Open Access Research

# BMJ Open The role of gendered constructions of eating disorders in delayed help-seeking in men: a qualitative interview study

Ulla Räisänen,1 Kate Hunt1,2

**To cite:** Räisänen U, Hunt K. The role of gendered constructions of eating disorders in delayed help-seeking in men: a qualitative interview study. *BMJ Open* 2014;**4**:e004342. doi:10.1136/bmjopen-2013-004342

► Prepublication history for this paper is available online. To view these files please visit the journal online (http://dx.doi.org/10.1136/ bmjopen-2013-004342).

Received 26 October 2013 Revised 5 February 2014 Accepted 13 February 2014



<sup>1</sup>HERG Health Experiences Research Group, Nuffield Department of Primary Care Health Sciences, University of Oxford, Oxford, UK <sup>2</sup>MRC/CSO Social and Public Health Sciences Unit, University of Glasgow, Glasgow, UK

Correspondence to
Ulla Räisänen;
Ulla.Raisanen@phc.ox.ac.uk

#### **ABSTRACT**

**Objectives:** To understand how young men recognise eating disorder (ED) symptoms and decide to seek help, and to examine their experiences of initial contacts with primary care.

Design: A qualitative interview study.

**Setting:** Men from across the UK were interviewed as part of a study of 39 young men's and women's experiences of having an ED.

**Participants:** 10 men aged 16–25 years with various EDs including anorexia nervosa and bulimia nervosa.

Results: The widespread perception of EDs as uniquely or predominantly a female problem led to an initial failure by young men to recognise their behaviours as symptoms of an ED. Many presented late in their illness trajectory when ED behaviours and symptoms were entrenched, and some felt that opportunities to recognise their illness had been missed because of others' lack of awareness of EDs in men. In addition, the men discussed the lack of gender-appropriate information and resources for men with EDs as an additional impediment to making sense of their experiences, and some felt that health and other professionals had been slow to recognise their symptoms because they were men.

**Conclusions:** Although increasingly common in young men, widespread cultural constructions of EDs as a 'women's illness' mean that men may fail to recognise ED symptoms until disordered behaviours become entrenched and less tractable to intervention. Men also report that such perceptions can affect the reactions of their families and friends, as well as health and educational professionals. Primary care professionals are well placed to challenge inappropriate perceptions of EDs.

#### INTRODUCTION

Eating disorders (EDs) are an increasingly common form of mental ill health and have been highlighted as a clinical priority area for Youth Mental Health in 2013–2016 by the UK's Royal College of General Practitioners. Early diagnosis and intervention can prevent

## Strengths and limitations of this study

- The study utilised well-developed and rigorous qualitative data collection and analysis methods.
- We succeeded in recruiting men with eating disorders, a hard-to-reach and under-researched group, who were prepared to talk openly about their experiences.
- Because these young men's experiences were collected as part of a study that recruited and interviewed both young men and young women using the same methodology, we are able to identify what is specific to young men's accounts of having an eating disorder.
- The study is limited to young people and does not contribute to understanding the experiences of older people with eating disorders.

the development of long-term, potentially life-threatening, psychiatric morbidity with estimated costs to the National Health Service (NHS) of £50 million in inpatient care, and an additional £5-20 million for outpatient and primary care. Anorexia nervosa (AN) has the highest mortality rate of all psychiatric conditions in adolescence.<sup>2</sup> Diagnostic guidelines<sup>3</sup> recognise four types of EDs: AN, bulimia nervosa (BN), binge eating disorder and eating disorder not otherwise specified (EDNOS).4 Environmental and genetic factors impact the risk of developing an ED. Up to 70% of cases of AN and BN have been estimated to be triggered by an adverse life event, such as abuse.<sup>2 5 6</sup> Existing psychiatric conditions<sup>7</sup> or substance abuse in the family,<sup>8</sup> certain personality traits (such as perfectionism and low self-esteem), 8-10 and complex sociocultural factors around body image are also risk factors.<sup>2</sup> 11 Treatment can include psychological and pharmacological interventions as well as dietary advice, but early diagnosis and intervention is important for long-term prognosis. 12

EDs are commonly characterised as conditions affecting teenage girls<sup>13</sup> but there are many similarities in symptoms, <sup>15–17</sup> treatment response<sup>18–20</sup> and prognosis in men and women with EDs.<sup>17</sup> Although evidence on gender differences in prognosis is limited, one recent cohort study found treatment outcomes in all EDs were better for men than women, when remission was measured by weight restoration and self-reported relapsing.<sup>21</sup> Some studies suggest that men with EDs are more likely to engage in obsessive exercise<sup>15</sup> <sup>17</sup> <sup>19</sup> <sup>22</sup> and have more psychiatric morbidity as a result of an ED.<sup>15</sup> <sup>19</sup> Homosexuality has also been cited in some studies as a risk factor for men.<sup>15</sup> <sup>17</sup> <sup>23</sup>

Estimates of the prevalence of EDs in men and women vary widely, depending in part on whether full or partial diagnostic criteria are applied and whether studies have been community or hospital based. However, all studies suggest lower rates of EDs among men. It has been estimated that 1 in 250 women, and 1 in 2000 men in the UK have AN, and the prevalence of BN and other types of EDs is considerably higher<sup>2</sup>; with BN and EDNOS thought to be more common in men than AN. 24 25 A commonly cited estimate, whose provenance is unclear, is that 10% of clinical ED cases occur in men,<sup>2 26</sup> but some data suggest that this prevalence could be as high as 25%.<sup>27</sup> Despite this uncertainty about prevalence, the incidence of EDs in men is rising,<sup>23</sup> although it is thought that statistics still underrepresent the prevalence of EDs among men. 13 23 28 29 This is, in part, because a lack of public awareness of EDs in men may delay or prevent men from recognising early signs of EDs and seeking help. 14 30 Lack of understanding and training among health professionals may also contribute to delays in diagnosing and treating EDs among men, 13 21 in part because men with EDs might account for symptoms regarding weight and dieting behaviours differently from women with EDs. 13 General practitioners (GPs) and other primary healthcare professionals play a pivotal role in recognising early symptoms of EDs and early referral for specialist care.<sup>31</sup>

Yet, to date, very little is known about how men recognise ED symptoms and decide to seek professional help.

Qualitative studies of men's experiences of EDs are sparse and have focused mainly on EDs and exercise, body image, dieting practices and sexual orientation. 32–36 One recent study explored men's experiences of recovery 20 and another examined men's experiences of specialist ED services. 22 This paper presents a qualitative study of the experiences of 10 young men with EDs, whose accounts were collected within the context of a larger study of young people's experiences of EDs. We aim to understand how young men recognise ED symptoms and decide to seek help, and their experiences of initial contacts with primary care. We focus on the following research questions:

- ► How do men make sense of their early (and later) signs and symptoms of disordered eating?
- ► How do they realise something might be wrong and require intervention?
- ► Are there perceived barriers to accessing primary care (or other) services for men with EDs?
- ▶ What are men's experiences of health professionals' responses to their initial presentations of ED signs and symptoms?

## **METHODS**

## Sample and data collection

The findings reported are part of a larger qualitative interview study with 39 young people (29 women and 10 men) with EDs in the UK, conducted to inform an online patient information resource (http://www.healthtalkonline.org/young-peoples-experiences/eating-disorders). In this paper we focus on the experiences of the 10 men who took part (table 1).

All interviews took place in the UK, either at the interviewee's home or a meeting room. Using maximum variation sampling,<sup>37</sup> participants were recruited using a variety of channels, including patient organisations, social media, healthcare practitioners and snowballing to elicit a wide range of experiences across the illness spectrum. Inclusion criteria for the participants were: (1) aged 16–25, (2) living in the UK, (3) experience of an ED (most participants had been diagnosed but also a couple of as yet undiagnosed cases were included) and

Table 1 Characteristics of the male study participants						
Pseudonym	Age at interview	Age at diagnosis	Type of ED	Employment status	Ethnicity	Sexuality
Participant 1	19	14	AN	Student	White British	Heterosexual
Participant 2	18	15	AN and EDNOS	Student	White British	Heterosexual
Participant 3	25	16	BN	Employed	White British	Homosexual
Participant 4	17	N/A	BN*	Student	White British	Homosexual
Participant 5	19	18	BN and AN	Student	White British	Heterosexual
Participant 6	17	14	AN	Student	White British	Heterosexual
Participant 7	22	19	BN	Employed	White British	Homosexual
Participant 8	20	N/A	AN and EDNOS*	Student	Latino	Heterosexual
Participant 9	21	20	AN	Unemployed	Mixed	Heterosexual
Participant 10	25	22	AN	Unemployed	White British	Heterosexual
*Undiagnosed, but self-identified ED type(s) listed in the table.						

AN, anorexia nervosa; BN, bulimia nervosa; ED, eating disorder; EDNOS, eating disorder not otherwise specified.

2

(4) not currently receiving inpatient treatment. In-depth interviews (conducted by UR) followed a bipartite structure. Initially, interviewees were invited to talk through their experiences of having an ED in as much detail as they wished. The researcher interrupted this free narrative as little as possible. In the second part of the interview, semistructured questions explored emerging and anticipated themes further. Questions around emerging themes probed topics initiated by the interviewee in the early narrative and anticipated themes examined topics from existing literature. Interviews lasted between 50 min and 2 h, were audio/video recorded with consent and transcribed verbatim. Transcripts were checked against recordings for accuracy and sent to the participants for editing and approval. For research purposes all transcripts were anonymised and pseudonyms are used.

#### Method of analysis

Earlier analysis (by UR) of all the 39 interviews informed the development of the online patient information resource. At this stage, the 39 transcripts were closely and repeatedly read (by UR). A coding structure was developed and the data coded to anticipated and emergent themes using the Nvivo V.9 software. Based on these themes, 27 topic summaries were written and published on the http://www.healthtalkonline.org website.

This paper is based on a more detailed analysis by both authors of men's experience of the process from symptom recognition to consultation and (potential) diagnosis. A qualitative interpretative approach was taken.<sup>38</sup> Ombining the methods of inductive close reading and constant comparison, subthemes in relation to the process of symptom recognition and help-seeking were examined in the accounts of the 10 men. Each coded data extract was read line by line to identify subthemes. Four subthemes were identified and analysed in more detail: (1) accounting for early signs and symptoms; (2) recognising the problem; (3) routes to helpseeking and (4) initial contact with healthcare services and information. These subthemes were summarised schematically and each occurrence of every subtheme was noted and compared with data from subsequent data extracts, using the 'One Sheet Of Paper' method to explore patterns and 'deviant cases', 40 the results of which are discussed below.

#### **RESULTS**

#### Accounting for early signs and symptoms

All of the men took some time to recognise their experiences or behaviours as potential signs and symptoms of an ED. Those who were subsequently diagnosed with AN described how they started to skip meals, sell their school lunches, restrict calorie intake and eventually go for days without food. Those with BN described starting to comfort eat or purge after an unusually large meal. These behaviours usually developed over months,

eventually becoming habitual. The men described developing daily routines around eating and weight management, such as obsessive calorie counting, exercise and self-weighing. Their problems often also manifested in other ways, such as self-harming or increasing isolation.

Men accounted for their initial inability to attribute their feelings and behaviours to possible signs and symptoms of an ED through gendered understandings of EDs. Participant 1 'didn't think for one moment [he] could be ill with an ED' and participant 2 said the possibility of an ED 'had not entered my head'. Participant 3 made sense of his developing routine of bingeing and purging as a personal coping mechanism rather than an indication of underlying pathology. He had never heard of BN and thought bingeing and purging was something he had 'made up':

I thought I made it up myself ... you know, something that only I did, you know, I never thought in a million years this was something that lots of people did, and deliberately did to cause damage to themselves. You know, it wouldn't have crossed my mind. Participant 3

Participant 4 thought of EDs as affecting 'fragile teenage girls [who are] very emotional'. He identified himself as 'one of the lads' in the rugby team and not someone who could have a problem with eating. Participant 2 had always thought EDs were 'something girls got'. Participant 1 framed his lack of awareness of EDs as congruent with society's understanding of EDs in men:

I didn't know men could get eating disorders then ... 'cos that would be like five years ago and there wasn't really much said about men with eating disorders then ... I didn't know the symptoms, didn't know anything, it was just, to me it was just happening. I didn't really know what was going on. Participant 1

Participant 1 did not at first interpret his disordered eating behaviours as symptoms of an illness, or as anything recognisable and treatable; rather he saw his symptoms as mundane aspects of his life, something that 'was just happening'. Indeed, all the men described having no or very little awareness of EDs in men; hence, the possibility that their symptoms could be caused by an ED, rather than reflecting idiosyncratic behaviours, was not readily considered as an explanation by men.

Men described a similar inability in friends, family and teachers to recognise their ED. Participant 5 was investigated for gastric problems for nearly a year during which time no-one, including parents and clinicians, suggested psychological reasons for his vomiting and weight loss. Participant 6 thought that people in school 'knew' he had a problem but it 'was not something that was ever discussed':

There was never any intervention by anyone [er] at school. I mean I think people knew something was wrong. I think since talking to some of my friends ...

they knew I was depressed. They didn't know that I had an eating disorder because I don't think any of us knew anything about eating disorders really. It wasn't something that was ever been discussed. Participant 6

Participant 2 described family tensions when his parents suggested that he was just being 'silly' about his eating issues.

[They] picked up on it every now and then, like my Dad would get angry if I hadn't had my breakfast. But it was never associated with any kind of eating disorder, ever, it was just, 'Stop being silly'. Participant 2

Thus, a lack of awareness of EDs in men meant that unusual behaviours could be misinterpreted as personal choices. Men presented themselves as lacking the kinds of responses from their immediate surroundings which might have aided earlier recognition and help-seeking.

## Recognising the problem

Symptoms and behaviours commonly continued for months or years before men began to recognise their behaviours as a problem; for many, they had become an entrenched routine. Some men described the realisation that something could be wrong as a gradual process, others as a sudden event. For some, once their problems could no longer be contained as a private 'daily thing' and impeded their social life or well-being, they began to recognise things were not right. Participant 7 'knew' for a long time his habitual bingeing and purging was causing problems but had no name, nor understanding, to make sense of it. Participant 8 said his 'personality changed' and he became more 'introverted' and 'isolated', and participant 3 described how obsessions around eating started to 'hold [him] back' from 'everything [he] wanted to do'. Participants 7 and 8 described a gradual realisation that things were 'not normal'.

For others, initial awareness of their ED was precipitated by a crisis point that led to a hospital admission or emergency referral. These crises were often linked to marked deterioration in physical health which for many functioned as a more tangible measure of their well-being. Participant 9 described how he became 'gaunt', his 'spine was protruding' and he was growing lanugo hair. During an emergency GP home visit, participant 9 was told he required immediate hospital admission, otherwise he could be sectioned under the Mental Health Act:

He [GP] was like, 'Either you come with me within the next twenty four hours, or I'm going to take you against your will.' And it hit me at that point that you know, from Monday to that Tuesday when I was admitted to hospital it was a case of you know you're working, you're earning a living, you, you know you're enjoying life, you know, well what, what I thought was life. But then from that Tuesday on you know, you, it's, a complete flip side to everything. Participant 9

The trigger to recognise their ED could be precipitated by others. Participant 10 had been restricting his food intake and losing weight for a long time before his girlfriend 'broke down' and confronted him about his behaviour, forcing him to re-evaluate the gravity and impact of his behaviour and recognise 'it was something I had to challenge'.

## Routes to help-seeking

In addition to the delay in help-seeking attributed to a lack of self-recognition, young men discussed fears of not being taken seriously by healthcare providers or not wanting to be a 'burden' on services. Sometimes these fears were represented as imagined, sometimes as borne out of past experiences. Before his emergency GP referral, participant 9 had seen a GP twice with AN symptoms. He says 'when they did see me they didn't do anything'. He goes on to explain that the GPs had wanted to weigh him, which he refused to do in a manner typical of people with AN, but nothing then followed.

As men often recognised their problem late in their illness trajectory, when disordered behaviours were embedded, they could be hesitant to seek help because they had become reluctant to relinquish behaviours which they felt had a purpose and function in their lives, something they couldn't 'live without'.

It [ED] created a significant barrier for me for everything that I wanted to do or wanted to achieve. Absolutely I knew that it was creating problems at the time. It was just very difficult because you know at the same time you know I can't live without it 'cos I wouldn't be able to cope, so that it was very much a conflict. Participant 3

Over time, men commonly became secretive about their behaviours, fearing judgement, forced interventions or hurting others' feelings. This secrecy, typical of ED sufferers, could also contribute to reluctance to consult, even once people realised their behaviour was not normal. Men also described uncertainty about how and where to seek help once they became concerned about their eating:

I didn't really know what, where to go or what to do to be honest. [Um] We've all heard of the like female anorexia and all of that. And everyone, I think I'd heard of anorexia [um] that isn't what I was going through as such. And I didn't really know what it was or where to go...

I did start googling it and I came across [um] eventually on Facebook the 'Men have eating disorders too', as well, and there was a couple of other websites that I looked at. [Um] But there's still in my opinion there's still no real information of what you do or where you go. Participant 7

Men also referred to generalised beliefs about genderappropriate expressions of emotion and help-seeking when explaining their reluctance, as men, to seek help: You've still got this again stigma attached to it [anorexia nervosa] that it's a woman's illness. But it's not. And it really really annoys me because it's not a woman's illness, and it affects men. And I don't know, I can't obviously say oh [um] it's harder for men, but there's different experiences for men because, you know, 'No I don't get ill, I'm a man'. You know, 'I don't get ill, don't need treatment, I don't have emotions.' Blah, blah, blah. Things like that. They, which could make it harder for a man to open up about it. Participant 5

# Initial contact with healthcare services and information

Eight of the men had been formally diagnosed with an ED. The other two identified with prolonged ED behaviours over years but neither had yet chosen to seek diagnosis. The route to diagnosis could be complex and lengthy, even when men presented late in their illness and were in need of specialist psychiatric services. Men could face a lengthy waiting list, during which time their symptoms escalated further. Even when men had made the decision to seek help, commonly someone else, typically their mother, took them to the first appointment. Usually the first contact with formal services was with their GP, although participant 3 preferred to see a locum GP because 'obviously [I] didn't have a relationship with that doctor, so that made it a bit easier to talk about stuff and I think I was so desperate anyway I just wanted to tell somebody' and participant 4 chose to see the school counsellor.

Once in the healthcare system, men recounted mixed experiences of interacting with health professionals. The initial appointment could dictate how willing men were to stay in touch with services. Some described positive experiences of their initial consultation. Participant 7's GP quickly realised that he was suffering from BN, gave him information about the illness, offered a referral and wanted to monitor him but participant 7 'was not happy it going any further':

I did make contact with my doctor ... I just said that what I had done and what had happened... he talked through the whole process [er] with me and explained that, the very serious side effects to doing that to myself. [Um] Obviously encouraging me you know for it not to continue doing what I can. [Er] He was happy to refer me [um] to someone, but you know that was my choice. [Um] I remember at the time not wanting anything to go as far as that. And so I declined that. Participant 7

Participant 1 described his first GP contact as 'very helpful', acknowledging his GP's willingness to offer support, but ultimately frustrating because:

Her [GP] struggle was that they haven't got the services to give to you. They want to but they just haven't got them. Participant 1

However, several men described having to go to the GP repeatedly before they felt they were being taken seriously or referred, and in a few instances an ED had been missed or misdiagnosed. Participant 2 was initially told he was 'going through a teenage fad' until his mother went to see the GP on her own; this precipitated a Child and Adolescent Mental Health Service (CAMHS) referral. When participant 3 first consulted and detailed his long-standing bingeing and purging, a locum GP actively rejected a diagnosis of BN, told participant 3 he was depressed and prescribed antidepressants, a clinical judgement which participant 3 attributed to his male gender:

At eighteen I went to the doctor, [um] I didn't know the doctor 'cos I was obviously new to the area, [um] and I spoke to her quite confidently about my, what I was going through, because by then I was very aware and the doctor said to me, [um], 'You haven't got bulimia, you're just depressed , ... I'm probably quite confident in saying that that was probably because you know I was male, you know I didn't live up to the stereotype of being young and female, [um] and because my, it had sort of had nothing to do with body image or weight or anything like that. I think that might have confused the doctor a little bit you know. Participant 3

Instances of misdiagnoses in specialist care were also reported. Participant 5 was told by a gastroenterologist after prolonged vomiting, severe weight loss and lengthy physical investigations that his problems were not physical. Rather than referring him for psychological treatment he was, in his words, told to 'man up' and 'not be weak but be strong and deal with the problem'. Participant 5 describes his reaction:

I didn't say anything. I was dumbfounded, like I couldn't believe a physician would say something like that, because I just thought, you know, if there's nothing physically wrong but something's happening surely that means there's something psychological. And if it's to the extent where I've lost three stone at this point, you know, shouldn't I be getting referred. ... basically I walked outside and punched a wall and broke my knuckle because I was so angry. That he'd sat there and called me weak and blah blah blah...

Right now it makes me so angry 'cos there was another two weeks after that where my life went, well it didn't go downhill but it just dropped off the edge. [Er] I wasn't talking to anyone, I was just angry all the time, exercising more, cut myself off, and then the suicidal thoughts started coming in. And I hurt myself quite a, in quite a few different ways, and I eventually tried to kill myself. Whereas quite possibly if he'd referred me to even a psychiatric nurse I'm pretty certain they could have gone like that [clicked fingers], and this is what's wrong. Participant 5

Only after an admission to accidents and emergency department following a suicide attempt were participant 5's problems recognised and he was immediately referred to an ED clinic for intensive outpatient treatment.

Men's accounts of the readiness and capability of GPs to provide relevant and appropriate information about EDs varied. Participant 7 was given information and advice, but still felt that 'I don't think there's any real information out there particular for men or any even awareness that it exists.' Participant 6 received no information until he was admitted under CAMHS, describing it as 'sod's law' as he 'needed it earlier'. Information that was made available was often viewed to be gender-blind or gender-inappropriate. Participant 1 thought the information was directed at women and described how the lack of male-specific information could provide a false sense of security for male patients. He wanted specific information on the impact of EDs on men:

like you hear like the side effects of having an eating disorder on like women. Like they can become infertile and stuff like that, but I've never seen any for men. So I like went and was like, 'Look, well what are they for men? 'Cos like that I could like have a side effect and I wouldn't know.

I think I read somewhere that men can become infertile by it, and I'm like, 'Yeah but no one tells you that'. They need to like tell you 'this could happen, that could happen'. Like you can get, I know you can get like osteoporosis which I've only seen like written about women, which is obvious it could happen in men as well. So it could lead like some people to think, 'Oh there's no side effects for men.' When there is and it's just not, you just can't, I think, I had to like scroll through the whole of the Internet trying to find bits of information. Participant 1

Only participant 5 mentioned being given malespecific information. He described the information as 'a scare sheet' which focused on the physical side-effects and symptoms of AN, and highlighted the possibility of impotence or lack of sex drive:

The only information I got was [er] a scare sheet basically. It was this was going to happen if you keep going. Basically the big one that they circled was, 'Oh you won't be able to be sexually active' for men. And that was the biggest thing. I got about five or six different sheets from them, and basically the main fact was, 'Oh yes, your organs won't work, you know. You'll lose nails, hair will thin. You cannot have sex', big massive writing basically. Participant 5

Men expressed a strong desire for balanced, gendertailored information. They felt that gender-blind information reflected wider societal constructions of EDs as predominantly or only affecting women.

# **DISCUSSION**

Men with EDs are underdiagnosed, undertreated and under-researched. <sup>13</sup> <sup>23</sup> <sup>28</sup> <sup>29</sup> In particular, there is a lack of qualitative research on men's experiences of EDs and a continuing perception of EDs as a 'female' illness. <sup>13</sup> <sup>17</sup> <sup>22</sup> Our findings suggest that men may experience particular problems in recognising that they may have an ED as a result of the continuing cultural

construction of EDs as uniquely or predominantly a female problem. The culturally prevalent view that EDs largely affect teenage girls meant that many of these young men only recognised their behaviours and experiences as possible symptoms of an ED after a protracted delay, mitigating possibilities of early intervention and improved prognosis. Models of help-seeking recognise that, when bodily or social functioning is disrupted, people evaluate their experiences in relation to 'illness representations' or 'stocks of knowledge' that help them make sense of their symptoms and decide on appropriate actions. 41-43 Thus, inappropriate understandings that EDs only affect young women can mean that men delay seeking medical advice, even when they recognise a significant deviation from the 'healthy normal'. Wyke et al<sup>44</sup> suggest that symptoms, responses and actions are simultaneously interpreted and evaluated in the light of this accumulated knowledge and through interactions with others. Thus, cultural expectations of health are an important influence on people's own attributions of symptoms and actions, and others' reactions. These young men's accounts suggest their own lack of knowledge was compounded by a similar lack of recognition in their social networks. Hence, many first presented late in their illness trajectory when their ED had become well established and less tractable to treatment. This reticence could be further consolidated by broader cultural assumptions about culturally appropriate behaviours, which render young men particularly reluctant to discuss symptoms of mental or emotional ill-health. 45–49

Reflecting on these findings on men in the light of the broader interview study with men and women with EDs, particular traits specific to the men's experience seem apparent. Men and women recounted an inability in themselves and others to recognise their behaviours as symptoms of EDs but dieting and losing weight were conceptualised as more 'normal', unremarkable and 'socially acceptable' behaviours in young women. Women failed to recognise their behaviours as an ED by normalising early changes in eating and mood and discarding an ED as a 'too severe' diagnosis. Women did not reject an ED diagnosis as a wholly inappropriate diagnosis for them unlike men, who did not come to consider the possibility of having an ED because of the inappropriateness of an ED as a socially available explanation for them as men. Men and women recounted a reluctance to seek help which stemmed from their ambivalence towards recovery<sup>50</sup> and both had experienced a prolonged diagnostic process. However, it was only men who recounted stories of explicit dismissal of their symptoms due to their gender and also reported additional challenges in lacking access to relevant and gender-appropriate information about EDs.<sup>22</sup>

The study has a number of strengths and limitations. It utilised well-developed and rigorous qualitative data collection and analysis methods. 40 Although men with EDs are a hard-to-reach group, we succeeded in recruiting men prepared to talk openly about their

experiences. The open narrative structure at the outset of the interview allowed men to spontaneously express their views about EDs as inappropriately characterised as a female-specific disease. However, since the remit of the wider study was to explore the experiences of young people with EDs; our research does not contribute to understanding the experiences of older men with EDs. This is an area that requires further research, especially in order to examine men's developing understandings of EDs across a longer illness trajectory.

The later an ED is diagnosed, the smaller the possibility of recovery and effective therapeutic interventions, leading to increased risk of serious sequelae including mortality. Other studies note that barriers to early diagnosis include difficulty or reluctance of men to recognise their ED<sup>21</sup> <sup>51</sup> and a lack of confidence about how best to seek help. This is compounded by widespread assumptions that EDs are largely, or exclusively, the preserve of women, <sup>13</sup> <sup>28</sup> <sup>52</sup> particularly teenage girls. Furthermore, gender differences in primary care consultation rates are most evident in late adolescence and early–mid adulthood <sup>53</sup>; hence, GPs may have fewer opportunistic encounters in which to identify symptoms in young men.

The construction of EDs as a 'woman's illness' has also been embedded in clinical practice. International Classification of Diseases (ICD) 10 and DSM IV (up to 2013) included amenorrhoea as a diagnostic criterion of AN<sup>13</sup> <sup>28</sup> and much patient information on EDs fails to feature men or discusses issues for women, such as the impact of food starvation on female fertility. This gender-bias might also be reinforced by current National Institute of Health and Care Excellence (NICE) clinical guidelines for the treatment and management of EDs which make no specific reference to EDs among men. <sup>54</sup>

In order to improve prognosis for men with EDs, early detection is imperative. Primary care clinicians have a key role in recognising early symptoms. Until information resources are made more appropriate for men with EDs, health service providers need to be particularly sensitive to men's needs in relation to an illness so strongly associated with women. Raising awareness of EDs more widely in society is also crucial to help men (and women) to recognise and seek help before their symptoms and behaviours become intractable. It is important to decouple the experience and (self-)management of EDs from feminised cultural imagery, resources and clinical practice if we wish to prevent men from (dis)missing signs and symptoms themselves, and prevent health and other professionals (eg, teachers) from overlooking signs and symptoms in boys and young men that they may readily recognise as indicative of EDs in young women.

Acknowledgements The authors would like to thank all the study participants for sharing their experiences for the study and Comic Relief for funding the original data collection. They also thank Sara Ryan, Sue Ziebland, Louise Locock and Helen Salisbury for comments on an earlier draft of the manuscript.

Contributors UR designed the study, collected the interview data, coded the data into NVivo software. UR and KH analysed the data and wrote the manuscript. UR and KH decided to submit the study to the BMJ Open. UR and KH revised the manuscript in the light of the reviewers' comments. UR and KH will act as guarantors for the work.

**Funding** This work was supported by Comic Relief grant number GR001-01521-MGYK.

Competing interests KH is funded by Medical Research Council (MC\_UU\_12017/3). UR received financial support for the study from which this manuscript arose via a grant from the DIPEx charity. KH was employed by UK MRC until 31 May 2013 and was seconded 0.2 FTE to Oxford University during 2013.

Ethics approval The study 'Narratives of health and illness for http://www.healthtalkonline.org (formerly DIPEx) and http://www.youthhealthtalk.org' was granted ethics approval by Berkshire Research Ethics Committee (09/H0505/66).

Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement Participants were invited to review their interview transcript and mark any sections they did not want used, before transferring copyright to the University of Oxford for use in research, teaching, publications and broadcasting. These carefully anonymised transcripts form part of a University of Oxford archive which is available to other bona fide research teams for secondary analysis. All researchers had full access to all of the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis.

Open Access This is an Open Access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 3.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited and the use is non-commercial. See: http://creativecommons.org/licenses/by-nc/3.0/

#### **REFERENCES**

- Henderson J. Costs of eating disorders in England: economic impacts of anorexia nervosa, bulimia nervosa and other disorders, focussing on young people, 2012. http://www.b-eat.co.uk/about-beat/ media-centre/press-releases/staggering-cost-of-eating-disorders/
- National Collaborating Centre for Mental Health. Eating disorders: care interventions in the treatment and management of anorexia nervosa, bulimia nervosa and related eating disorders. London: The British Psychological Society and Gaskell, 2004.
- American Psychiatric Association. Diagnostic and statistical manual of mental disorders: DSM-5. 5th edn. Washington, DC: American Psychiatric Association, 2013.
- Lilenfeld LR, Kaye W. Genetic studies of anorexia and bulimia nervosa. In: Hoek HW, Treasure JL, Katzman MA, eds. Neurobiology in the treatment of eating disorders. Chichester: Wiley, 1998:169–96.
- Schmidt U, Humfress H, Treasure J. The role of general family environment and sexual and physical abuse in the origins of eating disorders. Eur Eat Disord Rev 1997;5:184–207.
- Welch SL, Doll HA, Fairburn CG. Life events and the onset of bulimia nervosa: a controlled study. Psychol Med 1997;27:515–22.
- Strober M, Freeman R, Lampert C, et al. Controlled family study of anorexia nervosa and bulimia nervosa: evidence of shared liability and transmission of partial syndromes. Am J Psychiatry 2000;157: 393–401
- Lilenfeld LR, Kaye WH, Greeno CG, et al. A controlled family study of anorexia nervosa and bulimia nervosa: psychiatric disorders in first-degree relatives and effects of proband comorbidity. Arch Gen Psychiatry 1998:55:603–10.
- Fairburn CG, Welch SL, Doll HA, et al. Risk factors for bulimia nervosa. A community-based case-control study. Arch Gen Psychiatry 1997;54:509–17.
- Fairburn CG, Cooper Z, Doll HA, et al. Risk factors for anorexia nervosa: three integrated case-control comparisons. Arch Gen Psychiatry 1999;56:468–76.
- Striegel-Moore RH, Silberstein LR, Rodin J. Toward an understanding of risk factors for bulimia. Am Psychol 1986;41:246–63.
- Rosen DS. Identifying and treating eating disorders. Pediatrics 2003;111:204–11.

- Greenberg ST, Schoen EG. Males and eating disorders: genderbased therapy for eating disorder recovery. *Prof Psychol Res Pract* 2008;39:464–71.
- O'Hara SK, Smith KC. Presentation of eating disorders in the news media: what are the implications for patient diagnosis and treatment? Patient Educ Couns 2007;68:43–51.
- Bramon-Bosch E, Troop NA, Treasure JL. Eating disorders in males: a comparison with female patients. Eur Eat Disord Rev 2000:8:321–8.
- Fairburn CG, Harrison PJ. Eating disorders. Lancet 2003;361: 407–16.
- Woodside DB, Garfinkel PE, Lin E, et al. Comparisons of men with full or partial eating disorders, men without eating disorders, and women with eating disorders in the community. Am J Psychiatry 2001:158:570–4.
- Fernandez-Aranda F, Krug I, Jimenez-Murcia S, et al. Male eating disorders and therapy: a controlled pilot study with one year follow-up. J Behav Ther Exp Psychiatry 2009;40:479–86.
- Weltzin TE, Cornella-Carlson T, Fitzpatrick ME, et al. Treatment issues and outcomes for males with eating disorders. Eat Disord 2012;20:444–59.
- Bjork T, Wallin K, Pettersen G. Male experiences of life after recovery from an eating disorder. Eat Disord 2012;20:460–8.
- Støving RK, Andries A, Brixen K, et al. Gender differences in outcome of eating disorders: a retrospective cohort study. Psychiatry Res 2011;186:362–6.
- Robinson KJ, Mountford VA, Sperlinger DJ. Being men with eating disorders: perspectives of male eating disorder service-users. J Health Psychol 2013;18:1–11.
- Strother E, Lemberg R, Stanford SC, et al. Eating disorders in men: underdiagnosed, undertreated, and misunderstood. Eat Disord 2012;20:346–55.
- Striegel-Moore RH. The epidemiology of binge eating. Eur Eat Disord Rev 2000;8:344–6.
- Gotestam KG, Agras WS. General population-based epidemiological study of eating disorders in Norway. *Int J Eat Disord* 1995;18: 119–26.
- Muise AM, Stein DG, Arbess G. Eating disorders in adolescent boys: a review of the adolescent and young adult literature. J Adolesc Health 2003;33:427–35.
- Hudson JI, Hiripi E, Pope HG Jr, et al. The prevalence and correlates of eating disorders in the National Comorbidity Survey Replication. Biol Psychiatry 2007;61:348–58.
- 28. Crosscope-Happel C, Hutchins DE, Getz HG, et al. Male anorexia nervosa: a new focus. *J Ment Health Couns*
- Cohn L. Introduction to the special issue on males with eating disorders. Eat Disord 2012;20:345.
- Weltzin TE, Weisensel N, Franczyk D, et al. Eating disorders in men: update. J Men Health Gend 2005;2:186–93.
- Currin L, Waller G, Treasure J, et al. The use of guidelines for dissemination of "best practice" in primary care of patients with eating disorders. Int J Eat Disord 2007;40:476–9.
- Drummond MJ. Men's bodies throughout the life span. In: Blazina C, Miller D, eds. An international psychology of men theoretical advances, case studies, and clinical innovations. Routledge, 2011:159–88.
- Drummond MJ. Men, body image, and eating disorders. Int J Men Health 2002;1:89–103.
- Drummond MJ. Understanding masculinities within the context of men, body image and eating disorders. In: Gough B, Robertson S,

- eds. *Men, masculinities and health: critical perspectives*. Palgrave Macmillan, 2009:198–215.
- Morgan JF, Arcelus J. Body image in gay and straight men: a qualitative study. Eur Eat Disord Rev 2009;17:435–43.
- Wertheimer AV. Gay men with eating disorders and food, body image, and exercise concerns: a group treatment approach. Dissertation Abstr IntB Sci Eng 2007;67:6082.
- Coyne IT. Sampling in qualitative research. Purposeful and theoretical sampling; merging or clear boundaries? J Adv Nurs 1997;26:623–30.
- Green J, Thorogood N. Qualitative methods for health research. London: SAGE Publications Ltd., 2004.
- Gubrium JF, Holstein JA. Analyzing narrative reality. London: SAGE Publications, 2009.
- Ziebland S, McPherson A. Making sense of qualitative data analysis: an introduction with illustrations from DIPEx (personal experiences of health and illness). *Med Educ* 2006;40:405–14.
- Leventhal L, Brisette I, Leventhal H. The common-sense model of the self-regulation of health and illness. In: Cameron LD, Leventhal H, eds. The self-regulation of health and illness behaviour. London: Routledge, 2003:42–65.
- Pescosolido BA. Bringing the "community" into utilization models: how social Networks link individuals to changing systems of care. In: Kronenfeld JJ. ed. Research in the sociology of health care. Greenwich: JAI Press, 1996:171–97.
- Dingwall R. Aspects of illness (medicine in society). London: Wiley-Blackwell, 1976.
- Wyke S, Adamson J, Dixon D, et al. Consultation and illness behaviour in response to symptoms: a comparison of models from different disciplinary frameworks and suggestions for future research directions. Soc Sci Med 2013;86:79–87.
- Courtenay WH. Constructions of masculinity and their influence on men's well-being: a theory of gender and health. Soc Sci Med 2000;50:1385–401.
- Addis ME, Mahalik JR. Men, masculinity, and the contexts of help seeking. Am Psychol 2003;58:5–14.
- O'Brien R, Hunt K, Hart G. 'It's caveman stuff, but that is to a certain extent how guys still operate': men's accounts of masculinity and help seeking. Soc Sci Med 2005;61:503–16.
- Galdas PM. Men, masculinity, and help-seeking behaviour. In: Broom ATovey P, eds. Men's health: body, identity and social context. Chichester: Wiley-Blackwell, 2009:63–82.
- MacLean A, Sweeting H, Hunt K. 'Rules' for boys, 'guidelines' for girls: gender differences in symptom reporting during childhood and adolescence. Soc Sci Med 2010;70:597–604.
- Williams S, Reid M. Understanding the experience of ambivalence in anorexia nervosa: the maintainer's perspective. *Psychol Health* 2009:25:551–67.
- Copperman J. Eating disorders in the United Kingdom: review of the provision of health care services for men with eating disorders.
   Prepared for Eating Disorders Association, 2000.
- 52. Button E, Aldridge S, Palmer R. Males assessed by a specialized adult eating disorders service: patterns over time and comparisons with females. *Int J Eat Disord* 2008;41:758–61.
- Wang Y, Hunt K, Nazareth I, et al. Do men consult less than women? An analysis of routinely collected UK general practice data. BMJ Open 2013;3:1–7.
- 54. National Institute for Health and Care Excellence. Eating disorders: care interventions in the treatment and management of anorexia nervosa, bulimia nervosa and related eating disorders. London: National Institute for Health and Care Excellence, 2004.