Experiences of children and young people from ethnic minorities in accessing mental health care and support: rapid scoping review

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Disclaimer: This report contains transcripts of interviews conducted in the course of the research and contains language that may offend some readers.

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Scientific summary

Mental health care for young people from ethnic minorities

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Scientific summary

Background

Mental health problems are common and increasing among children and young people in the UK. Incidence rates are higher among young people from some ethnic minority backgrounds, who also experience mental health problems in different ways from those from non-ethnic minority backgrounds. However, currently, little is known about experiences of accessing mental health services from the perspectives of children and adolescents from ethnic minority backgrounds, and their families.

People from ethnic minorities are also more likely to use different sources of mental health support. For example, research has shown that, even when accounting for lower levels of need, adolescents of Indian ethnicity were less likely to use child and adolescent mental health services than their white peers, but more likely to obtain mental health support from siblings, other non-parental family members, teachers and primary care providers. There are also ethnic differences in mental health-care referral routes, with ethnic minority child and adolescent mental health services users more likely to be referred via education, social services, child health services or the criminal justice system than via primary care. Mental health service users from minority ethnic backgrounds may also be more likely than their white British counterparts to be referred to inpatient and emergency services and to be admitted involuntarily.

Perceived cultural and language barriers among people from ethnic minority groups may further compound other factors that deter care-seeking or that undermine engagement with services. Given the complexity of such determinants of access to and engagement with services, and the inevitable variation in these factors between different ethnic groups and for different mental health needs, it is important that health policy and research commissioning is informed by relevant and recent research.

One of four mental health research goals for 2020–30 for the National Institute for Health and Care Research, the Medical Research Council and other research funders is for more 'Research to improve choice of, and access to, mental health care, treatment and support in hospital and community settings' [Medical Research Council. *Mental Health Research Goals 2020 to 2030*. 2020. URL: https://mrc.ukri.org/documents/pdf/mental-health-research-goals-2020-2030/ (accessed 18 October 2021)]. This scoping review and report was commissioned by the National Institute for Health and Care Research Health and Social Care Delivery Research programme to inform the work of the Department of Health and Social Care's mental health research initiative.

Objectives

The study's objectives were to undertake a rapid scoping review to answer the following research questions:

1. What is the nature and scope of the qualitative evidence on the experiences, views and perceptions of children and young people from non-white British backgrounds and their parents/carers in accessing and engaging with mental health care and support in the UK?
2. What is the nature and scope of the qualitative evidence on the experiences, views and perceptions of those who refer to, provide and commission mental health care and support regarding how children and young people from non-white British backgrounds access and engage with mental health care and support in the UK?

A third objective, added after the agreement of the review protocol, was:

3. To summarise findings from within studies that relate to the two research questions (i.e. focused on seeking, accessing or engaging with mental health care and support), including providing illustrative quotations from study participants.

Methods

Bibliographic database searches were designed by an information specialist (SR) in consultation with the review team. Searches were carried out in Applied Social Sciences Index and Abstracts (ProQuest), Cumulative Index to Nursing and Allied Health Literature (EBSCO*host*), Health Management Information Consortium (Ovid), MEDLINE (Ovid), PsycInfo® (Ovid), Social Policy and Practice (Ovid), and Web of Science (Clarivate Analytics) on 23 June 2021.

Qualitative studies of non-white British participants aged 10–24 years who were receiving, requiring or seeking mental health services in the UK were sought. Studies that focused on travelling communities (including Roma, Gypsy and Irish Traveller communities) or on refugees, people seeking asylum or those who are stateless were included. Studies reporting data on any non-white British group(s) alongside data from white British groups were also included.

Studies were required to focus on access to or engagement with mental health services. Eligible studies could report the views, perceptions and experiences of non-white British children and/or young people requiring, seeking or receiving mental health care and support; their parents, guardians, carers or other relatives; health and social care professionals that refer to or provide care and support to such young people; other referrers and providers such as teachers, charity/voluntary-sector staff or staff working within the criminal justice system; and commissioners of mental health care and support for this population group.

A broad definition of 'mental health' was used, which encompassed the following mental health issues/conditions: anxiety disorders (including obsessive–compulsive disorder, post-traumatic stress disorder and other trauma-related mental health issues), depressive disorders, psychotic disorders, personality disorders, conduct disorders, eating disorders, disorders of addiction and misuse, disorders of sleep, somatoform disorders, attention deficit hyperactivity disorder, gender dysphoria, self-harming behaviours, general stress and mental/psychological well-being. We also used a broad definition of mental health services, including other less conventional sources of support. Only studies published since 2012 were included. This date limit was used mainly to reflect the different health service commissioning and funding levels for mental health care following the 2011 No Health Without Mental Health strategy and the 2012 Health and Social Care Act.

Titles and abstracts of bibliographic database search results were independently screened by two reviewers. Disagreements were resolved by discussion. Double, independent screening was conducted at full-text level. For each included study, data extraction and quality assessment were conducted by one reviewer and checked by a second, with disagreements resolved through discussion. Extracted data were used to categorise and describe studies according to type of mental health need, ethnicity of study samples and service context or other recurrent population characteristics across the studies (e.g. university students or refugees/asylum seekers).

The quality of included papers/reports was assessed using the 'Wallace criteria' for assessing the quality of qualitative research. They cover the clarity and coherence of a study in relation to its question, theoretical perspective, study design, context, sampling, data collection methods, data analysis methods, reflexivity, generalisability and ethics. Lower-quality studies were not excluded.

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Findings

We identified 22 qualitative research studies (published from 2012 onwards) on the experiences of young people from ethnic minority groups regarding access to or ongoing retention/engagement with mental health care and support. This review had a broad scope of inclusion: ethnic minority groups were broadly defined; participants could include relatives, service providers, commissioners and referrers as well as the young people themselves; and 'mental health care and support' could include specialist, third-sector and any alternative provision or support.

We found evidence from studies that had been conducted:

- among university students ($n = 4$ studies) and refugees/asylum seekers ($n = 5$ studies) experiencing a variety of mental health problems and from a range of ethnic backgrounds
- among those from ethnic minorities who are experiencing or need care for particular mental health needs/conditions – schizophrenia or psychosis ($n = 3$ studies, including one of university students), eating disorders ($n = 3$ studies, including one of university students), post-traumatic stress disorder/trauma ($n = 3$ studies, all of refugees/asylum-seeking young people), self-harm ($n = 2$ studies), obsessive–compulsive disorder ($n = 1$ study) and users of substance misuse services ($n = 2$ studies)
- among those in some ethnic minorities who are receiving particular types of treatment or intervention ($n = 1$ study in young people or their families engaging with multisystemic therapy, $n = 1$ study in young people receiving cognitive–behavioural therapy for mental health problems and $n = 1$ study in African Caribbean young people taking part in family-based talking therapy)
- to look at the perceived impacts of access to nature in urban settings on mental well-being for young people from various ethnic groups ($n = 1$ study).

Encouragingly, most of this research has been based on interviews or focus groups with the ethnic minority children or young people themselves. Only 3 out of the 22 studies did not include some data from the children or young people whose mental health needs were of interest. Other studies combined data from interviews with young people with interviews or focus groups with parents/carers or family members. The experiences of care professionals or care provider organisations were collected and analysed in only six studies, and experiences of service commissioners were captured in only one study.

In contrast to describing the types of mental health needs, services or ethnic groups for which there is research evidence, it is harder to specify those needs/groups for which there is no evidence, or not as much as one might expect or want. Fewer than one-third of included studies were wholly (or mostly) conducted in a particular ethnic minority group; such studies might reveal distinctive barriers to accessing care related to family and community circumstances, or the cultural beliefs of the young people, families and communities from those specific ethnic minority backgrounds. Two studies analysed experiences from both black and South Asian ethnic backgrounds, but did not distinguish any differences in experience that may have been associated with the different ethnicities.

Nevertheless, the included studies do indicate a range of potential factors that influence access to and engagement with mental health care for young people from different ethnic minorities. Factors highlighted by authors of some of these studies included:

- Lack of awareness and knowledge about some mental health issues/conditions, sometimes including underappreciation of the seriousness and misunderstanding of the causes of the conditions, both of which could deter care-seeking.
- Lack of trust in care professionals, potentially owing to perceptions of services or professionals as operating in a way that is not culturally sensitive and/or because of past experiences of feeling let down by services. Note that, among refugees or asylum seekers, this distrust had different root causes (such as fear of links to the justice/asylum system, and language differences) and different manifestations (such as resistance to paper-based assessment or therapy exercises).

- Lack of awareness/information about available services and support for mental health difficulties.
- Social stigma – either self-perceived by the young person and/or related to the services and institutions providing care.
- Culture-, community- and religion-specific reasons for either hiding/suppressing the admission of having mental health difficulties, or for seeking support from informal or alternative sources rather than mainstream mental health services.
- Differing expectations about mental resilience and levels of ease in talking about problems among different ethnic groups, and among boys/young men and girls/young women within particular ethnic groups.

Discussion

This rapid scoping review was conducted by an experienced team of reviewers according to a prespecified protocol, and with input from topic experts with relevant clinical and service provision experience. Searches were comprehensive and were developed and conducted by an experienced information specialist (SR). The review team systematically extracted relevant standard information from each study and assessed the quality of included studies using established criteria. This report meets Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews reporting criteria.

Perhaps the main limitation of this scoping review is that it was a scoping review, and we therefore did not formally synthesise any of the findings across studies. Instead, we briefly summarised each of the study authors' findings that related to our review questions, and compared them within groups of studies where it seemed relevant or it avoided repetition. It is also possible that use of a more explicit logic model would have enabled more structured insights.

There are several further limitations of our methods. First, we searched for and included only studies from 2012 onwards. Second, the speed with which this review was conducted (4 months) meant that we were not able to engage with relevant stakeholders as much as we would have liked. In particular, the review team would have liked to engage with young people with lived experience of mental health difficulties and from a variety of ethnic backgrounds.

Limitations of the evidence found

There were also limitations relating to the nature, methods and reporting of the 22 studies found. Only a minority of studies were of specific ethnic minority groups, and five of the included studies provided evidence from a mix of young people, including both white British and various ethnic minority backgrounds.

Finding 22 studies from the last 9 years may seem like a useful amount of qualitative research on these important issues, given the variety of problems and population groups for which there is research. However, there are inevitably other groups/conditions/services on which research might be needed. For example, there were relatively few studies in younger children (< 15 years old) or studies of access to services and support linked to schools. In England, there has also been a major shift in service provision towards increasing access to psychological therapies for common mental health problems, but none of our studies had directly investigated access to such services for young people from ethnic minority groups. Similarly, there were no studies on why and whether children, their parents/carers or other young people from ethnic minorities seek (or do not seek) care from their general practitioner for mental health difficulties. In addition, given that the scope of this review included both children and adults (aged 10–24 years), it is surprising that there were no studies

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looking at how children and their parents/carers from ethnic minorities experience the transition from children's/child and adolescent mental health services to adult mental health services.

Although it is valuable that so many of the studies were based directly on the experiences of young people themselves, and sometimes also their parents/carers, often the samples were very small and from limited geographic areas. More studies involving multiple perspectives and informants (e.g. clinician/practitioner, service commissioner, school teachers) may have yielded complementary insights on service design, management/staffing or resource-related barriers to improving the accessibility of services. If future studies do include subsamples of different stakeholders, then it is paramount that the source of quotations and the attributions of particular themes or other insights are better reported than was the case in many of the studies included in this review.

Conclusions

We found 26 papers or reports describing 22 diverse qualitative studies meeting our inclusion criteria. Most of the studies were well conducted and clearly described.

There were studies of refugees/asylum seekers ($n = 5$), university students ($n = 4$) and studies among young people experiencing particular mental health problems: schizophrenia or psychosis ($n = 3$), eating disorders ($n = 3$), post-traumatic stress disorder ($n = 3$, all in asylum seekers), substance misuse ($n = 3$), self-harm ($n = 2$), and obsessive–compulsive disorder ($n = 1$). There were also three studies of ethnic minority young people who were receiving particular mental health treatments: families engaging with multi-systemic therapy, young people receiving cognitive–behavioural therapy and African Caribbean young people taking part in family-based talking therapy.

Most studies had been conducted with young people or their parents from a range of different ethnic backgrounds. However, nine studies were about young people from particular ethnic groups: asylum seekers from Afghanistan ($n = 2$), and black and South Asian ($n = 2$), black African and black Caribbean ($n = 2$), South Asian ($n = 1$), Pakistani or Bangladeshi ($n = 1$) and Orthodox Jewish ($n = 1$) people.

We searched for but did not identify any studies conducted in Arab, Chinese or South-East Asian people (unless within refugee/asylum-seeking populations), or in Gypsy or Irish Traveller people. We also found no studies that were specifically aimed at understanding care-seeking or service engagement by those from ethnic minorities with personality disorders, conduct disorders, disorders of sleep, somatoform disorders, attention deficit hyperactivity disorder, gender dysphoria, general stress or those with autism/social communication disorders and/or learning disabilities (in which the primary focus was on mental health).

Future qualitative research and other studies in this area could be improved by:

- Purposively sampling young people and/or their parents from particular ethnic minority groups.
- Conducting larger studies that enable separate and comparative analysis of the experiences of those in different minority ethnic groups. Larger samples might also allow additional insights into how ethnic identity affects boys/young men or girls/young women differently.
- Including data from multiple stakeholders' perspectives – importantly from young people and their parents/carers, but also community members, care professionals, service providers, service commissioners and others who refer to mental health care.
- Focusing on the different routes to mental health care/support followed by those from ethnic minority groups, especially evidence from those professionals, whether in the NHS or in schools, who might identify and refer children and young people experiencing mental health difficulties to other services.
- Focusing on how children and young people from ethnic minority backgrounds experience being supported by multiple teams or services, for example when they have complex needs.

- Focusing on how the (lack of) ethnic diversity in the mental health workforce shapes the experience of children, young people or their carers seeking support for their mental health.
- Better reporting, especially in terms of describing the methods of data collection adequately.

In addition, more nuanced and context-sensitive insights may be yielded by conducting a more formal evidence synthesis of selected groups of qualitative studies. Such formal evidence synthesis should consider using an explicit theory or framework for understanding different stages and drivers of access to health-care services.

Study registration

This study is registered as https://osf.io/wa7bf/.

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This report

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