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'You're just a Guinea pig': Exploring the barriers and impacts of living with long COVID-19: A view from the undiagnosed

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Abstract

The COVID-19 pandemic had a disproportionate impact on ethnically minoritised and other marginalised communities, yet little is known about the impacts of long COVID-19 (LC) on this group. Living with LC takes its toll both physically, emotionally and financially and even more so when a diagnosis is hard to come by. By using qualitative interviews centring the view of undiagnosed and marginalised communities already classed as 'underserved' in the medical literature, we show the range of barriers and impacts faced by these groups in the UK, and the strategies of resilience they use. Whether trapped on a 'diagnostic odyssey' at the level of primary care, struggling to maintain employment and businesses, or managing family commitments, we argue many minoritised communities are caught in a liminal space of misrecognition, invalidation and ambiguity. We show how these impacts are generated by tensions and challenges in the process and categorisation of diagnosis, and how

LOCOMOTION-Consortium-List presented in LOCOMOTION-Consortium-List.pdf (leeds.ac.uk).
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this effects the daily lives of many individuals already on the receiving end of health inequity. We also offer some examples and suggestions for best practices.

KEYWORDS
diagnostic odyssey, emotional labour, health inequalities, invalidation, long COVID-19, marginalised communities, recognition

INTRODUCTION

Nearly two million people in the UK are reporting continuing symptoms of COVID-19 four weeks after contracting the virus (ONS, 2023) and approximately 17 million people in the WHO European Region within the first 2 years of the pandemic are reported to have continuing symptoms (WHO, 2022).

Despite a growing global concern, long COVID-19 (LC) is still a largely hidden condition and particularly so in ethnic minority communities (Khullar et al., 2023; Norredam et al., 2022). Our research study into LC amongst marginalised communities in the UK highlights the barriers patients face when accessing health-care support, the double-burden of being both marginalised but also having symptoms of a condition that is newly emerging[1] and under acknowledged in the popular consciousness of health-care professionals. We highlight the impacts of these barriers and centre the experiences of ethnic minorities and other underserved communities living with the symptoms of LC but without a clear diagnosis or access to specialist clinical support. Whilst we do use the terms minoritised communities and ethnic minorities throughout the article, we want to stress the importance of not wanting to present their experiences as monolithic. There are some subtle and some less subtle variations in the experiences of different groups and we have attempted to capture that; however, there are also similarities between different ethnic minority groups, and it is also important to represent that collectively, ethnic minorities experience an indiscriminate disadvantage that is racialised in origin.

We draw on qualitative research with 23 individuals living with the symptoms of LC, but positioned at various stages along a diagnostic journey. We explore the experiences of our interlocutors' and highlight the intersection of marginality, health and the process of diagnosing both the parameters of the conditions and how structural barriers reveal themselves yet again as ever present in this process. We chart what it is to be trapped in the liminal space of a diagnostic odyssey made more challenging by experiences of marginalisation and how structural barriers impede inclusive health-care provision. Whilst much has been written on the barriers to inclusive care, the context of LC as an emerging field in health-care provision allows us the space in which to rethink the design of services, to show how enduring and pervasive structural inequalities are, and, most importantly, what strategies may work to dismantle them.

Diagnosis

Mildred Blaxter (1978), though writing about 'social disorders' and alcoholism in particular, discusses the ways in which diagnosis is both a category and a process. The importance of

classifications in health diagnoses are two-fold: firstly, to provide useful information about populations (mortality, trends over time) and secondly for the development and practice of the science by enabling comparisons and generalisations to be made. What are the implications of this then for a condition that is relatively new, contains a raft of symptoms that can co-exist in various forms and severities and for which there is no overarching biomarker? Projects like LOCOMOTION, on which this research study is based, aim to answer these questions (Long COVID Study (LOCOMOTION) is Optimising NHS Services (leeds.ac.uk).

Blaxter (1978) points out, the 'art' or 'science' of diagnosis is concordant with the 'descriptions of the condition acceptable or available in the relevant universe of knowledge' (Ibid. p. 9) As such, this research highlights that our understanding of LC is a work in progress and that the question of acceptable knowledge, and we might add treatment, must not only be determined in conjunction with those with symptoms that are diagnosed, but also by those whose symptoms are yet to be diagnosed and are from those communities that are seldom heard yet suffered the greatest impact from the originator virus—COVID-19.

The structural inequalities that shape the lives of minoritised communities are further acted out in the spaces of the uncertainty that surround this condition. As Blaxter (1997 p. 747) also points out, illness biographies are accounts of social identity. However, not only does this mean that exploring the relationship between the condition and health inequality is epistemologically challenging because it is perhaps 'unreasonable to expect people to devalue [their] identity by labelling their inequality', it is made even more so by the diagnostic uncertainty of the condition itself (Barker et al., 2022). As such, patients not only have to labour in getting their condition recognised, they must also do so under conditions of structural inequality that they either must claim to be the victim of or necessarily obfuscate on the affective level of identity/self-preservation. This labour takes yet a further toll on the health and wellbeing of ethnically minoritised communities and particularly amongst those with fewer networks—or 'social capital' (Putnam, 2000)—and less ability to negotiate the health system—or 'cultural health capital' (Shim, 2010). Institutional racism coupled with other intersecting forms of disadvantage can have a direct impact on the ageing processes of the body. For example, Thomas et al. (2021) show how institutional racism shortens the length of telomeres, a biological indicator of accelerated ageing, amongst African American women and particularly for those with lower educational attainment. This indicates that the impacts of institutional racism are felt more strongly by those with intersecting disadvantages, which may further lengthen their diagnostic odyssey.

Whilst originally used to understand the longitudinal diagnostic process for rare and complex genetic conditions, the term 'diagnostic odyssey' is now commonly used to explain the diagnostic process both for individuals eventually diagnosed with a condition or disease and/or a cohort of individuals exhibiting similar symptoms striving for a diagnosis (Clare et al., 2023). Research studies on the diagnostic odyssey have largely focused on childhood disease and the anguish parents and carers feel when the origins of the child's health issues are unknown. It also often describes the process of diagnosis and how parents and carers are locked into a regimen of tests to find the origins of their child's ill health (Carmichel et al., 2015; Lewis et al., 2010). Moreover, many studies primarily focus on rare genetic conditions, and whilst some recent works focus on disparities in access to genetic testing amongst ethnic minorities, most is focused on the ethnic majority population.

The exceptions include, Fraiman and Wojcik (2021) who take a social determinants of health approach to understand the variations in diagnostic testing for ethnic minority children. Their work highlights how the violent history of eugenics and racialised experimentation

overshadows discussions on the inequities of access and rates of diagnostic testing amongst clinical geneticists. For conditions such as Cystic Fibrosis, Fraiman and Wojcik (2021) highlight how at every point in the pathway to diagnosis, from the lack of suspicion of the condition in ethnic minority children, through underrepresentation in newborn screening rates, to the interpretation of the tests themselves, there are delays (Ibid.: 296). Whilst the discrepancies in cancer screening amongst ethnic minority adults have been well documented for a number of years (Armstrong et al., 2005; Chavez et al., 1995; Tatari et al., 2020), very little has been done on adults experiencing the diagnostic odyssey at the point of primary care and even less from the perspective of ethnic minorities and other marginalised communities.

Some notable exceptions include Kam Bhui et al.'s, (2011) research study into chronic fatigue syndrome (CFS), which is also a symptom of LC and itself was a condition that struggled to be recognised (Cohn, 1999). Like long LC, CFS is disproportionately prevalent amongst White women, majority White populations and the middle classes. However, population-based research studies in the UK and America highlight how rates of CFS are higher in lower socioeconomic groups and in non-white populations. The first study into CFS to include a large ethnically diverse sample controlled for physical inactivity, age and anxiety and depression (Bhui et al., 2011) indicated that CFS rates were more likely a result of social status, power and greater exposure to adversity (Ibid. p. 9).

Similar findings were drawn by Bayliss, et al. (2014) who through a qualitative study into the diagnosis and management at primary care of CFS/ME (CFS/ME) amongst Black and ethnic minority people, highlight six themes that act as barriers to diagnosis. These included models of illness, access to care, language and understanding, family and community, religion and culture and stereotyping and racism. The authors noted, similar to Bhui et al., that whilst population studies highlight a higher frequency of CFS/ME in ethnic minority communities, the diagnosis is made less frequently. They draw attention to the challenges of receiving a diagnosis from the GP and how patients would move to a practice or GP that was often suggested to them by someone with CFS/ME in the hope of receiving a diagnosis. Patients, health professionals and community leaders also suggested that language barriers may exist that prevent diagnosis and management. In particular, health-care professionals suggested that because CFS/ME is a diagnosis of exclusion, some patients for whom English was not their first language struggled to describe all their symptoms. Because diagnosis also requires patients to attend multiple visits to exclude other conditions, these language barriers became more evident. One health-care professional in Bhui et al.'s study noted how access to care is made all the more challenging when English is not the first language (Ibid. p. 147). This suggests there is work to do to make clinics more accessible for a range of communities where English is not their first language. Community leaders noted how patients from ethnic minority backgrounds would more often turn to family for support with their symptoms and this is well-documented in the literature on support for long term conditions amongst minority groups (Mullard et al., 2023).

More worrying perhaps is the finding that patients, carers and community leaders believed that some health professionals held stereotyped views of different ethnic minority groups and cultures such as 'lazy, complainers, or work shy'. Wishing to avoid these labels, patients were then understandably reluctant to visit GPs with their symptoms (Bhui et al. p. 149). Whilst existing evidence gives a fairly comprehensive account of the various barriers to receiving a diagnosis, little is known about the impacts of the diagnostic journey on ethnic minorities in particular.

Impact of non-diagnosis

Lewis et al. (2010) make a useful contribution to our understanding of the experience of the diagnostic odyssey amongst ethnically minoritised communities. They draw a distinction between the inner impacts of not having a diagnosis and the outer more sociological impacts. Inner impacts are connected to emotional stress and mental health decline, whilst the outer impacts relate to the encounters with health professionals and support networks and to the wider determinants of health. They describe the frustration felt by parents when waiting to receive a diagnosis of their children's condition, with anxiety, a fear of the unknown and a sense of not being in control as inner affective impacts. However, whilst an inner and outer distinction is useful, it is also true that experiences in the world impact the inner affective dimensions of people's experience. As such, rather than focussing primarily on the negative internal consequences of structural inequalities, we must also consider mechanisms and structures to prevent those impacts from occurring in the first place.

Diagnosis remains central to medical epistemic practice and patients without a diagnosis are trapped as 'patients-in-waiting' (Timmermans & Buchbinder, 2010). Indeed, we struggled with what to call our cohort of interlocutors suffering with symptoms but with no diagnosis: they were not quite patients yet. Moreover, there is some debate over the term patients more generally as people with long term conditions are not necessarily considered patients at all times during their illness experience and some actively avoid being labelled as a patient at all (Jauho, 2019). As such, understanding the different experiences of the diagnostic journey can further elucidate the different forms of patient-hood that is practiced (Jeske et al., 2023) or how those diagnoses are contested and stigmatised (Burke, 2011; Campbell, 2021), which may even result in questioning whether a diagnosis really matters at all (Brossard & Carpentier, 2017). Our study explores what it is to exist in the liminal space of living with LC symptoms but without a clear diagnosis, particularly for minoritised communities.

METHODS

The overarching aim of the LOCOMOTION project is to generate and use the developing science around LC to guide how health services manage the condition and ensure that patient views and outcomes are at the heart of LC services. There are 10 clinical sites (LC services) spread nationwide participating in the study and include one in Scotland and one in Wales.

The study is divided into three workstreams. This article is based on the research aims of workstream 1, which are to explore the evidence behind what clinics and GPs should do in terms of investigation and treatment. Whilst we recognise that the 'root cause(s)' of LC are not yet known, there is still much that can be done to improve functioning, ability to work, and quality of life (Sivan et al., 2022). As part of this overarching research objective, our workstream has the following four core aims:

- To understand and address socioeconomic, gender and ethnic inequalities in LC and in LC service utilisation.
- To explore symptom recognition (including by clinicians), health-seeking behaviour, care pathways, motivations/disincentives to accessing health-care support and attitudes towards LC and stigma.

- To explore emotional touch points, patient support networks (such as peer support) and trajectories of care and to support incorporation of findings from these interviews into LC service co-design.
- To utilise evidence from our interviews to inform the development of outcomes across the whole project.

The first two of these aims build on our understanding of multilevel dynamics that create and maintain inequalities for marginalised groups through the mechanism of public services such as health care. For example, previous research studies have highlighted the influence of macro- (policy and societal) and meso- (institutional) level dynamics on the creation of barriers such as poor access, poor health literacy and mistrust within marginalised communities (Mir et al., 2015, 2019, 2020).

Following ethical approval for the study, patients were identified and recruited through five routes: (1) snowballing from interviews with LC clinic patients and (2) expert informants (e.g. other research project leads and national experts); (3) GP practices (information posters); (4) relevant community organisations (through information posters and local staff identifying potential participants) and (5) Social media, such as Facebook/Twitter (X).

Patients participating in the qualitative interviews are aged 18 or above with ability to provide informed consent and have either confirmed or suspected previous infection of COVID-19. They must be able to participate in interviews (i.e., through virtual means, telephone or face to face at a venue of mutual choice). We have achieved a diversity in terms of gender, age range, ethnicity and socioeconomic grouping, with most focus on groups that experience disadvantage: women, minority ethnic, deprived, disabled and homeless or traveller communities or those working with such groups.

Our sample was split into two cohorts: one, we called key informants (KI) who were health or community professionals working in the field of either COVID-19 or LC and had knowledge and experience of working on health inequalities and with marginalised communities (18 participants). The second cohort included 23 in-depth interviews with people living with LC symptoms (LC), identified as being from an 'underserved' community and yet to have received a diagnosis. Of the 23 participants living with LC symptoms, 14 self-identified as being from an ethnic minority, 10 of the 23 were from a low income background and 17 were women (see Table 1). Semi-structured interviews explored the following topics for both KI and LC participants, and questions were tailored accordingly:

1. COVID-19 history and continuing symptom biographies.
2. Impacts of LC: work, family, social, emotional/psychological and physical.
3. Support received and support barriers.
4. Attitudes towards LC: their own and those experienced from others.

Data was analysed using the Ritchie et al. (2003) framework analysis model for qualitative data analysis for applied policy research. Analytical themes were developed through a process involving data familiarisation, development of an initial coding framework to group data on similar topics (this drew on interview questions as well as issues emerging from interviewees themselves), assigning codes or subcodes to segments of text in each interview transcript and producing a chart of data from all interviewees to support mapping and interpretation across participants and within data from each interview. Two authors (Mullard and Mir) initially coded 20% of transcripts to check interpretations and resolve any differences in how codes were

TABLE 1 Shows demographic details for participants with long COVID-19 symptoms.

Consent code	Location	Ethnicity	Age range	Gender	Low SES
LC01	Birmingham	S. Asian	25–35	Female	
LC02	Kent	Black British	25–35	Female	Yes
LC03	Leeds	White British	?	Male	
LC04	Leeds	S. Asian	65–75	Male	
LC05	Leeds	S. Asian Pakistani origin	65–75	Female	
LC06	Newcastle	Mixed Portuguese	35–45	Female	
LC07	Leeds	Kashmiri/British	35–45	Female	
LC08	Durham	White British	35–45	Female	Yes
LC09 (&KI)	Birmingham	White British	45–55	Female	Yes
LC10	Newcastle	S. Asian Pakistani origin	45–55	Male	Yes
LC11	Newcastle	African/White British	35–45	Female	Yes
LC12	Wales	Black British Somalian	45–55	Female	Yes
LC13	Newcastle	Black British Caribbean	35–45	Female	
LC14	Aberdeen	White Scottish	35–46	Female	
LC15	Bradford	Pakistani British	45–55	Male	
LC16	Edinburgh	White British	25–35	Female	Yes
LC17	Dundee	White Scottish	45–55	Female	
LC18	Burnley	S. Asian Pakistani	45–55	Female	
LC19	Leeds	White English	55–65	Male	Yes
LC20	London	White English	35–45	Female	Yes
LC21	Leicester	S. Asian	35–46	Male	
LC22	London	Black British	35–45	Female	
LC23	Midlands	S. Asian	35–46	Female	Yes

assigned to text segments. NVivo software was used to code transcripts and produce data charts. For this article we draw on analysis of themes relating to COVID-19/LC history, support received and support barriers.

RESULTS

In this article we focus on three central themes that relate to the quest for diagnosis and epistemic understanding of the range of symptoms our interlocutors experienced. These themes focus on (1) questions of the perseverance and emotional labour required to continually fight for support, (2) the balance between validation and invalidation of the experiences patients had and how this is overshadowed by prejudice and discrimination and (3) the issue of problematic boundaries for a condition whose parameters are only now being defined. Moreover,

underpinning these more generic experiences are the underreported concerns and barriers faced by ethnic minority patients. These concerns are linked to their interactions with health-care professionals, both the fear of and the direct experience of discrimination during these encounters and the ways in which patients felt their diagnostic journey was further complicated by these encounters. These experiences were felt most acutely by our South Asian Muslim male and Black British of African descent female interlocutors. The intersections of religion, race, gender and ethnic origin further compounded fears about racialised discrimination and our interlocutors' capacity to navigate their diagnostic journey (cf. Okoro et al., 2022).

We can chart the experiences of ethnic minorities and other marginalised communities from their encounters at primary care and the effort it takes to even be seen in the first instance by a GP, then the labour required to get the necessary tests and then what happens once the test results are in. For many of our interlocutors the primary challenge begins even before they have discussed their symptoms with a GP. The following sections outline the key issues experienced by our interlocutors.

PERSEVERANCE AND EMOTIONAL LABOUR

Issues relating to the perseverance required in order to get a LC diagnosis and a referral to a LC clinic has been well-documented by various LC support groups and our patient advisory groups (https://www.longcovid.org/; https://LOCOMOTIONpatient-and-public-involvement/) and in the growing literature from similar studies (Baz et al., 2023). Indeed in one interview with a LC activist this was highlighted as the singular common feature shared by many people living with LC symptoms who have joined the growing network, long COVID-19 support. Moreover, the commonality of experience over the perseverance involved often brought people together in the online peer support setting. This enabled the sharing and 'off-loading' of frustration felt by those trapped on a diagnostic odyssey. This sharing of experience and receiving emotional support from similarly situated people helped build a degree of collective resilience. Knowing you were 'not alone' became both important to interlocutors but also a source of deepening frustration with the amount of people living with symptoms but not being seen. For many of those we interviewed even getting an appointment was a struggle, due to the nature of the condition, the range of symptoms they experienced and the gap between testing positive for COVID-19 and onset of LC. As one LC activist pointed out:

> So many people have such a poor understanding of what the symptoms of both acute and LC are that they have no idea. The other thing is that there can be a huge gap. You can by asymptomatic or have incredibly mild or indeed not mild [COVID symptoms]. You can then think you've completely recovered, and then even up to a year later we're seeing people who think they've completely recovered, gone back to their daily lives, and then they'll get hit by LC. But actually a gap is really common and so people have no idea that if they're suddenly getting arthritic joint pain or tremors in their hands or diarrhoea [that it could be linked to LC]. According to our survey and what we see anecdotally in the group, is still terrible. People are waiting months and months and months to be seen.
>
> (LC09/KI, White woman, 45–55 years)

Underfunding and the continual reforms to primary care, increasing waiting times, access issues, and potential impacts on patient health have been central issues explored at the level of primary care for a long time in the UK (Checkland, 2004; Ford et al., 2018; Kang et al., 2019). Moreover, the effects of the pandemic on waiting times as the backlogs are being cleared, with little additional resource, have added a new challenge to the delivery of both primary and secondary care (van Ginneken et al., 2022). These structural pressures are felt most acutely in contexts where patients experience marginalisation (Fenton et al., 2020). For example, many ethnic minorities work in the service industry, are self-employed, on zero-hour contracts or have caring responsibilities, meaning that they often do not have the time to wait in a queue on the phone. In fact, the frustration at having to do this was recounted by numerous participants, who were often also faced with unhelpful responses from health-care staff once they did get through. Very few were able to navigate a way through the barriers they described.

> You have to ring in at 8 o'clock in the morning. And that is a nonstarter because you've got, you're competing with about 20 other people. Em if you ring during the day, you get into this queuing system. A few times I've been told you're number 11 or number 12 in the queue! By the time we get to number one, they've cut you off!
>
> (LC04, South Asian Male, 65–75 years)

> You speak to different GPs every time you call the surgery. Em I had one who used to say 'it doesn't really matter what it is. You just need to rest and work less!' [laughs] and I'm like: 'I can't! Can you tell my boss that?'
>
> (LC06, Southern European, Female, 35–45 years)

> It's very difficult! I feel that I have little faith in speaking to the GP because I'm not getting anywhere since November 2020. It's now May 2022 and I've not got anywhere! I haven't had a referral to the LC clinic. I haven't had any treatment plan put in place in terms of my breathing...it's just, it's frustrating.
>
> (LC01, South Asian Female, 25–35 years)

> Getting through to the doctors in the first instance was always a problem. But I learnt very quickly to find other ways. Like the 111 service and the e-consult, which subsequently, the e-consult service only became useful in the last year and a half though. I think when they really managed to get it up and running properly. I don't know if that was the case or if it was just when I discovered it. But I found that to be the most useful service to get help quickly. And to get help from people who knew my record. Because sometimes I found myself speaking to people who had no clue what I was talking about, and just sort of very much lumped me in with everybody else!
>
> (LC12, Black British, Female, 45–55 years)

People with LC from marginalised groups responded to inadequate support in diverse ways, depending on their personal capacity and resources. However, what is highlighted is the emotional labour and perseverance involved in having to fight for diagnosis and care. Emotional labour is often understood in health-care literature as the added work of nursing staff, in particular, who both invest in and provide emotional support to those in their care (Theodosius, 2008). We refer to it in its more contemporary application to the added work that minoritised ethnic communities have to do to navigate their social worlds. Simply put, minoritised ethnic communities have to

develop an emotional resilience to the potential threat of and experience of racialised discrimination. Developing this resilience is a form of emotional labour that is not required of majority White communities and, as such, is an added barrier to accessing health care. As ways to manage this additional burden, many participants conducted their own research into LC as a way to develop strategies to cope with the continuing symptoms, and many reported learning about the care they could receive despite little contact with GPs. Once armed with this information, some felt better equipped to assert their needs and develop the resilience required to do so. Moreover, developing the cultural health capital necessary to navigate and communicate with health-care professionals can have a significant impact on a likely diagnosis (Shim, 2010).

> I read about the pathway, and actually I could be referred to the LC clinic. So I got back in contact with the GP and was quite assertive and just said, "look it's been this, this many weeks, there's no improvement. I feel a little bit worse. I do need to go to the clinic".
>
> (KI04/LC, South Asian woman, 25–35 years)

> I had to fight, a lot, every single step of the way [...]. And chasing. And making sure things were booked and ... things that I needed. I haven't seen a GP for nearly three years now.
>
> (LC02, Black British Female, 25–35 years)

In addition to seeking out their options for care with little support from health-care professionals, others sought support from peers and from their faith.

> I'm a person of faith. I have my faith. And I lean on that a lot and have been leaning on it a lot. Em and this, this [process] has really challenged me psychologically more than anything else.
>
> (LC10, South Asian male, 45–55 years)

Seeking and finding support outside of mainstream provision has a long history in the UK and particularly so for marginalised communities. The solidarity and reciprocity found through peer and faith community support helped to create the resilience required to fight for support and meet need (Karner & Parker, 2011; Wilson et al., 2023). Indeed, even the recognition of LC itself as a severe, enduring condition was generated out of the need for validation amongst people living with the symptoms (Callard & Perego, 2021; Rushforth et al., 2021). Moreover, the extensive support-seeking activities of those living with LC in our sample is symptomatic of a condition that is not widely recognised by health-care professionals and likely to be compounded by diagnostic delays for those from marginalised populations. The diagnostic delays and misrecognition from health-care providers has led many to feel their symptoms have been invalidated.

VALIDATION, INVALIDATION AND THE HARMS OF MISRECOGNITION

Long drawn out diagnostic experiences can have a significant impact on the mental health of patients. This is because the lack of recognition they have faced leads to an invalidation of their experiences. As the interlocutor above noted, they had been challenged psychologically, leading

them to question their position in the world with regards to their health and what the future might look like. In turn, these challenges led to an increased reliance on their faith and the support of their faith community. These invalidations can leave patients feeling that their symptoms are considered fictitious or questionable. This is made even more prominent when test results are returned normal. One interlocutor explained this in the following way:

> They said "Oh you have to do some blood tests." And all of them came back normal, the blood tests. But then my GP never picks up the phone. It will ring and ring and ring and ring! They never pick up the phone! And when they do pick up the phone, they say like "Oh well you're going to have to make an appointment with the GP or the nurse" Or, or "well your symptoms are not that, you know, serious". It's just like kind of brushed away like "oh it's nothing"!
>
> (LC11, Mixed-race, Black British female, 35–45 years)

Whilst many participants were fairly forgiving in their analysis of the lack of support, citing the contemporary nature of LC and the extreme pressures faced by doctors, many also felt abandoned and left wondering if their symptoms were real. Burke (2019) highlights the importance of encounters between physicians and patients and how patients can be left feeling 'it's all in their head'.

> ... A typical physician-patient interaction may proceed as follows: (1) the physician provides a rundown of normal investigations, (2) the patient is told they have no known medical diagnoses, (3) a brief awkward exchange occurs and (4) little further explanation, guidance, resources or facilitation of an appropriate referral process is given. Even if the infamous phrase is not explicitly stated, this sequence leaves the patient to infer for themselves that it must be all in their head.
>
> (Ibid.: e1)

In this description guidance, resources and even the mention of a clinical referral are included, yet still patients are left wondering if their illness experience is real. In the case of participant LC11 above, the encounters did not provide any potential for a clinical referral or treatment pathway, but instead the patient was told their symptoms were not that serious or that exploratory tests were inconclusive.

Steffan K. Herrmann (2011) draws the link between misrecognition and social exclusion to highlight the ways in which misrecognition, however benign, is a form of exclusion. Whilst Herrmann's case study of the holocaust was anything but benign, the theoretical framing of misrecognition that is put in motion is useful here. This is because the link between misrecognition and dignity is clearly made by Herrmann, which is in a similar way as debated earlier by Nancy Fraser (2005) and Axel Honneth (1996). There is a clear link between recognition, dignity and justice that can be played out in a variety of contexts (Mullard, 2023). For example, our interlocutors talked of the consequences of not being heard by health-care professionals and how this misrecognition of their symptoms invalidated their experiences and left them feeling dehumanised.

> I feel insignificant. Not important you know. It's like I have to realize that this doctor is so busy, and what am I supposed to do? He hasn't got time to actually look at what's actually going on. He can only do what he's planned for. And you know

> human beings aren't like that! We don't work like that. Well as I say, it makes you feel insignificant and worthless.
>
> (LC04, South Asian male, 65–75 years)

The misrecognition experienced by this participant has caused harm on the level of self and dignity. This interlocutor had also discussed feeling dismissed by GP receptionists who had chatted freely to White patients but struggled with eye contact and in pronouncing his name when addressing him. This all led the participant to feel less than their White counterparts, thus highlighting a clear affront to their dignity as a human being deserving of equal treatment. Such sentiments were expressed by some interlocutors to the extent that they felt less than human.

> With new things, that's what it feels like, you're just a guinea pig and they go like "here's a slip of paper. See you later." Because if they can't even deal with stuff that is well established, how the hell are they going to deal with LC?
>
> (LC13, Black British female, 35–45 years)

As Nancy Fraser (1998, p. 2) conceived, the harms of misrecognition require a consideration of both redistribution and dignity. She proposes these harms are situated in the domain of culture and identity and, as such, require additional attention that challenge the structural basis of inequality. Fraser suggests this can be achieved through a shared understanding of value-pluralism that can champion what she calls 'participatory parity'. For Fraser, recognising and respecting the diversity of values that exist within a society can lead to more equitable participation. However, in the 26 or so years since Fraser's proposition, attempts to level the playing field through policies such as 'equal opportunities' that aim to encourage a parity of participation have not been entirely successful. For example, gender and racial inequalities still exist in employment, education and health (for gender, Ruxo et al., 2021; for race and health, Nazroo, 2022). Systemic inequalities still persist and equal opportunities have come under considerable scrutiny as far back as their early inception with accusations from the left of tokenism (Creighton, 1977) and, in contemporary form from the right, a pejorative conceptualisation of 'wokeism' (Green, 2023). What perhaps is lacking in current actions to address health inequalities (and other inequalities) from both sides is an authentic recognition of our connectedness and shared humanity (c.f., Mullard, 2023). Better establishing this deeper mutual connection that goes beyond culture and identity may well generate the conditions for redistribution, participatory parity and a reduction in the newly emerging infectious diseases that lead to long term debilitating conditions such as LC. A vehicle for achieving this could be the one health approach that seeks to create an interdisciplinary recognition of our interdependency not only within our species but with all living things and their environments (Destoumieux-Garzón, et al., 2018). In order to better understand this interdependency, we might seek to explore in more depth the contexts and frequencies within which these misrecognitions and invalidations of patients' experiences exist and their consequences for wider society.

Allyson Bontempo (2022) calls for a systematic study of the invalidation of patient symptoms and through her narrative review suggests that the variability in language used to create feelings of invalidation needs to be recorded and measured. Her suggestion is to have a self-reporting measure for patients to document the occasions when they feel their symptoms have been invalidated. This may help to create a deeper understanding of the context and frequency of this phenomenon across a variety of symptoms and across demographic groups. Whilst useful for research, we also need to consider how best to use that data to inform service design.

Bontempo's findings suggest that invalidation is most likely to occur for conditions that present with nonspecific symptoms, are contested, are perceived as difficult to diagnose, and/or rare (Bontempo, 2022, p. 2106). As such, there may be different stages of validation/invalidation at play and validation might not simply be about receiving a diagnosis per se, but also that being listened to and heard in the first instance, and throughout their journey, are important issues for limiting the impacts of a diagnostic odyssey for people with newly emerging conditions. As one LC activist in our study put it:

> In the early days people were reassured, "oh my God! Someone is listening to me!" And they were validated.
>
> (LC09/KI, White woman, 45–55 years)

Validation, however, is not determined by a one-off encounter, it is unstable and whilst receiving a diagnosis was felt to be very important for many in our study, others and particularly for those who are classed as 'long haulers' felt the label of LC had not necessarily helped them and in fact had become a form of invalidation in itself. The same activist, for example, raised that even with a diagnosis, people can feel cast aside.

> The feeling of having someone listen, meant that they were coming out and saying they had a satisfactory experience! Have they come out having anything actionable to help them with their symptoms? No! And that's still very much the case! It's very much a postcode lottery.
>
> (LC09/KI, White woman, 45–55 years)

What is clear from this interlocutor's perspective is that validation is also dependent on meaningful action that has positive consequences for patients living with LC. However, for those at the start of their odyssey, receiving a diagnosis is important. It provides an immediate validation of their symptoms and experiences. To many it is the green light through which to get the health-care support they need. As one interlocutor put it:

> It would have been nice to have had some sort of support in terms of letting me know what the long term implications were [of covid] and whether there was any support. I mean I now know that there is support for LC. But I haven't been informed of that by either the medical surgery that I go to or by the doctors that I saw in hospital either. I was, I wasn't told of that. It's just through friends I have who [know about LC] that tell me it's possible.
>
> (LC05, South Asian female, 65–75 years)

For these interlocutors the degree to which they feel validated or invalidated is complex and it is not necessarily the case that a diagnosis automatically leads to a feeling of validation. As such, we should consider validating processes as ongoing phenomena, for which contexts are likely to shift and change for patients according to where they are in their illness biographies and journeys. This means health professionals have to have a mechanism through which to follow these patients, providing the right kinds of support along each part of the care pathway.

UNCERTAINTY, AMBIGUITY AND THE SOCIAL IDENTITY OF LC

The ambiguity and uncertainty expressed by our interlocutors shines a spotlight on the very tension Mildred Blaxter explicates in her work on the relationship between category and process in the art/science of illness diagnosis. Moreover, these relationships are further complicated by the fact that the origin of LC rests in the conjunctural moment of the COVID-19 pandemic, whereby the lives of many were upended by infection and the socio-political and medical disruption that created. As a result, there is an embedded interplay between the patients' social biography and symptom presentation. That does not mean that the condition is relegated simply to the social, but rather that the ambiguities of their condition are inherently tied to the socio-medical context of uncertainty around the extent of impact from the originator virus itself.

As such, the process of diagnosing and understanding LC also becomes a mechanism through which to understand the pandemic itself, its longer lasting effects and a socio-political climate that may be reluctant to invest too heavily in *knowing* and being responsible for recognising and providing support for its long term effects, despite health-care workers' desire to understand and help patients. As one key informant, a clinical academic and cardiologist leading in the field of COVID-19 stated:

> So for people who'd been hospitalised, but have been discharged, if you took that cohort four months later, 12% of them were dead and 30% of them had been re admitted. And there was a lot of new onset chronic disease, diabetes, cardiovascular disease and so on. So that, in a way was another reason why I, as a cardiologist or a non-communicable disease guy, is interested in the longer term effects.
>
> (KI06, ethnic minority male, 45–55)

Indeed, much of the uncertainty expressed by our interlocutors is centred around the raft of symptoms they are experiencing and an ambiguity over their origins. For example, many recounted the various COVID-19 infections they had experienced; however, some struggled to identify which infection had caused their ongoing symptoms and for some there was a gap between their positive COVID-19 test and their ongoing symptoms making it hard for them to be specific about which infection triggered their symptoms.

This ambiguity was reinforced in their interactions with health-care professionals that were less familiar with LC. This is, first, due to a denial of its existence on behalf of some health-care professionals and, second, that the current mechanism at primary care level to cope with the complex and multiple presentation of symptoms by patients with the condition is too weak. This creates a huge tension in the relationship between category and process because the infrastructure to manage and reconcile LC is floundering in a context of underfunding that goes back to the financial crisis experienced in Europe from 2007 onwards (Quaglio et al., 2013). This generates a series of mixed messages about care pathways that the patients then have to interpret and act upon. One KI06, who works in the voluntary sector in health inequalities and COVID-19 support, put it thus:

> I think the biggest barrier is the system itself or the institution and not knowing where to go. So [a lack of] information and then [patients] have to navigate where do they go. So, obviously, when they go to their GP and might be told, "oh, you can refer yourself", and then when they go to the clinic they say, "sorry, your GP has got to

> refer". The mixed messages causes a frustration for quite a few and that puts a barrier in itself because then patients don't know who to trust or who to believe.
>
> (KI03, South Asian male, 45–55 years)

Our interlocutors are in effect stuck between a rock and a hard place because presenting their symptoms involves recounting their illness narrative, which may involve up to 3 years of varying symptomatology in a context that does not have the resource to hold it. Moreover and as we know from many accounts in a variety of contexts, it is often those that are most marginalised by structural inequalities that bear the brunt of infrastructure weaknesses (Rodgers & O'neill, 2012).

However, it is challenging to tease out the experiences of ethnic minorities when, even though they were a group that were more prone to COVID-19 infection, their presence in LC clinic statistics is less common. As a Cardiologist, Clinical Academic and leader in the field of COVID-19 inequalities and LC put it:

> Nobody disputes the disproportionate effect [of COVID-19 on ethnic minorities]. But at the beginning people had been worried about the lack of people from ethnic minorities and lower socioeconomic status in the LC clinics of which, as you are well aware, there's 90 around England. People started thinking that there's less LC in those communities. Now, I think, personally, that that's not only highly unlikely, it's likely too implausible. I think it's much more likely that there's access issues, and presentation issues rather than that. People who are lower SES [socioeconomic status] and ethnic minorities are less likely to turn up to clinic.
>
> (KI06, ethnic minority male, 45–55)

When talking about the likely causes for the low representation of ethnic minorities in LC clinics he referred to his own study and the exploratory nature of such research:

> It's just a hypothesis, but we suspect that any difference between inequality and acute COVID versus in LC is, as I say, structural and to do with pathway rather than to do with the disease.
>
> (KI06, ethnic minority male, 45–55)

These hypotheses have been proved correct by a recent large study in which diagnosis was determined on the basis of LC symptoms rather than referral or self-report (Subramanian et al., 2022). Moreover, these concerns resonate with those expressed in studies such as Bhui et al. (2011), whereby the issue of underrepresentation and attendance at clinics is likely a structural inequality issue rather than the cultural behaviours of individuals. For example, many LC participants in our study expressed a concern that discrimination was taking place or indeed that they were reluctant to pursue medical support for fear of discrimination. This fear coupled with distrust in health-care professionals was brought to the fore during the COVID-19 pandemic in both America and the UK (Paul, et al., 2022; Smith, et al., 2022).

The KI06 offered a rich description of what he sees as the main issues to LC service delivery and the issues faced by ethnic minorities, in particular. Whilst he characterises these as being system/service, community and individual to highlight the intersecting challenges faced in developing good models for diagnosis and care for people with LC, it is clear that structural factors such as poverty and social status are also in play. In particular, he draws on geographical

differences between NHS services and the impact of different approaches adopted during the pandemic on the development of long COVID-19 clinics. For example, the geographic spread and limited health-care infrastructure in certain areas led to fragmented support compared to central London hospitals that had a huge burden on their ITUs during the pandemic, so LC support went to the hospital departments. Others adopted a centralised model but with several clinics spread across geographical areas of a city with different specialities 'chipping in'. In terms of community-level issues, he highlights gender and ethnic inequities that result in lower access for certain ethnic minority communities and 'women of a certain age'. The mistreatment and misclassifications of LC that can occur are also highlighted, such as the psychologising of the condition or the danger of it being conflated with the stigmatised diagnosis of CFS. This participant also highlights individual choices—that are likely to be heavily influenced by wider structural factors—with regards to accessing private health-care support and using social and cultural health capital to navigate and access services. As such, this interlocutor highlights the development of a tiered system, whereby those with social status, those who can afford to and those who have the social capital by virtue of working in the NHS get better access to support than those who do not.

> [the regional variation] affects access, how much people have a service and how much it's advertised locally and made available and how people know about it. [...] And also the attitudes of health professionals affect access as well. So if I see you and pigeonhole you as a woman of a certain age and likely to be more on the functional disease spectrum and there are people who have these views, then I'm less likely, even if there is a LC clinic, then I'm less likely to refer you to it.[...]
>
> Community wise, there are some bad things, where [...] we know from the first wave that people from certain ethnic minority backgrounds didn't trust the health system [...] in terms of vaccination strategy, in terms of the acute waves of the pandemic. They don't trust what the hospitals are doing, what the government is doing, what the GP is doing. And they're going to be difficult to get to the LC clinic. [...] one of the biggest barriers in LC, is the worry that people have that it's going to be psychologised and lumped in with chronic fatigue syndrome. [...] it's separating out the dichotomy between, "is this a physical or mental thing?" [...]
>
> And, then you have the individual level where people have their own beliefs or their own access issues. What you're seeing at the moment is a lot of people in London, for example, going to the private sector for the LC clinical services. And you can do that if you have the money. [... and] people who are health professionals from other places from Leeds or Sheffield or Dorset were asking to be referred to UCH [, the first LC clinic]. If I'm a taxi driver in South London, I wouldn't know to get referred there.
>
> (KI06, ethnic minority male, 45–55)

Whilst there is a lot to unpack in the three formulations put forward by this interlocutor, a multilevel categorisation is useful for understanding the competing challenges to the diagnosis and provision of health-care support for people living with LC. Key points to consider are (a) his discussion of trust in the sector, also supported by our interviews with people living with LC with no diagnosis; (b) the discrepancies in social capital between low socioeconomic lay

patients, wealthier patients and health-care professional patients also present in our data; (c) are the system/service barriers brought on in part by changes in working styles, structure and service development models and (d) the levels of acceptable knowledge that exists of the condition itself. All four feed into both the process and categorisation of diagnosis that Blaxter (1997) describes.

Given the multiple challenges facing LC diagnosis and support, we now aim to offer some examples of best practice that might be utilised at both the primary and secondary care levels.

GOOD PRACTICE IN LC DIAGNOSIS

Positive experiences of health-care support were mentioned by some participants in terms of the diagnostic process; however, these relied on committed individual practitioners rather than equitable care pathways. Being heard, believed and supported by their GPs was important to participants and this could provide the legitimacy needed for negotiating leave with employers:

> She was very compassionate and empathetic towards the fatigue that I felt. So she knew that she had to sign me off work and kept in contact with me as well over those three months.
>
> (KI04/LC, South Asian female, 25–35 years)

However, such support did not necessarily involve a holistic approach to LC, such as keeping track of symptoms to avoid a crisis situation:

> If there was anything that I was worried about, just call the surgery. And she would at least ... listen, document it. You know if, you know, she felt that it was something I would need to maybe represent at A&E for, she would support that sort of thing. But I really needed someone to monitor my symptoms. Definitely. That's what I needed.
>
> (LC02 Black British woman 25–35)

Support from a hospital neurologist was described as 'above and beyond' by the same participant but this was difficult to sustain in the context of an understaffed service that was not designed to respond to her constantly changing symptoms:

> it's very scary when you have all of these symptoms and they've come out of no-where! So, it's just not really good enough to have sort of like a one-off phone call with your neurologist now and again! And she was trying her best! But she was a locum so, and her clinics were always really busy. She would actually, she would call me out of the goodness of her heart at like ... the end of the clinic because she was worried. And that wasn't, that, that wasn't sustainable for her or for me. And anytime I called up to say like I really need to speak to her, it was like "oh well you don't have an appointment! You need to wait for an appointment through the post!"
>
> (LC02 _Black British woman 25–35)

Health-care support could be received as a result of participants' own awareness of care that should be made available, which was used in the following case to negotiate testing and referral.

> I read about the pathway, and actually I could be referred to the LC clinic. So I got back in contact with the GP and was quite assertive and just said, look it's been this, these many weeks, there's no improvement. I feel a little bit worse. I do need to go to the clinic. And she agreed, went for a screen with me and referred me to the clinic as well. I had to do a couple of other investigations as well, like ECG, blood test and a chest X ray as well [...] I worked quite well with the GP to get myself referred along the pathway.
>
> (KI/LC04 South Asian women)

The quality of care received by minority ethnic patients could also be enhanced through the cultural understanding and empathy they were offered from staff with shared beliefs, despite their different ethnic and faith backgrounds:

> I've had African nurses tell me, you know, yeah trust in God. You know, and say that to me and it's like, it's a beautiful thing you know. We've got completely different faiths. But that, that whole element of understanding that faith is a big part of me! [...] just that level of knowing what to say to, you know, that bedside manner, as it were, it's completely different.
>
> (LC10, South Asian man 35–45)

CONCLUSION AND RECOMMENDATIONS

It is clear from our participants that high levels of perseverance are required to get a diagnosis. The odysseys experienced involve considerable emotional labour, which is particularly felt by minoritised and disadvantaged communities. This adds to Blaxter's work by highlighting the granularity of experience and the additional toll that emotional labour requires of minoritised communities whilst on their diagnostic odyssey. It also builds on more recent debates in diagnosis studies that draw our attention to the variety of ways diagnosis is shaped by identity and is generative of new identities of patient-hood that can be both desired and contested.

The dual burden of having to fight to be heard in a context of structural inequalities takes its toll and could be part of the reason why so few people from ethnically minoritised communities reach the LC clinic doors. Moreover, this process is accompanied by feelings of invalidation and the misrecognition of symptoms. What is also clear is that the different levels of perseverance required relate to the social and cultural health capital of people living with long COVID-19. Some were able to draw on the social capital of family members who worked in the NHS or to source their own information on long COVID-19 through other means. There were, however, some for whom that social and cultural health capital did not exist and the intersections of disadvantage made it more difficult to seek the support they needed.

Practitioners were appreciated for responding to patient concerns, relieving the emotional burden and providing validation; however, such responses were limited to what they could do within their own remit. They were not able to provide all the support needed to deal with the uncertainty caused by the fluctuating symptoms of LC. Support was, thus, still lacking in important respects and the need for a more holistic and specialist approach to treatment and specific care pathways is indicated.

The intersectional disadvantage experienced by those with LC from minoritised ethnic and faith backgrounds could be reduced by staff who understood and empathised with their cultural

values and supported those for whom it was relevant to use faith as a resource for health. Our findings confirm the importance of acknowledging religious identity in such cases both as a potential support for psychological resilience and in terms of collaboration between mainstream health-care providers and community organisations with expertise in this area (Mir et al., 2015, 2019).

Overall, the process and categorisation of diagnosis involves an engagement with social identity. Not least because the harms of misrecognition have a greater impact on ethnically minoritised and already disadvantaged communities, but also because LC by definition involves a narrative recounting of illness experience. It is intimately tied to junctures and disruptions in the lives of individuals and therefore understanding and treating this condition requires adoption of a holistic view of health that goes beyond simply measuring the absence of disease symptoms. It requires consideration of the intersecting needs of individuals, their wider contexts and backgrounds, their quality of life and longer term wellbeing.

The research presented here highlights that the process of diagnosis has impacts both on individuals but also on the system itself. Our findings highlight the interplay between the category of LC and the process through which it is defined and understood by both health-care professionals and patients. However, our findings are not exhaustive, and we recognise that although we have a high degree of diversity and multistakeholder perspectives within our sample, we had no people living with LC from unhoused/homeless communities, few people with disabilities and low numbers of men. What is evident from our research study is that a whole systems approach is needed that can take into account the interaction of multiple elements that ultimately impact the experiences of minoritised groups living with LC across a wider sample than our study allowed. This may enable better recognition, treatment and support for people from minoritised groups living with the symptoms of this condition.

AUTHOR CONTRIBUTIONS

Jordan Mullard: Conceptualization (lead); investigation (lead); formal analysis (lead); methodology (equal); writing—original draft (lead); writing—review and editing (equal). **Ghazala Mir**: Conceptualization (supporting); funding acquisition (lead); methodology (equal); writing—original draft (supporting); writing—review and editing (equal); supervision (lead). **Chantal Herbert**: Writing—review and editing (equal). **Sophie Evans**: Writing—review and editing (equal).

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CONFLICT OF INTEREST STATEMENT

No conflicts of interest to report.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ETHICS STATEMENT

LOCOMOTION is sponsored by the University of Leeds and approved by Yorkshire & The Humber - Bradford Leeds Research Ethics Committee (ref: 21/YH/0276). The research and production of this article was carried out with strict adherence to ethical standards in research and intellectual integrity as set out by the Journal. Dissemination plans include academic and lay publications, and partnerships with national and regional policymakers to influence service specifications and targeted funding streams.

PATIENT CONSENT STATEMENT

Informed consent was granted by all participants in this study.

PERMISSION TO REPRODUCE MATERIAL FROM OTHER SOURCES

All secondary sources used in this article are publicly available.

STATEMENT ON AUTHORS

In recognition of the special issue we submit this article to, we disclose our ethnicity as the following: Jordan Mullard is a mixed race Black woman with African ancestry. Ghazala Mir is a British Pakistani Muslim woman. Chantal Herbert is Black British woman living with long COVID-19. Sophie Evans is a Black British woman living with long COVID-19. Not only are the experiences of Black women largely missing from the accounts of long COVID-19, they are also often missed in wider health research. As such we strongly thank our co-authors for giving their time and energy to not only sharing their experiences of long COVID-19, but also for contributing to this article.

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ENDNOTE

[1] We use the term 'newly emerging condition' to refer to the ways in which the condition is being understood in a health-care context. Many of our interlocutors have had ongoing symptoms for over 3 years and it is anything but new to them. However, for many GPs, long COVID-19 is still a fairly new condition for which the science is only just emerging.

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