Eating Disorders in Under-represented Groups: PPI Insights

Gemma Bridge and Christine Ramsey-Wade

Eating Disorders Health Integration Team, Bristol Health Partners

Centre for Appearance Research, University of the West of England, Bristol

Contents

Executive summary

Eating disorders (ED) and disordered eating do not discriminate by gender, age or ethnicity. Despite this, in the UK, compared to those from White British backgrounds, people from minoritised ethnic communities are less likely to present to ED support services, receive an ED diagnosis or receive specialist ED support. People from a range of minoritised ethnic backgrounds living in Bristol, with lived experience of EDs or disordered eating, were invited to take part in focus groups as part of PPI work to explore barriers to seeking ED support and methods of improving service uptake. Focus group discussions were conducted online via MS Teams. The questions were codeveloped with people from minoritised ethnic communities. Discussions were analysed thematically. Key themes included perceptions of thinness, a lack of awareness of ED's, stigma, taboo and shame, and a lack of trust in clinicians. Ideas for improving awareness, help seeking, and treatment uptake were considered. Community led, informational and/ or educational support and signposting was highlighted as a good potential approach to improving ED support services for minoritised ethnic communities in Bristol, UK. Further research is needed to explore the feasibility of developing and delivering community led approaches to improve ED awareness and

Introduction

Eating disorders (EDs) are mental health conditions characterized by abnormal eating behaviours or behaviours around food that negatively affect a person's physical or mental health and wellbeing (NHS, 2021; Neumark-Sztainer et al., 2011). When compared to those without these conditions, people with EDs are less likely to be employed, experience greater absenteeism and presenteeism, and have increased healthcare costs (Samnaliev et al., 2015). EDs also have the second highest mortality rate of any mental illness (Chesney, Goodwin and Fazel., 2014).

Ascertaining the global prevalence of EDs is important to ensuring health systems can support those with EDs, as well as act to prevent the conditions from arising (Le et al., 2017). Galmiche (2019) conducted a systematic review of 94 studies, published between 2000-2018, and calculated a weighted mean of lifetime ED prevalence to be 8.4% (range 3.3–18.6%) for women and 2.2% (range 0.8–6.5%) for men. Santomauro et al., (2021) conducted a burden of disease study and determined a global ED prevalence of 41·9 million (95% UI 27·9–59·0), with 17·3 million (11·3–24·9) people with binge-eating disorder and 24·6 million (14·7–39·7) people with other specified feeding or eating disorder (OSFED).

It has been estimated that prevalence of EDs in the UK could exceed 1.25 million people (Beat, 2023). What proportion of those suffering from EDs are from minoritised ethnic groups in the UK, which include all ethnic groups except the white British group (Gov.UK, 2021), is even less clear. However, research conducted in other countries indicates that ED's are experienced by people from a range of backgrounds. In their systematic review of ED prevalence studies, Galmiche (2019) explored regional prevalence of EDs and reported that in the Americas ED prevalence is estimated to be 4.6% (range 2.0–13.5%), in Europe it is estimated to be 2.2% (range 0.2–13.1%) and in Asia, estimated prevalence of EDs was 3.5% (range 0.6–7.8%). Individuals from minoritised ethnic groups may even be at a higher risk of developing EDs (Striegel-Moore et al. (2011; Taylor et al., 2007).

Despite the potential impact of EDs, less than a quarter of all sufferers (23%) seek clinical support (Hart et al., 2011). Those that do seek support are white females, who are over-represented at diagnosis and referral (Douglas, Balas and Gordon, 2021), as well as participants in randomized clinical trials (RCTs) for ED treatments (Burnette et al. 2022). These factors contribute to the development of the stereotype that EDs are more likely to occur in White affluent females (Sonneville and Lipson, 2018).

Treatment access and uptake rates are even lower amongst those from minoritised ethnic backgrounds (Sonneville and Lipton, 2018; Sinha and Warfa, 2013; Carrino et al., 2023). Reasons for this are multifaceted and relate to cultural, individual, and health system factors. At referral, healthcare providers often do not recognize EDs that present with signs and symptoms that fall outside the range of the ICD-10 criteria (WHO, 2019), as can occur with those from ethnic minoritised backgrounds (Belon et al., 2015; Franko, 2007). In support, Kanakam (2022) found that when working with females from minoritised ethnic backgrounds suffering from EDs, clinicians reported feeling restricted by existing guidelines that are not tailored to those from non-western backgrounds.

Commissioning groups acknowledge that efforts are needed to reduce low utilization of mental health services by ethnic minoritised patients (Joint Commissioning Panel for Mental Health, 2014). Such groups also recognize the need for services that are tailored to cultural and ethnic backgrounds of service users. Tailored services can be achieved through patient and public involvement (PPI), whereby people from minoritised ethnic backgrounds are involved with research and the design of services so that research and services are “carried out ‘with’ or ‘by’ members of the public” not just “‘to’, ‘about’ or ‘for’ them” (Involve, 2015).

Due to the potential impact of limited awareness, help seeking and low service uptake for ED’s and disordered eating on increasing health inequalities amongst those from minoritised ethnic communities, the aim of this paper is twofold. First to explore ED experiences of people from minoritised ethnic communities, and second, to identify and discuss support pathways for ED sufferers from minoritised ethnic communities. Healthcare providers, commissioners and ED therapists can use the findings shared here to inform their practice and the development of programmes and/or interventions to promote help seeking and treatment services.

Methods

Adults (≥18) from minoritised ethnic groups living in Bristol, UK, with direct or indirect lived experiences of EDs, were invited to take part in PPI group discussions or interviews. Recruitment was conducted via Twitter and WhatsApp, and was supported by Caafi health, a charitable organisation in Bristol that helps communities to get the health and care services they need.

The focus group discussions and interviews were carried out in January 2023 via MS Teams. Discussions lasted between 45 and 60 minutes. All discussions were conducted by the same qualitative interviewer, who has extensive experience of conducting similar research.

During the discussions and interviews, the participants were asked about their experiences of EDs, their ideas for changes and/or interventions required to overcome barriers to ED support and treatment within their communities. The participants were also asked about their views on a proposed research project. To support discussions, a question guide was developed (supplementary materials A). The question guide was discussed with members of the target communities during its development to ensure relevancy and understanding. Question wording was amended accordingly.

The discussions were audio recorded and later transcribed using MS Teams. Thematic analysis, informed by Braun and Clarke (2006), was conducted to identify themes and key concepts within the conversations. The process of analysis involved first reading through the transcripts and taking notes on potential codes. Next, the transcripts were reread, and codes identified. Codes were then grouped into themes, using the semi-structured interview questions as a guide for the development of the themes. Anonymised exemplar quotes were identified to support each theme.

Whilst ethical approval was not required for the PPI activity (PPI Ignite Network, 2023), all those that took part in group discussions and interviews were provided with information sheets about the purpose of the discussions, had the opportunity to ask questions before the discussions started, and were able to leave the group discussion or interview at any point without providing a reason. All those that took part also provided either written or audio consent before taking part. All participants were given £25 worth of online Asda vouchers after attending the group discussion or interview.

Results

Although both men and women were invited to take part in conversations, only women agreed to take part. Sixteen females (aged 18-42 years) from Somali, Indian, Bangladeshi and Caribbean communities took part in online focus groups or interviews. Three focus groups with between 2-5 people, and four interviews, each with one individual, were conducted.

Following transcription and analysis of the conversations, five themes were identified namely, food and community, conceptualisation of eating disorders, accessing eating disorder support, increasing awareness and reducing barriers to seeking support, and community led support. These themes and exemplar quotes are presented below and are also summarised in Table 2.

Theme 1: Food and community

All discussions started by exploring the perceptions of food within their families or communities. All participants agreed that food is critically important within their families and communities and in turn can make eating a stressful experience for those with concerns around their weight and/or body image.

> ‘So, everything really revolves around food. Specifically in Asian households, I mean that that's the case for a lot of cultures. Food is everything.’ - British Pakistani Female (30-35 years)

> ‘Within our family, people aren't that openly affectionate to each other, but you show you care because you offer food or you make food, you're providing the food’ – British Indian Female (40-45 years)

> ‘Eating has always been a big part of a family culture we. All get together, whenever anyone comes over, the one thing is just to feed and be fed.’ - British Pakistani Female (45-50 years)

Theme 2: Conceptualisation of eating disorders

Participants emphasised that those living in minoritised ethnic communities are exposed to the same media messaging as those from white/ western communities, and as such as aim for the same physical ideals. This, it was highlighted can lead to a viscous cycle of weight loss and disordered eating.

> ‘You just want to look good, but then all of a sudden it becomes an issue. Dipping into low BMI and stuff’. - British Pakistani Female (30-35 years)

> ‘Just because I'm ethnic and you're white doesn't mean that you don't want to be thin. We're all getting the same messages from media.’ - British Pakistani Female (30-35 years)

Compounding this, participants stated that weight loss and thinness are often perceived as positive amongst their families and communities. As a result, when individuals lose weight, they are praised. This, participants stated was in part due to the positive perceptions of thinness for increasing the likelihood of marriage, as well as the prevalence of overweight and obesity, the prominence of dieting within their communities. Moreover, they stated that GPs and other health practitioners were more likely to discuss health issues associated with overweight within their families and communities rather than underweight.

> There's like conditions and stuff like diabetes, heart problems that we’re more at risk of and really affect people. I know most people would overeat then under eat, but that still disordered eating. - British Pakistani female, 18-25 years

> People in our community and doctors, they tend to speak a lot about high blood pressure, diabetes, those sort of things seem to be the norm for like an Asian communities, but eating disorders and other things like that just aren't spoken about. - British Caribbean female

Cultural and religious celebrations can further exacerbate pressure around food and increase conversations and behaviours to promote weight loss.

> ‘We have Ramadan, fasting. That's coming up in March. That affects so many people. It is a religious thing, but people see it as an opportunity to lose weight because you're not eating all day, not until the evening. That's very triggering.’ - British Pakistani female, 18-25 years

Participants also discussed how the stressors of work, study and family can also impact people from minoritised ethnic communities and lead to disordered eating behaviours.

> ‘I got into this vicious cycle of binge eating, especially when I was studying, late evenings into the early, early hours and it wouldn't be until I got up the next morning and I look and see all these rappers and all these packets and I'll be like, did I actually eat all that in one sitting?’- British Caribbean female

Theme 3: Accessing support for EDs and disordered eating

Despite the participants stating that ED’s and disordered eating behaviours are prevalent within their communities, participants agreed that there is a general lack of conversation between individuals and family members about these conditions. As a result of this, individuals who struggle with ED’s or disordered eating feel unsupported, are unaware of the support that is available and do not know who they can speak to about their concerns.

> ‘I didn't really think there was anything. I thought it was just something really that I had to deal with myself. Because it's not like anorexia or bulimia or something. Those ones feel like they're more officially categorised and need that level of support and this other one, this little slot that I fit into, I just need to deal with it myself.’ – British Indian Female (40-45 years)

> ‘Even if the services are there, if they came in, you'd still have a majority of the population just not knowing. Oh, I didn't realise you could do that. I didn't realise I had a problem. I didn't realise I could get help’ – British Indian Female (40-45 years)

> ‘Disordered eating is not something we discuss in the community, between ourselves or in the family... Discussion is still not at the level that it should be, or the awareness is not that much’. - British Somali Female

Participants went on to state that compounding this lack of conversation are concerns around shame being brought on their families and worries about being stigmatised due to having a mental health condition. These concerns limit the likelihood of people seeking help for an ED or disordered eating condition. Such concerns were compounded by pressures to be thin to fit in with western ideals and to improve chances of marriage.

> ‘Specifically in minority cultures, is that mental health is just brushed away, not considered important. It's not just a conversation around disordered eating. It is an umbrella problem for all mental illnesses.’ - British Pakistani Female (30-35 years)
>
> ‘My cousin, a girl, I think it was the same as me. Like it was a lot of stigma in her family. And so she didn't seek support from it. She needed it really, really badly that she was such a traumatised child.’- British Pakistani Female (18-25 years)
>
> ‘I wish eating disorders weren’t so stigmatised as so many more people would have recovered... you fear something and so would never openly admit it because you're so shameful of it.’ - British Pakistani Female (18-25 years)

Theme 4: Increasing awareness and reducing barriers to seeking support

After considering the range of barriers to seeking help, participants discussed how to increase awareness of EDs and disordered eating within their communities. Increasing awareness of EDs and disordered eating and highlighting the possible seriousness of the conditions was mentioned as being of particular importance. Participants suggested that increasing access to information about ED’s in public places such as supermarkets and at worship centres could help.

> ‘Posters in a supermarket with a QR code maybe. you can scan it and get further information. Leaflets in the GP surgery, leaflets in mosque in churches. These spaces are used for other things, not just for one.’ - British Caribbean female
>
> ‘I think to be able to get the word across on a on a mass scale. I think places like mosques and churches and places of worship is where you could get all people,’ - British Bangladeshi female

However, it was highlighted that even with additional information and increased awareness, reducing barriers to seeking help is still an important consideration. One of the suggested ways to do this, several participants stated, was to increase the number of clinicians with lived experience both of ED’s but also of living within a minoritised ethnic community. This, they stated could help to improve trust and feelings of being understood.

> ‘Employ more staff, doctors, therapist that have actually had lived experience. Because if you have lived experience, you understand how complicated the situation is, how there's so many barriers to seeking help, and how, like messy it is. And it's not just a straightforward process’ - British Pakistani Female (18-25 years)

Theme 5: Community led support

One of the key suggestions for how to support people from minoritised ethnic communities who are experiencing an ED or struggling with disordered eating was being able to speak to someone who understands their culture and food related experiences. They went on to state that if this person was available regularly within their community, then going to them for advice or signposting would be less daunting.

> ‘Having a representative from each Community and you can just email or phone meet face to face and you know that person has the basic information and nutrition guidelines that would be good.’ - British Pakistani Female

> ‘I think some something in the community would be helpful because it would just be a maybe a little bit less daunting than going to a professional or just to be able to tell somebody that what you're doing and get advice’ - British Pakistani Female (30-35 years)

> ‘I think people maybe feel more understood when it's coming from your own community rather than something from like outside.’ - British Indian Female

Discussion

Seeking help for ED’s and disordered eating amongst people from minoritised ethnic communities is low. This impacts on health outcomes and overall wellbeing. As such, we carried out a series of PPI focus groups and interviews to explore barriers and discuss ideas to overcome them.

Participants stated that awareness of, and conversations about ED’s is limited within their communities, hampering help seeking behaviours. This supports previous research highlighting that people with ED’s often require family or friends to encourage them to access care (Evans et al., 2011).

Positive perceptions of thinness within families and communities also impeded help seeking for EDs and disordered eating. In support, Wales et al. (2017) reported that young females in South Asian families are considered better able to get married if thin in turn promoting thinness, whilst Channa et al. (2019), who conducted a case study of a young female of South Asian heritage suffering from an ED, noted that the individual was conscious about her weight from around the age of 16 and highlighted that thinness had been heavily discussed within her family, propelled by concerns around marriageability.

Lack of help seeking also stemmed from limited trust in clinicians, especially those without specific lived experience. Wales et al., (2017) noted that a lack of trust of clinicians offering mental health support limits help seeking behaviours. The authors noted that there is scepticism within minoritised ethnic communities of ‘talking therapies’.

Shame, taboo and stigma were also barriers stated to seeking help. Kanakam (2022) noted that stigma was a barrier to help seeking and recovery time for people from Asian backgrounds. Whilst Wales et al., (2017) reported that families feel shame about mental health conditions such as EDs, and as such turn a blind eye. The authors note that individuals often have the attitude of “just getting on with it” rather than actively seeking help. More recently, Goel et al., (2023) reported that mental health stigma, as well as social stigma i.e. the fear of ostracization, were important reasons for not seeking treatment for ED sufferers. Such findings suggest that education about the prevalence of mental health conditions, and the normalcy of needing help, could help to support more people with EDs to access treatment.

As well as identifying barriers, the present study sought to identify methods to improve access to ED support. Increasing awareness of EDs through easy to access information in community locations such as supermarkets, as well as increased access to trustworthy community members with lived experience of EDs were noted. In support, similar methods to improving help seeking were noted by Wales et al. (2017).

Although the sample size is relatively small, and was limited to participants from one English city, possibly limiting the findings beyond the UK context, it does provide insights into important barriers to consider when supporting people from minoritised ethnic communities to access help for ED’s and disordered eating. Further research could explore barriers within a wider population sample and/or include clinicians to consider their perspective on barriers to ED help-seeking among minoritised ethnic communities.

Recommendations

It is necessary to increase awareness of the racial inequities in the treatment and uptake of treatment for disordered and eating and eating disorders between those from White/ western backgrounds and those from marginalised ethnic communities amongst clinicians, researchers and mental health professionals. This could be done through early clinical training, regular continuing education workshops, and/or through online courses.

A lack of awareness of disordered eating and eating disorders amongst people from minoritised ethnic communities, especially those in older age groups, may contribute to a lack of treatment uptake, and may exacerbate social stigma and taboo surrounding mental illness. Educational campaigns and tailored information for communities is needed to raise awareness of these conditions, how they develop and what support is available for sufferers.

At present, diagnosis, support and treatment for those with eating disorders/ disordered eating is largely based on the experiences of people from white/ western backgrounds. To reduce health inequalities, and improve outcomes for people from minoritised ethnic communities, it is necessary to work with communities to develop programmes of support, as well as increase the inclusion of people from minoritised ethnic communities in eating disorder research.

Further research is needed to explore eating disorder perceptions, conceptualisations and treatment experiences amongst those from other minoritised ethnic communities to ensure that the barriers and opportunities to support, and prevention are well understood and can be fully considered in clinical practice and research.

Acknowledgements: The authors would like to thank all those that took part in PPI conversations and would like to acknowledge the support of Caafi health in recruiting a diverse range of participants for the conversations.

References

Beat (2023) Prevalence. (Online) Available from: https://www.beateatingdisorders.org.uk/about-beat/policy-work/policy-and-best-practice-reports/prevalence-in-the-uk/. [Accessed 10/01/24]

Belon KE, McLaughlin EA, Smith JE, Bryan AD, Witkiewitz K, Lash DN, et al. Testing the measurement invariance of the eating disorder inventory in nonclinical samples of Hispanic and Caucasian women. Int J Eat Disord. 2015;48:262–70.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative Research in Psychology, 3(2), 77-101. https://doi.org/10.1191/1478088706qp063oa

Burnette, C. B., Luzier, J. L., Weisenmuller, C. M., & Boutte, R. L. (2022). A systematic review of sociodemographic reporting and representation in eating disorder psychotherapy treatment trials in the United States. International Journal of Eating Disorders, 55(4), 423-454.

Carrino, E. A., Flatt, R. E., Pawar, P. S., Sanzari, C. M., Tregarthen, J. P., Argue, S., Thornton, L. M., Bulik, C. M., & Watson, H. J. (2023). Sociodemographic and clinical characteristics of treated and untreated adults with bulimia nervosa or binge-eating disorder recruited for a large-scale research study. Journal of eating disorders, 11(1), 126. https://doi.org/10.1186/s40337-023-00846-4

Channa, S., Lavis, A., Connor, C., Palmer, C., Leung, N., & Birchwood, M. (2019). Overlaps and Disjunctures: A Cultural Case Study of a British Indian Young Woman's Experiences of Bulimia Nervosa. Culture, medicine and psychiatry, 43(3), 361–386. https://doi.org/10.1007/s11013-019-09625-w

Chesney, E., Goodwin, G. M., & Fazel, S. (2014). Risks of all-cause and suicide mortality in mental disorders: A meta-review. World Psychiatry, 13(2), 153–160.

Clark, M. T. R., Manuel, J., Lacey, C., Pitama, S., Cunningham, R., & Jordan, J. (2023). Reimagining eating disorder spaces: a qualitative study exploring Māori experiences of accessing treatment for eating disorders in Aotearoa New Zealand. Journal of Eating Disorders, 11(1), 22.

Evans, E.J., Hay, P.H., Mond, J., Paxton, S.J., Quirk, F., Rodgers, B., Jhajj, A.K. and Sawoniewska, M.A. (2011), “Barriers to help-seeking in young women with eating disorders: a qualitative exploration in a longitudinal community survey”, Eating Disorders, Vol. 19 No. 3, pp. 270-85.

Franko DL. Race, ethnicity, and eating disorders: considerations for DSM-V. Int J Eat Disorder. 2007;40:S3.

Galmiche M, Déchelotte P, Lambert G, Tavolacci MP (2019) Prevalence of eating disorders over the 2000-2018 period: a systematic literature review. Am J Clin Nutr. 109(5), 1402-1413.

Gordon, K. H., Perez, M., & Joiner, T. E., Jr (2002). The impact of racial stereotypes on eating disorder recognition. The International journal of eating disorders, 32(2), 219–224. https://doi.org/10.1002/eat.10070

Gov.UK (2021) Writing about ethnicity (Online) Available at: https://www.ethnicity-facts-figures.service.gov.uk/style-guide/writing-about-ethnicity/ [Accessed 16/03/24]

Hart, L. M., Granillo, M. T., Jorm, A. F., & Paxton, S. J. (2011). Unmet need for treatment in the eating disorders: A systematic review of eating disorder specific treatment seeking among community cases. Clinical Psychology Review, 31(5), 727–735.

INVOLVE (2015) What is public involvement in research? (Online) Available from: http://www.invo.org.uk/find-out-more/what-is-public-involvement-in-research-2/. [Accessed 16/03/24]

Joint Commissioning Panel for Mental Health (2014). Guidance for commissioners of mental health services for people from black and minoritised ethnic communities.

Kanakam N. (2022). Therapists' Experiences of Working with Ethnic Minoritised Females with Eating Disorders: A Qualitative Study. Culture, medicine and psychiatry, 46(2), 414–434. https://doi.org/10.1007/s11013-021-09721-w

Lacey, C., Cunningham, R., Rijnberg, V., Manuel, J., Clark, M. T. R., Keelan, K., Pitama, S., Huria, T., Lawson, R., & Jordan, J. (2020). Eating disorders in New Zealand: Implications for Māori and health service delivery. The International journal of eating disorders, 53(12), 1974–1982. https://doi.org/10.1002/eat.23372

Le, L. K. D., Barendregt, J. J., Hay, P., & Mihalopoulos, C. (2017). Prevention of eating disorders: A systematic review and meta-analysis. Clinical psychology review, 53, 46-58.

Malson, H., Tischner, I., Herzig, H., Kitney, D., Phillips, C., Norweg, S., ... & Oldham-Cooper, R. (2022). Key stakeholder perspectives on primary care for young people with an eating disorder: A qualitative study. Journal of Community & Applied Social Psychology, 32(2), 288-301.

Moreno, R., Buckelew, S. M., Accurso, E. C., & Raymond-Flesch, M. (2023). Disparities in access to eating disorders treatment for publicly-insured youth and youth of color: a retrospective cohort study. Journal of Eating Disorders, 11(1), 10.

Neumark-Sztainer, D., Wall, M., Larson, N.I., Eisenberg, M.E. and 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, Vol. 111 No. 7, pp. 1004-11.

NHS (2021) Overview – eating disorders (Online) Available from: https://www.nhs.uk/mental-health/feelings-symptoms-behaviours/behaviours/eating-disorders/overview/ [Accessed 14/12/23]

PPI Ignite Network (2023) PPI Ignite Network statement on research ethics committee approval (Online) Available from: https://ppinetwork.ie/resource/ppi-ignite-network-statement-on-research-ethics-committee-approval/ [Accessed 16/03/24]

Rodgers, R. F. , Berry, R. , & Franko, D. L. (2018). Eating disorders in ethnic minorities: An update. Current Psychiatry Reports, 20, 90. 10.1007/s11920-018-0938-3

Samnaliev, M., Noh, H. L., Sonneville, K. R., & Austin, S. B. (2015). The economic burden of eating disorders and related mental health comorbidities: An exploratory analysis using the US Medical Expenditures Panel Survey. Preventive medicine reports, 2, 32-34.

Santomauro, D. F., Melen, S., Mitchison, D., Vos, T., Whiteford, H., & Ferrari, A. J. (2021). The hidden burden of eating disorders: an extension of estimates from the Global Burden of Disease Study 2019. The Lancet. Psychiatry, 8(4), 320–328. https://doi.org/10.1016/S2215-0366(21)00040-7.

Sinha S, Warfa N. (2013) Treatment of Eating Disorders Among Ethnic Minorities in Western Settings: A Systematic Review. Psychiatria Danubina. 25(2):295–299.

Solmi, F., Hatch, S. L., Hotopf, M., Treasure, J., & Micali, N. (2014). Prevalence and correlates of disordered eating in a general population sample: the South East London Community Health (SELCoH) study. Social psychiatry and psychiatric epidemiology, 49(8), 1335–1346. https://doi.org/10.1007/s00127-014-0822-3

Sonneville, K. R., & Lipson, S. K. (2018). Disparities in eating disorder diagnosis and treatment according to weight status, race/ethnicity, socioeconomic background, and sex among college students. The International journal of eating disorders, 51(6), 518–526. https://doi.org/10.1002/eat.22846.

Striegel-Moore RH, McMahon RP, Biro FM, Schreiber G, Crawford PB, & Voorhees C (2001). Exploring the relationship between timing of menarche and eating disorder symptoms in Black and white adolescent girls. International Journal of Eating Disorders, 30(4), 421–433.

Taylor JY, Caldwell CH, Baser RE, Faison N, & Jackson JS (2007). Prevalence of eating disorders among Blacks in the National Survey of American Life. International Journal of Eating Disorders, 40(S3), S10–S14.

Wales J, Brewin N, Raghavan R, Arcelus J. Exploring Barriers to South Asian Help-Seeking for Eating Disorders. Mental Health Review Journal. 2017;22(1):40–50. doi: 10.1108/MHRJ-09-2016-0017.

World Health Organization (2019) The ICD-11 Classification of Mental and Behavioural Disorders: Clinical Descriptions and Diagnostic Guidelines. Geneva: World Health Organization.

Table 1. Summary of barriers to accessing eating disorder treatment amongst those from minoritised ethnic backgrounds

Barrier	Description	Examples of people from minoritised ethnic groups impacted by this barrier
Research participants primarily white so treatment not culturally appropriate	People from minoritised ethnic backgrounds are less likely to be recruited, assessed, and retained in ED research.	Several minoritised ethnic groups - Burnette et al. 2022; - Goel et al., 2022
Poor fit of diagnostic criteria	Current diagnostic criteria and assessment tools for EDs are largely based on the experiences and presentations of those from white, western nations.	Several minoritised ethnic groups - Kanakam, 2022 Māori - Clark et al., 2023
Perceptions of thinness	Weight loss is regarded positively due to the high prevalence of overweight and obesity. There is also a positive association with thinness related to the pressure for females to be thin to get married. Not feeling 'good enough'	South Asian - Wales et al., 2017
Lack of clinicians from minoritised ethnic backgrounds	Not having clinicians from the same ethnic background can make it harder for people to seek support for EDs. Lack of bilingual clinical support.	Several minoritised ethnic groups Latino, Black - Moreno et al, 2023 South Asian - Goel et al., 2023
Lack of awareness of eating disorders and their treatment	A lack of knowledge of EDs and their potential seriousness acts as a barrier to seeking support and treatment. This is particularly apparent amongst older members.	South Asian - Wales et al., 2017 - Goel et al., 2023

	EDs not considered as serious as other health conditions. Not knowing where to go for support, and not knowing what support is available.	
Lack of trust in clinicians	Skepticism within the community of those offering ‘talking therapies.’ Families try to help sufferers rather than getting professional support. Also concerns that the healthcare provider may share the diagnosis with others, especially if they are within the same community.	South Asian - Wales et al., 2017
Shame, taboo, and stigma	Shame felt by individuals with EDs and their families impacts on seeking support. Families shame can lead to them turning a blind eye. EDs are considered taboo amongst families. Diagnosis could result in exclusion from society, blame, and permanent scars. Stigma – both mental health conditions, and socially, are important barriers to seeking ED support. People are worried about being ‘labelled.’	Several minoritised ethnic groups - Kanakam, 2022 South Asian - Wales et al., 2017 - Goel et al., 2023
Predisposition of physical causes	ED patients from ethnic minoritised backgrounds avoid talking about their mental health, instead preferring to refer to physical health. People in the South Asian community look for physical causes, such as a ‘thyroid disorder,’ to explain the weight changes seen in EDs.	Several minoritised ethnic groups - Kanakam, 2022 South Asian - Wales et al., 2017

Table 2. Themes and exemplar quotes from PPI conversations with people from minoritised ethnic communities living in Bristol, UK

Theme	**Example quotes**
Food and community	So, everything really revolves around food. Specifically in Asian households, I mean that that's the case for a lot of cultures. Food is everything. - British Pakistani Female (30-35 years) Within our family, people aren't that openly affectionate to each other, but you show you care because you offer food or you make food, you're providing the food – British Indian Female (40-45 years) Eating has always been a big part of a family culture we. All get together, whenever anyone comes over, the one thing is just to feed and be fed. - British Pakistani Female (45-50 years)
Conceptualisation of eating disorders	I've always got it in the back of my head I'm very worried about gaining weight. It's always been a thing for me and I think as I've got older, you notice it more, so I'm not completely relaxed about food. I feel like I have to think too much. - Female, Indian heritage (30-40 years) You just want to look good, but then all of a sudden it becomes an issue. Dipping into low BMI and stuff. - British Pakistani Female (30-35 years) Just because I'm ethnic and you're white doesn't mean that you don't want to be thin. We're all getting the same messages from media. - British Pakistani Female (30-35 years) There's like conditions and stuff like diabetes, heart problems that we're more at risk of and really affect people. I know most people would overeat then under eat, but that still disordered eating. - British Pakistani female, 18-25 years People in our community and doctors, they tend to speak a lot about high blood pressure, diabetes, those sort of things seem to be the norm for like an Asian communities, but eating disorders and other things like that just aren't spoken about. - British Caribbean female
Accessing eating disorder support	Specifically in minority cultures, is that mental health is just brushed away, not considered important. It's not just a conversation around disordered eating. It is an umbrella problem for all mental illnesses. - British Pakistani Female (30-35 years) My cousin, a girl, I think it was the same as me. Like it was a lot of stigma in her family. And so she didn't seek support from it. She needed it really, really badly that she was such a traumatised child. - British Pakistani Female (18-25 years)

	I wish eating disorders weren't so stigmatised as so many more people would have recovered... you fear something and so would never openly admit it because you're so shameful of it. - British Pakistani Female (18-25 years) I didn't really think there was anything. I thought it was just something really that I had to deal with myself. Because it's not like anorexia or bulimia or something. Those ones feel like they're more officially categorised and need that level of support and this other one, this little slot that I fit into, I just need to deal with it myself. – British Indian Female (40-45 years) Even if the services are there, if they came in, you'd still have a majority of the population just not knowing. Oh, I didn't realise you could do that. I didn't realise I had a problem. I didn't realise I could get help – British Indian Female (40-45 years) Disordered eating is not something we discuss in the community, between ourselves or in the family... Discussion is still not at the level that it should be, or the awareness is not that much. - British Somali Female
Increasing awareness and reducing barriers to seeking support	Employ more staff, doctors, therapist that have actually had lived experience. Because if you have lived experience, you understand how complicated the situation is, how there's so many barriers to seeking help, and how, like messy it is. And it's not just a straightforward process - British Pakistani Female (18-25 years) Posters in a supermarket with a QR code maybe. you can scan it and get further information. Leaflets in the GP surgery, leaflets in mosque in churches. These spaces are used for other things, not just for one. - British Caribbean female I think to be able to get the word across on a on a mass scale. I think places like mosques and churches and places of worship is where you could get all people, - British Bangladeshi female
Community led support	Having a representative from each Community and you can just email or phone meet face to face and you know that person has the basic information and nutrition guidelines that would be good. - British Pakistani Female I think some something in the community would be helpful because it would just be a maybe a little bit less daunting than going to a professional or just to be able to tell somebody that what you're doing and get advice - British Pakistani Female (30-35 years) I think people maybe feel more understood when it's coming from your own community rather than something from like outside. - British Indian Female

Supplementary materials A.

Question guide for interviews and focus groups

Information before starting:

- Thank you for agreeing to take part in this conversation.
- You will be compensated for your time at a rate of £25/ hour. This will be in the form of ASDA vouchers. Please give us your email address, and these will be emailed out to you after our meeting.
- You are free to leave at any time, without giving a reason. Please tell me in the chat function if you are leaving.
- We will be audio recording the conversation so that we can listen back and take notes on what we discuss.
- No video will be saved, and we will not be able to identify you individually from the recording.
- We will not record any personally identifiable information.
- Do you have any questions at this point?

Questions

We are planning to undertake a research project to develop information and resources or similar, to better support people from underrepresented ethnic communities to seek and access support, if they need it. Before undertaking this work, we need to understand more about you. This is so we can better understand the experiences and perceptions of the group you represent.

Community

1. How would you describe your ethnicity? For example, Bangladeshi, Pakistani etc.
2. What age group are you in? 18 to 25, 26 to 35, 36 to 45, 46 to 55, 56 or over
3. What is your gender?

Food in general

1. What role does food have in your family / religion / community? (A healthy relationship includes relaxed eating, choosing the items that you like, and practicing balance and flexibility in your eating.)
2. Would you describe your current relationship with food as being healthy?
3. If not, why do you feel that it is not a healthy relationship?

4. Has your relationship with food changed at any point, if so how and what caused that change?
    a. Prompts: Work? Family? Concerns about body image? Health?
5. Do you, or anyone you know have a difficult relationship with food?
    a. Prompts: For example... using food to manage stress or emotions?
6. We call difficult relationships with food disordered eating. Are you aware of the term disordered eating?
7. Disordered eating is a term used to describe eating behaviors that may negatively affect someone's physical, mental, or emotional health but that do not qualify or fulfil the criteria for an eating disorder. For example, avoiding certain foods or food groups. What words or phrases do you use to talk about food and disordered eating, if any?
8. What factors do you think may increase the risk of you, or those within your community, from developing disordered eating behaviours or a negative relationship with food?
    a. Prompts: Family expectations? Personal expectations? Low self-esteem?
9. What could help with this, in your view?

We would like to know more about how eating disorders and/or disordered eating are experienced by people from underrepresented ethnic communities in the UK.

Conceptualization

1. What do you understand by the term eating disorder? (An eating disorder is a mental health condition where food is used to cope with feelings and other situations. Unhealthy eating behaviours related to eating disorders may include eating too much or too little, worrying about your weight or body shape, or doing things such as excessive exercise or purging before or after eating.)
2. Do you or your friends/ family use another term or concept to describe eating disorders?

Accessing support

1. Have you been diagnosed with an eating disorder?

IF YES...

2. Did you refer yourself to support or did someone else? If someone else, who?
3. What was your experience of getting an eating disorder diagnosis?
    a. Prompt: Take a long time? Have to see multiple clinicians? Not feel listened to?
4. Did you seek further specialized support for your eating disorder? If yes, where did you seek support from?

5. Did you feel like you were listened to?
6. Did you feel that the support was appropriate?
7. What could have been better?

IF NO...

8. Where would you go to access support if you were concerned you had an eating disorder or were concerned about your relationship with food?
9. Prompt: Friends or family? GP? Community worker? School/ university staff?
10. Would you go to your GP/ doctor if you thought you, or a family member had an eating disorder? If not, why not? And where would you go instead?
11. Have you, or someone you know, experienced any challenges in getting specialist support for an eating disorder, or concerns about relationship with food, when that support was needed?
12. If so, what challenges were they?
13. If not, what challenges do you think might be experienced?

Information seeking

1. Have you ever been provided with information on eating disorders or disordered eating? If so, who provided the information?
    a. Prompt: School? Work?
2. What was it?
    a. Prompt: Leaflet? Website link? A talk?
3. Where would you go to get information about mental health conditions such as eating disorders?
    a. Prompt: Talking to friends or family? From TV? From a book/ magazine? Somewhere else?
4. What do you think could help you to gain more knowledge about eating disorders?
    a. Prompt: An information session at a community centre? A programme about eating disorders? An information leaflet? Something else?

The project

We are planning to undertake a research project to explore experiences of eating disorders amongst those from underrepresented ethnic communities. As part of this work, we hope to understand 1) how people think and talk about issues with food or eating, 2) where people from within such communities go to seek help, and 3) what is needed to better meet the needs of people from these communities. An important part of this work is to increase awareness of eating disorders amongst communities. One way we could do this would be to 1) support people to become community champions. These champions, who would sit as part of their community, would share knowledge about eating disorders and help others to know where to seek help.

1. Do you think that a community champion programme could help to raise awareness of eating disorders within your community?
    a. If so, why?
    b. If not, why not?
2. What other approaches do you think could be used to increase awareness of eating disorders in your community?
    a. Prompt: Videos? Online course?

We are also keen to increase the distribution and downloading of a self-help eating disorder app amongst those from a range of underrepresented ethnic backgrounds to increase awareness of eating disorders and improve access to early support services.

1. Do you think a self-help app would be helpful in increasing awareness of eating disorders in your community?
    a. If yes, why?
    b. If no, why not?

We are also thinking about developing a peer-to-peer clinician training scheme where doctors share their knowledge with each other. We hope that this will help health professionals to learn how to identify an eating disorder in people from different ethnic backgrounds, when to refer people on for further support, and what support could be provided in the first instance.

2. What do you think should be part of this training to help clinicians better meet the needs of people from within underrepresented ethnic communities with eating disorders or difficult relationships with food?
    a. Prompt: First person experiences? Descriptions of eating disorder symptoms in different communities? Cultural factors related to food?
3. Do you have any other ideas about how to make our services more attractive and helpful for people from your community who struggle with food or eating?
    a. Prompt: Outreach / psycho-ed for wider community / elders? Education / training from the community to educate health professionals about food/eating practices? A ‘train the trainer’ model of community leader training to enhance ED literacy (awareness, identification and signposting) at ground level? Anything else?