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Title

People from ethnic minorities seeking help for Long Covid: a qualitative study

Running Head

Ethnicity and lived experiences of Long Covid

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People from ethnic minorities seeking help for Long Covid: a qualitative study.

Abstract

Background: People from ethnic minority groups are disproportionately affected by COVID-19, are less likely to access primary healthcare and report dissatisfaction with healthcare. Whilst the prevalence of Long Covid in ethnic minority groups is unclear, these groups are under-represented in Long Covid specialist clinics and Long Covid lived experience research which informed the original Long Covid healthcare guidelines.

Aim: To understand lived experiences of Long Covid in people from ethnic minority groups.

Design & setting: Qualitative study with people living with Long Covid in the UK.

Method: Semi-structured interviews with people who self-disclosed Long Covid were conducted (between June 2022 and June 2023) via telephone or video call. Thematic analysis was conducted. People living with Long Covid or caring for someone with Long Covid advised on all stages of the research.

Results: Interviews were conducted with 31 participants representing diverse socio-economic demographics. Help-seeking barriers included little awareness of Long Covid or available support and not feeling worthy of receiving care. Negative healthcare encounters were reported in primary healthcare; however, these services were crucial for accessing secondary or specialist care. There were further access difficulties and dissatisfaction with specialist care. Experiences of stigma and discrimination contributed to delays in seeking healthcare and unsatisfactory experiences, resulting in feelings of mistrust in healthcare.

Conclusion: Experiences of stigma and discrimination resulted in negative healthcare experiences and mistrust in healthcare, creating barriers to help-seeking. Empathy, validation of experiences, and fairness in recognition and support of healthcare needs are required to restore trust in healthcare.

Novelty statement

The study explored the lived experiences of people from ethnic minority groups living in the UK accessing healthcare services for Long Covid. Experiences of stigma and discrimination create mistrust in healthcare and are barriers to acceptable and appropriate healthcare.

Keywords

Long Covid; primary healthcare; ethnic minorities

How this fits in

People from ethnic minority groups are less likely to present to primary healthcare for Long Covid. This study explored the lived experiences of Long Covid amongst people from ethnic minority groups. Participants were often previously unaware of Long Covid or available support and some described not feeling worthy of receiving care. Experiences of stigma and discrimination contribute to a lack of trust in healthcare professionals and services, and are common in previous negative healthcare encounters. Receiving empathy, validation, and fairness in recognition of symptoms, and support is needed to enhance trust and safety in healthcare.

Introduction

Long Covid, the patient-preferred term¹, is the experience of persistent symptoms for more than 12 weeks following a COVID-19 infection. In early 2023, Long Covid was estimated to affect 1.9 million adults in the UK². An estimated 200 million people are thought to be affected globally³. The National Institute for Health and Care Excellence (NICE)⁴ use the term post-acute COVID-19 syndrome. Symptoms can be physical, cognitive, or psychological⁵ with debilitating impacts on people's daily lives⁵⁻⁷. People living with Long Covid describe difficulty accessing healthcare or feeling that they are not believed by General Practitioners (GPs)⁸⁻¹². GPs describe their own challenges managing people with Long Covid¹³.

People from ethnic minorities were disproportionately affected by the COVID-19 pandemic – related to socio-economic deprivation and working in COVID-19 exposed sectors^{6,14}. However, the evidence on the prevalence of Long Covid amongst ethnic minority groups is conflicting¹⁵⁻¹⁹. People from these backgrounds are less likely to present to primary healthcare as indicated by clinical coding of Long Covid²⁰, are less likely to gain access to Long Covid clinics^{21,22}, and are under-represented in Long Covid research^{8,23}. In general, people from ethnic minorities report less satisfaction with primary healthcare due to factors including lack of care demonstrated by practitioners, a lack of trust in professionals and being less involved in decision-making²⁴.

People living with Long Covid experience stigma^{12,25} where they are devalued or discredited by society because of their condition²⁶. Stigma is not an uncommon experience for people living with health conditions which have a history of sensationalism in the media, such as mental health difficulties or HIV^{27,28}. People may experience health-related stigma in different ways, such as through social exclusion, rejection, blame, and negative attitudes associated with their health condition²⁹. Stigma can be further impacted by intersections with pre-existing inequalities, such as a person's gender, ethnicity, or sexuality^{28,30}. The damaging impact of stigma on healthcare access and experiences, as well health outcomes, is well documented^{27,28,31,32}. Stigma experiences may be wide-ranging for people living with Long Covid from ethnic minority backgrounds. For example, there may be stigma attached to having COVID-19 from others in various community settings³¹, and patients may suffer discrimination in healthcare (e.g. related to racism³³). All of this may contribute to avoidance of the 'Long Covid' label, and disengagement with healthcare and/or inadequate healthcare experiences, thus potentially widening health inequalities^{28,32,34}.

Our study aimed to explore the lived experiences of Long Covid in people from ethnic minorities in the UK focusing on experiences of accessing healthcare.

Methods

Qualitative methodology was used to understand experiences of Long Covid, enabling exploration of lived experiences³⁵, which are crucial to informing care and management of health conditions^{4,36}. Further details can be found in the study protocol³⁷. Ethical approval was obtained from the University of Westminster (ETH2223-1313).

Advisory groups

A patient advisory group consisting of 1 male and 6 females living with or caring for someone living with Long Covid, from a range of ethnic minority backgrounds, complemented an expert advisory group of 6 members interested in Long Covid and ethnic minority health. Patient advisors helped develop the project aims whilst both groups advised on study design, methodology, analysis, and dissemination.

Participants

Adults, aged >18 years, with self-disclosed Long Covid, were recruited via advertisements through social media, support groups, university sites, faith/religious networks, community organisations, and advisory groups. We purposively sampled³⁸ people from an Arab, Black, South Asian or any minority mixed background. Participants were asked to describe their ethnicity; the exact phrase provided was used to identify participant quotes. Participants completed a Long Covid checklist (based on World Health Organisation definition³⁹) confirming participants experienced COVID-19 symptoms (probable or test confirmed) lasting 12 weeks or longer; symptoms were not explained by another condition; and symptoms generally impacted their everyday functioning. Seeking healthcare or receiving a Long Covid diagnosis was not necessary for study inclusion.

Data generation

A topic guide directed one-to-one semi-structured interviews (see Table 1) and was modified iteratively as data were generated and analysed. Participants provided informed consent prior to the interview. Interviews were conducted online, using video software (Microsoft Teams^R), with the camera turned on (at least initially to confirm participant identity)⁴⁰ or via telephone.

Interviewers were four females from different backgrounds (two were British White, one was Polish White and one South Asian) and one male from an Australian White background. Interviewers had varying years of qualitative expertise and were unknown to participants. Interviews were conducted in English between June 2022 and June 2023 (duration: average 1:36, range 00:54-04:31, hr:min). Interviews were digitally recorded, transcribed, and anonymised. Participants received a debrief form (including details of Long Covid support) and a shopping voucher following the interview.

Analysis

Anonymised interview transcripts were uploaded into NVivo software for coding. The first author read all transcripts and analysed the data iteratively using inductive thematic analysis⁴¹ and constant comparison⁴². Interpretation of the findings were discussed with the study authors, patient and

expert advisory groups, and during two online public stakeholder workshops, attended by people living with Long Covid, carers, researchers, healthcare professionals, and members from Long Covid charities. All authors were involved in debating and developing multiple iterations of the manuscript until finalised.

Findings.

Participant Demographics.

Thirty-one participants were interviewed with a range of socio-economic demographics and experiences (see Table 2). The themes developed include: 'symptoms and seeking help'; 'navigating healthcare access'; and 'experiences and perceptions of stigma and discrimination'. Illustrative data is provided to support the analysis. Data extracts are labelled using pseudonyms, gender, and ethnicity.

Symptoms and seeking help

Acute COVID-19 symptom severity varied. Some participants described mild symptoms that were manageable at home, often requiring adjustment to their daily routines. Other participants described more severe symptoms resulting in them seeking urgent medical attention and/or leaving them feeling scared, helpless and/or debilitated. Although many participants described pre-existing conditions, most described themselves as relatively healthy previously:

'...The first day I had a bit of a fever. Umm and then for a couple of days after that I had some difficulty breathing and I had a lot of joint pain and fatigue...I'm usually quite healthy and I like do exercise and stuff, so that was the first for me, like not being able to breathe properly...so I kind of just had to lie down or just sit down...' Aarya, Female, Bangladeshi

Participants described a slow realisation that they were not recovering following an acute COVID-19 infection. They either seemed to take a long time to recover, or felt better and then experienced relapsing symptoms:

'...I just thought like "ohh I need to start going to bed earlier or I must just be tired from work"...I never thought it was like a disease. But then it just started getting worse and worse, and then it started getting to a stage where like I was really noticing it...' Hassan, Male, South Asian and White Heritage

Participants described ongoing symptoms relating to different parts of their body, with some also describing disruptions to their family lives, daily routines and/or their employment. Some symptoms were so severe they led to participants being unable to carry out ordinary daily tasks and seeking medical attention:

'My body just kind of went "woof"...I couldn't stay awake for a whole day...I would get vertigo...the most basic things just became impossible...I didn't have the energy to...prepare a meal...brush my teeth or stand up in the shower...just all sorts of really basic bits of self-care or like home kind of management would just not happen...I stayed off work...for just over a year...I started to get just like mental fatigue as well...trying to concentrate at the

computer...would just make me feel nauseous for the rest of the day and really tired...’ Abi, Female, Black Asian

Sometimes a lack of awareness of Long Covid as a condition - or that support might be available for their symptoms - was related to delaying help-seeking:

‘People aren’t aware that it’s [Long-Covid] really a thing, or that what they’re experiencing might be linked to it [COVID-19]...I would have asked for help if I knew there was treatment available...if there was something that I knew existed...’ Aarya, Female, Bangladeshi

Other participants described delaying help-seeking, because of cultural barriers, such as believing they need to look after others before themselves. Some participants made comparisons with others who were worse off, and so felt they were not a candidate for care⁴³, delaying help-seeking:

‘...I’ve always found it hard to make my needs known...and I think that’s a cultural upbringing thing...looking after other people first...’ Naomi, Female, Asian

‘...I just live with it, there’s no support for it. I just live with it, and I feel it’s not as bad as other people...my symptoms are mild comparing with others because it is long-term...’ Jamila, Female, Arabic

Navigating healthcare access

When seeking healthcare for symptoms, participants commonly came up against complex and inflexible primary healthcare systems, making it difficult to access a GP appointment. Participants described how their symptoms, such as, breathlessness, memory, or concentration difficulties hindered access and made it difficult to speak to a doctor and communicate symptoms:

‘...It’s been quite negative because every time we try to call the GP or like we tried to call 111 it was like, it was basically just really, really hard to reach someone...and once you get through, they’d be like “call this person or try this other service” so we’re just kind of going in a roundabout...’ Aarya, Female, Bangladeshi

‘...It was really hard to even have a phone call with that doctor because I kind of have to...write your thoughts down beforehand, my mum suggested that. Write it all down so you don’t forget.’ Naomi, Female, Asian

Many participants therefore described how the barriers associated with navigating primary healthcare systems (i.e. getting an appointment, difficulties communicating their symptoms or concerns) meant they needed the help of wider systems of support, such as family members:

‘...If not for some assistance that my wife’s brother could actually [provide], I don’t think I would have been admitted [to hospital], because they were inferring that we could just go back home...the help that I got from a GP was through my wife’s brother...he called the GP in for me...so he was actually just concerned.’ Peter, Male, Black British

GPs were recognised by participants as gatekeepers to wider support for Long Covid. However, notably, participants spoke about the need to become ‘your own doctor’. They described how they felt they had become experts in their condition from their own research and experience to

navigating ongoing or further support. This typically involved participants lobbying for investigations, medication, or referrals to specialist services:

'I'm having to chase my own results and sort of be hypervigilant...I'm constantly having to test my results...speak to my GP to see if they've got it [results], to see if they want to do something about it...' Meera, Female, British Indian

A few participants saw their GP as excellent and described positive interactions. They described receiving recognition and being believed, which were crucial to their mental health and feelings of trust and safety:

'...My GP is amazing...I've seen two separate GPs in the past couple of years...I feel so, so lucky to have this amazing surgery...most doctors I've met have not taken that approach, but my GP absolutely does. So, he really, really listens...I totally trust him...' Adunola, Female, Black African

However, a more common experience described by participants was healthcare not meeting their needs. Many participants did not feel they had support from GPs (or other primary care services). Some participants put this down to GPs having limited awareness and knowledge of Long Covid, as well as limited time or resources, and/or available clinical treatments or investigations:

'I'd say the NHS, the GPs, specialists, and A&E have been, I don't know, if they are well enough informed or can't keep up with the research or restricted by what they can do. Apart from ruling out any other problems, I have received pretty much zero support from them. All the advice has been terrible...' Antonio, Male, Latino

Most participants said GPs seemed to have little empathy for their suffering and seemed to have little interest in engaging with Long Covid:

'My GP never really thought that she needed to do anything really, basically...she just said, "oh well, you'll get better"...' Hassan, Male Pakistan, Mixed heritage

'...It's almost as if they would rather not know because they don't know how to fix [Long-Covid].' Meera, Female, British Indian

Referrals to onward care were perceived by those who attempted to access this support as difficult to obtain. Barriers to accessing secondary care (including Long Covid specialist clinics) included a lack of awareness from the participants about available services, as well as primary care providers not being aware of the referral processes involved:

'I've been passed from pillar to post, chasing referrals with the hospitals because either my GP has done it on the wrong form, or they've done it incorrectly.' Samira, Female, British Indian

'I didn't know there is a special clinic that deal with after COVID [Long Covid], the problem, no no-one mentioned anything.' Jamila, Female, Arabic

Participants generally needed to be persistent in advocating for referrals to onward care:

'I reported it to my GP...but I had to really push before my GP referred me to the Long Covid clinic.' Deepti, Female, British Indian

Many times, participants reflected on their disappointment when they accessed Long Covid clinics. Care did not seem to match participants' symptoms, and thus support was perceived as unhelpful.

'...a cardiologist give me a medical advice to drink fruit juice and try not to think about being ill...I had a doctor tell me that I have to stop resting and actually push through exercise to feel better...I've been to a Long Covid clinic which was basically one doctor, he's a pulmonologist and he said because I can breathe properly, he can't really help me with anything else...'

Antonio, Male, Latino

Some participants were able to access appropriate support in terms of being believed and/or referred for more in-depth investigations. One participant described this was only after doing intensive research and lobbying for the referral, while another described joined-up care:

'I [doctor] believe everything you're saying and we're finding long haulers have this post inflammatory issue going on and all these other issues that tests are coming back normal, but there's something very wrong going on here...so, he sent me for another MRI scan but with a more specialized perfusion...that came back showing I had myocarditis, heart inflammation...'
Ahmed, Male, Chile, White Heritage

'The person that got in touch with me was, for the [Long] Covid clinic, an occupational therapist. She has been an absolute godsend...I've described her as the lynchpin in all this because she's collating everything, she's going back to the multidisciplinary team and she's just helping me emotionally as well...fantastic.'
Samira, Female, British Indian

Experiences and perceptions of stigma and discrimination

Participant experiences of health-related stigma²⁹ were evident in narratives of interactions with others. Here, participants reflected on a lack of awareness of Long Covid being linked to the stigma around the condition:

'...They don't know what Long Covid is...if they knew about it, they...will be less quick to judge...it's not really...talked about...when you treat a particular illness or sickness, it's expected that you feel better, completely and no like lingering symptoms...something like Long Covid is really difficult for people to understand...'
Winston, Male, Black/Caribbean

Participants described how others treated them differently because of their Long Covid symptoms:

'So many people are still not aware of the post [Long] COVID. They're still thinking it's COVID-19 as it were, and many people are still scared of contracting the COVID, so you need to like, explain to them...look, this is not COVID, this is just...not something to be scared of.'
Jevaun, Male, African Caribbean

One participant described how they did not want to connect their ongoing symptoms with COVID-19:

'I think I've left COVID-19 behind...I don't want to link it [symptoms] to COVID-19, but I don't want to believe it still because of COVID-19 that I'm still having these symptoms...'
Char, Female, Black African

Consequently, participants needed encouragement from personal networks to provide validation that their symptoms might be linked to COVID-19, or that symptoms were real or worthy of accessing healthcare:

'I need to be sure...I think I'm okay talking to someone who is close to me, will actually give me a talk to guide me, and then, I would be able to access the doctor, and then, know what the issue actually is, so I can be free.' Char, Female, Black African

However, seeking support from wider systems of support, such as family members was not always helpful. Some participants anticipated stigma in that they described the need to hide their symptoms, as they expected prejudice, and this was especially reported by females:

'...In our culture and community, people don't understand. You always have to pretend [not to have symptoms]...they would make nasty remarks about me...' Manya, Female, South Asian

Some participants described how they hid psychological symptoms or resisted mental health labels (e.g., anxiety), meaning they could not talk to others, or discuss the full range of symptoms they were experiencing, as they worried how they would be perceived by others, including by healthcare professionals. They anticipated being discredited, dismissed, or not receiving adequate healthcare:

'...It's also just hard to talk about because, yes, you do think, gosh, am I losing my mind, and you wonder how people will perceive you because of that.' Farah, Female, Middle Eastern Heritage

'I mean, because of my experiences, I started denying anxiety. I don't have anxiety because I realised once anxiety comes into the mix, you get dismissed. So, that was another thing. I just started saying "no, I'm not anxious about anything at all, nothing"...' Paulette, Female, British Black Caribbean

Many participants anticipated experiencing negative healthcare encounters because of previous experiences in healthcare. For instance, a common experience described by participants was having their accounts discredited or dismissed by healthcare professionals:

'So, I didn't [see healthcare for Long Covid symptoms] that's probably because I just assumed they would just say, like, "just rest" or whatever. Yes, so I would say that my past experience with the dismissiveness, so there's no point trying to address this.' Anjali, Female, British Indian

Participants attributed being treated differently because of certain characteristics about themselves like ethnicity, gender, mental health and body type (intersectional stigma^{28,30}). Participants considered the treatment they received (e.g. gaslighting) to be linked to their ethnicity and racism in particular:

'...I mean, you're going for help, so people ignoring you and you feel like you're not feeling pain, possibly because you're a Black person, you're lying...' Paulette, Female, British Black Caribbean

'...I don't like being in the hospital, especially white hospital...there is a way you are being treated...maybe because you have been seen as probably an ethnic minority...' Peter, Male, Black British

Other participants believed that healthcare professionals saw other markers (like mental illness or their weight) as the cause of their symptoms, and so this could get in the way of receiving treatment:

'...They always pull it back to your weight, because it seems to be the easiest thing and the most obvious thing for them to comment on...the discriminatory act comes into it because it's almost like saying well, you are responsible for your weight, therefore it is on you that this has happened.' Samira, Female, British Indian

Several female participants experienced intersectional stigma^{28,30} in particular, and described the difficulties of having their symptoms taken seriously, as healthcare professionals might think they are overreacting because they are female, or that the Long Covid condition itself might be discredited as it is associated mainly with women:

'...I don't have any evidence of it, but I sometimes feel like if I was a man I would be taken more seriously. I'm not sure why but I've had healthcare professionals...questioning my symptoms and they're trying to convince me or suggest that my symptoms are actually things like anxiety or, you know, being overly worried about COVID or that I'm exaggerating my symptoms.' Farah, Female, Middle Eastern

Notably, when participants felt discriminated against because of ethnicity, body type or gender this reduced their feelings of safety and trust in their healthcare. This medical mistrust⁴⁴ hindered help-seeking and quality of care received, with participants feeling anxious or stressed about seeking further healthcare support, with some only seeking healthcare as a last resort:

'...I've experienced racism and sexism in my healthcare...I'm really nervous about going to the doctors now, I will not go unless I am desperate now, basically...with my Long Covid, I didn't actually seek help until it got to eight months...and then I am still dismissed...' Deepti, Female, British Indian

'I got distrust of medical staff now, especially now, especially as a person of colour. I don't trust anything they say or do. It [is] just experiences after experiences after, experiences, time after time.' Paulette, Female, British Black Caribbean

Participants wanted fairer treatment from healthcare professionals. For example, one participant reflected on how they wanted to be treated the same as people from a White background:

'...that treatment would just be fair...just like everybody else is treated...but I feel my people should also be, my people should also be treated in that way.' Peter, Male, Black British

Participants advocated that their suffering needed to be taken at face value by health professionals, for things to improve for people like them, including recognition that their suffering is equal to white patients, regardless of how they present their symptoms:

'Not be gaslighted, not be fobbed off, not be pushed from pillar to post. Just to be treated. If I come in with symptoms, treat me the same you would as if it was a Caucasian person.' Anthony, Male, Black American

Discussion

Summary

People from ethnic minority groups, and males, are under-represented in research into the lived experiences of Long Covid, which has informed current NICE healthcare guidelines⁴. This study explored lived experiences of Long Covid in men and women from ethnic minorities, substantially adding to the literature on Long Covid experiences among these groups¹¹. Participants described a range of reasons why they delayed help-seeking (e.g. unaware of Long Covid as a condition, or available support, not feeling a candidate for care). Accessing primary care involved barriers, such as inflexible or complex systems, symptoms getting in the way of communication with doctors, and lack of interest in Long Covid in primary care. Secondary care or specialist Long Covid clinics could require persistence in asking for a referral and/or chasing a referral. Long delays in accessing specialist Long Covid services were common. Many participants expressed disappointment with the care they ultimately received in both primary and secondary healthcare.

Participants from ethnic minority backgrounds reported experiencing additional burdens when accessing and receiving healthcare for Long Covid. For example, they described experiencing health-related stigma that intersected with ethnicity, gender, body type and mental health status. Participants who wanted their suffering to be recognised also advocated for fairer treatment. Experiences of stigma and discrimination reduced participants' trust in healthcare and were clear barriers to accessing good care.

Further analyses related to the wider data from this study will be published elsewhere led by the second author. This further analysis focuses on the need for recognition and legitimacy for Long Covid, how medical ambivalence manifests for patients, and the important role of wider sources of support.

Strengths and Limitations

A key strength of the study is participant diversity in terms of ethnic minority background, equal representation of males and females, socio-economic status, and residence across the UK. However, there were fewer representations from older age groups (60+ years). It is unknown if participants migrated to the UK or if English was their first language, which may impact accessing healthcare and could be explored in future research. Experiences were from a range of ethnic minority groups, and thus experiences may not be representative of a single ethnic minority.

Another key strength of the study is involvement from a diverse patient advisory group, in terms of ethnicity and residence across the UK, in all stages of the research as well as involvement from an expert advisory group at key stages of the research. This resulted in research that contributed to wider understanding of Long Covid in diverse groups. Criteria for Long Covid was participant self-disclosed, based on the WHO clinical case definition of post Covid-19 condition³⁹; this meant the inclusion of people who had not accessed healthcare for their symptoms⁴⁵. Involvement and engagement with the advisory groups and stakeholder workshops guided the interpretation of findings, providing support to the analysis. Experiences were not directly compared with people from

White backgrounds. To better understand the specific challenges faced by people from ethnic minorities (beyond ethnic minority people's perceptions of the issues), a comparative analysis would be needed.

Comparison with existing literature

The current findings echo research showing ethnic inequalities in accessing healthcare^{46,47}. However, they add considerable nuance to our understanding of why people from ethnic minority backgrounds are less likely to access primary care for Long Covid²⁰, and why, when primary care services are accessed by these groups, they report less satisfaction with care received²⁴, adding to what we know about experiences from people from White backgrounds^{8-10,13}.

Despite specialist Long Covid services established across England^{48,49}, some of our participants were unaware of services, or experienced difficulties accessing them. This is consistent with an inadequate representation of patients from ethnic minorities in Long Covid clinics^{21,22}. Moreover, some participants expressed dissatisfaction with care received from Long Covid clinics, consistent with the experiences of disadvantaged groups¹¹.

Typical experiences for people living with Long Covid, regardless of ethnic background, include difficulties accessing healthcare, not being believed by their doctor, lack of understanding or knowledge of Long Covid from their doctor, overstretched and complex health systems, and needing to advocate to get care^{8-10,12,13}. People from ethnic minority backgrounds experienced additional burdens associated with Long Covid, particularly linked to fearing prejudice from others (within the community and healthcare). This often resulted in delayed help-seeking and denying aspects of their condition, such as psychological symptoms, which is consistent with previous research indicating that stigma can be a particular barrier to disclosing mental health problems for people from ethnic minorities^{28,50}. Participants also experienced anticipated stigma where care expectations were based on previous negative healthcare encounters, intersecting with racism, body type or gender^{28,30}, delaying health-seeking. They also believe that they receive less favourable treatment compared to people from White backgrounds, and they connect this to their ethnicity (intersectional stigma)^{28,30}. These findings are consistent with racism contributing to ethnic inequalities in healthcare access, as well as dissatisfaction with care received^{51,52}. In all, the various kinds of discrimination experienced by participants resulted in reduced trust in healthcare. Such 'medical mistrust'⁴⁴ is often seen in ethnic minority groups accessing care for Long Covid¹¹, and other conditions, including mental health and maternity care^{53,54}. Consequently, people from ethnic minority backgrounds in general may feel less deserving of receiving care than other groups⁴³. When care was sought many were dismissed, confirming their expectations - and for some intensifying the emotional burden - of living with Long Covid.

Implications for research and/or practice

Primary care is the first point of contact for accessing support for Long Covid⁵⁵; it has a crucial role in reducing health inequalities for under-served groups⁵⁶, including people from ethnic minorities, who are less likely to access these services²⁰. Our findings suggest that this may be due to health-related and intersectional stigma²⁸⁻³⁰. People fear poor care or discrimination, which reduces trust in

healthcare. Dismissing or discrediting people's suffering can result in people feeling discriminated against because of their ethnicity, body type or gender contributing to people not receiving adequate care. Moreover, there was a lack of awareness of Long Covid symptoms or available support services as well as participants not feeling worthy of receiving care⁴⁴. However, support from people's social networks may facilitate help-seeking behaviours.

Findings from this study have informed development of the Long Covid support tool: <https://long-covid-care.org.uk/> (led by STIMULATE-ICP⁵⁷) to help raise awareness of Long Covid symptoms and available support for both people who may have Long Covid symptoms and healthcare professionals. NICE Long Covid guidelines⁴ were updated in 2024 however, lived experiences from diverse groups are still not represented; the current findings should be considered when managing people with symptoms (probable or confirmed) of Long Covid.

Participants' accounts of being dismissed, disbelieved, or discredited speaks of epistemic injustice (i.e. not acknowledging or undermining people's knowledge or experiences)⁵⁸ when seeking healthcare for Long Covid⁵⁹, especially related to racism and sexism⁶⁰. Key recommendations from the NICE guidelines for Long Covid are to believe, listen to and legitimise people presenting with symptoms indicating Long Covid⁴. The findings presented here further highlight the importance of these recommendations for people from ethnic minority backgrounds who face additional challenges when seeking care and support for Long Covid. Awareness-raising strategies to reduce stigmatising beliefs or behaviours from healthcare professionals are needed to deliver care that is non-discriminatory to improve patient care. Empowering GPs to be welcoming and open^{61,62} when presented with limited treatment options and limited understanding of a condition, such as Long Covid, is needed. In the case of Long Covid a focus on listening, believing and empathising⁹ will help healthcare professionals connect with patients, thus improving patient experiences of warmth in healthcare encounters which people from ethnic minority⁶³ backgrounds are calling for in healthcare. This is a crucial step for patients to gain trust in healthcare professionals and services, and may go some way to restoring epistemic justice in healthcare⁶⁰.

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Ethical Approval

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Tables

Table 1. Interview Topic Guide.

• Experiences of symptoms
• Impact of symptoms
• Use of wider support systems
• Experience of healthcare services or other supports
• Support and treatment preferences
• Facilitators/ barriers to accessing support
• Facilitators/ barriers to accessing support
• What recovery might look like
• Experiences of stigma, discrimination, and racism in healthcare
• Culture, religion and spirituality

Table 2. Participant characteristics: socio-demographics characteristics and year of COVID-19 infection.

Characteristic	N (%)
Gender:	
Male	15 (48.4)
Female	16 (51.6)
Age range (years):	
20-29	9 (29.0)
30-39	10 (32.3)
40-49	6 (19.4)
50-59	4 (12.9)
>60	1 (3.2)
Missing	1 (3.2)
Ethnicity background:	
Arab	3 (9.7)
Black	10 (32.2)
South Asian	10 (32.2)
Mixed heritage	6 (19.4)
Other	2 (6.5)
Occupational background:	
Student or not employed	7 (22.6)
Healthcare sector	4 (12.9)
Educational / professional sector	10 (32.3)
Transport sector	3 (9.7)
Sales/ customer services	4 (12.9)
Skilled trade	2 (6.5)
Missing	1 (3.2)
Ladder for community standing	
1-3	3 (9.7)
4-7	20 (64.5)

8-10	3 (9.7)
Did not want to answer	4 (12.9)
Missing	1 (3.2)
Living Location	
Southern England	6 (19.4)
London and Greater London	13 (41.9)
Midlands	4 (12.9)
Northern England	3 (9.7)
East England	1 (3.2)
Scotland	1 (3.2)
Wales	2 (6.5)
Missing	1 (3.2)
Pre-existing condition	
Yes	15 (48.4)
No	16 (51.6)
Year of first Covid-19 infection	
2020	14 (45.2)
2021	11 (35.5)
2022	5 (16.1)
Unknown	1 (3.2)

*Subjective social status measured using the MacArthur Scale of Subjective Social Status ladder (Goodman et al., 2001); a higher score represents higher social standing in a persons' community.