Medical ambivalence and Long Covid: The disconnects, entanglements, and productivities shaping ethnic minority experiences in the UK

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ABSTRACT

Structural violence - related to 'isms' like racism, sexism, and ableism – pertains to the ways in which social institutions harm certain groups. Such violence is critical to institutional indifference to the plight of ethnic minority people living with long-term health conditions. With only emergent literature on the lived experiences of ethnic minorities with Long Covid, we sought to investigate experiences around the interplay of illness and structural vulnerabilities. Thirty-one semi-structured interviews with a range of UK-based participants of varying ethnic minorities, ages and socio-economic situations were undertaken online between June 2022 and June 2023. A constant comparison analysis was used to develop three over-arching themes: (1) Long Covid and social recognition; (2) The violence of medical ambivalence; and (3) Pathways to recognition and support. Findings showed that while professional recognition and support were possible, participants generally faced the spectre and deployment of a particular mode of structural violence, namely 'medical ambivalence'. The contours of medical ambivalence in the National Health Service (NHS) as an institution had consequences, including inducing or accentuating suffering via practices of care denial. Despite multiple structurally shaped ordeals (like healthcare, community stigma, and sexism), many participants were nevertheless able to gain recognition for their condition (e.g. online, religious communities). Participants with more resources were in the best position to 'cobble together' their own approaches to care and support, despite structural headwinds.

1. Introduction

Long Covid is a community-defined term to describe the persistence of symptoms beyond 12 weeks following an acute SARS-CoV-2 infection unexplained by other causes (Callard and Perego, 2021). Long Covid affects an estimated 1.9 million people in the UK (Office for National Statistics, 2023). Amongst ethnic minorities, we argue that Long Covid experiences are inextricably tied to underlying structural inequalities, including via racism, but also other dynamics like gender and sexism (Smyth et al., 2024). We employ the term 'structural violence' to highlight the systemic ways in which social structures and institutions harm certain groups (Farmer, 2004). Structural violence creates the conditions for structural vulnerabilities. While structural violence focuses on the broad and indirect systemic harms imposed by structures, structural vulnerability points to the risks encountered (and susceptibility to harms experienced as a result) by particular groups (Rhodes et al., 2012). While structural violence focuses on the outcomes, structural vulnerability focuses our attention on lived experience, particularly the limitations imposed on social groups. As argued in this paper, for ethnic minorities living with Long Covid, structural violence in the NHS leads to vulnerabilities like suffering and a sense of isolation. Yet, it does not preclude validation and productive entanglements in some NHS encounters, or elsewhere. As also outlined in our paper, the violence of institutional racism is deeply implicated in medical ambivalence.

1.1. Legitimacy, ambivalence and Long Covid

First described in 2020, Long Covid quickly became a relatively high-profile condition, with only gradual evidence of biological aetiologies accumulating (Greenhalgh et al., 2024). Initially elaborated in social – and then legacy - media platforms (Rushforth et al., 2021), Long Covid was increasingly investigated by researchers (Hossain et al., 2023; Kingstone et al., 2020). Yet, it remains a neglected sphere of healthcare, steeped in ongoing battles over its legitimacy (Roth and Gadebusch-Bondio, 2022), anxieties about economic impacts (Cutler, 2022), and concerns about the potential for recovery (Hossain et al., 2023). *Long haulers*, as they were colloquially called in 2020, emerged to challenge assumptions about swift Covid-19 recoveries (Callard and Perego, 2021). Often positioned in moral terms, Long Covid became a condition highlighting the struggle between the desire to press ahead from what Demertzis and Eyerman (2020. p. 428) described as a "compressed cultural trauma", and the lived reality of continuing affliction. Much of the struggle is centred on the crisis of legitimacy that Long Covid has encapsulated, in common with other illnesses that ill-fit biomedical classification systems (Dumes, 2020). This uncertainty allows a kind of ambivalence around care to develop, creating conditions through which things like recognition and dignity become disallowed (Fraser, 1995). The politics of recognition in terms of ethnic minorities goes well beyond the acknowledgement of differences: it means equally respecting minorities as are majorities (Chin and Levey, 2023). Recognition is needed to address the unique needs and structural vulnerabilities that minorities face in healthcare delivery and policy making. As explored in this paper, medical ambivalence and associated practices of institutional neglect have disproportionate impacts on already marginalised communities.

1.2. Structural vulnerabilities, long-term health conditions and Long Covid

There is a vast literature on long-term health conditions in the UK which highlights the links between structural, institutional, individual and biological processes. This literature shows how through 'isms' like racism, sexism, ableism and classism, various healthcare groups come to be regarded as more disposable than others (Montesi and Calestani, 2021). For ethnic minorities, this can mean they have to demonstrate extraordinary needs and reach a higher level of believability than other groups to be regarded as worthy of care. Hackett et al. (2020) have demonstrated how perceived racial discrimination is strongly linked to poorer health outcomes like diabetes. Some ethnic minorities with long-term health conditions come to fear healthcare to the extent that they manage by denying symptoms, expressing scepticism about healthcare and/or avoiding it, while turning to other means of support, like religion (Shafiq et al., 2021). In the area of mental healthcare, there can be an over-reliance by professionals on medication, along with oppressive and coercive clinical encounters recounted (Bansal et al., 2022). Here, minorities report how their compelling realities - like racism - are side-lined in healthcare. Added to this is a dehumanising lack of professional compassion experienced, as well as a disregard for minority views on mental illness (which more frequently align with social rather than psycho-biological causality preferred by modern psychiatry) (Ridge et al., 2023). Research in the area of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), which has some similarities to Long Covid (Bayliss et al., 2014), has outlined how wider structural vulnerabilities play out in ethnic minority communities, including via lack of awareness of the condition.

There is an emergent literature on Long Covid and ethnic minorities. Minorities were disproportionately exposed to SARS-CoV-2 due to higher levels of social deprivation, as well as occupational exposures (Lopez et al., 2021; Shabnam et al., 2023). However, evidence about risks of Long Covid among ethnic minorities is mixed (Louie and Wu, 2023; Norredam et al., 2022), although more recent research indicates that certain minority groups are at increased risk of Long Covid symptoms compared to their white counterparts (Mkoma et al., 2024; Wang et al., 2024). Some qualitative research with ethnic minorities in the UK has highlighted how stigma and discrimination impede help-seeking and diagnoses (Smyth et al., 2024). Similarly, Mullard et al. (2024) have highlighted the extraordinary persistence needed by marginalised patients to get a diagnosis of Long Covid. Here, ethnic minority communities and those from other marginalised backgrounds highlight how they often become ensnared in misdiagnoses and misrecognition.

Long Covid research lacks sufficient representation of minoritised voices (Rushforth et al., 2021): A critical need if we are to better design practice and policy approaches to suit all sections of society. By better understanding the specific discontents of minority groups with Long Covid, deeper insight into structural vulnerabilities can be developed (Montesi and Calestani, 2021). Furthermore, a focus on Long Covid experiences can help highlight how patients with new health conditions develop narratives around their symptoms and circumstances, and the implications for healthcare engagement (Greco, 2012). While ME/CFS research, for instance, has cast spirituality as presenting barriers to healthcare in long-term conditions (where fatigue may be seen as caused by spirits) (Bayliss et al., 2014), the role of spirituality in Long Covid is unknown. Furthermore, researchers in the UK argue that those most affected by the condition should shape study designs and interpretations to ensure research is relevant (Pearce, 2021). Not only does our Long Covid research focus on ethnic minorities specifically, but it is the first such research to be grounded in such public involvement. What's more, we know that each long-term condition is unique. For SARS-CoV-2, this included its recent appearance and viral causality. This context influences specific types of "recursive cascades" (Manderson and Warren, 2016, p. 491), whereby structures (e.g. online communities) combine to shape health outcomes. Finally, there is no other research that we are aware of on Long Covid and ethnic minorities that has focused specifically on a conceptual analysis of structural vulnerabilities. The research question which drove our qualitative exploration was, "Situating our study amongst previous research on complex long-term conditions in the UK, and with particular attention to structural violence, like medical ambivalence, what are the challenges to - as well as potentials for - productive relations of care and support?"

2. Methods

2.1. Overview

We employed a qualitative design using semi-structured interviews, allowing for in-depth exploration of the issues facing underrepresented ethnic groups when it comes to Long Covid (Rushforth et al., 2021; Smyth et al., 2022). We recruited from these groups because they were disproportionality affected by Covid-19 (Sze et al., 2020), yet there were concerns they were not accessing Long Covid clinics (Dean, 2023), despite often working in public-facing roles and living in deprived areas, which are known risk factors for Long Covid (Shabnam et al., 2023). Ethical approval was obtained from the University of Westminster (ETH2122-1074 & ETH2223-1313).

2.2. Recruitment of participants

Advertisements via posters, videos and/or messages on social media, online support groups, university sites, faith/religious networks and community organisations were used to recruit participants with likely Long Covid. We purposively recruited those with self-identified Long Covid (recovered or current), to explore experiences among people who had not necessarily sought healthcare and/or had not received a Long Covid diagnosis (Alwan, 2022). Eligibility for participation included being aged over 18 years, self-identifying from an ethnic minority background, and living in the UK. Long Covid eligibility was determined via a hybrid of participant self-identification of having had Long Covid,

with the researcher using a checklist with the potential participant (based on NICE and WHO criteria for Long Covid (NICE, 2020; WHO, 2021)) to ensure that: i) Covid-19 symptoms were probable or confirmed by a test for at least 12 weeks or longer; ii) symptoms were not explained by another condition; and iii) symptoms impacted everyday functioning. Study advertisements used plain English and culturally appropriate language and images (e.g. about typical symptoms) to recruit. We used purposive sampling (Patton, 2014), to recruit people with a range of genders, ethnicities (people from Arab, Black, South Asian, and mixed backgrounds), ages and socioeconomic statuses.

2.3. Data collection

One-to-one semi-structured interviews were conducted online, between June-2022 and June-2023, averaging 1 h:36 min (range 54 min to 4 h:31 min). Thirty interviews were conducted online using Microsoft Teams[R], one was conducted by telephone. Participants were encouraged to have their cameras turned on for video interviews at least at the start to confirm participant authenticity (Ridge et al., 2023; Smyth et al., 2024). Interviews were conducted in English. To maximise inclusivity and accessibility, an interpreter was available for the interview to be conducted in a language other than English (none requested this facility). Interviews were conducted by several members of the research team: including four female members (3 of various White ethnicities and 1 of South Asian ethnicity) and one White male. Participants were made aware that they would be asked about sensitive topics, although feedback from participants indicated the therapeutic nature of telling their stories (Birch and Miller, 2000). Participants were offered regular breaks – or the option to continue the interview another day - to reduce fatigue impacts.

While the interview guide included a topic list, the researcher encouraged participants to narrate from before Covid-19 to the current day. Topics covered included the time they were infected; support accessed; ongoing symptoms; use of wider support systems; and interactions with healthcare professionals. Additionally, to explore the multiple layers of support and their importance in the management of health, participants were presented with a diagram of concentric circles (Kennedy et al., 2015). Participants were asked to imagine the centre circle as representing themselves and the inner circles representing the most important support systems. Outer circles represented less important supports. During the interview, participants were asked who and what support systems they would place in the corresponding circles. The interview guide was modified iteratively. For example, direct questions on experiences of discrimination and racism were added at the request of the expert advisory panel. Participants provided informed consent prior to the interview. Interviews were digitally recorded. Participants provided socio-demographic data at the end of interviews (e.g. age, gender, marital status, ethnicity, occupation, living location, and year of SARS-CoV-2 infection). They were also asked to rate their subjective social status using a modified 1–10 'ladder' measure, with the top ('10') of the ladder representing a higher social standing (Goodman et al., 2001).

2.4. Participants & analysis

Thirty-one participants (15 males, 16 females) ranging from 20 to 60 years of age (M age = 36.97, SD = 11.25), with a range of socio-demographics (See Table 1) took part. Participants' self-described ethnicity was recorded (and is used in identifying quotes). Subjective social status ranged from 1 to 9 (M = 5.35, SD = 1.81). The year of the first SARS-CoV-2 infection is also presented in Table 1. Interviews were transcribed verbatim by the interviewer or a professional transcribing agency, all were anonymised and checked for accuracy. Participants were invited to comment on their anonymised transcript; only one participant took up this opportunity. A coding scheme was initially developed inductively from the qualitative data itself by (re)reading

Table 1

Participant characteristics: socio-demographic characteristics and year of Covid-19 infection.

Characteristic	N	Percentage (%)
Gender:		
Male	15	48.4
Female	16	51.6
Age range (years):		
20–29	9	29.0
30–39	10	32.2
40–49	6	19.4
50–59	4	12.9
>60	1	3.2
missing	1	3.2
Ethnicity[a] 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	32.2
Transport sector	3	9.7
Sales/customer services	4	12.9
Skilled trade	2	6.5
Missing	1	3.2
Ladder for community standing[b]		
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
Year of first Covid-19 infection[c]		
2020	14	45.2
2021	11	35.5
2022	5	16.1
Unknown	1	3.2

[a] Note: Race is a social construct (Gannon, 2016), and the current advice is to use terms like "ethnic minority groups" (Khunti et al., 2020).
[b] Subjective social status was measured using the MacArthur Scale of Subjective Social Status ladder (Goodman et al., 2001); a higher score represents higher social standing in a person's community.
[c] Three participants had later reinfection of Covid-19.

data (Azungah, 2018), mainly by authors PG, NS and DR. These 'open' codes were refined and finalized with input from all the authors, as well as the Patient Advisory Group, to ensure that important categories were not missed. The codes of particular interest to this paper were those that were 'relational' in nature, i.e. where participants' agency and meaning-making were 'emergent', rather than focused on the individual (Burkitt, 2015). Such codes included racism, gender, discrimination, systems of support, help-seeking, religion, emotion and affect, and healthcare. Anonymised transcripts were entered into NVivo software for coding by PG (Hilal and Alabri, 2013). Relevant coding reports and queries were generated and read by more than one author (PG, NS and DR), and debated. Through a process of constant comparison (where each bit of data was compared with other similar data) (Glaser, 1965), open codes and their links were examined. It became clear that emergent relational themes like legitimacy, violence, ambivalence and recognition were important to making sense of the data. Thus, codes were combined to develop these themes (Braun and Clarke, 2006), which are explored under three headings in the results section. The initial draft of

the paper was developed by the first author and circulated amongst all authors for further comments and debate. Multiple rounds of feedback were invited. Refinements of the paper, including after anonymous reviewer feedback, were additionally circulated electronically until all authors approved the manuscript.

2.5. Advisory groups

People living with (or caring for someone with) Long Covid from Black or South Asian backgrounds (1 male and 6 females) were involved in the research design, including developing study aims, recruitment processes, interview topics and interpretation of results. We also involved a diverse group of academics and healthcare professionals (N = 5) interested in Long Covid and ethnic minority health as an expert advisory group. This group advised on recruitment and the interview topic guide. To facilitate our interpretations of the data and prioritise 'themes', we discussed our findings with both patient and expert advisory groups, as well as at two online stakeholder workshops including the public, charities and professionals.

3. Findings

Our findings are organised to outline structural vulnerabilities (e.g. lack of Long Covid information in communities), and how they relate to medical ambivalence (e.g. uncertainties around accessing care and resultant suffering), as well as opportunities in networks beyond the NHS (e.g. online connections and productive discourses in religious organisations). Illustrative data is given to support the analysis throughout.

3.1. "… And people don't trust your word, that is traumatic": Long Covid and social recognition

One problem in gaining recognition for symptoms facing participants was that people with Long Covid could appear well despite experiencing debilitating symptoms. Thus, a disconnect is routinely set up between what participants experience, and what others (including family and medical practitioners) observe. Subsequently, participants reported barriers in terms of what their loved ones and communities could comprehend about their illness:

'[People] say, 'Oh, why don't you just do some exercise?' They're just ignorant … But, you know, doctors don't know what it is … So, it's a very terrible illness and the quality of life is very low … people don't understand.' Male, Bangladeshi, aged 30–39.

Our participants emphasised the social dimensions of their mental health difficulties. During the acute infection phase, participants were initially traumatised by the prospect of death, especially given the media emphasised the risks to ethnic groups:

'I started coughing up blood and I was terrified. It was so scary because I thought that was the end. On the news you'd find that everybody, ethnic minorities in particular, the survival rate wasn't great … ' <cries> Female, British Indian, aged 30–39.

Subsequently, mental health was frequently undermined when participants were not believed about their Long Covid symptoms by healthcare professionals, and they did not get appropriate help. In turn, mental health difficulties could be met by a lack of understanding in some communities, since such problems were frequently stigmatised and poorly understood there:

'I would say in terms of mental health that my community generally doesn't really understand it. I think my parents are reasonably supportive but also don't fully get it … I find that quite frustrating … Physical health they get and will try and help with, but mental health they don't really get.' Female, British Indian, aged 50–59.

As participants' Long Covid symptoms evolved, new traumas unfolded related to the perceived social distance the condition could insert. One distinctive feature of Long Covid symptoms was that their strangeness was difficult for others to accept, e.g. body vibrations and brain zaps: *"… crazy, crazy symptoms … these mad changes to your physical and mental health, and people don't trust your word, that is traumatic …"* (Female, Black African, aged 40–49). Subsequently, many participants reported feeling distant from their communities, helpless, angry, and abandoned. Distance from communities was compounded by the novelty - and thus lack of knowledge - about the condition:

' … I mean, at that point I didn't know about Long Covid. Obviously, no one knew about Long Covid and everyone's attitude was like, ''well, you're not dead, so Covid wasn't really that serious.'' Male, South Asian and White heritage, aged 18–29.

Not surprisingly, recognition of Long Covid became critically important to participants. They frequently had a need to connect to others with the condition, and to establish a safe space to talk to those who could understand the unusual condition. Institutionally, the same media that had stoked fears about Covid-19 also carried stories elaborating on Long Covid, helping to get the word out in minority communities:

' … at some point somebody wrote a newspaper article in The Guardian, *and it described me … I [subsequently] found that invaluable to talk to other people in the same boat.'* Female, Asian, aged 50–59.

Distinctive to Long Covid as a long-term condition was the fear of re-infection with SARS-COV-2 causing worse symptoms. This meant many participants withdrew physically from others to avoid potentially worsening their symptoms via re-infection. However, extending the value of video calls during lockdown, online means of connecting could replace in-person socialising to some degree:

' … The fact that my exposure to Covid was through a friend … we have social media, we can hold Zoom meetings, over Skype … I just lost interest in physical meetups … ' Male, Black American, aged 18–29.

Another feature of Long Covid was that 'suicide talk' was deployed as a way of communicating the high levels of suffering involved when the gravity of symptoms was not well understood. None of our participants reported suicidality. However, one reflected on how they could well understand the process by which people became suicidal. Another participant indicated how talk of suicide, despair about symptoms and lack of hope for recovery were communicated (e.g. online) in ways that could validate suffering:

' … I was reading just yesterday about people who have become very depressed and reached the point of being suicidal … I can see how they got there. I'm not depressed, I'm not suicidal. But I can see how one could get there.' Female, British Indian, aged 30–39.

' … He [acquaintance on Twitter killed himself] … I understand where he's coming from … they're thinking, 'Is this my whole life? Is it going to be like this? I can't take it.' Male, Bangladeshi, aged 30–39.

Another element of Long Covid severity (perhaps shared with conditions like ME/CFS) was the suddenness of the disablement experienced. Here, people describe how they were left without social support compared to people disabled in more established ways (like chronic pain from injury, as well as mobility (e.g. arthritis), sensory (e.g. visual), cardiovascular, and cognitive (e.g. dementia) disabilities). Long Covid was rapid in onset and frequently severe, yet lacked the legitimacy of other disabling conditions. Participants reported being expected to find ways to cope with their new disability:

' … I feel very let down. It's not me, there's so many of us with Long Covid and we're just lying down in bed all day, you know, I could be working, I could be making money, I could be paying taxes … I want to be a member

of society. I'm disabled, I don't want to live my life like this, and it happened overnight.' Male, Bangladeshi, aged 30–39.

People talked about their work, with colleagues and work modifications being vital to managing Long Covid. While some participants were positive about the kinds of adjustments and support workplaces offered, others noted how workplaces operated in unhelpful ways:

'I'm very lucky I have a very stable job where I'm allowed to stay at home and I have a family that can look after me, but if I didn't have the support network that I have, I would probably be in the streets to be honest.' Male, Black American, aged 18–29.

'I felt like my workplace had abandoned me … I felt like nobody cared … They rang me …, "Are you back at work on Wednesday? You're coming back on the Wednesday?". I remember thinking 'Are they being for real?' Female, British Black Caribbean, aged 50–59.

3.2. "… You can be in hell, and they still refuse to help": the violence of medical ambivalence

A minority of participants reported that they had received good care from the NHS. For example, *"… my GP has been brilliant, brilliant"* (Male, Pakistani-Asian, aged 40–49). In general, however, participants were not enthusiastic about the healthcare they had received. The narratives revealed the nuanced nature of structural vulnerabilities participants experienced in their healthcare, frequently to do with racism, but also including other dimensions like gender:

'Being a brown disabled female, I've got lots of things against me. I mean, being female, you don't get taken so seriously by doctors, they're very quick to label you as hysterical and when I had pneumonia, they kept telling me I'm just anxious and tried to put me on diazepam when I had pneumonia … I have a kidney complication with my disease and my rheumatologist, I kept flagging up to her that my blood tests keep coming out abnormal, and it turns out my kidney complication is apparently really common in people of Indian origin … and she was very dismissive.' Female, British Indian, aged 40–49.

One level of institutional racism had to do with *common stories recounted* that participants told about themselves or of others (e.g. family) to do with healthcare prior to Long Covid. As one participant said, *"Obviously I've got brown skin, so all my life I've had to deal with racism, discrimination so you can understand the subtleties involved"* (Male, white and Chilean heritage, aged 30–39). Subsequently, participants assumed they would also face discrimination with their Long Covid, even if they could not pinpoint any particular incident. For example, one participant believed both sexism and racism were at play, yet was not able to recall specific episodes:

'I don't know whether racism was a part of it, but on the other hand, because racism is just a part of the culture, and sexism is a part of the culture, then basically … of course racism and sexism would have been a part of the way they would have treated me, but I can't put my finger on a specific incident that was obviously race-impacted … ' Female, Black African, aged 40–49.

The next level had to do with actual *suspected interpersonal racism* regarding Long Covid. As institutionalised racism in healthcare involves invisibility and deniability (Bansal et al., 2022; Ridge et al., 2023), participants could not be certain they had actually experienced discrimination. However, a number of participants pointed to the subtle nature of microaggressions – unintentional actions or remarks – that are nevertheless discriminatory:

'[Healthcare practitioners] that aren't from a similar cultural background are … I think I was slightly taken aback; I don't think it's negative racial [bias], you know, but I think that there's no recognition that you are

different, and it's not that they're being racist because they're not. They're not treating you badly.' Female, British Indian, aged 30–39.

Participants were often reluctant to identify a healthcare interaction as discriminatory or racist. Here, some people interpreted racism as about interpersonal interactions but needed strong evidence, such as *"they actually verbally say something racist"* (Female, British Indian, aged 30–39). Frequently, it could be difficult to work out if a healthcare professional was just a "horrible" person, rather than discriminatory:

' … You know, I've had really awful doctors in other places, and I don't know whether it's misogynoir that I'm experiencing from them or if it was just that they're horrible people, you know. So, I told about this patronising GP that I had dealing with my son's milk allergy, at that surgery, the doctor who headed up the practice was horrendous … I [also] heard stories from other people saying how awful he was. … ' Female, British African, aged 40–49.

The final layer was '*confirmed' racism*, whereby a number of participants believed they were able to compare their experiences to those of white people to prove racism. Here, currency was given to (what is commonly reported in the literature on long-term health conditions) that white voices and suffering were taken more seriously by healthcare professionals, compared to the treatment they received:

'I had to get an advocate because this people [health practitioners] are not hearing me. Maybe I am not articulating enough, maybe when they hear, maybe when they hear me speak, they hear a [Black African] person. That's what I kept thinking … so they can just fob me off. So, I had an advocate, I had a white advocate, and she does all the speaking for me …. whatever she's saying is what I told her to say, and for some reason the [doctor's] reaction is different.' Female, British Black African, aged 50–59.

It is against this background of generally poor Long Covid care (as highlighted in our previous work (Kingstone et al., 2020; Smyth et al., 2024), that institutionalised kinds of racism played out. Adding to the complexity, other kinds of discrimination (e.g. sexism) were also thought to play out, as also highlighted in other work (Au et al., 2022). The result was considerable uncertainty in interpreting care. Thus, structural violence in action was difficult to trace. Taken together, participants' accounts suggest that ambivalence in healthcare is by design. Like our participants, we are not able to be certain if ambivalence (some care offered, but then no more on offer) is connected to discrimination or Long Covid more generally in any particular episode:

'I found that really it was upsetting when I did call [the doctors], and it was just clear that you were not expected to do that, like, "You've had what we wanted to give you, and then and that's that.''' Female, Black and Asian heritage, age not stated.

Ambivalent healthcare meant that some participants retained some hope about gaining professional recognition for their suffering, yet others had given up. Ambivalence is an exceedingly difficult kind of care to negotiate. For instance, many participants believed that professionals withheld warmth (positive regard, kindness) related to their ethnic minority status. Thus, like the extraordinary distress required of ethnic minorities for recognition in other long-term health conditions, it was thought that a greater level of suffering (than demonstrated by white patients) was required of them to get similar care:

'For ethnic minority people, their symptoms are not taken as seriously, and it takes a greater level of suffering for a GP to recognize that something's happening.' Female, Bangladeshi, aged 18–29.

Participants also recognised that their GPs were gatekeepers to the wider NHS of treatment possibilities, and so practitioners had power over them:

'… *It's kind of shown a light on how, how much power they have over you … it's kind of amazing that you can be in hell, and they still refuse to help … '* Male, White and Chilean heritage, aged 30–39.

The potential for exclusion from specialist healthcare added considerable drama to GP consultations. Even if people were referred for further care by GPs, medical ambivalence was also rife in secondary care, where long waits and disappointments following referrals were widely reported. Some believed they had been simply forgotten about in the referral pathway. Others did gain access to further care, including Long Covid clinics, but then struggled to get the kind of care they needed. A long wait for an appointment could end in another referral pathway or treatment that appeared inappropriate:

'One stage, I went to my doctor with my ear pain and my hearing. I was telling that I might get deaf … the clinic, Long [Covid] clinic and they're waiting for me to get deaf and then they probably look after me … I was really stressed and worried that … I'm not that old [to] start losing hearing now you see. So that's shocking, shocking.' Male, Pakistani, aged 40–49.

In the face of this overall picture of medical ambivalence, participants longed for healthcare that recognised and legitimised them. The minority of participants who reported doctors who took their experiences at face value, not only felt better connected to their practitioner but also had space to explore their condition safely. In the quote below, concordance in ethnicity was able to overcome structural violence whereby the wellbeing of minority patients was not regarded highly:

He [Black doctor] asked me, 'How are you feeling and what's been happening', and I just started crying because nobody has ever asked me that before. And he said to me, ''Don't worry, anything you say to me, I believe you … '' Female, British Black Caribbean, aged 50–59.

Medical ambivalence becomes a critical vehicle for reproducing structural vulnerabilities such that many participants reported being distraught not only by Long Covid symptoms, but also by their healthcare encounters, which included gaslighting about their symptoms:

Honestly, that's how it felt. I was like 'These people are trying to drive me crazy because I know that this is happening, and they're telling me it's not happening.' Female, British Black Caribbean, aged 50–59.

Various participants reported disengaging from the NHS due to the perceived traumas involved in trying to extract care. An interesting feature of our Long Covid sample was that some participants were relatively well off (e.g. doctors, engineers). These participants were better placed to do their own research, push for referrals, get treatments through private healthcare (although private healthcare can at times also de-legitimise Long Covid), and/or via complementary therapies. These participants ended up developing their own self-care (e.g. vitamins, meditation, food choices) and healthcare (e.g. private healthcare, alternative practitioners) approaches through necessity, which at times could mean turning away from an NHS that was perceived as providing few if any treatment options:

'… I don't even bother going to my GP anymore. I just took it upon myself and one, hope that I get better on my own and two, research and spend my own money to access all the other stuff [private healthcare, complementary and alternative care]' Male, Black American, aged 18–29.

3.3. "… You're in the dark hole and there's a shining light, shining on you": pathways to recognition and support

As outlined above, it can be difficult for participants to accept their symptoms and the legitimacy of their own Long Covid, let alone convince others they have a medical condition. Socially, participants many times had instincts to disconnect from others: Cultivating social connections to support themselves in their struggle was not always how participants initially thought about their condition. Nevertheless, many concluded that their social connections were – compared to healthcare – *the* one thing that could make a difference in living with Long Covid. As one participant crystalised it, *"I've realised that actually there's more help from patient support groups than there is from medics"* (Female, British Indian, aged 40–49). A critical way to connect was online. Here, Twitter/X^R accounts became prominent in the pandemic, with health experts and/or patients connecting to talk about Long Covid, better cope, and find hope for recovery (Awoyemi et al., 2022). There also were various Facebook Long Covid support groups, and even charities established by people struggling to improve after Covid infection (e.g. Long Covid Support). While it was acknowledged, *"you gotta be really careful online"* because of potential harms like misleading information (Female, white and Black African heritage, aged 20–29), online alliances were highlighted by our participants as generally beneficial in overcoming isolation, gaining recognition, as well as sharing information about what works:

'Just searching online, like on Twitter, Facebook groups and just getting in touch with other people who have the same problem, and then link up with researchers and doctors and just online resources and then you learn from other people's experiences and any research that comes out and try different things that has helped different people … some things help and some things don't.' Male, Latino, aged 30-39

People also talked about how they were many times supported by networks of families and friends. Importantly, Long Covid symptoms could be so severe that without family support, some participants did not believe they could survive, *"If I didn't have my family, it would be a disaster … I can't go to the bathroom …"* (Male, Bangladeshi, aged 30–39). Interestingly, participants also found that others could step in to help when close networks failed them:

'My sister got me through the darkest times when I found myself in the darkest hole … none of my closest friends, and these are friends I've been lifelong friends with, none of them reached out saying I hope you're doing better … [a recruiter] … went out of his way, contacted the manager and director of the department and said '[Participant's name] has really struggled and it would be really beneficial if we could help him''. Male, White and Chilean heritage, aged 30–39.

Cultivating connections was central to participants with Long Covid (re)establishing meaning in life, and better managing their Long Covid. However, connections were not straightforward. For example, supportive others could also be a source of frustration, *"sometimes he [husband] is the cause of my stress and exhaustion …"* (Female, British Indian, aged 30–39). Entrenched gender roles and/or sexism from partners were also highlighted by women with Long Covid:

'I was still having like [to], you know, entertaining my daughter for at least half of every day and doing you know, some of the bedtimes and meals and things … I was under pressure to kind of, perform wellness despite not being very well …" Female, Black and Asian heritage, age missing

Although not always helpful, e.g. *"They [religion] don't understand … I'm not allowed to complain in front of anyone about my aches and pains"* (Female, South Asian, aged 50–59), religion or spirituality, and associated organisations could be another critically important support. Significantly, in contrast to the NHS, some religious organisations were said to recognise and actively support those with Long Covid:

'This is the main reassurance we had, actually from our religious people and all that. From the lectures that are online or on TV or from our [religious place of worship] as well. So, it was very strengthening and very reassuring for what happened because they were talking about it a lot. More than anywhere else … ' Female, Arabic, aged 40–49.

'[The] support that actually received from this [charity organisation] and my church group, they really actually helped me to lessen the worries I had. Because I was really worried for my, for my, for my family'. Male, Black British, aged 30–39.

Not only was providing community support a feature of some faith communities, but spirituality was frequently spoken about in positive ways in terms of how people coped with Long Covid, e.g. prayer to improve wellbeing, ideas that a higher power would help them, that fate was in the hands of a benevolent higher power, and/or that recovery was possible:

'Oh yes, I'm religious so, yeah, it helps to pray … I believe prayer works … But it doesn't mean I won't take my medication and the rest.' Female, Black, aged 20–29.

'I believe it's just the reason that I got cured. I mean, God is involved in everything you know.' Male, Mixed African-Caribbean, aged 30–39.

4. Discussion

The focus of this paper was on the struggle to extract recognition, care and support by ethnic minority people living with Long Covid, and the role of structural vulnerabilities therein. Previous research shows that for long-term health conditions, ethnic minorities struggle with structural violence (Page-Reeves et al., 2013), making it difficult for them to be regarded as worthy of care (Montesi and Calestani, 2021). Not surprisingly, minorities many times come to mistrust healthcare, turning elsewhere for support, like religion. However, stigma and lack of information in communities about health conditions can limit the kinds of support available (Boeck et al., 2022). This creates a form of health entrapment forged by structural violence. As discussed in the introduction, the literature suggests ethnic minorities are disproportionately exposed to SARS-CoV-2, and some minorities are at comparatively high risk of Long Covid symptoms. However, community stigma and unhelpful NHS approaches get in the way of minoritised people receiving a diagnosis of Long Covid, let alone adequate care. We uncovered the multiple, structurally baked-in ordeals experienced by participants. Participants were initially alarmed about Covid-19, especially via media images of 'othered' minorities as inextricably linked to the pandemic and death (Poole and Williamson, 2023). Subsequently, ongoing Long Covid symptoms were experienced as disabling, disturbing and strange, making it difficult for their communities to connect with participant experiences. Whether or not participants received good or poor treatment (and it was usually considered inferior) from the NHS, they experienced what can only be described collectively as 'ambivalent care', which was highly alarming for participants. Here, we showed how the underlying trauma of assumed, interpersonal and institutional racism (and sometimes with added sexism) played out in care. Ambivalent care had consequences outside the NHS, such as when participants were left troubled by the NHS, yet mental health itself was stigmatised in communities. Nevertheless, one feature of the pandemic (different to other long-term health conditions) was high levels of Covid-19 publicity, with experts and patients being brought together by circumstances on platforms like X[R] and Facebook[R]. Such online forums can foster supportive coalitions for mutual support, although there are potential harms (like limited hopeful patient stories available) (Day, 2022). In addition to spirituality and religion providing support for ethnic minorities as already documented in the literature, we found that religious institutions also step up to provide a space to cultivate productive Long Covid *discourses* (unlike the NHS), as well as practical community interventions. The lack of adequate care at the beginning or end of NHS referral pathways compounded participant traumas which other sources of support mitigated to an extent. Importantly, participants had varied access to resources: The relatively well-off were most able to do research themselves, find ways to circumvent ambivalent NHS care, and gain access to private medical and alternative care.

'Medical ambivalence' is the 'acceptable' face of structural violence, but we have shown how brutal it can be. The concept of medical ambivalence has been applied to other conditions, (Newman et al., 2006). For example, in attention-deficit/hyperactivity disorder (ADHD), patients with the condition may be wary about the impact of pharmaceutical treatments (Loe and Cuttino, 2008). In our development of the concept, medical ambivalence is the surface experience of patients receiving performative healthcare, pointing to deeper structural violence facing such patients. Here, patients with Long Covid may sometimes be met with belief and empathy from GPs. However, often participants' hopes of recognition are dashed, as they are met with cold disbelief and discrimination. Subsequently, they may or may not get a referral for secondary care. The referral may or may not lead to good care, or it may lead to professionals just going through the motions. There is the front-stage hopeful rhetoric of available care, exemplified via the appearance of Long Covid clinics relatively early on in the pandemic (The Lancet, 2020). The backstage reality was of relatively inaccessible clinics varying in their approaches, lack of awareness of such clinics, long waiting lists and disappointing clinical interactions. It is hard not to conclude that if the system is not designed to perpetuate patient distress, it does little to assuage it.

Medical institutions themselves might be ambivalent about a health condition (or groups of patients, including those of particular ethnic groups or genders) if they are unwilling to challenge vested interests and the ways they think about - and do - things (Bansal et al., 2022; Montesi and Calestani, 2021). Rather than 'unintended consequences' of a pandemic, existing structures serve the status quo, while keeping up appearances of unintentional harms (Broom et al., 2023), thus allowing authorities to evade accountability. The pandemic has been steeped in institutional failures of recognition, including ongoing failures to adequately educate health professionals and the public about Long Covid itself. Fraser's (2020) political conceptualisation of recognition suggests that recognition alone is not sufficient for social justice. Fraser instead highlights the need to consider both recognition and redistribution, since misrecognition and economic inequalities are both embroiled in social injustice. However, in Honneth's (1995) more psychological-moral account of recognition, misrecognition itself is the key source of social injustice, as it undermines a person's capacity to develop their identity, dignity and self-realisation. While Honneth's emphasis on interpersonal relations and moral status is helpful, so too is Fraser's emphasis on structural inequalities and the need for participatory parity. Until equality, our participants refuse to be passive recipients of structural violence. NHS ambivalence sparks the active search by ethnic minority patients for Long Covid knowledge, recognition and support elsewhere, including via online support forums, private care and religious organisations. These kinds of approaches created out of necessity show that while structures can limit the potential for recognition, collective actions and other institutions can challenge what is recognised in positive ways. Thus, coalitions of those living with Long Covid are adeptly navigating organisational pathways and agitating for change.

Structural violence in the NHS contrasted with social networks that were diverse enough to frequently allow support to be sourced somewhere. Racism was not remarked upon as a feature of these social networks, although sexism was. Nevertheless, an encouraging level of safety, legitimisation and recognition could thrive outside of the NHS. While religion, for example, is in decline in England and Wales (Office for National Statistics, 2022), religious affiliations can be relatively high in many ethnic minority communities (Jaspal, da Silva Lopes and Breakwell, 2021). We found that ethnic minority peoples' involvement in religious communities could provide valuable emotional and practical support. If not, their relationship to a higher power and their use of prayer or faith could also provide support, as suggested in other areas such as mental healthcare (Ridge et al., 2023). Structural violence in the NHS reproduces and amplifies existing struggles around ethnicity and gender in particular (Au et al., 2022; Lokugamage et al., 2020). Hence,

estranged clinical care encounters dominated the intersubjective accounts of our participants, forged in acknowledgements of historical injustices in healthcare, and further mediated through the disorder created by the pandemic milieu.

5. Conclusion

Due to NHS ambivalence, productive entanglements generally emerged outside of the NHS, where social coalitions could help repair and renew narratives of Long Covid. Here, the trauma of medical neglect and gaslighting (Au et al., 2022), could be acknowledged and worked through to some extent. Subsequently, Long Covid as a site of suffering worthy of support could be established, albeit in defiance of the medical authorities. While we successfully recruited a good range of genders, ages, social classes and ethnic minority people living with Long Covid, we were unable to find participants who were non-English speaking, and only one participant was over the age of 60: Future Long Covid research could usefully endeavour to include these additional voices. In terms of policy development, we found that people from ethnic minority backgrounds living with Long Covid judge they are especially disbelieved, and that their suffering is minimised, resulting in trauma and inequitable care. The delivery of safe and equitable person-centred care ultimately requires that clinicians understand the concept of medical ambivalence. Only with awareness raising can clinicians understand the change needed to respond to the lived experiences of people from ethnic minority groups. Training could help practitioners respond to patients with raised levels of positivity, hope and kindness. At the very minimum, the NHS should provide the human qualities of support that minorities are able to obtain elsewhere, such as online or in religious communities. This change could have a transformative impact on care, regardless of advances in Long Covid treatments. Here, service user involvement in the design of services would ensure authentic and meaningful co-production of services to meet the needs of minoritised groups.

CRediT authorship contribution statement

Damien T. Ridge: Writing – original draft, Supervision, Project administration, Investigation, Funding acquisition, Formal analysis, Conceptualization. **Alex Broom:** Writing – review & editing, Writing – original draft, Conceptualization. **Nisreen A. Alwan:** Writing – review & editing, Writing – original draft, Funding acquisition, Conceptualization. **Carolyn A. Chew-Graham:** Writing – review & editing, Writing – original draft, Funding acquisition, Conceptualization. **Nina Smyth:** Writing – review & editing, Supervision, Investigation, Funding acquisition, Conceptualization. **Dipesh Gopal:** Writing – review & editing, Methodology, Funding acquisition. **Tom Kingstone:** Writing – review & editing, Writing – original draft, Funding acquisition. **Patrycia Gaszczyk:** Writing – review & editing, Project administration, Formal analysis, Conceptualization. **Samina Begum:** Writing – review & editing.

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Declaration of competing interest

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Data availability

The data that has been used is confidential.

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