



## Exploring Barriers to South Asian Help-Seeking for Eating Disorders

Journal:	<i>Mental Health Review Journal</i>
Manuscript ID	MHRJ-09-2016-0017.R1
Manuscript Type:	Research Paper
Keywords:	eating disorders, help-seeking, mental health, barriers, South Asian, ethnicity

SCHOLARONE™  
Manuscripts

## Exploring Barriers to South Asian Help-Seeking for Eating Disorders

### 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

1  
2  
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).

11  
12  
13  
14  
15  
16  
17  
18  
19  
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).

37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60  
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.

1  
2  
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.  
8  
9  
10  
11  
12

13  
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.  
21  
22  
23  
24  
25  
26  
27

## 28 29 **Method**

30  
31  
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).  
36  
37  
38  
39

### 40 *Recruitment and Participants:*

41  
42  
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  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
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.  
8

9  
10  
11  
12  
13  
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.  
17  
18  
19

20  
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.  
25  
26  
27  
28

29  
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.  
34  
35  
36  
37

38  
39 The research study was approved by the Research Ethics Committee of De Montfort  
40 University and the local NHS Research & Development office.  
41  
42  
43  
44  
45

46  
47 *Insert Table 1 about here*  
48  
49  
50

#### 51 52 *Interviews:*

53  
54  
55 All the focus groups were conducted by the same experienced, qualitative interviewer (JW).

56  
57 All groups were conducted in English. An interpreter was present for three of the community  
58  
59  
60

1  
2  
3 focus groups who provided translation, as required, into Gujarati. The groups lasted for  
4  
5 approximately one hour. Focus groups were audio-recorded and subsequently transcribed  
6  
7 verbatim.

8  
9  
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  
13  
14 invited to comment on: attitudes towards mental health issues, particularly ED's and DE;  
15  
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  
19  
20 modified to incorporate emerging themes from the focus groups. The clinicians were asked  
21  
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

28  
29  
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).  
41  
42 All quotations used have been anonymised.

#### 43 44 45 **Results**

46  
47  
48 The information from all the focus groups (people in the community and clinicians) was used  
49  
50 to reach the themes. Thematic analysis revealed three main core themes: 1) Cultural  
51  
52 aspects affecting the identification of ED's and/or DE in the SA community living in the UK;  
53  
54 2) Barriers to help-seeking and access to services for the treatment of ED's; 3) Suggestions  
55  
56 for improving help-seeking and access to services. A summary of the themes and sub-  
57  
58 themes can be found in table 2.  
59  
60

1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

*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)



1  
2  
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.  
7  
8  
9

10  
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)  
16  
17  
18  
19  
20  
21

22  
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.  
25  
26

#### 27 28 1.2 The role of food in the South Asian community:

29  
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.  
34  
35  
36  
37

38  
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)  
44  
45  
46  
47  
48  
49

50  
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*  
55  
56  
57  
58  
59  
60

1  
2  
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)*  
6  
7  
8  
9

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.  
14  
15  
16  
17

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)  
22  
23  
24  
25  
26  
27

## 28 **Theme 2. Barriers to help-seeking and access to services**

29  
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.  
32  
33  
34

### 35 *2.1 Lack of knowledge about eating disorders*

36  
37  
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.  
42  
43  
44  
45

46  
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  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 media. Those aware of ED's recognised that both males and females were at risk of  
4  
5 developing these, but that they were more common in females  
6

7  
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)  
10

11  
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.  
17  
18  
19  
20  
21

22  
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)  
25  
26

27  
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)  
31  
32  
33

34  
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)  
39  
40  
41  
42

43  
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.*  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

## 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

1  
2  
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.  
6  
7

8  
9  
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)*  
15  
16  
17  
18  
19

20  
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.  
23  
24

25  
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)  
33  
34  
35  
36  
37  
38  
39

40  
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.  
44  
45

46  
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)  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
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)*  
6  
7  
8  
9

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.  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28

### 29 *2.5 Difficulties keeping privacy within the family*

30  
31  
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.  
36  
37  
38  
39

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'...*  
43  
44  
45  
46  
47 *(Respondent 22, female >25)*  
48

### 49 *2.6 Worries about confidentiality*

50  
51  
52 There were some issues around approaching the GP. Whilst many acknowledged they  
53 understood healthcare professionals were bound by confidentiality there were some  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 concerns around this. These concerns seemed to be related to health information being  
4 shared with other family members without patient authorisation.  
5  
6

7  
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)  
10  
11

12  
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)  
16  
17  
18

19  
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.  
23  
24

25  
26 *'It's not unusual to see an Asian patient has requested not to see an Asian therapist'*  
27

28  
29 (Clinician 5)  
30

### 31 2.7 The care pathway

32  
33

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.  
38  
39  
40  
41

### 42 **Theme 3. How to improve help-seeking & access to services**

43  
44

45  
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.  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
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.  
7  
8

9  
10  
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)  
14  
15  
16

17  
18  
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.  
21  
22

23  
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)  
27  
28  
29

30  
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.  
40  
41  
42  
43  
44  
45  
46  
47  
48

49  
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.  
55  
56  
57  
58  
59  
60



1  
2  
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)*  
6  
7  
8

9  
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)*  
12  
13

14  
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.  
18  
19

20  
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)*  
23  
24  
25

26  
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.  
30  
31

32  
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)  
35  
36  
37

## 38 **Discussion**

39

40  
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.  
43  
44

45  
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**  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
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.  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26

27  
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.  
33  
34  
35  
36  
37

38  
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.  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 These findings confirm a previous study among SA women receiving treatment for an ED  
4  
5 (Hoque, 2011).  
6

7  
8 Lack of help-seeking also stemmed from concerns about stigma. This may lead people to  
9  
10 either ignore or keep the issue within the family. This is a wider issue than just ED and will  
11  
12 clearly take time to change, but education would appear to be the first step to widen  
13  
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  
17  
18 recent analysis by Brown *et al.* (2014) found that SA people seeking informal help for mental  
19  
20 health problems were most likely to do so from family rather than friends. This fear of stigma  
21  
22 is not limited to the SA community. A recent systematic review by Clement *et al.* (2015)  
23  
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  
27  
28 stigma.  
29

30  
31 Family living circumstances, especially those living in an extended family group, were also  
32  
33 found to hinder help-seeking. This is allied with concerns that information may be shared, by  
34  
35 healthcare professionals, with other family members even though they understood  
36  
37 confidentiality issues. Confidentiality is an area that could be emphasized by healthcare  
38  
39 professionals, particularly to this minority ethnic group.  
40

41  
42 The study also aimed to seek ways of improving access to specialist services for ED's. The  
43  
44 study found that information regarding mental health problems including ED's displayed  
45  
46 outside of healthcare settings e.g. in community centres & temples, could be helpful. This  
47  
48 may promote discussion around mental health problems, including eating issues, and  
49  
50 improve education. Many ED services are part of the NHS which has, for example, school  
51  
52 nurses who could help deliver information about ED's and improve mental health literacy in  
53  
54 general. Drop-in centres could be used to help members of this community access services,  
55  
56 potentially for all mental health issues. This may allay concerns around the care pathway but  
57  
58  
59  
60

1  
2  
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.  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29

### 30 References

31  
32  
33 Abbas, S., Damani, S., Malik, I., Button, E., Aldridge, S. & Palmer, R.L. 2010. A comparative  
34 study of South Asian and non-Asian referrals to an eating disorders service in Leicester, UK.  
35 *European Eating Disorders Review*, Vol 18 No. 5, pp 404-9.  
36  
37

38  
39  
40 Agüera, Z., Brewin, N., Chen, J., Granero, R., Kang, Q., Fernández-Aranda, F. & Arcelus, J.  
41 2016. Eating symptomatology and general psychopathology in patients with anorexia  
42 nervosa from China, UK and Spain: A cross-cultural study. Submitted  
43  
44

45  
46  
47 American Psychiatric Association 2013. *Diagnostic & statistical manual of mental*  
48 *disorders* (5th ed.). Washington DC, APA.  
49

50  
51  
52 Bhugra, D. & Bhui, K. (2003). Eating disorders in teenagers in East London: a survey.  
53 *European Eating Disorders Review* 11:46-57  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 Braun, V. & Clarke, V. 2006. Using thematic analysis in psychology. *Qualitative Research in*  
4 *Psychology*, 3(2), 77–101.

7 Brown, J., Evans-Lacko, S., Aschan, L., Henderson, M.J., Hatch, S.L., & Hotopf, M. 2014.  
8 Seeking informal and formal help for mental health problems in the community: a secondary  
9 analysis from a psychiatric morbidity survey in South London. *BMC Psychiatry*, 14(1), p.1.  
10  
11

14 Button, E., Reveley, C. & Palmer, R.L. 1998. An ethnic comparison of eating attitudes and  
15 associated psychological problems in young British women. *International Journal of Eating*  
16 *Disorders*, 23 pp.317-323.  
17  
18

21 Chowbey, P., Salway, S. & Ismail, M., 2012. Influences on diagnosis and treatment of eating  
22 disorders among minority ethnic people in the UK. *Journal of Public Mental Health*, 11 (2)  
23 pp. 54-64.  
24  
25  
26

28 Clement, S., Schauman, O., Graham, T., Maggioni, F., Evans-Lacko, S., Bezborodovs, N.,  
29 Morgan, C., Rüsch, N., Brown, J.S.L. and Thornicroft, G., 2015. What is the impact of mental  
30 health-related stigma on help-seeking? A systematic review of quantitative and qualitative  
31 studies. *Psychological medicine*, 45(01), pp.11-27.  
32  
33  
34  
35

37 Cooper, C., Spiers, N., Livingston, G., Jenkins, R., Meltzer, H., Brugha, T., McManus, S.,  
38 Weich, S. & Bebbington, P. 2013. Ethnic inequalities in the use of health services for  
39 common mental disorders in England. *Social psychiatry & psychiatric epidemiology* 48(5)  
40 pp. 685-692.  
41  
42  
43  
44

46 Evans, E.J., Hay, P. H., Mond, J., Paxton, S.J., Quirk, F., Rodgers, B., Jhajj, A.K. &  
47 Sawoniewska, M.A. 2011. Barriers to help-seeking in young women with eating disorders: A  
48 qualitative exploration in a longitudinal community survey. *Eating Disorders*, 19 pp. 270-285.  
49  
50

53 Fountain, J. & Hicks, J. (2010). Delivering race equality in mental health care: report on the  
54 findings and outcomes of the community engagement programme 2005-2008. *International*  
55  
56  
57  
58  
59  
60

School for Communities, Rights and Inclusion (ISCRI), University Central Lancashire, Lancashire

Hoque, S. 2011. An exploration into the experience of an eating disorder and the journey into treatment for British South-Asian women: What can we learn? Doctorate thesis in Clinical Psychology, University of Leicester, Leicester, UK.

La Fontaine, J., Ahuja, J., Bradbury, N.M., Phillips, S. & Oyebode J.R. (2007) Understanding dementia amongst people in minority ethnic and cultural groups. *Journal of Advanced Nursing* 60(6) 605-614

Mumford, D.B., Whitehouse, A.M. & Platts, M. 1991. Sociocultural correlates of eating disorders among Asian schoolgirls in Bradford. *The British Journal of Psychiatry*, Vol 158, pp. 222-8.

Mukadam, N., Cooper C. & Livingston G. 2010. A systematic review of ethnicity and pathways to care in dementia. *International Journal of Geriatric Psychiatry* 26:12-20

Mukadam, N., Waugh A., Cooper C. & Livingston G. 2015. What would encourage help-seeking for memory problems among UK-based South Asians? A qualitative study. *British Medical Journal Open* 5:e007990

National Centre for Social Research (2002). Ethnic minority illness rates in the community (EMPIRIC) Quantitative Report. The Stationery Office, London

Neumark-Sztainer D., Wall M., Larson, N. I., Eisenberg M. E., Loth K. 2011. Dieting and disordered eating behaviors from adolescence to young adulthood: Findings from a 10 year longitudinal study. *Journal of the American Dietetic Association* 111(7):1004-11

NVivo, QSR International Pty Ltd. Version 11, 2015

Office of National Statistics, Census 2011, website: [infuse2011.ukdataservice.ac.uk](http://infuse2011.ukdataservice.ac.uk)

accessed 24/08/2016

1  
2  
3 Pike, K.M., Hoek, H.W. & Dunne, P.E. (2014). Cultural trends and eating disorders. *Current*  
4  
5 *Opinion in Psychiatry* 27:436-442  
6

7  
8 Pike, K.M. & Dunne, P.E. (2015). The rise of eating disorders in Asia: a review. *Journal of*  
9  
10 *Eating Disorders* 3:33  
11

12  
13 Solmi, F., Hatch, S.L., Hotopf, M., Treasure, J. & Micali, N. 2014 Prevalence and correlates  
14  
15 of disordered eating in a general population sample: the South East London Community  
16  
17 (SELCoH) study. *Social psychiatry and psychiatric epidemiology* 49(8), pp. 1335-1346  
18

19  
20 Soh, N.L. & Walter, G (2013). Publications on cross-cultural aspects of eating disorders.  
21  
22 *Journal of Eating Disorders* 1:4  
23

24  
25 Waller, G., Schmidt, U., Treasure, J., Emanuelli, F., Alenya J., Crockett, J. & Murray K.  
26  
27 2009. Ethnic origins of patients attending specialist eating disorder services in a multi-ethnic  
28  
29 urban catchment area in the United Kingdom. *International Journal of Eating Disorders* 42  
30  
31 459-463  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

Table 1: Focus group composition

	<b>Participants</b>	<b>Number of participants</b>	<b>UK/non-UK born</b>	<b>Gender</b>	<b>Age category</b>
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

1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60



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