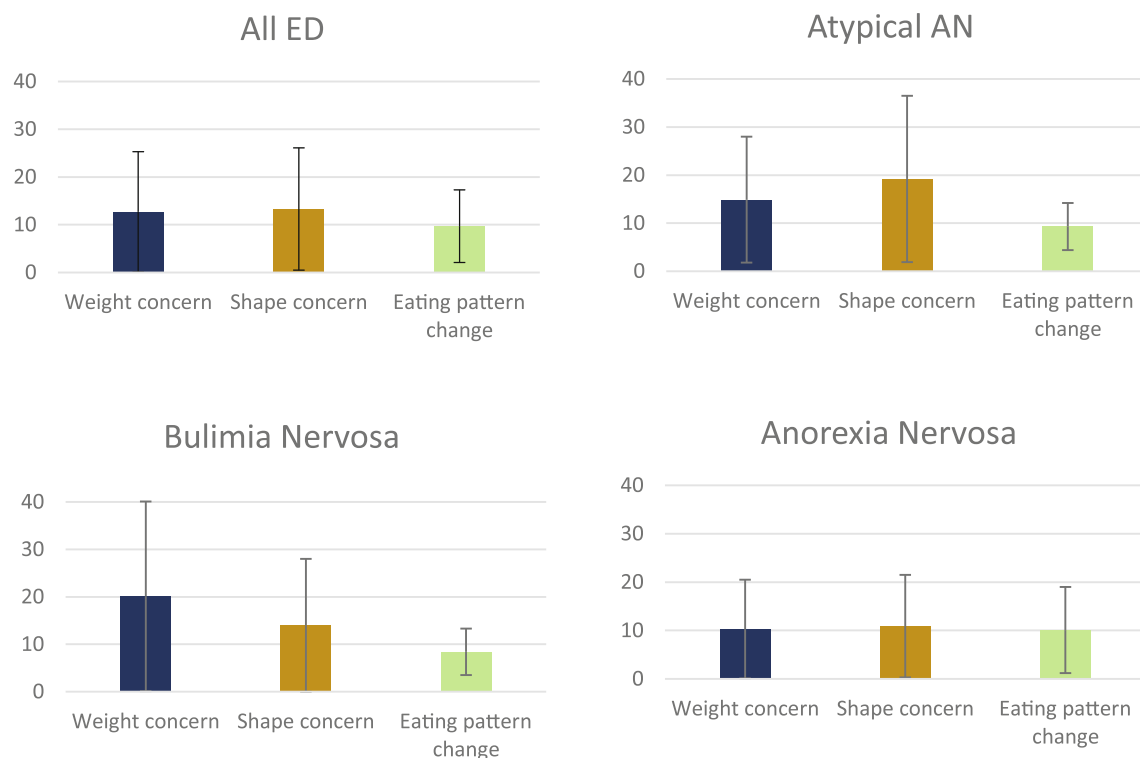
#### 4.1 | Chronology of symptoms

When symptoms were categorized into domains corresponding to the three core areas of ED psychopathology (eating pattern change, shape and weight concerns), most parents reported their child having worries around their body shape and weight about a year before

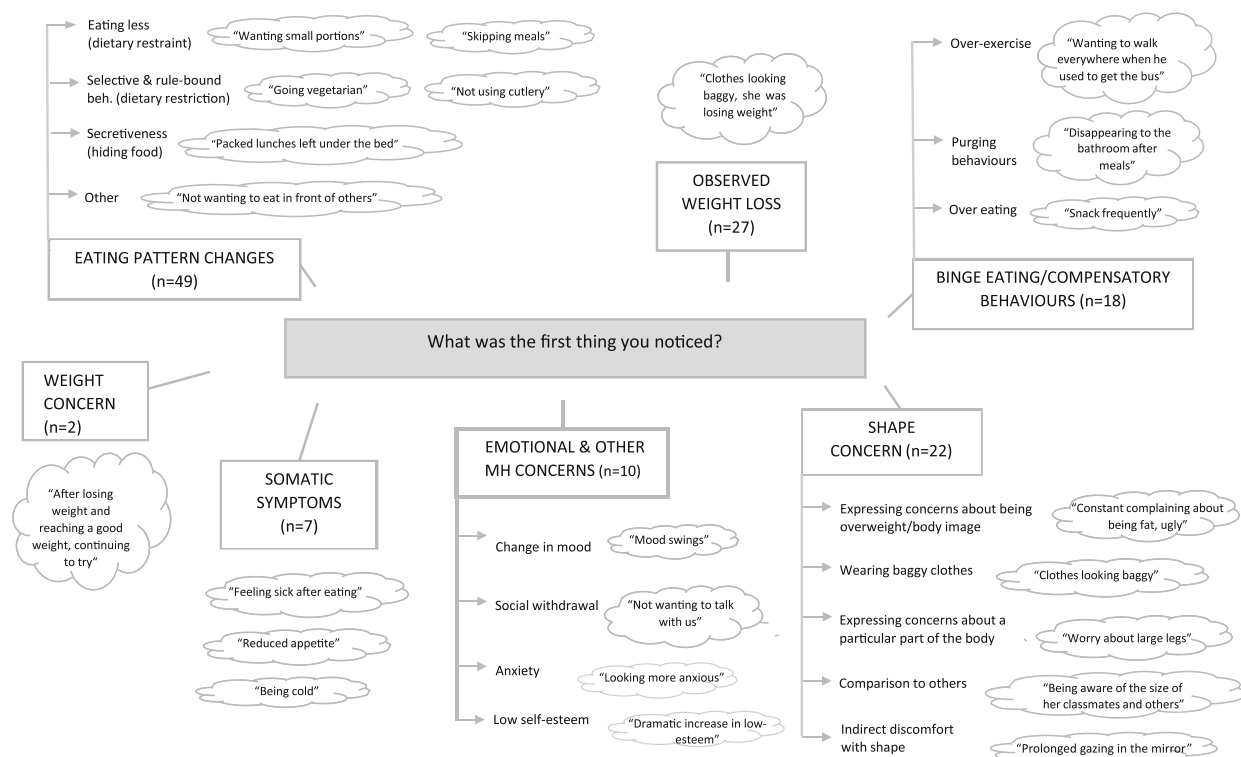
**TABLE 1** Clinical characteristics of patients

Dx	Age	%BMI	EDE-Q global score	EDE-Q restraint	EDE-Q eating concern	EDE-Q shape concern	EDE-Q weight concern
Anorexia nervosa $N = 50$	M 15.09 (SD: 1.58)	M 81.26 (SD: 8.05)	M 3.95 (SD: 1.44)	M 4.1 (SD: 1.6)	M 3.5 (SD: 2.1)	M 4.5 (SD: 1.4)	M 4.1 (SD: 1.5)
Bulimia Nervosa $N = 10$	M 15.27 (SD: 0.97)	M 105.27 (SD: 10.26)	M 4.64 (SD: 0.37)	M 4.1 (SD: 0.6)	M 4.2 (SD: 1.1)	M 5.2 (SD: 0.4)	M 4.9 (SD: 0.5)
Atypical Anorexia $N = 18$	M 14.14 (SD: 1.67)	M 88.72 (SD: 8.88)	M 3.51 (SD: 2.05)	M 3.7 (SD: 2.1)	M 3.1 (SD: 1.9)	M 4.1 (SD: 2.3)	M 3.7 (SD: 2.0)

Abbreviation: M, mean.



**FIGURE 1** Chronology of symptoms (parent observed behaviours indicative of weight concern, shape concern and eating pattern change): mean time (in months) and SD between parent perceived symptom onset and first assessment



**FIGURE 2** Thematic analysis with example quotes of parents' responses to the question "What was the first thing you noticed?"

referral, followed a few months later by changes in eating pattern. In about 8% of this sample, symptoms were observed over 3 years before referral and a symptom history of over 3 years has been linked to a poorer response to treatment (Treasure et al., 2015).

Individuals with AN showed a shorter than average time from observed symptom onset to referral as compared to AAN and BN. For AN, time between symptom onset and referral was similar across the three symptom domains (about 10 months). Eating pattern change was the most recent area of concern noticed across all diagnostic groups and thus may have heightened anxiety leading to consultation. Both weight and shape concern preceded eating pattern change for both AAN (where shape concern was first observed) and BN (where weight concern was the initial cluster), which may be associated with a prior history of overweight (Villarejo et al., 2012).

## 4.2 | Qualitative findings of first signs

When parents were asked to respond to an open question about initial signs ("what was the first thing you noticed?") they commonly reported changes in eating pattern, specifically their child becoming more rigid/rule-bound with regard to their eating. This is an external change in eating behaviour, likely to be observed by parents; examples include becoming vegetarian, counting calories on food packages, declining high calorie foods and carbohydrates or not using cutlery. Other eating pattern changes identified were dietary restraint (turning down food, not finishing/skipping meals) and secretiveness/hiding food. Whilst parental symptom reports relied on retrospective recall in this study, it is likely that changes in observable behaviours were recognized by parents early on. Previous research has also emphasized the importance of awareness among healthcare professionals of disordered eating behaviours as an indicator of potential psychopathology regardless of weight status (Hughes et al., 2019).

When parents were asked specifically about body image and shape concerns, they acknowledged these symptoms early on in the course of their child's ED. However, when parents were asked for their own reports of initial signs through an open question, such concerns were less common. This could link with the high frequency of negative cognitions about shape and weight in the general adolescent population (Hughes et al., 2019) which may mean that parents do not consider such thoughts as indicative of ED psychopathology; about 60% of girls aged 13 sampled in a cohort study reported being afraid of gaining weight or becoming fat, which coupled with a Western societal aspiration for thinness (Thompson & Stice, 2001), contributes to the labelling of such perceptions as common concerns or "normative discontent" (Micali et al., 2014; Rodin et al., 1984). However, the shape concerns which worried parents included a reluctance to shop for clothes, asking to diet, comparison to others and frequent mirror gazing. While it is not possible to infer what children and adolescents were thinking based on parent report, the existing research regarding the co-occurrence of unhelpful thinking styles and ED behaviours suggests that these thoughts were present in this sample of young people during the months prior to referral. Unhelpful thoughts of this kind

are likely to drive individuals to establish rigorous control around food (Fairburn, 2008), leading to dietary restraint, bingeing and/or inappropriate compensatory behaviours.

Binge eating and compensatory behaviours were reported with a similar frequency, although young people often try to conceal such symptoms from family members (Mariano et al., 2013). Our data suggest that a significant proportion of parents may in fact have been aware of these behaviours. Weight concerns were reported by very few parents, although for a significant proportion it was observed weight loss that first alerted them to the possibility of an ED. Weight loss is diagnostically key in restrictive EDs and is likely indicative of more persistent and more severe illness, and therefore potentially quite a late sign. Interestingly, other signs and symptoms such as frequent weighing or amenorrhoea (Treasure et al., 2020) were not reported by parents. This may be because they are easier to conceal from parents and likely to be indicators of more severity with other symptoms observed earlier.

Comorbidity between restrictive EDs and mood disorders such as anxiety and depression is approximately 50% (Buhren et al., 2014) yet these were only noticed by a minority of parents in this sample. Somatic symptoms such as apparent decrease in appetite, fatigue, being cold or feeling sick after eating were also reported early on in their child's presentation. GP consultations in the adolescent age group are almost exclusively for physical symptoms although about a quarter have underlying psychiatric disorders, highlighting the importance of screening for psychopathology in primary care (Gledhill et al., 2003).

Parents often initiate consultations with healthcare professionals to discuss concerns about their child's possible ED; young people themselves often view their ED ego-syntonic and minimize or deny their symptoms (Starzomska & Tadeusiewicz, 2016). Although parents in this study were aware of some early symptoms suggestive of an ED, we do not know whether parents tried to address these difficulties with their child prior to help seeking. However, only a small proportion of participants (6.4%) had consulted professionals (dietitian/counsellor/paediatrician/therapist) before the consultation, which led to referral and initial assessment with the specialist ED team. Thus, parents may normalise concerns and accommodate behaviours to avoid conflict or try to manage abnormal eating behaviours within the family (Schmidt & Treasure, 2006). When a child develops an ED, parents often experience a low sense of caregiving competence to manage the eating difficulties (Nagl et al., 2016) and this may be exacerbated by a change in the parent-child relationship which becomes characterised by dysfunctional communication styles and high expressed emotions (Whitney et al., 2012), leading to further parental disempowerment. Parents may have consulted other health care professionals such as GPs prior to specialist CAMHS referral although these may be under reported particularly if consultations were prompted by somatic symptoms.

Overall, this study found that shape concerns preceded weight concerns and changes in eating pattern for most young people. This highlights the importance of understanding the relationship young people have with their body image. However, changes in eating

behaviour were most commonly retrospectively recognised by parents as being the start of the ED. The challenge for parents is knowing when to be worried and how to disentangle these symptoms from distress over shape and weight that is reported by about 20% of adolescents (Bartholdy et al., 2017). For young people of previously healthy weight (as was largely the case in this sample), shape and weight concern accompanied by changes in eating behaviour may help identify those who are developing an ED. This information is potentially useful in improving early identification of ED by parents and healthcare professionals.

### 4.3 | What does this mean for clinicians?

Including parents in the assessment and treatment of young people with an ED is highly recommended in the National Institute for Health and Care Excellence (NICE) guidelines (2017). Parents and young people may consult primary care at different stages in the course of an ED, and when families perceive clinicians to be listening and validating their concerns, this can positively influence further engagement with primary and specialist services (Dimitropoulos et al., 2015). However, GPs often feel de-skilled in the management of child and adolescent mental health disorders and receive little training in this area (Reid et al., 2010). Whilst significant weight loss is likely to be a cause of concern to primary care clinicians, for families consulting early in the course of the illness, this may not yet be apparent. It could be helpful for clinicians to be aware of the early symptoms and signs parents might notice that may be indicative of the later development of an ED. Enquiry about changes in eating pattern (wanting small portions, skipping meals, refusing high calorie foods, avoiding eating with other people, episodes of overeating and hiding food), pervasive fear of weight gain (counting calories/fats/sugars, dieting, exercising more and frequent weighing) and dissatisfaction with body weight and shape (frequent negative comments about own appearance and wearing baggy clothes) are useful questions for clinicians screening for EDs. Some questions to assess eating psychopathology are included in Table 2.

Additionally, young people presenting to primary care with non-specific physical complaints should be asked about possible ED symptoms as well as considering other potential diagnoses (Yeo & Hughes, 2011) and screening for psychopathology. Early recognition of EDs, particularly in children and adolescents, is heavily reliant on parental report, perhaps more so than for some other child mental health disorders. Therefore, parents' observations, even if they seem vague and subtle, should be taken seriously with concerns monitored and followed up because the ED is likely to have been present for a considerable period by the time families seek specialist help.

### 4.4 | What does this mean for parents?

Many of the early symptoms, which parents report, are observable behavioural changes. Parents should trust their intuition if they

**TABLE 2** Questions that GPs/clinicians could use in the assessment of a possible emerging ED

Changes in eating pattern	<p>Have portion sizes at mealtimes changed?</p> <p>Is she/he skipping meals/snacks?</p> <p>Is she/he refusing to eat specific type of foods? Which?</p> <p>Is she/he avoiding eating in front of other people?</p> <p>Is the young person avoiding social plans that involve eating out?</p> <p>Have you noticed that your child periodically eats large amounts of food?</p> <p>Have you noticed that food is missing at home?</p> <p>Have you found food/food packaging hidden in the house?</p>
Pervasive fear of weight gain	<p>Is she/he following a diet?</p> <p>Is she/he exercising more than usual?</p> <p>Is the young person weighing themselves more than usual?</p> <p>Have you noticed the young person talking more about food and/or being more interested in knowing the caloric content of food?</p>
Dissatisfaction with body weight and shape	<p>Is the young person making negative comments about their appearance?</p> <p>Has their style of clothing changed? In what way e.g. are they wearing more baggy clothes?</p>

become concerned about a possible ED. Young people are unlikely to raise concerns themselves in the same way that they might become worried about developing other mental health problems. It is common for children and adolescents to have concerns about their weight and shape at some point, particularly as their bodies change during puberty, or if they are overweight or obese (Bartholdy et al., 2017). Importantly, changes in eating behaviour can often be viewed positively at first (e.g. eating is seen as more 'healthy') and parents need to try to understand what is driving their child to change their eating behaviour: when persistent and coupled with negative body image and weight concerns this may be an indicator of psychopathology.

### 4.5 | Limitations, strengths and future directions

This study was a secondary analysis of data previously collected in order to inform evaluation of a parenting group intervention offered to families of young people referred to a specialist community ED service for the first time (Rosello et al., 2020). The dataset included some qualitative information collected by self-report questionnaire from parents about early onset symptoms and this information formed the basis for this qualitative analysis. Despite reliance on



qualitative methodology, retrospective data collection may have led to recall bias. Generalizability may be limited by reliance on one clinic. Nonetheless, the clinic was the principal provider for a large population (around 1 million) located in a National Health Service community setting and thereby free at the point of access, and the sample was typical of those presenting to specialist ED services at this age. Despite these limitations, the findings of this study are novel and provide information from a parent's perspective about early ED symptoms in young people, with externally observable changes in behaviour raising early parental concern. A common general misconception about patients with EDs is that they need to look unhealthy or underweight; however, at an early stage this may not be the case (Bulik, 2016). For most clinicians and parents, EDs are seen as associated with changes in weight; the findings from this study help to broaden that understanding and raise awareness of other signs and symptoms that may occur earlier and need to be taken into consideration and screened for to better identify possible EDs in young people. Improved detection of emerging EDs means that prompt referral to specialist care and early intervention can be offered.

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## CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

## DATA AVAILABILITY STATEMENT

Due to its nature, the data are not available on a public repository. However, it is available on request to the author of correspondence.

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