



Exploring Barriers to South Asian Help-Seeking for Eating Disorders

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Abstract

Purpose Referrals to specialist eating disorder services from the South Asian (SA) community are under-represented, despite research suggesting that disordered eating attitudes and behaviours of SA people are similar to the population in general. The study aimed to identify the reasons for this and sought to inform ways to encourage help-seeking.

Design/Methodology/Approach A qualitative methodology was used to investigate barriers to help-seeking for eating disorders among the SA community. A key informant focus group was conducted with clinicians working within the local specialist eating disorder service (participants n=16, 12 female, 4 male). Six focus groups were conducted with members of the SA community in Leicester, UK, (participants n=28, 23 female, 5 male) recruited from a local university, two charities and Children, Young People & Family Centres.

Findings A number of themes emerged as possible factors for delaying early access to help: lack of knowledge about eating disorders and their potential seriousness; ideals regarding body shape; family living circumstances, and the role of food in the community. Participants acknowledged stigma among their community associated with mental health issues, including eating disorders, and concerns about confidentiality when approaching services, particularly primary care.

Originality/value General practitioners and specialist services need to be aware of the potential barriers to help-seeking for eating disorders as early specialist help is recommended for effective treatment. An educational campaign around eating disorders specifically designed with the SA community in mind may improve awareness, reduce stigma and promote early help-seeking.

Keywords Eating disorders, help-seeking, barriers, mental health, South Asian, ethnicity

Paper type Research paper

Introduction

Disordered eating (DE) refers to a wide range of abnormal eating behaviours that include excessive dieting and unhealthy weight control practices (Neumark-Sztainer *et al.*, 2011). The severity and frequency of behaviours is not enough to fulfill a diagnostic criteria for an eating disorder (ED), hence the use of subclinical eating disorders (ED's) or DE in the literature. DE has been shown to be an important risk factor for the development of ED's and a target for early prevention of ED development (Neumark-Sztainer *et al.*, 2011). ED's is a term covering the broad categories of anorexia nervosa (AN), bulimia nervosa (BN) and binge eating disorder (BED) as defined by the Diagnostic and Statistical Manual of the American Psychiatric Association (APA, 2013).

Historically ED's were thought to be 'Western culture-bound syndromes' (Soh & Walter, 2013); however ED's are increasingly documented in diverse countries and cultures worldwide and appear to be increasing in, for example, the Asian regions with rising industrialisation, urbanisation and globalisation (Pike *et al.*, 2014). Pike and Dunne in their review of the rise of ED's in Asia (2015) suggest that ED's are not culture-bound or culture-specific, but culture-reactive. Soh and Walter (2013) found that African, Latin American and Hispanic groups were the most studied cultural groups with all other ethnic groups, including South Asian (SA) (those who originate from the Indian subcontinent), having few articles published on ED's. They concluded further research was required in this area to remove barriers to accessing care.

A number of studies have examined ED's among those from minority ethnic backgrounds in the UK. A recent population survey in South East London found a high prevalence of DE amongst minority ethnic populations, including SA (Solmi *et al.*, 2014). These findings confirm previous studies from the United Kingdom (UK). An earlier study in the UK showed that the prevalence of BN amongst schoolgirls from the SA community in Bradford was higher than for their white counterparts (Mumford *et al.*, 1991). Bhugra and Bhui's study

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3 (2003) amongst teenagers in London showed differences across cultural groups with those
4 from an 'Asian' background being significantly more likely, than those from a white or
5 African-Caribbean background, to be compulsive eaters, to fast, and to think food dominated
6 their lives. Despite these findings, referrals from members of this community to specialist ED
7 services covering large SA populations are under-represented (Abbas *et al.*, 2010, Waller *et*
8 *al.*, 2009, Button *et al.*, 1998). However, on referral to such services, no significant clinical
9 differences between the SA and non-South Asian women have been found (Abbas *et al.*,
10 2010).

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20 Waller and colleagues (2009) hypothesised that the low number of SA people accessing ED
21 specialist services may be explained by the lack of identification at primary care level.
22 Another possible explanation maybe the fact that SA people do not present at primary care
23 services requesting help for ED or DE. The National Psychiatric Morbidity Survey in the
24 United Kingdom (UK) may explain this trend as data showed SA people suffering from
25 mental health problems were less likely to contact their GPs compared to their white and
26 black counterparts (Cooper *et al.*, 2013). Whilst the survey did not explore the reasons why
27 minority ethnic people may be less likely to consult their GP for mental health problems they
28 noted reasons cited by other researchers. For SA with dementia, a sense of stigma and a
29 lack of knowledge about mental illness and services alongside disillusionment with doctors
30 and exclusion from services (La Fontaine *et al.* 2007) were reported. Also for dementia was
31 the feeling that care is a family responsibility (Mukadam *et al.*, 2010). Fountain and Hicks
32 (2010) in their study with a large proportion of Asian participants found fear of stigma and
33 shame may prevent those with mental health problems from seeking help. Other studies
34 have indicated that individuals of SA origin may somatise psychological distress, presenting
35 to services in the form of physical complaints rather than mental health issues (EMPIRIC
36 report, 2002).

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Chowbey and colleagues (2012) aimed to explore the influences on diagnosis and treatment
of ED's among people from minority ethnic communities using a qualitative methodology.

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3 Although the authors did not exclusively look at the SA population their findings are of
4 interest. The study found that low awareness of ED's particularly among older people was an
5 important barrier to early help-seeking. This study was limited by including people from
6 different minority ethnic communities, which does not make it generalizable to the whole SA
7 population living in the UK.
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14 In order to reduce healthcare inequalities for those from a SA background in the UK, this
15 study aimed to identify barriers to help-seeking for ED's among this community using a
16 qualitative methodology. The findings are expected to provide information to facilitate help-
17 seeking for ED & DE and improve access to specialist services for members of the SA
18 community. Given the dearth of research in this area a qualitative inductive approach was
19 seen as appropriate. One of the main advantages of this methodology is the rich, in-depth
20 understanding of participant experience it provides.
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28 29 **Method**

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32 The study took place in 2015 in Leicester, a city in the Midlands of England, UK with a high
33 SA population. According to the most recent census data, just under one-third (31.8%) of the
34 population living in the city identifies as SA (Asian/British Asian Indian, Pakistani or
35 Bangladeshi) (ONS, Census 2011).
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40 *Recruitment and Participants:*

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43 South Asian community: Six focus groups with members of the local community who self-
44 identified as SA were undertaken. The groups included younger and older individuals, those
45 who were migrants and those who were born in the UK. Both men and women were invited
46 to attend. Recruitment was enabled through a University, two local charities and Children,
47 Young People & Family (CYP&F) Centres. Recruitment for the University group was via
48 posters at the university, an email to students, and a student careers fair. Interested students
49 were given or emailed a participant information sheet. Recruitment for the charity and
50 community groups was enabled by the researchers attending the centres where they were
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3 able to present the study. Those interested were provided with participant information
4 sheets and a time and date for the focus group. Focus groups were held on the university
5 campus and at the charity & CYP&F centres as appropriate. All participants gave written
6 consent prior to the initiation of the study and received a £10 gift voucher for their
7 attendance.
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14 A total of 28 people participated in the groups, 23 women and 5 men. Of the six focus
15 groups two were conducted with young people aged 18-25 years, these were a mix of men
16 and women, four were conducted with women aged between 25-65 years of age.
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21 Clinicians from specialised services: Every member of the local specialised ED service was
22 provided with an open invitation to participate in a focus group for clinicians via email. This
23 key informant group was included to provide the reflective experiences of working with
24 individuals from a SA background.
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30 A total of 16 ED professionals took part in the focus group (4 males, 12 females) and
31 included consultant psychiatrists, ED therapists, staff from a specialist ED inpatient ward and
32 a clinical psychologist. The clinicians' experience of treating people with ED's ranged from 1
33 to 25 years.
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39 The research study was approved by the Research Ethics Committee of De Montfort
40 University and the local NHS Research & Development office.
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47 *Insert Table 1 about here*
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51 52 *Interviews:*

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55 All the focus groups were conducted by the same experienced, qualitative interviewer (JW).
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57 All groups were conducted in English. An interpreter was present for three of the community
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3 focus groups who provided translation, as required, into Gujarati. The groups lasted for
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5 approximately one hour. Focus groups were audio-recorded and subsequently transcribed
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7 verbatim.

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10 A semi-structured interview schedule was developed by the research team to address the
11
12 specific research questions outlined earlier. The participants from the local community were
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14 invited to comment on: attitudes towards mental health issues, particularly ED's and DE;
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16 awareness and understanding of ED's; where and when help would be sought; barriers to
17
18 accessing care and how to encourage help-seeking. The interview schedule was continually
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20 modified to incorporate emerging themes from the focus groups. The clinicians were asked
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22 to note, in particular, any barriers to help-seeking they had encountered in treating
23
24 individuals from this community suffering from an ED.

25 26 27 Data analysis

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30 Thematic analysis was employed to examine the focus group transcripts. This provides a
31
32 rich description of the data set which highlights the most prominent and important themes
33
34 (Braun & Clarke, 2006). Data analysis was undertaken by the first author (JW). Initial ideas
35
36 for coding were generated through familiarisation with the transcripts and the data were
37
38 transferred into NVivo 11 (QSR, 2015). Codes were sorted into potential themes which were
39
40 reviewed and refined during on-going analysis and discussion with other authors (JA & NB).
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42 All quotations used have been anonymised.

43 44 45 **Results**

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48 The information from all the focus groups (people in the community and clinicians) was used
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50 to reach the themes. Thematic analysis revealed three main core themes: 1) Cultural
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52 aspects affecting the identification of ED's and/or DE in the SA community living in the UK;
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54 2) Barriers to help-seeking and access to services for the treatment of ED's; 3) Suggestions
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56 for improving help-seeking and access to services. A summary of the themes and sub-
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58 themes can be found in table 2.
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Insert table 2 about here

Theme 1. Cultural aspects affecting the identification of eating disorders/disordered eating

Cultural aspects related to eating may make the recognition of problematic eating behaviour more difficult.

1.1 The positive view of thinness:

Many interviewees from the SA community explained that weight loss would almost always be commented on positively among the community. This was due to several factors. Some mentioned that, as obesity was a problem in the community, weight loss was seen as healthy. People were thought to be much more motivated to seek help for being overweight than underweight. It was unlikely that a person who had lost weight would be considered to be suffering from an ED although there was awareness that some people lost weight in an unhealthy way, such as starving themselves for a period of time rather than doing a gradual weight loss programme or exercise. There was a general lack of appreciation in the community of the risk of developing an ED if a person had lost a lot of weight, or ate in a disordered way.

'A lot of people actually say we're not losing weight the right way, they don't exercise they're just starving themselves. So they might not be sick or whatever but they're just starving themselves and sometimes when they are starving themselves ... families and friends say 'you look nice' so it's quite a positive attitude towards it when it is not a very positive thing to do. So sometimes I think once they start getting positive compliments ... they carry it on'
(Respondent 4, female, >25)

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3 Some people discussed the positive view of thinness in young people in order to get
4 married. Being overweight in the SA community, especially for girls of marrying age, was
5 seeing negatively, and the pressure of not becoming overweight in order to marry was
6 present from young age.
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11 *'Culturally it's kind of when the girl gets to a certain age or a boy gets to a certain age it's*
12 *about getting married so you need to be a certain weight or you won't find a partner. And I*
13 *think sometimes parents do put that into children's heads. Like 'oh don't over eat now, you*
14 *need to start losing weight now' so they talk about weight a lot...'* (Respondent 4, female
15 >25)
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23 However, once married it was noted to be less of an issue to be slim. Many said there was
24 no pressure from either their partners or family to be a certain size.
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27 28 1.2 The role of food in the South Asian community:

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30 Many of the interviewees described the important role of food among their community. Food
31 was always present at celebrations and it was an excuse to meet with others. It was thought
32 that people who did not join in such occasions would be considered antisocial rather than
33 experiencing difficulties around food.
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39 *'...generally whenever we celebrate or do anything social it revolves around food and usually*
40 *quite high fatty sugary foods and then we have the counter side where you are trying to stay*
41 *in shape and control everything...a conflict particularly as an adult where your lives evolve*
42 *you have a bigger social circle and family commitments ... I don't know, I think there's so*
43 *much emphasis on food it makes it quite difficult.'* (Respondent 22, female >25)
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51 *'If someone would not eat with others they wouldn't think there's something wrong with them,*
52 *they'd think that she's being anti-social, and say you know why don't you want all this good*
53 *food...what's wrong with you? It's lovely food... there's something not quite right but they*
54 *wouldn't think that she needs or he needs support...I think my family would get quite angry*
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3 *if...there was an individual not eating or picking or you know saying 'I don't want this' all the*
4 *time. They'd think...there's all this lovely food about and it's like why aren't you eating this,*
5 *being disrespectful' (Respondent 2, female >25)*
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10 There was a general consensus that there was too much unhealthy food consumed in the
11 SA community and overeating was commonplace at family and community events. This was
12 seen as something of a conflict of interests as eating higher calorific foods was at odds with
13 maintaining or losing weight.
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18 *'The amount of oil...fried foods, fatty foods, sugary foods. I think that's what the other*
19 *problem is. From a young age.....people don't know what a balanced diet is. It's always the*
20 *chapatti with the oily curry...I think if you make a chicken salad (it's like) you haven't eaten*
21 *today.'* (Respondent 28, female >25)
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27 **Theme 2. Barriers to help-seeking and access to services**

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30 Several subthemes were found within this section that may act as barriers for people to
31 access help when suffering from an ED or DE.
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34 *2.1 Lack of knowledge about eating disorders*

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38 When discussing eating problems, people were more likely to mention obesity, diabetes and
39 health issues associated with being overweight rather than ED's. It appeared that lack of
40 knowledge, and understanding regarding ED's were dependent on several factors, such as
41 age.
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47 Younger, UK born, participants appeared to be more aware of ED's than older members of
48 the community, especially those not born in the UK. Many of the older, but also a few of the
49 younger participants, were not aware of the terms AN and BN but did recognise that they
50 had seen, or knew of, people with DE. Participants were more aware of the term AN than
51 BN. Some younger people noted that information on ED's had been taught in schools which
52 had aided their awareness alongside other sources such as articles and programmes in the
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3 media. Those aware of ED's recognised that both males and females were at risk of
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5 developing these, but that they were more common in females
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8 *'I'm more aware if it because of the media, I see programmes about it I see magazine*
9 *articles.'* (Respondent 15, female <25)
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12 Place of birth was also commented on as influencing knowledge about ED's and DE. It was
13 mentioned that for those who had been born and brought up in a culture where food had
14 been scarce, knowledge would be especially low and ED's perhaps not readily understood.
15 This also meant that there may not have the language to express ED's and sufferers may
16 have difficulty conveying what they were experiencing to older family members.
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23 *'...our parents don't know much about it, especially if they're from places like India and*
24 *Pakistan and Africa ...'* (Respondent 1, female >25)
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28 *'Several (patients) have communicated how hard it is to communicate that (their ED) to their*
29 *parents if the parents have limited English because the kids, the ones we see, don't have the*
30 *language to go back and describe it'* (Clinician 2)
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35 *'My grandma for example it didn't exist to them because they lived in a time when food was*
36 *scarce anyway, so it was very different, you cooked your meal you ate it, it wasn't a big deal.*
37 *I think our lifestyles have changed and that's kind of developed this'* (Respondent 21, female
38 >25)
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44 *'...what you'll have for a lot of the second generation girls...they won't have a history of*
45 *eating disorder or a language for this whole thing of dieting and wanting to be thin ...because*
46 *their mums will have come from India...then actually women didn't diet, you were lucky if you*
47 *managed to find enough food ...So these girls will come from families where you don't have*
48 *...oh yeah my mum always dieted' ...that understanding of size...that will not be understood.*
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54 *So for them I think there will I be that added sense of isolation actually they can't talk to*
55 *perhaps their mothers, aunts about it.'* (Clinician 3)
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2.2. Lack of understanding of the seriousness of ED

Some participants explained that ED's were less serious than other problems associated with eating which can cause medical problems e.g. diabetes, and cholesterol which could lead to heart attacks. Participants also mentioned that ED's were less serious than other mental health problems e.g. schizophrenia, depression and anxiety and the fact that, in their view, it could easily be treated by eating more or less. Whilst a minority commented that specialist psychological help was needed a few mentioned that families would try to help the sufferer by taking them on holiday or for an outing. They believed that this would be sufficient to instigate a change in behaviours. There was a comment that some may view the world of 'talking therapies' with some scepticism, seeing it as 'a money making profession' rather than serious medicine.

'I just think ... eating disorders they're easily fixed so why go seek help if you can do it yourself? ... You have your family, you have support you can fix it yourself. ...someone who has diabetes something like that is more severe & they need to go to a doctor. Someone who has anorexia, sort it out yourself.' (Respondent 14, male <25)

2.3 Eating problems seeing as a physical problem

Weight loss and weight gain were also likely to be associated with suffering from a physical problem rather than a mental health one. This was linked to those with a general lack of awareness about ED's.

'I don't think in the South Asian community we think of eating disorders. If we see someone losing weight or gaining weight they think to the more traditional diseases and they tell you something like you might have thyroid problem...' (Respondent 16, female <25)

2.4 Stigma associated with mental health:

There was a clear indication that any mental health problem, which may be thought of as reflecting negatively on the family/individual, would aim to be hidden or at least not openly

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3 discussed. Some thought this went wider than just mental health in that anything that may be
4 thought of as being detrimental, whether health wise or not, would be kept hidden. ED's
5 were no different to this.
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10 *'A lot of that stems from people thinking about what others will think about that...the reason*
11 *is not so much the problem itself but is what others will think of us ...will they see us as*
12 *crazy mental people they don't want to associate with? I think that is the reason for the circle*
13 *of secrecy. People are afraid how others how the wider society ...will see them' (Respondent*
14 *21, female >25)*
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21 Many thought that families turned a blind eye to mental health problems and had an attitude
22 of 'just getting on with it' rather than actively seeking help.
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26 *'I think it's just they brush so much under the carpet like so many issues are coming through*
27 *now this generation that wasn't dealt with. I think their objective when they came to the UK*
28 *was come here settle, work, get a roof on top of their heads, everything else was just sort*
29 *yourself out and that escalates now into problems I think. They continue doing that, they*
30 *don't need to do it now because they've got a house they've built themselves up and their*
31 *families are financially secure now but they still don't still see it as whatever, kind of blinded*
32 *still.'* (Respondent 28, female >25)
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41 Participants explained that if people were concerned about stigma and shame they were
42 more likely to delay their presentation to services and this has implications for successful
43 treatment. One of the clinicians noted that this was particularly true for Asian males.
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47 *'I saw a young girl recently and she certainly presented very late. She's now in her early 20's*
48 *but she's been purging since she was 11. Her brother says it's been known in the family,*
49 *she's been a BMI of 14 for years now which is very sad as she's already chronic really in*
50 *terms of how long she's been unwell...she's had no treatment at all. One of the barriers*
51 *there is the family just not willing to think about mental health there's a big stigma, a barrier*
52 *about that...'* (Clinician 1)
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3 *'I've had 2 or 3 (Asian males) who were more bulimic who've presented years after it started,*
4 *always avoided coming...the ones I've seen ... have been very ashamed...something that's*
5 *hidden' (Clinician 2)*
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10 There was a school of thought that people would be much more willing to access help for
11 physical rather than mental health problems. This seemed to be because physical problems
12 are more obvious, potentially more serious and can only get better with medical intervention.
13 A minority saw the GP as dealing with physical problems only. Respondents thought
14 sufferers were much more likely to seek help for a mental health problem once they were
15 experiencing physical effects as a result of this. One of the clinicians noted that SA people
16 can present to services citing physical issues for a mental health problem. This may be due
17 to translation issues where they lack the language to relay the eating difficulties they are
18 experiencing.
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29 *2.5 Difficulties keeping privacy within the family*

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32 It was noted how a persons living situation may hinder their help-seeking for mental health
33 problems. An adult living with their extended family may find it difficult to attend regular
34 therapy sessions if they do not want to share the reason for their absences with other family
35 members.
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40 *'I went to counselling once and I always made an excuse at that time of that week...I didn't*
41 *want to tell my in-laws where I was going. Every week it was a coffee morning or something*
42 *which then had its own problems, because 'she's always going out for coffee'...*
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47 *(Respondent 22, female >25)*
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49 *2.6 Worries about confidentiality*

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52 There were some issues around approaching the GP. Whilst many acknowledged they
53 understood healthcare professionals were bound by confidentiality there were some
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3 concerns around this. These concerns seemed to be related to health information being
4 shared with other family members without patient authorisation.
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8 *'...you all know the confidentiality rule applies but probably, self-consciously, they're thinking*
9 *it won't apply because they're Asian communities'* (Respondent 4, female >25)
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13 *'...one of the...Asian patients I worked with said she was really worried about coming*
14 *because she was worried that her GP would tell... her parents that she'd been...I don't think*
15 *it had happened to her but she perceived it as a worry and it delayed her going'* (Clinician 4)
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20 Fear of confidentiality was not restricted to the GP as one of the clinicians noted that it was
21 not unusual for a SA patient to request to see a non-SA therapist when presenting to
22 specialist services.
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26 *'It's not unusual to see an Asian patient has requested not to see an Asian therapist'*
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29 *(Clinician 5)*
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32 *2.7 The care pathway*

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34 Many understood that GP's would need to refer patients to specialist services for treatment
35 for an ED. This evoked some concerns about being taken seriously and a referral being
36 made. Some thought that those who presented to their GP with an ED and who did not get
37 referred for treatment initially may not seek help again.
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42 **Theme 3. How to improve help-seeking & access to services**

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46 Participants were asked for suggestions for improving help-seeking and access to services
47 for members of this community. Education was key for many, some commented that they
48 had learnt about ED's at school, albeit briefly. Education was required firstly to raise
49 awareness of ED's and secondly to highlight the seriousness and potential consequences of
50 such disorders.
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3 Some mentioned recent publicity about mental health problems within the SA community, a
4 Bollywood actress who had depression and spoken openly about this, and the issue of
5 autism being depicted in films had raised awareness of mental health and this was
6 welcomed.
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11 *'I think now some of the Bollywood films are now starting to put mental health issues into the*
12 *films. ... things like autism as well that's into two of the major films ...but it's quite light-*
13 *hearted...'* (Respondent 4, female >25)
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19 Some commented that if issues were portrayed either on Asian TV channels or in everyday
20 soap operas on television it could lead to family discussions about the issues raised.
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24 *'...sometimes when we're watching EastEnders, Coronation Street and certain topics like*
25 *this come up, normally as a family we discuss it, ... maybe not many Asian families have*
26 *that discussion'* (Respondent 4, female >25)
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31 Participants suggested using case studies (as part of the education to the community) from
32 service users with a SA background detailing the reasons a person sought help, and the
33 consequences of receiving help. Their view was that this could help those with little
34 understanding of ED's to appreciate what they are, how they may manifest, what help is
35 available and how to access care. Whilst there were varied levels of agreement about who
36 listened to Asian radio, this appeared to be a useful forum for putting such information
37 across. Generally participants thought listening to information was a better way to inform
38 than having to read it so did like the idea of radio, television, films as well as workshops in
39 school and colleges.
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50 Participants thought that posters and leaflets would, on their own, have limited utility in
51 improving understanding of ED's. However they may be of use alongside other sources of
52 information provision. They could prove useful especially if they were put up outside of
53 healthcare settings in community centres, mosques and temples. It may let people know that
54 it is acceptable to talk about such issues and encourage discussion.
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3 *'Maybe Asian community centres, temples and stuff, if they put them (posters) there they'd*
4 *be like hold on a second why has that poster been put up here here? ... maybe that would*
5 *be more helpful' (Respondent 16, female <25)*
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10 *'The temples and mosques...they have noticeboards...that in itself would say maybe it is ok*
11 *for us in this community to talk about eating disorders' (Clinician 3)*
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15 It was thought that posters should depict a range of people, highlighting that anyone can
16 suffer from an eating disorder, and they are not restricted to any gender, age or minority
17 ethnic group.
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21 *'It's not just for them so you wouldn't just have an Asian face on it, that's not what you are*
22 *doing, you're just letting the Asians also be aware of it' (Respondent 24, female >25)*
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27 The clinicians thought the focus of both leaflets and posters should be on not being
28 ashamed of having an ED and not to suffer, but to seek help. Confidentiality, at point of
29 contact with NHS services, should also be stressed.
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33 *'I think another thing that would be good is defining what it is. Everybody's perception of*
34 *anorexia or eating disorders may be different...'* (Respondent 22, female >25)
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38 Discussion

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41 As the number of people from the SA community attending ED specialised services is low
42 (Abbas *et al.*, 2010), the main aim of this study was to identify the barriers for help-seeking.
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46 **This study is not without limitations. This was an exploratory study with a small sample size**
47 **of 44 individuals (mainly females) taking part in focus group discussions. The sample had**
48 **wide age ranges, particularly for the older age group of 25-65 years; this had the benefit of**
49 **including older members of the community, although no older men participated. It was**
50 **limited to one city therefore the results may not be generalizable to other countries but it is**
51 **likely to be generalizable within the UK. As the interviews took place in groups, some**
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3 interviewees may not have been able to share their own experiences. The key informant
4 focus group with 16 participants was too large and would have benefited from being two
5 smaller groups. The participant information sheet stated the research was concerned with
6 eating problems which, whilst necessary, may have affected participation by those with
7 limited knowledge in this area being less likely to attend. Research did not include GP's who
8 could have provided insight on how and when help was sought by members of this
9 community. In spite of the limitations this is the first study that focuses solely on the SA
10 community living in the UK aimed at understanding what can professionals do to enable ED
11 sufferers to access appropriate services. Future studies could seek to implement some of
12 the recommendations and evaluate their effectiveness in ED help-seeking among this
13 community. It would be prudent to investigate the key themes emerging from this research in
14 larger, quantitative studies.

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28 Previous studies that have explored access of care among people from minority ethnic
29 groups with ED's have demonstrated the existence of cultural barriers among different
30 communities (Chowbey *et al.*, 2012). In view of the importance of culture in the manifestation
31 of ED's and access to help (Agüera *et al.*, submitted), this study focussed on one specific
32 culture, the SA community living in the UK.

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39 The study found that lack of awareness and understanding about ED's is potentially key in
40 not seeking help when suffering from an ED or DE. As many people with ED lack the
41 motivation to access help (Evans *et al.*, 2011), they do rely on family and friends to
42 encourage help-seeking. Among the SA community a lack of awareness by other family
43 members may delay the sourcing of professional help. Education, at all levels, would help
44 recognition of ED's within the family and may also dispel myths that ED's are relatively trivial
45 illnesses and potentially remedied without therapeutic intervention. This appeared not to be
46 unique to ED's but mental health problems in general as several respondents explained that
47 they would mainly attend the GP for physical problems. Indeed it was the medical
48 complications from an ED which may encourage people to attend primary care services.

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3 These findings confirm a previous study among SA women receiving treatment for an ED
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5 (Hoque, 2011).
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8 Lack of help-seeking also stemmed from concerns about stigma. This may lead people to
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10 either ignore or keep the issue within the family. This is a wider issue than just ED and will
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12 clearly take time to change, but education would appear to be the first step to widen
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14 understanding that mental health issues can affect anyone, and that those suffering from
15
16 mental health problems should not feel shame, be stigmatised or discriminated against. A
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18 recent analysis by Brown *et al.* (2014) found that SA people seeking informal help for mental
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20 health problems were most likely to do so from family rather than friends. This fear of stigma
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22 is not limited to the SA community. A recent systematic review by Clement *et al.* (2015)
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24 examining the impact of mental health-related stigma on help-seeking, whilst not ED
25
26 specific, concluded that minority ethnic populations were disproportionately deterred by
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28 stigma.
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31 Family living circumstances, especially those living in an extended family group, were also
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33 found to hinder help-seeking. This is allied with concerns that information may be shared, by
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35 healthcare professionals, with other family members even though they understood
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37 confidentiality issues. Confidentiality is an area that could be emphasized by healthcare
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39 professionals, particularly to this minority ethnic group.
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42 The study also aimed to seek ways of improving access to specialist services for ED's. The
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44 study found that information regarding mental health problems including ED's displayed
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46 outside of healthcare settings e.g. in community centres & temples, could be helpful. This
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48 may promote discussion around mental health problems, including eating issues, and
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50 improve education. Many ED services are part of the NHS which has, for example, school
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52 nurses who could help deliver information about ED's and improve mental health literacy in
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54 general. Drop-in centres could be used to help members of this community access services,
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56 potentially for all mental health issues. This may allay concerns around the care pathway but
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3 would require investment. Whilst wanting to encourage all to seek help from specialist ED
4 services where appropriate, for those who feel they are unable to access help in this way
5 due to family circumstances or confidentiality fears, even if unfounded, self-help manuals,
6 programmes and websites may have increased utility. Accessing such resources online
7 could potentially be an ideal way to educate, inform and offer help. However in order to seek
8 help, sufferers need to be aware of the signs and risks of ED's which can only be achieved
9 through improved education. The media was mentioned as an important vehicle to both
10 educate and inform about ED's. A recent study by Mukadam *et al.* (2015) also highlighted
11 the need for personal narratives to encourage help-seeking in the SA community, in this
12 instance for dementia. Using local Asian radio stations to highlight ED case studies may be a
13 useful way of informing, particularly older members of the SA community, about ED's and
14 the treatments available. Whatever the route, steps need to be taken to reduce healthcare
15 inequalities for those from a minority ethnic population.
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Table 1: Focus group composition

	Participants	Number of participants	UK/non-UK born	Gender	Age category
Focus group 1	Clinicians (Key Informants)	16	not applicable	4 male 12 female	not applicable
Focus group 2	Charity group	5	4/1	5 female	25–65 years
Focus group 3	Charity group	8	1/7	8 female	25–65 years
Focus group 4	University students	4	2/2	2 male 2 female	<25 years
Focus group 5	University students	3	2/1	3 male	<25 years
Focus group 6	CYP&F centre	6	5/1	6 female	25–65 years
Focus group 7	CYP&F centre	2	2/0	2 female	25–65 years

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Table 2: Core themes, themes and sub-themes

Core themes	Themes	Sub-themes
1. Cultural aspects affecting the identification of eating disorders & disordered eating	1.1. The positive view of thinness	<ul style="list-style-type: none"> • Weight loss seen as healthy • Marriage and slimness
	1.2. The role of food in the SA community	<ul style="list-style-type: none"> • Importance of food for celebrations • Overeating commonplace
2. Barriers to help-seeking & access to services	2.1. Lack of knowledge about ED	<ul style="list-style-type: none"> • Younger, UK born more aware of ED • Delayed help-seeking
	2.2. Lack of understanding of the seriousness of ED's	<ul style="list-style-type: none"> • Seen as less serious than other mental health problems • Usefulness of psychological therapies
	2.3. Eating problems seen as physical problem	<ul style="list-style-type: none"> • Weight changes likely to be associated with physical problem
	2.4. Stigma associated with mental health	<ul style="list-style-type: none"> • Reflecting negatively on individual/family • Deal with on own • Help-seeking for physical aspects of ED more likely
	2.5. Family circumstances	<ul style="list-style-type: none"> • Family living situation may hinder help-seeking
	2.6. Confidentiality	<ul style="list-style-type: none"> • Concerns that GP may inform family
	2.7. The care pathway	<ul style="list-style-type: none"> • Specialist referral may deter
3. How to improve help-seeking & access to services	3.1. Education	<ul style="list-style-type: none"> • To raise awareness of ED • To highlight seriousness & potential consequences • Case studies helpful
	3.2. Posters & leaflets	<ul style="list-style-type: none"> • As an adjunct to other information provision • Useful if put outside of healthcare settings e.g. Asian community centres, temples