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Help-seeking and accessing treatment for eating disorders: a systematic review of qualitative studies with a focus on ethnic differences

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PLAIN ENGLISH SUMMARY

Eating disorders (ED) are serious mental health conditions that can be life-threatening. However, few people seek help for these conditions, and this problem is even worse among ethnic minority groups - even though they experience eating disorders at similar rates to white populations. This paper reviewed previous research to identify what stops and helps people from getting treatment for eating disorders in the UK. The review paid special attention to whether ethnic minorities face different challenges.

14 studies were examined, only 2 focused specifically on ethnic minority experiences. The common barriers that prevent people from accessing care are: strict guidelines that exclude people from treatment, bad experiences with healthcare professionals, difficulty recognising their symptoms, trouble finding about available services, and lack of support from family and friends. What helped people access care included: better education about ED, easier-to-understand information about symptoms, easy to access healthcare services, and supportive communities. The studies exploring the experiences of people of South Asian heritage revealed barriers specific to their communities including concerns about doctor-patient confidentiality, and pressures linked to marriage and beauty standards. These studies also suggested that raising awareness about eating disorders through culturally familiar channels could help more people seek treatment.

ABSTRACT

Background: Eating disorders (ED) are serious mental health conditions characterised by disordered eating behaviour and associated emotional distress. EDs are associated with high rates of mortality and morbidity, yet rates of help-seeking remain low. There is a misconception that EDs only affect “skinny, white, affluent girls” (SWAG) although anyone can be affected. Likewise, despite similar rates in minoritised ethnic communities, studies suggest that help-seeking from these populations remain low. The aim of this review was to identify key barriers and facilitators to accessing ED treatment in the United Kingdom (UK) and explore whether experiences vary by ethnicity.

Subjects and Methods: A systematic review of qualitative and mixed methods studies was conducted following PRISMA guidelines. PsycINFO, Embase, Medline and CINAHL databases were searched for relevant studies published since 2013. Two independent reviewers screened titles/abstracts and reviewed full texts. Eligible articles were coded in NVivo to generate themes following Braun and Clarke’s thematic analysis framework.

Results: Out of 14 included studies, two focused exclusively on experiences of minoritised ethnic individuals. Across the studies, commonly shared barriers to accessing care included rigid ED guidelines, negative healthcare professional experiences, difficulty in self-recognising ED, low accessibility and awareness of services, and negative social relationships. Reported facilitators included improving education and recognition of EDs, informed and accessible delivery of care, and supportive communities. Two studies with participants of South Asian heritage highlighted additional barriers, such as concerns about doctor-patient confidentiality, and marriage-related pressures linked to beauty standards. Unique facilitators included suggestions for raising awareness of eating disorders through culturally relevant platforms.

Conclusion: A more holistic approach is required from services and guidelines to tackle stigma associated with EDs and make services more accessible. There is a lack of primary research focusing on minoritised ethnic communities, and further research is required.

Key words: eating disorders, ethnicity, help-seeking, service use, barriers & facilitators

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INTRODUCTION

Eating disorders (ED) are serious mental health conditions characterised by disordered eating behaviour and associated psychological distress (American Psychological Association, n.d.). EDs include anorexia nervosa (AN), bulimia nervosa, binge eating disorder, and other atypical eating disorders and are associated with high morbidity and mortality rates (NICE, 2024). Despite this, help-seeking and treatment access remain low (1); only 17-31% of individuals that meet a diagnostic screening criteria for an ED seek treatment (2).

EDs can affect anyone irrespective of age, gender, ethnicity and background (3). However, a common misconception is that EDs are conditions of “skinny, white, affluent girls” (SWAG) (4). This misconception can have significant clinical implications. Large-scale studies have reported no meaningful differences in prevalence between ethnic groups (5). In some cases, rates of specific ED types, notably bulimia, are even higher among minoritised ethnic populations (5,6,7). Yet, referrals for ED treatment in specialist eating disorder services remain disproportionately low in these communities (8).

Most research into ethnic variation in access to ED treatment has been conducted in the US; however, some UK-based studies have highlighted differences in access (9). For example, et al. (10) found that South Asian women in Leicester received only one third of the expected referrals; among women aged 16-34, those of Asian ethnicity constituted only 4.5% of the total female referrals despite comprising 13.8% of the female population in Leicester. Similarly, Waller et al (11) reported substantially lower referral rates for the ethnic minority groups in a South London catchment area relative to their population prevalence.

Several factors contribute to this inequity. The SWAG stereotype may delay recognition of symptoms among both patients and clinicians. Waller et al. (11) noted that clinicians may avoid food-related discussions with minoritised ethnic patients due to assumptions that EDs predominantly affect White individuals. Other barriers include confidentiality concerns in doctor-patient relationships, stigma, and cultural factors such as living in multigenerational households (12, 13).

Although systematic reviews of barriers and facilitators to ED treatment access exist (8, 14, 15), none have been recently updated and few have focused specifically on ethnic differences in help-seeking experiences.

Consequently, the present systematic review explored perceived barriers and facilitators to ED help-seeking in the UK, drawing exclusively on qualitative studies, with particular attention to ethnic differences. It aimed to examine socio-cultural influences on help-seeking and treatment access across both majority White and minoritised ethnic communities. Specifically, it aimed to address:

1. What are the barriers and facilitators to accessing ED treatment in the general UK population?
2. How do the experiences of people from minoritised ethnic backgrounds differ from those of the majority White population?

SUBJECTS AND METHODS

This systematic literature review followed Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines (16) and used a thematic approach to synthesise qualitative findings. Pre-registration was not undertaken given the time constraints of an undergraduate medical research project. For the purposes of this review, individuals of minoritised ethnic backgrounds in the UK are defined as those who do not identify as White British or Irish.

Information sources, search strategy and selection process

A systematic search was conducted to identify relevant studies. PsycINFO, Medline, Embase, and CINAHL were searched on 23rd October 2024 with an updated search conducted on 9th June 2025. Google scholar and the university library system were also searched. Search terms were collated with the guidance of an academic librarian (Table 1). Boolean operators (AND, OR and NOT) were used between search terms to widen searches based on synonymous terms and limit searches when two or more separate themes were required for extraction. An advanced UK filter developed by NICE data science researchers was used for PsycINFO, Medline and Embase to address variations in UK geographical representation across these databases (no equivalent filter was available for CINAHL) (17). The search was limited to studies published since January 2013 to capture new evidence since the review by Sinha & Warfa (8).

Table 1. Search terms used for screening on databases

Search Terms
• (eating disorder*) OR (feeding disorder*) OR (anorexia nervosa) OR (bulimia nervosa) OR (binge eating disorder*) • AND (experience*) OR (view*) OR (perception*) OR (attitude*) OR (opinion*) OR (interview*) OR (qualitative) OR (interview*) OR (thematic analysis) OR (narrative) • AND (access*) OR (help-seeking*) OR (barrier*) • AND (patient) OR (service user) OR (carer*) OR (caregiver*) OR (parent*) OR (family*) • AND adapted UK filters for each database developed by data science researchers at NICE

Abbreviations: NICE: National Institute for Health and Care Excellence; UK: United Kingdom.

Articles from the initial search were imported into EndNote to remove duplicates, then into Rayyan systematic review platform for eligibility screening based on inclusion and exclusion criteria (Table 2). Two reviewers (MC, MD) independently screened titles and abstracts, and reviewed the full text of identified papers, resolving discrepancies through discussion.

Table 2. Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Primary data	Systematic review; study does not contain primary data
Study containing data on help-seeking processes and experiences of accessing treatment	Study not discussing access to support e.g. risk factors of ED, treatment efficacy
Study participants are of any age	N/A
Study participants are of any ethnicity	N/A
Views of service users, parents, carers, members of public	Views of healthcare professionals
All types of eating disorders	Mental health conditions; if data on ED in context of other mental health conditions is not extractable
Study within the UK	Study outside of the UK
Study published within January 2013 - 9 th June 2025	Study published outside January 2013 - 9 th June 2025
Qualitative and mixed-methods (if qualitative data extractable) study	Non-qualitative study
Written in English	Not written in English

Abbreviations: ED: Eating Disorder; UK: United Kingdom.

Quality assessment, data extraction and analysis

Critical appraisal of the quality of the included papers was conducted using the JBI tool (18).

A data extraction template was created in Microsoft Excel, and two reviewers independently extracted data under the following categories: author, year of publication, country of origin, participant size and characteristics, study design, study aim, study outcomes such as barriers

and facilitators of ED treatment access. Data extraction results were compared for consistency.

Thematic analysis was conducted following Braun & Clarke's (19) six step guide, enabling systematic identification of patterns and concepts across the included studies. Although Thomas and Harden's (20) thematic synthesis was developed specifically for synthesising qualitative findings across studies, Braun and Clarke's framework was selected here due to its methodological flexibility and suitability for mapping and synthesising experiential data without the primary aim of generating new theoretical constructs. Full text articles were imported into NVivo for coding and theme generation in relation to the research questions. Two reviewers independently coded all articles and the final coding framework was derived through a collaborative discussions and consensus. Where a theme appeared across multiple contexts (e.g. stigma), it was examined separately within each setting rather than consolidated, in order to reflect meaningful differences in its expression and to enable more targeted recommendations.

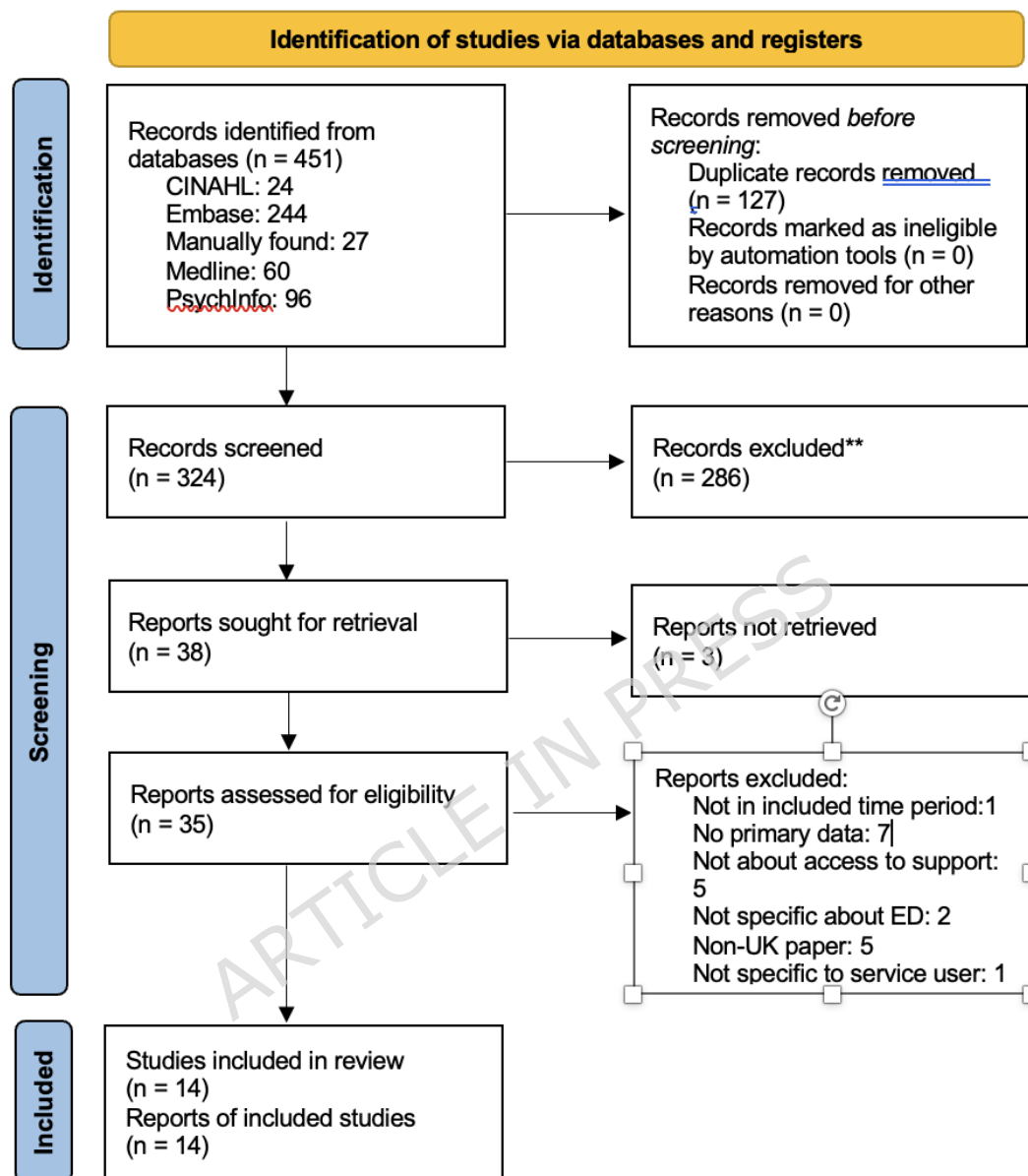
RESULTS

Characteristics of Included Studies

Figure 1 presents the PRISMA flow diagram illustrating the search process (16). Of the 451 papers screened, 14 met the inclusion criteria and were included in this review. All 14 articles satisfied the standards set by the appraisal tool (Table 3).

Figure 1. PRISMA 2020 Flowchart

Abbreviations: ED: Eating Disorder; UK: United Kingdom.



[Insert Table 3 here]

Table 4 summarises the characteristics and findings of the included studies (n=14), 13 of which were qualitative and one mixed-methods (21). Participants included self-identified or clinician-diagnosed service users, parents, carers, and community members, the sample sizes ranging from 4 to 1704. The study by Bye et al. (22) included service users who were pregnant or postnatal women. The reported age range was from under 10 to over 65 years old

– this encompassing the ages of participants with eating disorders who were interviewed as well as the age of patients whose carers or parents were interviewed. Data collection methods included semi-structured interviews, focus groups, online chatrooms, surveys, and workshops.

At least 70% of participants in each study identified as women or female. Two studies focused exclusively on individuals of minoritised ethnic background, one including UK-born and UK-based South Asian participants (Asian/British Asian Indian, Pakistani, or Bangladeshi) (12), and the other featuring a UK-born Indian participant (23). Six studies included people of both White and minoritised ethnic backgrounds. Three studies included only White British/Irish participants, and three studies did not report participant ethnicities. None of the mixed-ethnicity study findings were reported by ethnicity.

In total, five barrier themes and three facilitator themes were identified, each with associated subthemes. The identified themes reflect patterns that emerged across the majority of included studies and pertain to general ED help-seeking. Barriers specific to pregnancy and the postpartum period, reported by Bye et al. (22), are listed in Table 4 but are not discussed further in this review. Participant quotes drawn from the included papers are referenced as Q(*number*) in Tables 5 and 6.

[Insert Table 4 here]

Barrier Themes

Rigid ED Guidelines

Not ill Enough. Service users reported being dismissed by HCPs due to their weight being "not low enough" (Q1) (24, 25, 26, 27, 28). One individual with over 10 years of living with anorexia nervosa was denied support for this reason (24).

Non-individualised care. Participants identified that the rigidity of a "one-size-fits-all" approach posed a significant barrier to care (24), where factors such as high staff turnover impeded the development of trusting relationships, thereby neglecting the individual needs of patients. For example, one participant with ED refused inpatient treatment as it was unfeasible to her caregiving responsibilities as a mother (Q2) (29). Expanding on this, South Asian participants highlighted that a one-size-fits-all model assumes individuals can communicate mental health problems clearly and directly (12). One clinician further observed that South Asian service users can initially present with physical symptoms of mental health conditions, suggesting that a lack of culturally and linguistically appropriate framework can obscure eating-related distress.

Negative HCP encounters

GP stigma and lack of knowledge were commonly cited barriers to treatment access. Service users reported negative experiences, describing GP comments as "dismissive", "triggering" (27, 30), and "insensitive" (31). One GP dismissed clear signs of an ED, attributing parental concerns as overprotection while accepting the patient's denial (Q3) (25).

Difficulty in Self-Recognising ED

Perceptions of Beauty. Beauty standards hindered help-seeking and encouraged diet cultures (12, 23). South Asian participants discussed marriageability as a pressure in maintaining these beauty standards (Q4).

Self-stigma. Some service users felt undeserving of support, a sentiment intensified during COVID-19 when one participant felt it came "at the expense of others" (28, 31). This sense of unworthiness was echoed by a mother with ED, who believed societal expectations of maternal selflessness to be a barrier to seeking help (29) (Q5).

Service Resources

Low awareness of available services. Participants highlighted difficulties finding appropriate services. A student reported having to conduct extensive searches due to limited advertisement and ED-related health information at universities (31).

Poor Service Accessibility. University students faced challenges accessing support due to restrictions on dual GP registrations at home and at university (31). Post-pandemic hybrid treatment formats (online and in-person) were hindered by digital illiteracy, lack of internet access, and privacy or safe home environments (21).

Social Relationships

Stigma from Community. Some parents felt "embarrassed" discussing their child's ED diagnosis. One South Asian participant cited mental health stigma as a barrier to ED disclosure, creating a "circle of secrecy" due to fears of negative family impact (12). Fear of compromised confidentiality was also reported within the South Asian community (Q8) (12).

Lack of Family Support. One service user suggested that having a supportive family might have encouraged her to seek help earlier (Q9) (23). Similarly, parents and carers described their denial of the ED diagnosis experienced by their loved ones to be a barrier to early help-

seeking (32). Social isolation, such as living alone, having a smaller social network, or during the COVID-19 lockdown, further obscured harmful eating behaviours, delaying opportunities to accept and confront the dangers of disordered eating (28).

[Insert Table 5 here]

Facilitator Themes

Spotting ED at the blink of an eye

Improving ED understanding and recognition. Service users and their parents suggested methods to improve ED understanding and recognition, such as blogs written by service users with lived experience, artistic representations, ED education in schools, and improving internet resources (12, 24, 32). Some parents found the internet particularly helpful (32). Members of the South Asian community suggested featuring ED case studies into soap operas, radio programmes, and community spaces (12).

Service providers making the first move. Some service users, families, carers, and partners reported always making “the first move in every direction” (26). One university student suggested regular screening to identify individuals who may not seek support themselves (Q11) (31).

Delivery of Care

Accessible services. University students with ED experience suggested to improve the visibility of ED services and information on campus (31). Service users commented that hybrid treatment formats offered flexibility, reduced travel time, and provided recorded resources for missed sessions (20, 31).

Care Informed by Lived Experiences. Several HCPs with personal histories of AN suggested that training informed by people with lived experiences could prevent substandard and “offensive” care (30). Parents echoed this sentiment describing HCPs with “hands-on experience of eating disorders” as “invaluable” for care delivery (26).

Supportive People Around You

Healthcare professionals. Positive initial encounters with HCPs such as GPs and therapists were reported to encourage help-seeking (24, 25, 26, 30, 31). University students living with ED emphasised that such interactions could motivate first-time help seekers as well as supporting relapses (31).

Supportive Family. Families were described as playing a central role in facilitating access to services. One parent of a 16-year old service user described their own repeated attempts to self-manage her child’s disordered eating behaviours through methods such as verbal confrontation or implementing reward systems. When these methods proved unsuccessful, families reported that this often became the point at which professional support was sought (32). Environmental changes, such as family holidays, were also described as important moments for recognising difficulties due to more time together at meals. This provided opportunities for a parent to notice concerning behaviours and to initiate contact with services (32).

Partners. One South Asian individual with ED discussed the pivotal role her partner played in encouraging help-seeking (23). She felt comfortable confiding in her partner, whose understanding of AN, gained through a family member's experience, provided empathy and support, helping her feel less isolated (Q16).

Peer support and solidarity. Some service users with over ten years' experience of living with ED commented on the power of "camaraderie" and solidarity when building a supportive community in case the system fails you (24). This positive impact was contrasted by findings suggesting that even well-meaning family members and loved ones could not fully understand participants' struggles due to the absence of lived experience, thereby limiting the support they could provide (26).

[Insert Table 6 here]

DISCUSSION

This systematic review examined barriers and facilitators to accessing ED services in the UK, with particular attention to ethnic differences in help-seeking experiences. By applying a dual lens, the review sought to identify both shared challenges and facilitators, as well as factors uniquely affecting minoritised ethnic communities. However, only two out of 14 studies focused solely on the experiences of minoritised ethnic individuals, specifically South Asian participants (12, 23), and six studies with participants of diverse ethnic backgrounds did not report findings according to ethnicity. The absence of such data precluded us from addressing our second research question, which in itself constitutes a finding, reflecting a notable gap in the existing literature.

In most studies, stigma and lack of education emerged as overarching barriers to help-seeking and access to services; whether originating from HCPs, the patient's own understanding of their ED, or concerns about potential changes to social standing within the wider community. When coupled with clinical guidelines that fail to account for the heterogeneity of ED

experiences, these factors often leave individuals feeling confused, misunderstood or ignored in the early stages of illness. Consequently, help-seeking for ED often takes place at later stages when the condition has worsened (33). This may be particularly relevant for minoritised ethnic individuals, as identified recently by healthcare professionals in the West Midlands, UK (9). In a review examining disparities in mental healthcare of ethnic minority patients across Western countries, Lepièce et al (34) noted a failure in services' adaptability to ethnic minorities' varying needs and presentations. In a study examining caregiver experiences, results showed that 47.8% of participants knew how to access services, and only 40.4% felt that their loved one was assessed as soon as necessary (35).

However, this review also highlights that supportive services and relationships, alongside increased awareness and education around EDs, can encourage help-seeking and improve initial treatment experiences. An Australian survey of 439 parents with children experiencing EDs identified the symbiotic nature of receiving and giving support: parents who felt educated and supported by HCPs reported feeling better able to encourage help-seeking for their children, establishing a better prognosis for them (36). Similarly, a UK-based survey of 360 adults caring for a loved one with an ED found that those caring for children felt more confident in managing their loved one's symptoms compared to those caring for adults (35). While this is reflective of child and adult discrepancies generally in healthcare service, it suggests that ED treatment for adults could also benefit from more carer involvement when appropriate.

The importance of family relationships became especially evident during the COVID-19 pandemic. In this review, Brown et al. (28) reported that those with negative family or social relationships found a worsening of their ED symptoms, causing a delay in help-seeking. This

sentiment is supported by an Italian study which used the McMaster Family Assessment Device and the Binge Eating Scale to quantify and demonstrate the direct correlation between dysfunctional family relations and dysfunctional eating habits during the pandemic (37). The negative close relationships combined with social isolation meant a greater reduction in problem solving behaviour and information exchange between family members, contributing to less help-seeking.

Both studies centred on South Asian communities identified overarching themes consistent with those found across the broader review. Channa et al. (23) identified lack of family support, limited understanding of EDs and rigid diagnostic guidelines as key barriers, while Wales et al. (12) similarly found poor understanding of EDs and limited family support to be key barriers. Nevertheless, although the findings of both Channa et al (23) and Wales et al. (12) reflect the wider review themes, they were specific to South Asian culture. For example, Wales et al. referred to a lack of family support and education stemming from the belief that thinner appearances enhance marriageability, while Channa et al. (23) attributed fears of losing face in the community as a cause of reduced family support. Both studies highlight the importance of reputation in the wider community and its effect on immediate family relations, which in turn impacts patients with ED. While this is not unique to South Asian culture, it is particularly salient within it, making it essential to consider when exploring help-seeking among South Asian communities. An audit found that among early intervention psychiatric patients, South Asians were more likely to miss appointments and refuse medication (38). The authors theorised that a lack of understanding of family dynamics within services, as well as mental health stigma in the community, contributed to these outcomes - barriers consistent with those identified in this review. In a study exploring the Sikh community's understanding of psychosis and its impact on help-seeking in the UK,

Kular et al. (39) found that stigma was evident, particularly in relation to taking medication and a cultural tendency to keep mental illness within the immediate family.

While grouping ethnicities together may obscure diverse and nuanced experiences, evidence reveals similar experiences between different minoritised ethnic groups regarding healthcare in the UK. A meta-ethnography on healthcare inequalities across 14 ethnic groups found that participants experience a “monocultural Eurocentric” delivery of treatment (40). This suggests that by not belonging to the dominant “monoculture”, minoritised ethnic individuals share some form of a collective experience. However, we were unable to identify this due to lack of studies focusing on minoritised ethnic individuals.

Discussions of community stigma are often framed as an isolated problem within a single ethnic group. However, there has been less exploration of dialogue across different minoritised ethnic communities, or of their integration within the broader White British community. For example, a study looking at help-seeking for mental health problems in minoritised ethnic communities (41) drew on Howard Becker’s labelling theory (42) to explain hegemonic dialogues between groups. Becker argued that dominant social groups assign labels to other populations, and once a group is labelled as “deviant”, that label comes to define how they are seen by others. Such processes risk compounding the difficulties faced by both individuals with EDs and members of minoritised ethnic communities.

Scholars have highlighted how longstanding colonial practices continue to shape ethnic collective psyches today. This often manifests as a heightened sense of shame and ongoing postcolonial struggles linked to systemic racism (43, 44, 45). A US review found that Black individuals reported the most negative experiences in accessing ED treatment among

minoritised ethnic groups (46). This illustrates the nuanced ways in which systemic racism operates and underscores that, while exploring collective minority experiences is invaluable, they should not be oversimplified (4).

Equally, one should not assume that individuals from the same ethnic group share identical experiences. This seems to be particularly salient when considering generational differences within minoritised ethnic communities. While some studies report higher ED prevalence among second generation immigrants compared with first generation immigrants (47), other evidence suggests that acculturation is not always linear. For example, in the case study by Channa et al. (23), the service user's sister demonstrated similar stigmatising attitudes to those of the parents' generation. Moreover, acculturation to a Western culture does not necessarily facilitate recognition of or help-seeking for EDs. For example, a study looking into help-seeking behaviours of Pakistani women found that Islam was described as encouraging individuals "to reach your full potential" which in turn supported help-seeking (48).

Taken together, these findings suggest that stigma around EDs cannot be understood solely at the individual or cultural-group level. Instead, it must also be situated within wider historical, structural and intergenerational contexts.

Strengths and limitations:

To our knowledge, this is the first systematic review to thematically analyse UK qualitative studies on experiences of help-seeking and accessing ED treatment, with a particular attention on ethnic differences in barriers and facilitators. Two independent reviewers conducted the main steps of the review process, and NVivo software aided in coding and theme development.

A key limitation of this study was the small number of articles exploring minoritised ethnic perspectives. The studies by Channa et al. and Wales et al. (12, 23) used differing methodologies, with Channa et al. focusing on one case and Wales et al. gathering multiple perspectives through focus groups. However, both studies focused exclusively on participants of South Asian background, a diverse group encompassing multiple ethnicities, and the available research was insufficient to capture the diverse voices within the wider community. Expanding the review inclusion criteria to other Western countries could provide a more comprehensive analysis of the experiences and views of minoritised ethnic populations (1). Furthermore, although two researchers independently generated codes and themes following Braun & Clarke's (19) guidelines on thematic analysis, the nature of such analysis is never truly devoid of biases.

CONCLUSION

Stigma and lack of understanding of EDs remain central barriers to accessing treatment. Conversely, facilitators of help-seeking include improved awareness and recognition of EDs, care that is both accessible and informed by lived experience, and the availability of supportive networks. While these findings apply broadly, they carry particular weight for minoritised ethnic populations, who often face additional structural and cultural barriers to accessing support. This suggests that a revision of guidelines is long overdue, yet the lack of research in this field makes it difficult to suggest empirical alterations.

The scarcity of UK-based research focusing on the help-seeking experiences of minoritised ethnic groups underscores both the need for more research focused solely on marginalised groups and the risk of continuing to overlook diverse needs and collective minority experiences within ED care. Much existing work has provided valuable but primarily

descriptive accounts of disparities, e.g., documenting lower rates of help-seeking or later diagnoses. Future studies should move beyond descriptions to also engage with sociological and intersectional perspectives, examining how structural inequities, cultural narratives, and systemic biases contribute to these observed differences.

By amplifying diverse voices and embedding inclusivity at the heart of research and practice, the field can progress toward a more holistic, accessible, and patient-centred approach to ED care which recognises the unique contexts in which individuals experience and seek support for disordered eating.

Abbreviations:

ED, Eating disorder

‘SWAG’, ‘Skinny white affluent girl’

HCP, Healthcare professional

Declarations

Ethics Approval: This research does not involve human subjects, animals, or sensitive data.

Consent for Publication: Not applicable

Availability of Data and Materials: All data analysed during this systematic review are included in the published studies cited in this article. No new data were generated as part of this review.

Competing Interests: None to declare.

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Author's Contributions:

- Melissa Chang & Manvir Dobb are joint first authors; they jointly carried out the search, coded and interpreted the data, and drafted the manuscript.
- Helena Tuomainen supervised all phases of project and critically reviewed and revised the manuscript.

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Table 3. Visual summary of findings from JBI Critical Appraisal

Questions	1	2	3	4	5	6	7	8	9	10
Brown et al. 2021	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Bye et al. 2018	--	✓	✓	✓	✓	X	X	✓	✓	✓
Byrom et al. 2022	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Channa et al. 2019	✓	✓	✓	✓	✓	X	X	✓	✓	✓
Cribben et al. 2021	--	✓	✓	✓	✓	X	X	✓	✓	✓
Curry & Andriopoulou 2023	✓	✓	✓	✓	✓	X	✓	✓	✓	✓
Fitzpatrick et al. 2023	--	✓	✓	✓	✓	✓	X	✓	✓	✓
Joyce et al. 2019	✓	✓	✓	✓	✓	X	✓	✓	✓	✓
Malson et al. 2021	--	✓	✓	✓	✓	X	X	✓	X	✓
Mitrofan et al. 2019	--	✓	✓	✓	✓	X	X	✓	✓	✓
Murphy-Morgan et al. 2024	--	✓	✓	✓	✓	X	X	✓	✓	✓
Robinson et al. 2020	--	✓	✓	✓	✓	X	✓	✓	--	✓
Thomson et al. 2014	--	✓	✓	✓	✓	X	X	✓	✓	✓
Wales et al. 2017	--	✓	✓	✓	✓	X	X	✓	✓	✓

Q1. Is there congruity between the stated philosophical perspective and the research methodology? Q2. Is there congruity between the research methodology and the research question/objectives? Q3. Is there congruity between the research methodology and the methods used to collect data? Q4. Is there congruity between the research methodology and the representation and analysis of data? Q5. Is there congruity between the research methodology and the interpretation of results? Q6. Is there a statement locating the

researcher culturally or theoretically? Q7. Is the influence of the researcher on the research, and vice- versa, addressed? Q8. Are participants, and their voices, adequately represented? Q9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body? Q10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?

✓ - yes; ✗ - no; -- - unclear

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Table 4. Overview of the studies included in the review

Author	Participants	Type of ED	Aims	Barriers	Facilitators
Brown et al., 2021 Qualitative study (UK)	10 SU (White)	AN = 6 EDNOS = 2 BN = 1	Explore the impact COVID-19 and associated public health measures on adults with EDs in UK	• social isolation • lack of routine and structure • accessibility of support • increased responsibility/changes of accountability due to lockdown	• accessibility of support • increased responsibility/changes of accountability due to lockdown
Bye et al., 2018 Qualitative study (UK)	101 SU who were pregnant or postnatal women (ethnicity unreported)	AN = 34% EDNOS = 25% BED = 24% BN = 16%	Understand the barriers to disclosure and identification of ED in pregnancy and postnatally as perceived by women with past or current ED, and midwives and health visitors working in the UK NHS.	• Fear of judgement for affecting child • Fear of unwanted referrals to social services • Lack of opportunity to discuss with HCPs • Prefer self-management – fear of not being understood • Dependent on mental health status – symptoms ok at the time so did not disclose	N/A
Byrom et al., 2022 Qualitative study (UK)	118 SU who were students (86% White British, 14% Non-White)	AN	Understand experience of students with EDs, focusing on first encounters with ED services and support seeking and suggest improvements	• Feeling like not deserving support • Vulnerability in disclosing • Long waiting times, limited service capacity • Lack of awareness of support available • Variable levels of understanding from GPs • Navigating complex referral pathways	• 8 noted smooth process • Supportive GP

				• Lack of ED-specific support • Lack of continuity of care	
Channa et al., 2019 Qualitative study (UK – West Midlands)	1 SU (UK-born South Asian Indian)	BN	• Examine cultural and psychosocial factors that influences the development of EDs and help-seeking attitudes • Recognise psychiatric categories as cultural – disentangling how culture ‘comes to matter’ in lived experiences of EDs • Display that cultural nuances should provide an evidence base to design appropriate support services, thus reduce health inequalities and barriers to treatment	• No family help or lack of understanding of condition • Patient fear that family would disregard her condition • Talks of mental health taboo in family or sign of weakness – cross-generational issue • Tight diagnostic framework of bulimia • Stigma – and imposing fear of stigma on self	• Support from white boyfriend (different cultural backgrounds) • Reading about other people’s stories with same diagnosis
Cribben et al., 2021 Qualitative study (UK)	32 parents (96.9% White)	AN	To establish parents’ experiential perspectives of ED care in the UK, compared with guidance published by Beat, a UK eating disorders charity, and Academy for Eating Disorders, the leading international eating disorders professional association.	• Feeling excluded from service access with child • HCPs not valuing carer’s feedback • Children not wanting parent’s involvement – hiding symptoms from them • Strict admission criteria which children didn’t meet and issues with NICE guidelines/adherence by GPs • GP’s knowledge of condition	• Feeling including in ED services • GP’s knowledge of condition

Curry & Andriopoulos, 2023 Qualitative study (UK)	4 SU who were SCP (ethnicity unreported)	AN	To explore the dual-experiences of AN recovered service providers	• dismissive service gatekeepers – especially from GPs – trivialised their condition, showing lack of understanding • “wait and see” approach from GPs • lack of care and compassion for condition from HCPs • stigma – many HCPs seemed to not like or not want to deal with AN patients	• having a “caring” professional who listened and understood condition – able to “separate individual from condition” • training of HCPs from those with lived-experience of HCPs
Fitzpatrick et al., 2023 Qualitative study (UK)	6 SU who were mothers (White British)	AN	• explore lived experiences of how adult women, particularly mothers experience ED access and treatment and how it differs from SWAG stereotype • identify how ED services can be improved for this group	• “selfless mother” - putting others first as a mother, and guilt for putting oneself first • Doctors suggesting form of treatment which didn’t work with looking after children eg. Being admitted • Blamed by HCPs and family for setting bad example to children • Being condescended to by HCPs • HCPs putting them under stereotype of anorexic that isn’t aware of their condition, infantilising patient	• Being taken seriously by HCP • Being offered continuity of care from the get-go
Joyce et al., 2019 Qualitative study (UK)	8 SU (ethnicity unknown)	N/A	• experiences of receiving input from services for long-term ED • social, political, cultural	• weight not “low enough” (social stereotypes) • previous negative experiences with professional support • not "worthy of care" guilt of	• help from managers, families, partners, and professionals

			narratives which impact these experiences	receiving care due to •absence of care system connecting with 'patients as people'- creating 'anxiety and distrust'	
Malson et al., 2021 Qualitative study (UK)	22 SU (1 Asian British, 1 Black African, 1 Mixed race, 1 Taiwanese, 1 Not disclosed, 17 White/White British)	AN = 10 EDNOS = 7 BN = 2 Other = 3 (self-identified)	Under how young people with current/past ED and carers experience primary care provision	•GP's lack of knowledge about EDs •GP's weight-based understanding of ED •GP normalising weight loss in AN as normal/just growth •concerns from carer/parent dismissed by GP •stereotypes of young people, women, mothers, EDs	•GPs knowing about ED's •GP listening to concerns to 'act swiftly to facilitate appropriate support'
	10 carers (9 White/White British, 1 Mixed Race)	AN = 9 AN with BED = 1			
Mitrofan et al., 2019 Qualitative study (UK)	19 SU (1 ethnic minority)	AN = 2/3 BN/other/atypical ED = 1/3	Young people and parent's experience of care for ED	•weight based referrals/admission •lack of knowledge of ED with HCP	• individualised treatment approach at first contact: addressing 'physical and psychological recovery'
	11 parents (White British)	N/A			
Murphy-Morgan et al., 2024 Mixed methods study qualitative & quantitative (UK)	27 SU (1 South Asian, 18 White British/Irish, 3 White other, 5 other)	AN: 15 EDNOS: 8 Other: 2	•challenges and benefits of receiving remote care for EDs during the pandemic •identify barriers to remote care	•poor internet connection-reliance on internet	•remote support enables treatment without travel, time saved with convenience

Robinson et al., 2020 Qualitative study (UK)	1704 carers (ethnicity unreported)	AN: 552 BN: 134 BED: 100 ARFID: 63 other: 40	Address caregivers' experiences of ED service and its subsequent impact on caregiving burden	•dismissive GPs •GP lack knowledge/expertise on EDs whether missing symptoms of triggering comments •'weight-orientated' treatment: encouraging even more danger to make themselves 'ill enough'	•ability to access private treatment- to overcome barriers of BMI not low enough, or waiting list too long
Thomson et al., 2014 Qualitative study (UK)	8 parents (White British/Irish)	AN	•reasons for delayed parental recognition (how did they recognise ED) •parental decisions behind help-seeking process	•weight loss or exercise as positive, normal growth, or short-lived phase •parental denial •lack of understanding of ED •stereotypes of ED (families and affected people) •secrecy and deception with ED behaviour •not understanding what the threshold for help is •fear of damaging parent-child relationship (betrayal) •HCP denial	•internet research for parents •when attempts to 'fix' DE habits fail- triggering help •change in environment exposing pathology e.g. holidays •parental acceptance •being assertive with HCP
Wales et al., 2017 Qualitative study (UK – Leicester)	28 members of community who both migrants and born in UK (Asian/British, Asian Indian, Pakistani, Bangladeshi.	N/A	•identify barriers to help-seeking ED among South Asian population in UK •attitudes towards mental health issues (particularly EDs and DE) •awareness and understanding of ED	•weight loss as positive (due to rising obesity, concerns of marriageability) •food role (celebratory, social) •lack of awareness about ED and not seen as serious condition •ED as physical health problem •mental health stigma	•education in school •media (with personal narratives): TV, soap opera, Bollywood, Asian radio •leaflets/posters in community centres, places of worship

			•where and when help would be sought •how to encourage help-seeking	•lack of privacy (living conditions) •confidentiality concerns •stigma	•self-help resources accessible online
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Abbreviations: ARFID: Avoidant/Restrictive Food Intake Disorder; AN: Anorexia Nervosa; BED: Binge Eating Disorder; BMI: Body Mass Index; BN: Bulimia Nervosa; CYP: Children and Young People; DE: Disordered Eating; ED: Eating Disorder; EDNOS: Eating Disorder Not Otherwise Specified; GP: General Practitioner; HCP: Healthcare Professional; N/A: Not Applicable; NICE: National Institute for Health and Care Excellence; NHS: National Health Service; SU: Service User; SWAG: Skinny, White, Affluent Girls; TV: Television; UK: United Kingdom.

Table 5. Barriers to ED Treatment Access: Themes, Subthemes, Quotes

Themes	Sub-themes	Quotes (Q)
Rigid ED guidelines	Not ill enough	Q1: “When my [ED] issues first started I couldn’t access NHS help due to the guidelines stating I needed a BMI [below] 17.0 (despite displaying every other symptom) which was taken as encouragement to continue.” (Byrom et al., 2022)
	Non-individualised care	Q2: “Vicky clearly related the sense that the inpatient eating disorder treatment on offer was unacceptable to her as a mother in that it did not take account of the fact that living apart from her children (as a single parent) for any extended period of time was inconceivable to her.” (Fitzpatrick et al., 2023)
Negative HCP experiences	N/A	Q3: “My mum first took me to the GP when I had just turned 14 ... I protested and said there was nothing wrong - and the GP foolishly took my word for it and told my mum that she was just being an overprotective mother, despite the fact that my face was gaunt and I was struggling to walk.” (Fitzpatrick et al., 2023).
Difficulty in Self-recognising ED	Perceptions of beauty	Q4: “Some people discussed the positive view of thinness in young people in order to get married. Being overweight in the SA community, especially for girls of marrying age, was seeing negatively and the pressure of not becoming overweight in order to marry was present from young age” (Wales et al. 2017)
	Self-stigma	Q5: “The guilt as a mother, that you're being so selfish to put yourself first. As well, I mean, I used to feel so guilty about going to this counselling, like because you do just put your kids first naturally, but why would I be thinking about myself? This wasn't right.” (Fitzpatrick et al., 2023)
Service Resources	Low awareness of available services	Q6: “Some participants (interviewees and survey respondents) were still unaware of any suitable services. “I don’t think I have ever even seen anything to do with eating disorders since I have been at uni[versity] until I got the email about this research. I haven’t seen a single poster, not a single anything to do with it. – Male, 18 – 20, undergraduate (interview)” (Byrom et al. 2022)
	Poor service accessibility	Q7: “In addition to challenges with internet connection, participants talked about familiarity and literacy with online platforms. This included issues around initial setup and gaining access (e.g., how to register for accounts). Downloading apps could often be difficult to do, with little advice and guidance on how to install or use them, including how installation and screen views may differ across devices (e.g., laptop vs mobile phone).” (Murphy-Morgan et al. 2024)

Social Relationships	Stigma from community	Q8: “Fear of confidentiality was not restricted to the GP as one of the clinicians noted that it was not unusual for a SA patient to request to see a non-SA therapist when presenting to specialist services.” (Wales et al. 2017)
	Lack of family support	Q9: “She suggested that if she had come from a supportive family with whom she may have been able to confide her emotional distress then she may have sought formal help earlier.’ (Channa et al. 2019)

Abbreviations: BMI: Body Mass Index; ED: Eating Disorder; GP: General Practitioner;

NHS: National Health Service; SA: South Asian.

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Table 6. Facilitators to ED Treatment Access: Themes, Subthemes, Quotes

Themes	Subthemes	Quotes (Q)
Spotting ED at the blink of an eye	Improving ED understanding and Recognition	Q10: “Participants hoped such awareness would reduce social stigma surrounding EDs and ensure students with EDs are listened to and met with compassion. “Providing information about the signs of a developing ED and how to recognise it in yourself/friends.” (Byrom et al. 2022)
	Service providers making the first move	Q11: “I think there should be regular screenings for most students (short surveys or assessments sent out by personal tutors) so that students who don’t seek out help can at least be flagged.” (Byrom et al., 2022)
Delivery of Care	Accessible services	Q12: “Students’ suggestions included advertising in a range of places, having more information available about different services and greater signposting to ED services within university; “Make specific information widespread about any available support.”” (Byrom et al., 2022)
	Care informed by lived experiences	Q13: “Janet shared her belief that lived-experience is a valuable asset when training professionals and providing them with accurate education. She identified the education of professionals as a protective factor against poor or “offensive” care, and her narrative suggested she feels this is a responsibility that she cannot bear alone.” (Curry et al., 2023)
Supportive people around you	Healthcare professionals	Q14: “Early interactions with services are important for shaping motivation and enthusiasm to engage with treatment” (Byrom et al., 2022)
	Supportive family	Q15: “Parents made serial unsuccessful attempts to reason with or reward their children in order to change their eating habits. The failure to effect change was often the trigger for parents to instigate professional help-seeking: RE: ‘BOY, AGE 16’; ‘MRS F’ I decided to seek help from my GP when I realised that the discussions that I had with x about eating and trying to bribe him with extra tennis weren’t working.” (Thomson et al., 2014)
	Partners	Q16: “I didn’t really have anyone to talk to, other than my boyfriend....Yeah. My boyfriend’s [family member] had anorexia, and her family, erm, are the most supportive people I could ever imagine.” (Channa et al., 2019)
	Peer support and solidarity	Q17: ““I did like all the people that were trying to help me, they did their best. I just didn’t feel like they ever completely got me. In fact the people who did make me feel that way were often people that had experienced an eating disorder as well.’ (YP2)” (Mitrofan et al., 2019).

Abbreviations: ED: Eating Disorder; GP: General Practitioner.

Figure 1. PRISMA 2020 Flowchart

Abbreviations: ED: Eating Disorder; UK: United Kingdom.

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