

# **Key Stakeholder Perspectives on Primary Care for Young People with an Eating Disorder: A**

## **Qualitative Study**

### **Short running title Primary Care for People with Eating Disorders**

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# **Key Stakeholder Perspectives on Primary Care for Young People with an Eating Disorder: A Qualitative Study**

## **Abstract**

This paper examines the provision of primary care for young people with an eating disorder within the UK from the perspectives of three key stakeholder groups: young people with an eating disorder, carers of young people with an eating disorder and General Practitioners (GPs). 22 young people with an eating disorder (aged 16-25) and 10 carers completed qualitative questionnaires or participated in interviews about their experiences of seeking primary care from GPs. 41 GPs participated in either focus groups or interviews about delivering care to young people with eating disorders. Interviews and focus groups were audio-recorded and transcribed verbatim. All data were then analysed qualitatively using thematic analysis. Our analysis indicates that GPs often felt they lacked the necessary knowledge and/or resources to provide adequate support to young people with an eating disorder who they also often viewed as a 'difficult' patient group. Young people and carers expressed mixed but predominantly negative experiences, reporting that GPs often lacked adequate understanding of eating disorder, failed to take participants' concerns seriously and delayed referring patients to specialist services. Our findings indicate a need for interventions that will improve primary care provision and access to appropriate support for young people with an eating disorder.

**Keywords:** young people, eating disorders, carers, general practitioners, primary care, qualitative research.

## **Key Stakeholder Perspectives on Primary Care for Young People with an Eating Disorder: A Qualitative Study**

### **Introduction**

Eating disorders (EDs), including primarily Anorexia Nervosa, Bulimia Nervosa, Binge Eating Disorder and Other Specified Feeding and Eating Disorder (formerly Eating Disorders Not Otherwise Specified, APA, 2013), are serious mental health issues which may now be one of the most common mental health problems (PHSO, 2019), affecting as many as 1.25 million people in the UK alone (Treasure and Russell, 2011). They have a significant impact on physical, psychological and social wellbeing (B-eat, 2015; Brown et al, 2016) with some of the highest levels of morbidity and mortality associated with any mental health problem (Treasure, Schmidt and Hugo, 2005). They primarily (but not exclusively) affect young people, particularly girls and young women and can endure for years (B-eat, 2015; Brown et al, 2016; O'Brien et al., 2016; Steinhausen, 2002). Treatment duration is often lengthy, relapse rates are high and many require one or more hospital admission, often for extended periods (Szmukler et al, 1998; B-eat, 2015). Studies also suggest that hospital admissions for EDs have risen sharply in recent years (B-eat, 2015;; Barber et al., 2019) and there are indications that cases of EDs among young people may have doubled, tripled or even quadrupled during the recent COVID-19 pandemic (RCPCH, 2020).

Research clearly demonstrates that delays in access to specialist treatment strongly predict poorer outcomes for people with an ED (e.g. B-eat 2017; Schoemaker, 1997; Treasure & Russell, 2011; Zipfel et al., 2000). Self-starvation may have lasting impacts (Brown et al 2016), symptoms may become increasingly entrenched over time and there is

growing evidence that full recovery is predicated on intervention occurring within three years of the onset of the problem (Treasure, Stein and McGuir, 2015; Brown et al 2016).

For many individuals, a general practitioner (GP) will be their first port of call in seeking help for an ED (PHSO, 2019) and GPs inevitably often play a crucial role in identification of EDs, referral to specialist services or other appropriate support and in ongoing monitoring and management of patients' needs (B-eat, 2017; Redston et al., 2014). As gatekeepers to specialist services, GPs may play a vital role in facilitating (or hindering) early intervention and hence in reducing (or exacerbating) the severity and duration of EDs (Brown et al, 2016). Yet studies also indicate that GPs may find these tasks difficult (Waller et al., 2014). They may be unaware of unmet needs, for instance, underestimating prevalences (Currin et al., 2009; Reid et al., 2009; Waller et al., 2014), and may lack adequate knowledge or training about EDs (Seah et al., 2017 Reid et al., 2009 Leahy et al., 2013). Indeed, a lack of training in medical schools about EDs was 'a consistent theme in the evidence' presented to a recent UK Parliamentary inquiry (PHSO, 2019; see also Ayton and Ibrahim, 2018). Other studies have found a similar picture. Girz et al. (2014), for example, found that the majority of the 880 Canadian physicians taking part in their survey had received less than five hours training about eating disorders while Mahr et al.'s (2015) national survey of accredited residency programs in the USA across a range of medical disciplines found that only 19% of the 637 responding programmes offered either elective or scheduled rotations on eating disorders while for family medicine that figure fell to 12%.

Researchers have also begun to investigate patients' and carers' perspectives on primary care for people with EDs. The importance of heeding service user voices is increasingly widely recognised by both academics and clinicians (Holmes et al., 2021; Malson et al., 2008) and the inclusion of carers' perspectives within that is all the more important in the context of services

for young people (Treasure et al., 2005). A recent survey of 1693 individuals with experience of an ED and of their families and friends (B-eat, 2017; see also Marsh, 2017) revealed mixed experiences of GP care with only 34% feeling that their GP knew how to help them; only 30% being referred to specialist services and 52% rating the quality of GP care as poor or very poor. A similar survey (Anorexia Bulimia Care, 2014) likewise found 63% of participants felt that their GP did not offer suitable help or advice while 45% felt their GP was neither caring nor understanding about their condition. Similarly, Lazare et al. (2019) found that patient experiences varied considerably but were often characterised by delays in diagnosis and referral. This picture is very likely to be even worse for those who do not fit the stereotyped image that people with an ED will be underweight, White, middle class, cis-gendered, heterosexual, able-bodied young women (see Bordo, 2009; Rice, 2021). Evidence clearly suggests that, for example, those from ethnic minorities are even less likely to be referred to specialist services (Chowbey et al., 2012; Solmi et al., 2016). Thus, while there may be many instances of good primary care for people with an ED, there may be considerable scope for improvement.

## **Research Aims**

It is therefore vital to develop an in-depth understanding of how young people with an existing or emerging ED, their carers and GPs experience primary care provision for this patient group. Yet, our knowledge of these experiences and perspectives remains limited and further research is required (Allen & Dalton, 2011; Cadwallader et al., 2016). This project aims therefore to provide a multi-perspectival, qualitative analysis of the experiences and perspectives of these three key stakeholder groups.

## **Methods**

### ***Design***

The study was developed in consultation with people with lived experience of EDs; its aims developing out of conversations during an event organised to elicit the views of service users, ex-service users, carers and voluntary sector workers about priorities for service development and research. Drafts of research materials such as information sheets and survey questions and, later, provisional analyses were also shared and discussed at subsequent similar events. The study took a qualitative approach to investigate how primary care for young people with an ED was experienced by (i) young people with an ED, (ii) carers of young people with an ED and (iii) GPs. We used a combination of semi-structured interviews, focus group discussions and qualitative surveys (see Braun and Clarke, 2013) to generate a multi-perspectival corpus of in-depth data which we analysed using thematic analysis (Braun and Clarke, 2006, Braun et al., 2017).

### ***Participants***

The young people and carers in this study were recruited via a local eating disorders service; via a research recruitment scheme in the Psychology undergraduate programme of a local university and via the email lists, websites and social media posts of local and national eating disorder support groups and other relevant voluntary and public sector organisations in the UK. Twenty-two young people (aged 16–25) who self-identified as having experience of an ED and ten adults who identified as carers of young people with an ED were recruited to the study. The decision to recruit participants on the basis of self-identification rather than formal diagnosis was made primarily to ensure we did not exclude those whose existing or emerging ED had not been recognised. Ten of the young people taking part identified their ED as 'Anorexia Nervosa', two as 'Bulimia Nervosa', seven as 'Eating Disorders Not Otherwise Specified' (now renamed as 'Other Specified Feeding and Eating Disorder') and three as 'Other'. Seventeen identified as young women, four as young men and one as non-binary. One participant identified as Asian British, one as Black African, one as mixed race, one as

Taiwanese, one chose not to say and the remainder identified as White or White British. They had experienced inpatient and outpatient treatment (n=8), outpatient only (n=6) and neither (n=8). Ten carers participated in the study including nine mothers (aged 48-56) and one brother (aged 18) of a young person with an ED. Nine identified as White or White British and one as mixed race. They described the young person they cared for as having experienced both inpatient and outpatient treatment (n=8) or outpatient only (n=2) for either anorexia nervosa (n=9) or anorexia nervosa with binge eating disorder (n=1)

Forty-one GPs also participated in the study. Thirty-one GPs (twenty-eight women and three men) were recruited via a local GP training organisation. They included fourteen newly qualified GPs, seven locums and ten GPs attending a training day on an unrelated issue (addiction). An additional ten GPs (nine women and one man) with some known experience of EDs were also recruited. Nine were recruited from a list of GPs who had contacted a local ED service for advice and one was recruited via personal contacts.

### ***Procedure and Data Collection***

Young people who self identified as having an ED and carers of young people with an ED were offered the choice of completing an online qualitative survey or taking part in a semi-structured interview. A link to the online survey was made available to potential participants which took them to an information sheet and consent form before allowing access to the survey. Participants who preferred to take part in an interview were emailed information sheets and consent forms and returned signed copies of consent forms prior to the interview taking place.

All twenty-two young people who participated in the study and seven of the carers chose to complete the survey. Three carers chose to take part in telephone interviews. Both the

questionnaire and the interview schedule consisted of ten open-ended questions asking about participants' experiences of primary care for themselves or a young person with an ED including questions about helpful and unhelpful aspects of the care provided and about how they felt their care could have been improved. Interviews were audio-recorded, transcribed verbatim and anonymised. Interview transcripts and survey responses are identified by YP (young person) or C (carer) followed by a participant number.

Thirty-one GPs took part in one of three focus groups conducted during GP training days and meetings hosted by a local GP training organisation. All attendees at these events were provided with an information sheet and invited to participate in a focus group discussion timetabled to take place during a break in the event. Participants were asked to discuss their experiences of providing care for young people with an ED, including their experiences of identifying individuals with EDs, referral processes, and managing patients' needs and their views on how they might be better supported in providing appropriate care. The ten GPs with some known experience of EDs were invited to participate in a 15-20 minute semi-structured one-to-one telephone interview. Potential participants were invited to participate and sent an information sheet via email. For those expressing an interest, a time was arranged for the interview which followed the same topics as those used in the focus groups. All interviews and focus groups were audio-recorded, transcribed verbatim and anonymised. Focus group transcripts are identified by FG1 (newly qualified GPs), FG2 (locums), FG3 (GPs attending a training day on addiction) and interview transcripts by a participant number (GP1, GP2 etc).

Our decision to use three different methods of data collection - interviews, surveys and focus group discussions<sup>1</sup>- was primarily a pragmatic choice designed to maximise the likelihood of people's participation. While we would have preferred to have interviewed more young people and carers, we felt that the option to participate via an online survey would allow us to



include a greater number and potentially a greater diversity of people who might not have felt comfortable being interviewed. The decision to conduct focus group discussions as well as interviews with GPs was similarly intended to maximise our ability to recruit GPs (whose surgeries are often extremely busy) by conducting focus groups in breaks at events they were already attending rather than asking them individually for their time during their working days. And, while interviews are still often viewed as generating richer data than focus group discussions and surveys, in practice both the surveys and focus groups also yielded rich data and useful insights (see also Braun et al., 2017).

### ***Data analysis***

All data were analysed qualitatively using Braun and Clarke's (2006) six-stage process of thematic analysis within a broadly realist epistemological framework in which participants' accounts were taken as more or less transparent expressions of their views and experiences. Each of the datasets produced by our three participant groups – young people, carers and GPs – was closely and repeatedly read, resulting in coding categories that were then used to systematically collate the data. We then searched for, reviewed and refined themes within the coded data. At this point we searched across as well as within the three datasets to develop a picture of the relationships between them as well as the prominent and defining features, commonalities and variations within each dataset. Summative labels and synopses of our themes and subthemes were then produced and reviewed in relation to the quotes within those themes.

### **Results**

In defining and reviewing themes across our three datasets it became apparent that there was considerable convergence in the experiences of young people and carers in seeking support for themselves or the person for whom they care. GPs' accounts also dovetailed with both of

these sets of account but in some ways, as outlined below, they were also quite distinct. In the analysis that follows we have therefore presented the experiences of young people and carers together followed by those of GPs.

Across all three of our participant groups there was a mix of both positive and negative experiences of seeking or providing primary care. For young people with an ED and for carers positively construed experiences were characterised by instances of GPs knowing about EDs, expressing empathy, listening to participants' concerns and acting swiftly to facilitate appropriate support (see also Lazare et al., 2009). For instance:

It's all been great... We discussed the symptoms that I was showing and he [the GP] asked what kind of support my Mum and I were looking for. (YP4)

I was very lucky in that I had a very kind GP who asked me a little about myself and some of the things causing me stress. ...[He] was very kind and encouraging rather than dismissive, brusque and annoyed like some other GPs I had. (YP2)

However, receiving good quality care was described as a 'matter of chance' (YP3) and negative experiences predominated (see also B-eat, 2017; De la Rie et al., 2006; Rother & Buckroyd, 2004; Tierney, 2005). And, as our analysis below illustrates, negative experiences were characterised by these same issues, i.e by a lack of knowledge, empathy, listening or swift referral. It is therefore these negative experiences on which we focus in discussing our two main themes: (1) GPs knowledge about EDs and (2) attitudes towards patients and carers.

#### *A lack of knowledge about EDs*

Young people and carers frequently gave accounts of GPs having over-narrow views of EDs, reporting that GPs appeared unaware of behavioural and attitudinal aspects of EDs or of the psychological distress involved. They often commented that, unless the young person had a very low BMI, GPs often failed to recognise that there was a problem.

All [the GP] said was that my weight was not low enough, so she couldn't refer me to the eating disorder services of the hospital. To be honest, I felt so low at this time that hearing this just made me think: if that's what they want, I'll make sure I'll eat even less and lose the weight they want me to lose! (YP3)

[The GP] weighed and measured her [participant's daughter], told her she was still within the normal range but I felt he had not 'heard' the fact it wasn't her actual weight I was worried about but that she had lost weight and was resisting eating. (C3)

Indeed, participants suggested that even when weight loss was recognised, it was often minimised as being 'just a phase' and as 'normal' particularly for teenage girls.

The GP (who hadn't seen the patient) reassured me it [her daughter's weight loss] was probably "just a phase". (C5)

[What people need from a GP is] Not being told that they are a normal weight and basically it's a 'teenage phase'. (YP15)

At some point within the next year, after more weight loss, my mother sent me to see the GP again, who told me these feelings and behaviours were 'normal for a girl my age' and that I would 'grow out of it'. (YP11)

Thus, not surprisingly, many participants also reported that GPs often delayed making referrals to specialist services or other forms of support, sometimes with devastating consequences.

She [participant's daughter] had withdrawn emotionally. She was a mess, unrecognisable. Her personality was quite different. She was isolating herself from others. She didn't appear to have a lot of self-pride so her appearance was looking dishevelled...and he [the GP] said: well I'm afraid I can't do anything. (C7)

I took my daughter to the GP because she had stopped her periods. I told the GP that she had become vegetarian and that she had lost weight. ... No follow up was offered except 'return if it gets worse'. ... my daughter is now in a Tier 4 unit which has a huge financial cost to the NHS and to us, as well as the emotional cost to the whole family. (C1)

GPs' accounts about working with young people with EDs were also predominantly quite negative. This included the challenges they face as GPs generally, such as high workloads and trying to support people with complex problems within 10 minute consultations. In addition, though, and corresponding with the accounts of young people and carers, GPs' accounts were frequently characterised by their views that they are unfamiliar with and under-educated about EDs and uncertain about how they should provide care.

I wouldn't know how to support them apart from just talking it through and try to fuddle (laughter) my way through, doing my best. (FG3)

I think a lot of GPs aren't really clear about what, what we should be doing. (GP5)

It's not something I was taught about at medical school and it's not something I've had any training on since. (GP8)

Not surprisingly, GPs' estimates of how often they saw a young person with an ED varied considerably but many felt that they rarely saw patients with EDs.

It's not something that we, is part of our bread and butter working life and things, you know. It would be something that we'd need to look up. (GP1)

I can't say I've seen an awful lot. (FG2)

It's not something you might see every day. You think: oh god what was that website?  
... So you think: I haven't got time for that so right, it's er, Google doesn't give you a quick answer. Let's just, um (laughter) (FG3)

The possibility that GPs might be under-estimating the prevalence of EDs in their surgeries was not voiced but, in talking about their lack of knowledge and familiarity with EDs, GPs did express concern about identifying EDs.

Then you sort of do get the suspicions that it might be an ED, um, but then it's kind of, I don't know, yeh, I, I find it difficult to actually come to the conclusion that: yes they do [have an ED] unless they openly say they do. (FG1)

It's a bit subjective, yeh. It might be handy if there was, um, I don't know if there are screening questionnaires or criteria or something like that, which could just make it a bit more straightforward about what you do. (FG3)

GPs also voiced concerns about a variety of issues including receiving too much or too little information in communications from specialist services, as well as feeling under-resourced and ill-equipped to manage the complex needs associated with EDs

I do feel, er, ignorant about the, and I don't have enough time to deal with the sort of more complex issues of the anorexic thinking and the way to recovery, um, I mean I'm good at picking up on the physical stuff but, but the sort of more deep-rooted mental stuff but, so maybe some teaching about that but perhaps, more importantly, you know we haven't got the time to do all that type of therapy maybe, easier access to some therapists possibly based in the community if that's allowed, I think that would be fantastic. (GP3)

More frequently, however, GPs in our study expressed concern and uncertainty about patients who they felt were not of a 'sufficiently' low weight to warrant referral to specialist services.

There's the clear cut anorexia, you know very, very low BMI and then there's the teenage girl I saw a couple of weeks ago, you know, brought in by mum, um, who, outward appearance is ok but she was only eating one meal a day so perhaps the early stages but then: what to do? (FG2)

An area I think as GPs we struggle with most, that there are young patients who we know aren't quite right, don't look too bad on a piece of paper either. BMI isn't that

awful at the time but parents are very worried. They don't fit the criteria for being seen by CAMHS but, you know, that doesn't feel very good when we know the longer it goes on the worse it gets. (GP6)

Dovetailing again with young people's and carers' accounts of GPs being under-educated about EDs and delaying referrals to specialist services, GPs here talk of their lack of knowledge and familiarity with EDs, of lacking the necessary resources as well as the training and of being uncertain and therefore hesitant about what to do, particularly when a young person's BMI is not already very low.

#### *Negative views about young people and carers*

In the quotes above GPs are presented as often failing to provide adequate appropriate care for young people with an existing or emerging ED because they do not understand the complex nature of eating disorders, view low BMI as a necessary prerequisite for action and/or misinterpret 'teenage weight-loss' as 'just a phase'. Our second theme illustrates how this situation may be compounded by negative views about young people and carers seeking help for a young person with an ED. In this theme young people's and carers' experiences are characterised by feeling that they are sometimes viewed in derogatory ways and that consequently their concerns are not taken seriously. For instance,

[What was unhelpful was] basically, not being taken seriously, and having almost the impression that your GP thinks you're a fraud, making people think that you have an eating disorder just to get attention. (YP3)

[I need] to be listened to and taken seriously, not be treated like an attention seeker.  
(YP1)

Even when I talked to my GP the first time, I was made to feel invalidated because of my weight, and it wasn't passed on. (YP11)

While EDs can be experienced by people of any age, gender and ethnicity, the experiences related by our participants here appear to be shaped in particular by culturally dominant, misogynist stereotypes of young women as self-obsessed, emotionally unstable, vain and/or untrustworthy (see e.g. Katzman and Lee, 1997; Jeffreys, 2005) that have been evident in medical accounts about eating disorders since the emergence of 'anorexia nervosa' as a diagnostic term in the late nineteenth century (Malson, 1998).

Significantly, both young people and carers in our study also reported that carers' concerns as well as those of young people themselves were also often dismissed by GPs. For instance,

My mum first took me to the GP when I had just turned 14 ... I protested and said there was nothing wrong - and the GP foolishly took my word for it and told my mum that she was just being an overprotective mother, despite the fact that my face was gaunt and I was struggling to walk. (YP1)

I needed the GP to take seriously what I was saying ... I had no idea what to do. I was honestly despairing what, how do I do this, how do I make her eat um. Nobody, nobody helped me with that. (C6)

I like to think that if somebody else went to the GP in the same circumstances, they would be asked the right questions, and their Mum's cry for help would be taken seriously. (YP10)



Thus, from our participants' perspectives, carers appeared to be often framed as 'over-protective mothers' worrying unnecessarily about their 'attention-seeking' daughters.

GPs' accounts also appeared to corroborate, at least partially, those of young people and carers in suggesting that, for various reasons, they viewed young people with EDs as a 'difficult' patient group. Firstly, not surprisingly, but in stark contrast with representations above of young people as 'attention seeking', GPs referred to the fact that young people with an ED may not recognise or want to admit to a problem.

Um, not knowing whether they're being honest because I mean I think we rely in general practices that we just believe our patients and just work with what patients are telling us their symptoms are and, yeh, just working on that but we know that ED patients do sometimes get into deceitful ways of being and won't want to admit to certain things. (GP6)

I think there's that issue, um, combined with the whole sort of ED secretive behaviour that goes with that. (GP4)

Thus, GPs talked about the difficulties they had in diagnosing EDs in the absence of patients admitting a problem. The framing of these patients as sometimes 'deceitful' perhaps also implies a moralising lens through which they may be viewed as 'difficult'. Added to this, and corresponding more closely with young peoples' and carers' accounts, was a view that these patients may be 'difficult' *because* they are young people. In the interview extract below, for example, 'teenagers' are presented as typically 'a hard group to communicate with'.

I think teenage, I mean it's a problem with teenagers in general really is that they are quite a hard group to communicate with, I, um, and I don't think I'm alone in that I think, unless you've got teenagers and are at ease with communicating with them then it is quite tricky. (GP4)

The fact that young people might be accompanied by a parent was also often viewed as an additional difficulty. In the extracts below parents appear as a further barrier to GP-patient communication and, in the second extract, perhaps more concerningly and echoing the accounts above, parents are again presented as 'over-anxious' and as possibly worrying unnecessarily about their child.

Um, it's quite difficult because they often come in with a parent, um, and it's often the parent that does the talking, um, and so it's, I do, it takes quite a lot of confidence I think on the part of the GP to, er, tell the parent to leave the room and focus just on the young person and to get their viewpoint and I think for that reason it, it is quite hard. (GP4)

It's always a balance between the kind of parental anxiety, is it proportionate? Is it appropriate? When do I refer this kid who doesn't want to be referred? (FG2)

In short, GPs often felt that they lacked the knowledge, training and resources to provide appropriate care for young people with an ED but also often seemed to view these young people as 'difficult' patients because of the complex nature of EDs, because patients may find it hard to admit their problem, and because they may be viewed as 'uncommunicative teenagers' often accompanied by potentially 'over-anxious' parents.

## Discussion

The aim of this study was to develop an in-depth understanding of the experiences of young people with an ED and of carers in seeking care for their own or a family member's ED, and of GPs' experiences in delivering care for those seeking help for an ED. Our findings that young people and carers reported mixed but predominantly negative experiences of primary care converge with those of previous studies (B-eat, 2017; De la Rie et al., 2006; Rother & Buckroyd, 2004; Tierney, 2005). Their accounts were prominently defined by experiences of GPs often lacking sufficient knowledge about EDs and of often feeling that they were being judged negatively and that their concerns were dismissed.

Converging with these accounts and with the findings of other studies (Currin et al., 2009; Reid et al., 2009; Waller et al., 2014), GPs in our study also reported feeling under-educated about EDs, under-resourced and unsure about how to respond to young people and carers with ED concerns. They expressed particular concern about young people who they felt were not (yet) at a sufficiently low weight to warrant referral. Of course, low BMI may be required for referral to some ED services in the UK and elsewhere. However, this is often not the case: in the locality where GPs in this study were recruited, although waiting times between assessment and treatment are often lengthy, there are no BMI thresholds for children's or adults' services. Given the importance of early referral to specialist ED services in producing positive outcomes (e.g. Hamilton et al, 2015; Schoemaker, 1997; Treasure & Russell, 2011; Zipfel et al., 2000), this finding, and its convergence with young people's and carers' accounts of delayed referrals, is of particular concern, adding to the weight of evidence that training for doctors about EDs and readily available information is inadequate and urgently requires improvement (e.g. PHSO, 2019; B-eat, 2017). With the growing evidence of a large surge in cases of EDs during the recent pandemic (RCPHC, 2020, see also Jayanetti, 2021) and reports in the press (Marsh, 2021), of people being denied treatment for EDs across the UK because they are not

considered sufficiently thin, the need for improved primary care provision, for young people with an eating disorder can be seen as all the more pressing.

Our analysis indicates a need for education for GPs and other primary care providers about psychological as well as physical symptoms, about the importance of early intervention and of not relying on low BMI as the key diagnostic for EDs. But our findings also suggests a need to challenge attitudes towards young people and carers seeking help for their own or a loved one's ED. The accounts of all three stakeholder groups - GPs, young people and carers - suggest that GPs appear sometimes to be informed by familiar and persistent negative cultural stereotypes (see e.g. Haines et al., 2016) whereby young people are viewed as 'difficult' and uncommunicative; young women are viewed as 'attention seeking', untrustworthy, emotionally unstable and vain and mothers are viewed as 'over-anxious' and unreliable witnesses of their child's wellbeing and where disordered eating, weight loss and psychological distress are minimised as 'just a teenage phase'.

This framing of ED concerns as 'normal' can also, of course, be understood in the context of culturally normative body dissatisfaction and weight-loss behaviours particularly among adolescent girls (see Duarte et al., 2016; Grogan, 2016) and in the context of the well-documented increased prevalence of mental health problems including widespread anxiety, depression, self-harm and eating disorders among young people, particularly girls (Girlguiding, 2015; Plan-UK, 2016; B-eat, 2018). These contexts may elucidate how ED concerns become normalized and minimized (see also Malson and Burns, 2009) but they also clearly indicate the urgency with which we should address the shortfalls in primary care provision that are indicated by our findings. An urgency that is further underpinned by the growing evidence, as noted above, of, first, the additional systematic failure to recognize EDs in those who do not fit the stereotype that people with an ED are invariably underweight, White, middle class,

cis-gendered, heterosexual, able bodied young women (Chowbey et al., 2012; Solmi et al., 2016) and, second, the importance of early intervention in facilitating positive outcomes for people with EDs (e.g. Hamilton et al, 2015; Schoemaker, 1997; Treasure & Russell, 2011; Zipfel et al., 2000).

While our analyses are based on quite large samples sizes for a qualitative study and, we think, very usefully provides a multi-perspectival analysis, our study is nevertheless limited in that our participants are primarily young White women with experience of anorexia, White mothers of young women with experience of anorexia and female GPs living in a specific area of Southern England. Further research is clearly needed with more diverse groups of participants. Additionally, recruiting larger numbers of GPs would have enabled us to examine potential differences between groups of GPs, to explore, for example, whether newly qualified GPs' views differ from those who have been practicing for years or whether the views of those who have had contact with local ED services differ from those who have not. Certainly further research is required to ascertain the views and experiences of more diverse groups of young people, carers, and GPs as well as of other relevant professionals such as practice nurses, school mental health leads and youth workers in seeking or providing support for young people with an existing or emerging ED. Such research could also usefully offer an opportunity to further investigate the causes of delayed referrals and the potential solutions to those obstacles to early intervention.

## **Conclusions**

The potential damage to young people's lives caused by delays in providing appropriate support and in referring patients to specialist ED services is well-recognised (e.g. Hamilton et al, 2015; Schoemaker, 1997; Treasure & Russell, 2011; Zipfel et al., 2000). GPs play a central role in facilitating access to those services, particularly for older adolescents in the UK who

cannot be referred through Child and Adolescent Mental Health Services. The findings from the current study provide a multi-perspectival, qualitative analysis of primary care services provided by GPs for young people and their carers seeking support for an ED and strongly indicate a need both to improve training and resources for GPs and to challenge potentially negative cultural stereotypes that may hinder the provision of appropriate support for young people with existing or emerging EDs.

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#### **Endnote**

1. Please contact the corresponding author for copies of data collection tools.