A cycle of invisibilisation: a qualitative study of Brazilian health system factors shaping access to long COVID care

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ABSTRACT

Introduction Long COVID (LC), an often-debilitating infection-associated chronic condition (IACC), affects millions of people globally. Globally, LC patients struggle to access timely, appropriate care, often experiencing disbelief, misunderstandings or being diverted from healthcare. Few studies have examined health system factors influencing LC healthcare access, especially in the Global South. Drawing on the concept of candidacy, we examine health system factors influencing access to LC care in Brazil's public healthcare system (*Sistema Único de Saúde*, SUS) and theorise implications for equitable access to public healthcare for IACCs globally.

Methods We conducted a patient-engaged, qualitative study in the city of Rio de Janeiro. 29 individual semi-structured interviews were conducted with SUS professionals from administrative leaders to multidisciplinary primary and specialist care staff (November 2022 to July 2023). Verbatim transcripts were analysed using a pragmatic thematic analysis.

Results LC patients' candidacy for care is invisibilised within SUS through multiple, interacting processes. Interplay of an over-burdened health system, prioritisation of resources in response to (flawed) evidence of demand, misalignment of LC patient capacities and demands of navigating fragmented services, complex referral processes, professionals' lack of LC knowledge and disregard of the severity and morbidity of a chronic condition amid acute demands, led to the under-recognition of LC by healthcare professionals. Professionals' under-recognition perpetuates administrators' de-prioritisation of resources, policies and training necessary to ensure access to appropriate care, creating a cycle of invisibilisation.

Conclusion Urgent action to disrupt a cycle of invisibilisation is essential to mitigate patients' suffering and intensification of inequalities. Disrupting this pernicious cycle requires more than narrow clinical education efforts. Improved surveillance, education, patient involvement, attention to moral injury and building on existing multidisciplinary strengths may enhance access to LC care. Doing so offers wider benefits beyond patients with LC. We call for a paradigm shift in clinical approaches to IACCs.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Accessible healthcare care for long COVID (LC)—an infection-associated chronic condition (IACC) affecting millions of people globally with potentially debilitating impacts on the quality of life, employment and social participation—is critical.
⇒ Internationally, patients experience diagnostic odysseys and struggles in accessing appropriate care for LC; yet to date, there has been a minimal examination of health system factors affecting access to care, especially in the Global South.

WHAT THIS STUDY ADDS

⇒ Competing demands, lack of LC knowledge and perceived limited care options on the part of professionals, and limited surveillance, policies or training driven by health system administrators combine in a 'cycle of invisibilisation' of LC, undermining LC patients' access to care.
⇒ Theorising the fundamental processes of invisibilisation, through concepts of candidacy, epistemic injustice and disease prestige offers generalisable insights relevant to healthcare for other IACCs and other national health systems.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ This study provides evidence-based recommendations for countering invisibilisation and improving access to care for IACCs like LC and increases the understanding of processes of invisiblisation relevant to promoting global equity in access to care for IACCs.

INTRODUCTION

With growing evidence of the prevalence, personal and societal costs of long COVID (LC) globally, ensuring access to healthcare for LC is critical to mitigating these costs and avoiding further intensification of inequities due to the COVID-19 pandemic. Yet, worldwide, many individuals suffering from LC find themselves rejected or diverted as candidates for healthcare.[1] Of the limited literature addressing health system factors

shaping access to LC care, most of it is situated in the Global North.[2] This paper presents a theorised, qualitative examination of the 'supply-side' health system factors influencing access to public healthcare for LC in Brazil.

LC prevalence and impacts

LC (or post-COVID-19 syndrome) is an infection-associated chronic condition (IACC)[3] (or 'post-infectious disorder'). LC refers to persistent symptoms after a SARS-CoV-2 infection, which may endure for months or years,[4] with some estimates of recovery after 2 years as low as 7.6%.[5] It is a complex, multisystem condition with a vast array of symptoms—which may present in a relapsing and remitting pattern—commonly including fatigue, post-exertional malaise, cognitive dysfunction and joint and muscle pain.[6 7] Contestation over definitions and the current absence of definitive biomarkers complicate LC diagnosis by clinicians.[3]

Widely used estimates that 10–20% of SARS-CoV-2 infections lead to LC symptoms indicate many millions of people are affected globally.[4 8] LC has substantial impacts on the quality of life, social participation and employment, affecting household finances and the wider economy.[9] Among adults with LC, a US survey indicated over 75% experience activity limitations,[10] while a nationally representative study in Mexico found 14.1% experienced incapacitating symptoms.[11] Myalgic encephalomyelitis/chronic fatigue syndrome, often diagnosed in people with LC,[12] is associated with lower health-related quality of life than renal failure, type 2 diabetes and several cancers.[13]

In Brazil, almost 39 million cases of COVID-19 have been officially recorded, which is likely an underestimate.[14] LC prevalence estimates in Brazil range from 24.7% to 81.0% of adult COVID-19 patients.[15–17] Contemporaneously to this qualitative study, our team conducted a survey generating population prevalence estimates among patients previously hospitalised for COVID-19 within public hospitals in Rio de Janeiro City (Portela *et al*, LC in the population of COVID-19 hospitalised patients discharged from SUS' hospitals in Rio de Janeiro City, Brazil: a patient-engaged survey, under review): only a minority reported a full recovery after 24 months; 71.3% experienced at least one frequently occurring LC symptom and 39.3% self-reported having LC. Economic analysis suggests LC could cost the Brazilian economy over US$11bn in lost work hours in 2024.[18]

Accessible care for LC

We regard access to healthcare to be a human right and essential for a dignified quality of life. In many countries, including Brazil, COVID-19 disproportionately impacted those already made vulnerable by structural harms.[14 19] LC represents a further threat to health equity, as those with the greatest exposure to COVID-19 also face known disparities in access to healthcare, and limited resources to shoulder the health, social and economic burdens of a debilitating chronic condition.[20 21] Accessible healthcare,

particularly public healthcare—such as the *Sistema Único de Saúde* (SUS) in Brazil—is thus essential.

Ensuring equitable access to appropriate LC care demands an understanding of the factors shaping the *recognition* of LC. Despite a history of contestation over its existence,[22] patient-led movements have galvanised significant advances in scientific understanding of LC and evidence-based rehabilitation and management.[23 24] Yet, the international literature is replete with reports of patients experiencing dismissal, diversion and psychologization by health professionals; burdensome, costly diagnostic odysseys; and struggles to access appropriate care within fragmented healthcare systems.[1 25–27] Struggles to gain recognition as legitimate candidates for medical intervention have long been documented among patients living with other IACCs.[28]

Conceptualisation of healthcare access: candidacy

The concept of candidacy emphasises the dynamic, social patterning of access to healthcare.[29] Within this conceptualisation, healthcare access entails contextually contingent negotiations between individuals and health services within a field of possibilities shaped by policy, healthcare systems and life conditions.[29–31] Given this paper's aims, we focus on the features of the original candidacy framework[29] which reflect or are determined by *health systems and healthcare professionals* and which set the stage for interactions between health services and service-users: operating conditions; permeability; adjudications and offers. (We do not examine the four patient-side-only features: patients' recognition of their need for care, their navigation of services, their appearance at services or their reactions to offers of care.)

Operating conditions are dynamic, contingent and locally specific, ranging from macro-level influences on the allocation of resources and configuration of services, local pressures and policy imperatives, to the dynamics of settings in which care takes place and perceived or actual availability of resources. Operating conditions set the context for permeability, adjudications and offers.

Permeability of health services reflects how the structure and organisation of health services determine whether patients qualify for those services. The ease with which people can use services (how 'permeable' they are) is contingent on the alignment between health services' demands and patients' capacities, needs, resources and values. Vulnerabilities in access arise when gaining entry demands more from service users than they can afford, or when there are multiple gatekeepers or complex rules for who qualifies for care.

Presented with a patient with a possibly ambiguous condition,[1] healthcare professionals make 'adjudications' of whether an individual is a legitimate candidate for care, and make 'offers', or no offer, of healthcare. Professionals' 'repertoire of typifications' shapes their judgements of whether a patient's presentation aligns with their professional understanding of disease constructs, categories and care options.[29] Professionals'

(non)recognition of LC and eligibility for healthcare also reflects the normative and material realities of their local contexts.

Study objectives

Through the theoretical lens of candidacy, we examine health system factors influencing the recognition of LC and patients' eligibility for medical care and the implications for equitable access to public healthcare for LC. On this basis, we aim to make recommendations for improving healthcare for IACCs such as LC in Brazil and beyond.

Study setting

This qualitative study is part of a mixed-methods study investigating the prevalence, impacts and healthcare for LC in Rio de Janeiro City. SUS is a national but decentralised system that aims to provide universal, comprehensive care. Within Rio de Janeiro City, some SUS services are managed by the Municipal Health Department, others by the State or Federal level. SUS has massively expanded access to health services and improved health outcomes, with increasing permeability being a driving concern.[32] Nonetheless, inequalities in healthcare access and outcomes persist, perpetuated by chronic underfunding, austerity policies and the pressures brought by COVID-19.[33] During the pandemic, the federal government's COVID-denialism and anti-vaccination stance created additional challenges, although SUS's decentralised structure offered some autonomy in response at the regional level.[34]

METHODS
Patient and public involvement

A patient-engaged interdisciplinary and international collaboration underpins our study. In addition to expertise from lived experience, our team gathered health researchers with expertise in the local health system and fields including social psychology, healthcare improvement, social work, community health, epidemiology and medicine. Two co-authors live with LC, one in Brazil. They contributed at every stage, from study design through dissemination. Our advisory group included members with expertise in SUS. Member reflections during our analysis[35] with a diverse sub-sample of the research participants and the advisory board yielded feedback on the analysis and its implications for the health system. Public involvement is ongoing, with patients involved in the production of dissemination videos and a stakeholder workshop forthcoming.

Ethical approval was granted by the *Escola Nacional de Saúde Pública* Research Ethics Committee, Rio's Department of Health Institutional Review Board, Brazil's National Committee of Ethics in Research and the Harvard Chan School Institutional Review Board. Informed (verbal) consent was obtained (audio-recorded) from all interview participants.

Table 1 Interview participant details. (Labels in parentheses correspond to the labelling of excerpts from the interviews of participants in each category)

Participants' location in SUS and roles	Number
Administrative level (administrators) Department of Health senior leaders, area coordinators	7
Primary healthcare professionals (PHC professionals) Managers, physicians, nurses, community health agents, physiotherapists	11
Rehabilitation and post-COVID-19 clinics (specialist professionals) Managers, physicians, physios, social workers, psychologist	11
Total number of participants	29

SUS, *Sistema Único de Saúde*.

Study design and methods

To examine challenges and opportunities for the recognition of and access to healthcare for LC from the perspective of SUS staff in Rio de Janeiro City, between November 2022 and July 2023, we conducted 29 semi-structured interviews with SUS professionals involved with LC care planning, monitoring and provision (see table 1). Our sampling approach prioritised depth and diversity of perspectives over breadth and representativeness[36] and was oriented to achieving sufficient information power within the project scope.[37] We purposively sampled for diversity of professional roles including senior departmental administrators, administrative area coordinators and multidisciplinary, frontline primary and specialist care staff and for diversity in socioeconomic status of the population served by frontline services, including staff from four different administrative areas serving high-income neighbourhoods as well as large favelas. Advisory team members facilitated access to Health Department SUS employees and post-COVID-19 clinic representatives. Through snowballing and direct outreach, we recruited area coordinators, primary healthcare (PHC) professionals and professionals in rehabilitation and specialist post-COVID clinics.

Interviews explored SUS staff's perceptions of LC and associated care needs; current LC care pathways and provision; challenges, gaps and opportunities for improvements in SUS LC care; opportunities and challenges for patient involvement and patient-centred care (see online supplemental file 1). Two researchers (BC and BS) conducted interviews (in Portuguese) in a private space in health services or virtually. Interviews lasted 32 to 117 min (average 64 min) and were audio-recorded and transcribed verbatim.

Data were analysed in Portuguese. Collaboration on analysis was enabled by the translation of 22 transcripts (quality checked by bilingual interviewers BC and BS), reading and memoing by English-only-speaking team members. Additionally, selected coded excerpts were translated (using a Harvard-approved AI platform) to support coding and analysis discussions.

We took a pragmatic qualitative analysis approach, combining elements of different but epistemologically coherent approaches to thematic analysis to fit the goals of the study.[35] We first coded the data using *a priori* codes reflecting research questions, healthcare structures and care pathways and our patient-engaged stance: understandings of LC; organisation of services; diagnosis, referral and care pathways; challenges, gaps and opportunities; patient involvement; and contextual features. We used those *a priori* codes to organise and collate data by topic. Using principles of reflexive thematic analysis,[38] we then engaged in iterative inductive exploration and thematising of this coded data using an organic coding process to support the identification of conceptually coherent themes. In this phase, we used candidacy theory and research[1 29] as a lens through which data were interpreted,[38] ultimately organising our themes into operating conditions, permeability, adjudications and offers. The validity of the data analysis was supported and challenged through the engagement of the team's multiple perspectives.[39] The whole author team was involved in the iterative analysis through regular meetings. We present data using illustrative, anonymised quotes.

RESULTS

Key components for LC care in Rio de Janeiro City comprised (i) PHC units, in line with the general SUS tenet that primary care is the 'gateway' to other services and responsible for care coordination; (ii) rehabilitation outpatient services; (iii) two specialist post-COVID-19 outpatient clinics (municipal government-run and state university-run), initially established to serve hospitalised COVID-19 patients post-discharge and subsequently expanded to non-hospitalised patients with a broader array of post-COVID-19 needs. Post-COVID-19 clinics co-located multidisciplinary teams variously comprising nurses, physiotherapists, social workers, psychologists and physicians. Some considered these new clinics a proactive, even exceptional response by the Department of Health, given the perceived uncertainty surrounding LC.

> We set up a specific outpatient clinic. We do not have that for practically any disease. […] We still do not know if it really is [LC] or if, indeed, the [patients'] issue is more related to [their] Intensive Care Unit duration or other health problems. (Administrator, 101)

However, interview data also suggested a widespread perception that there were few SUS patients needing care for LC. Primary care clinicians reported encountering few, if any, LC patients, while administrators and post-COVID clinic staff pointed to the high number of unfilled appointments in post-COVID clinics.

> What I see [of LC] is very related to respiratory issues, […] Recently, I mean over the last few months let's say, this year, I haven't seen that many cases. (PHC professional, 209)

> There were idle appointment slots […] When we look at the SISREG [SUS referral system], which is a public

website, we see that the demand for post-COVID rehabilitation is almost zero. (Specialist professional, 205)

Over time, these unfilled appointments—interpreted as a lack of demand—led to reduced resource allocation and dilution of these clinics' specialised post-COVID-19 focus.

Yet, contrary to this perceived lack of demand, our contemporaneous Rio-focused survey indicated a high LC burden among SUS patients, as do other Brazilian epidemiological studies covering this period.[16 17] As one post-COVID-19 clinic manager observed, 'We know and believe patients with LC exist—so where are they?' (201). Our analysis of SUS staff interviews, presented below, examines health system factors shaping this apparent paradox, finding that interacting macro- and micro-level influences on permeability, adjudications and offers functioned to obscure recognition of LC and candidacy for LC care within SUS.

Operating conditions
Overburdened, under-resourced system

Participants described SUS as overburdened and under-resourced, reporting struggles with high turnover and shortages of health professionals, overwhelming PHC caseloads and bottlenecks between primary and secondary care. Under-funding was keenly felt and exacerbated by the socioeconomic vulnerability of much of the enrolled population, with many demands rooted in social drivers such as malnutrition and urban violence.

> The Ministry of Health withheld forty billion reais, compared to [previous years…] so we have a budgetary challenge to sustain the network that is not simple and not trivial. (Administrator, 101)

> Food insecurity is an issue, as well as violence […] employment and income issues, basic sanitation, infrastructure, and mental health is another concern. (PHC professional, 214)

The COVID-19 pandemic further intensified challenges for SUS due to direct effects on the population's health, exacerbation of backlogs and the toll on SUS workers themselves. Alongside a perceived desire among some to 'move on' from the pandemic, professionals recognised the continued strains wrought by COVID-19.

> We come out of a pandemic with several issues, right […] so we have, well, a demand almost 60% higher in Primary Care, which may be related to COVID, which may be related to the lack of access these people had during this whole pandemic time. (Administrator, 102)

Rationing scarce resources based on 'hard evidence' of demand

In this context, the allocation of scarce resources had to be prioritised. Participants described a guiding logic whereby allocations were made in response to evidence of demand in the referral system or evidence of disease prevalence captured by the health surveillance system.

Our findings suggest a perceived absence of such 'hard evidence' to legitimise prioritisation of LC within health

system planning. Administrators said they lacked 'solid, quantitative scientific evidence about (LC) symptoms and their prevalence' (101); planning area managers lacked information about expected LC cases in their territory. Municipal administrators explained that health surveillance systems 'are not calibrated for LC' and 'don't have variables that allow surveillance to identify it (LC prevalence)' (Administrator, 106).

Participants' account further indicated relatively little managerial attention to LC in the deployment of resources, including training and guidance for clinical staff. Except for some post-COVID clinic staff, most participants were unaware of the Federal Ministry of Health LC technical document issued late 2021[40] or the ICD code U09.9 for Post-COVID-19 condition. The municipal health plan reportedly contained no LC-related targets. Frontline and managerial staff noted the absence of LC training, guidance or targets incentivising professionals to address LC.

> Among our main macro actions as the Municipal Health Secretariat, Long COVID is not a priority, although rehabilitation as a whole is considered. (Administrator, 103)

> We have little investment and training for health professionals on what is labelled as post-COVID syndrome. [By contrast] during COVID, the Ministry of Health did countless training sessions and clinical discussions on COVID. (Administrator, 104)

Permeability of services

A key consideration for 'supply-side' aspects of permeability is the extent to which services' structure, organisation and qualifications for access align with the specific needs and capacities of SUS users with LC symptoms.

SUS users' limited capital and unevenly distributed, poorly coordinated services

SUS users almost universally faced lengthy waits for appointments in primary and rehabilitation services. Accessing multi-specialty care entailed a *series* of lengthy waits over months and navigating multiple appointments at different places and times—something LC patients can often ill-afford, physically or financially.

> Sometimes the patient needs four tests for the clinician to make a diagnosis, but then they need to go to four different places, they need to wait in four different lines, and this can take months, time during which diseases, health problems can worsen, right? (Specialist professional, 201)

The staff believed the uneven distribution of services within the city (eg, locations of the two post-COVID-19 clinics; PHC units with no doctor), and SUS users' limited access to transportation or knowledge of how to access specialist clinics exacerbated access barriers.

> I keep imagining how many people are out there lost and without access [...] due to financial issues, being less privileged, or less educated, it's a series of things, and then there's no network, neither from family nor from services,

and the person will be left out there, adrift. (Specialist professional, 202)

Participants suggested Community Health Agents could help improve the permeability of services but felt these professionals lacked time and bureaucratic support that would allow them to effectively 'bridge the gap between the patient and (primary care) team' (PHC professional, 215). Additionally, communication gaps between primary and specialist care hampered PHC professionals' ability to effectively fulfil their designated care coordination responsibility, creating a 'big bottleneck in investigating more complex problems' (PHC professional, 217). Specialists not providing information back to the referring primary care professional ('counter-referral') was a consistent complaint.

> It's no use having a super-equipped, really cool service [...] and then the [PHC] team requests that spot and we don't know what was done, the patient can't explain, we don't know what therapeutic plan there is, or what our role is in supporting and caring for that person. (PHC professional, 214)

Complexity and ambiguity of referral to post-COVID-19 clinics

Establishment of two, new post-COVID clinics increased permeability of services in so far as these clinics were able to offer many (though not all) patients rapid access to specialist post-COVID care. Co-location of specialists enabling patients to see multiple professionals within a single visit was well aligned with LC patients' needs and constraints.

> [Patients] think they're going to die in a queue, they think they're going to wait for months in line. But in our outpatient clinic [...] within 48 hours, they already have an appointment scheduled [...] This is the beginning of a big dream within public healthcare [...] When the patient arrives here, they are truly attended comprehensively. If they need a colonoscopy, an endoscopy, we can provide that [...] we have our own laboratory. (Specialist professional, 201)

To access post-COVID clinics, patients needed a referral from PHC. However, not all PHC professionals we interviewed were aware of these clinics. Further obstacles were created by ambiguity and confusion among primary care professionals about the criteria and processes for referral to a post-COVID-19 clinic. Clinics had differing referral qualifications, such as whether evidence of a positive test for COVID-19 was required (something many Brazilians lacked access to throughout the pandemic[41]). Referral processes within the decentralised SUS system were also complex; for example, one post-COVID clinic was managed via the municipal regulation system ('SISREG'), the other by the state system. Interviewees expressed frustration and concern for the patients unable to reach LC services, while appointments within post-COVID clinics lay 'idle'. Despite clinic staff's pro-active efforts to provide extra guidance, patients were not always referred using the correct system, if at all.

I'm not seeing [LC clinic] in the SISREG for post-COVID anymore. I looked, at least I didn't find it (PHC professional, 218)

Thus, the permeability of services was curtailed by the structure and organisation of services set by the health system and by confusion among professionals themselves.

Adjudications and offers of care for LC

Limited understanding among professionals about the nature of LC, ambiguity around diagnosis and potential care pathways interacted to undermine professionals' recognition of patients' eligibility as candidates for appropriate LC care.

Scepticism and limited understanding of LC in clinicians' repertoire of disease constructs

LC as a potential diagnosis or disease category appeared weakly established within professionals' repertoire of typifications,[29] limiting recognition of LC as the basis for a patient's candidacy for care. Among participants at all levels of the municipal health system, our data indicate patchy and variable understanding of LC. Professionals' explanations of symptoms were permeated with fallacies and largely limited to respiratory and other symptoms typical of acute COVID, to the neglect of common LC symptoms such as fatigue, cognitive impairment or joint pain; no participants mentioned post-exertional malaise or the common relapsing-remitting nature of the condition. We also found evidence of scepticism of the existence of LC as a distinct nosological entity (eg, as opposed to symptoms reflecting 'the deterioration of pre-existing diseases' (Specialist professional, 201)); of psychologisation (wherein practitioners attributed patients' symptoms to grief or other psychological responses); and of the trivialisation of debilitating LC symptoms like fatigue or memory loss as nothing more than what 'a lot of people are going through' (Specialist professional, 203).

We often have symptoms that we attribute to COVID-19 but are not always directly linked to the disease process of the virus - the symptoms are often linked to the life changes these people endured [...] related to mental health issues and stress. (Administrator, 101)

I was thinking: 'Guys, is she [researcher] going to ask me if I believe in Long COVID?' (laughter). I think if there was one question, perhaps, that I was waiting for [...] in this interview, it was this one. [...] Yeah, many colleagues don't believe in Long COVID. (PHC professional, 217)

Although chronic sequelae of infectious disease are not new,[42] professionals' perceived LC as a 'very new disease' (Administrator, 102), an 'unexpected' and 'non-standard' (Specialist professional, 212) consequence of infectious disease. PHC staff indicated it was not routine to ask patients whether they had had COVID-19, though more likely when a patient was recently hospitalised or displayed symptoms similar to acute COVID.

Respiratory conditions are more likely to be seen as connected [to LC] by professionals; I think with non-respiratory

conditions, that connection is hardly made. (Administrator, 104)

Difficulties diagnosing LC

In addition to the lack of training or protocols, participants described many challenges associated with diagnosing LC: lack of specific biomarkers or tests for LC, 'normal' results from common screening tests (eg, 'normal' CT scans in patients with chest pain) and fear of missing other (potentially serious) causes made clinicians hesitant to diagnose LC.

I confess that, sometimes, I had difficulty knowing whether it was actually related to COVID or whether it was an individual issue for the person, you know? Because of the pandemic, of being cooped up. Especially when it was a cognitive symptom, like, you know, memory changes, you know, I was a little concerned. (PHC professional, 218)

The perceived value of efforts to diagnose LC was further undermined by a perception of limited options for treating LC: as one physician summed it up, 'Why would we identify something if we don't know what we're going to do with it?' (PHC professional, 214).

Offers focused on treating individual symptoms rather than LC

The combination of factors discussed thus far undermined professionals' propensity to base a patient's candidacy for care on a diagnosis of LC. Instead, if offers of care were made at all, they tended to be based on more easily or objectively identifiable individual symptoms.

Overstretched frontline staff faced stark choices in who and how to prioritise. Many were frank that attention to LC was unlikely amidst competing demands, often of patients with urgent, more objectively diagnosable conditions and/or associated with institutional incentives (eg, tuberculosis).

Considering all the other problems we encounter in the community, vulnerability, gestational syphilis, maternal and infant mortality [...] I don't think Long COVID is a priority. (PHC professional, 214)

One practice common among some healthcare teams was to medicate the symptoms of patients with potential post-COVID-19 sequelae without further investigations. LC severity and COVID-19 morbidity were downplayed, while overburdened staff prioritised efforts to prevent mortality from acute disease.

If the patient isn't severely ill, they are not a priority. We just address their pain, prescribe, and goodbye. [...] In my view, I think [if] the person has improved [from COVID], is doing well, didn't die, is there, let's move on to the next, you know? [...] The next person who needs more. (PHC professional, 215)

In addition to patchy awareness and confusion about referral pathways, PHC staff lacked information about which specific services were available in the post-COVID-19 clinics and whether their patients could get care for the symptoms presented. Instead, clinicians
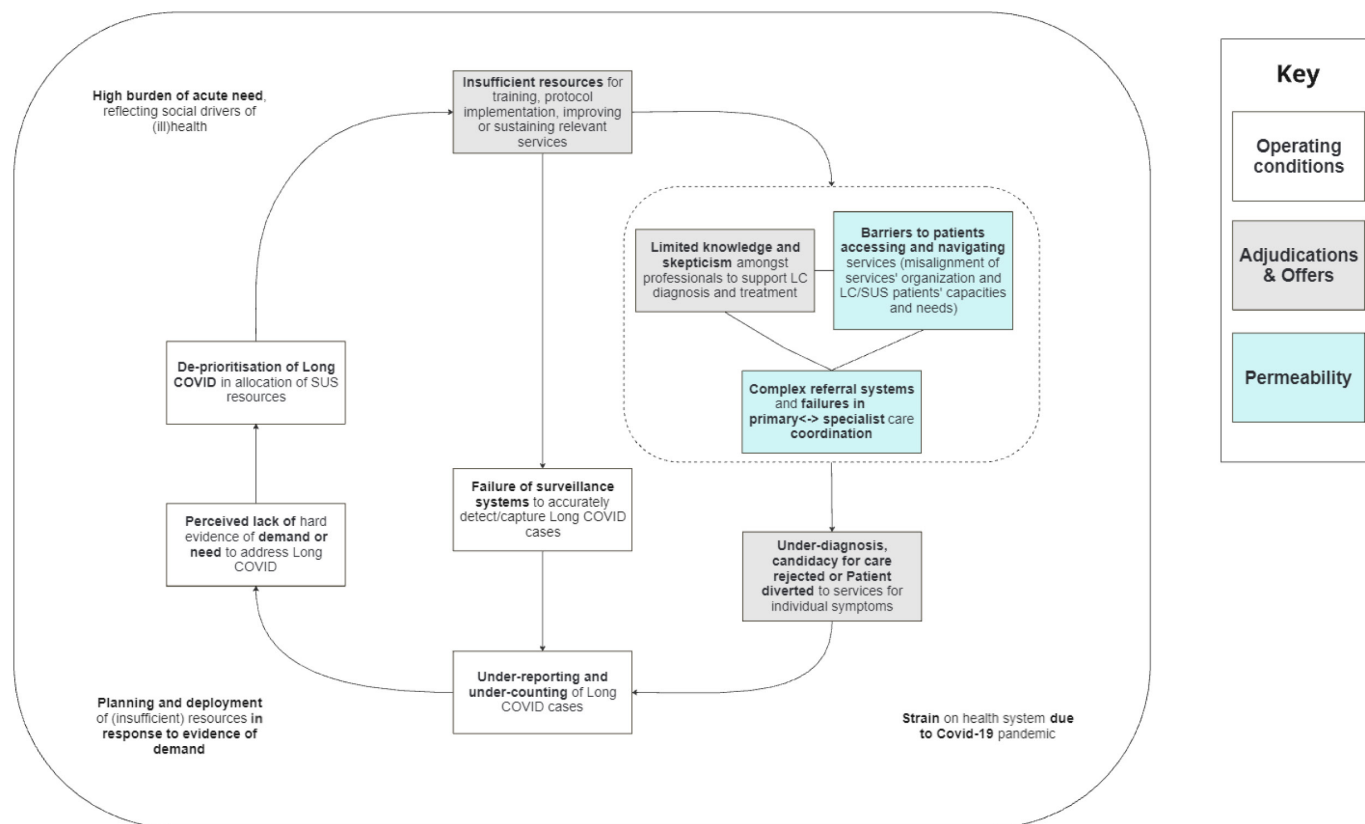
Figure 1 Cycle of invisibilisation of long COVID (LC) within *Sistema Único de Saúde*. This figure depicts macro- and micro-level influences on a cycle of invisibilisation, whereby interacting features of health system permeability, adjudications and offers at the sharp end are driven by and perpetuate de-prioritisation, insufficient recognition and response to demands for care for LC at the blunt end.

often chose to refer patients to a specific specialist—or multiple specialists—for (each) specific symptom.

> I don't know what's available. For example, I never knew, I never had knowledge of what [Post-COVID clinic] actually offers. What are the services, what are the specialists, I can't tell you. For example, I don't know if there is olfactory rehabilitation there. (PHC professional, 218)

> We didn't have an established pathway of referring to [post-COVID clinic]. It was always according to the symptom he was showing. (PHC professional, 220)

In addition to potential impacts on patients (eg, navigating/waiting for multiple appointments, fragmented care), symptom-based offers meant that even where LC may have been suspected, the LC ICD code was not necessarily registered in a patient's medical records or in the regulation system. Combined with scepticism and the lack of understanding of LC, this further drove under-recognition and under-reporting of LC within the health system.

Synthesis: a cycle of invisibilisation of LC within SUS

Synthesising our examination of the 'supply-side' health system factors shaping candidacy for LC care points to a cycle of invisibilisation, creating vulnerabilities in access to appropriate care. As represented in figure 1, macro-structural features and managerial (in)attention at the

blunt end interact with and perpetuate lack of recognition of LC in the adjudications and offers made by professionals at the sharp end of care. Compounded by limitations in the health surveillance data, this lack of recognition leads to under-reporting and under-counting of LC cases which is interpreted as a lack of demand for care for LC. As one senior administrator (104) observed, *'The planning occurs based on demand, and if there are underdiagnoses and underreporting, we have a problem. I believe that we still have underdiagnosis of Long COVID'*.

The consequent de-prioritisation of LC amid many, urgent competing demands perpetuates insufficient allocation of resources for LC care. De-prioritisation is reflected in resource reductions diminishing availability of dedicated post-COVID-19 services, and in insufficiency of training, protocols or incentives to address the inadequacies in LC clinical knowledge. Hence, failures to refer candidates for LC care to post-COVID-19 services or to capture cases of LC in the regulation system may persist, perpetuating the disconnect between staff perceptions of demand for care for LC and epidemiological data on the prevalence of systems. This recursivity between macro- and micro-level features at the blunt and sharp ends of the health system risks perpetuating a vicious cycle of under-recognition of patients with LC and of their eligibility for medical care.

DISCUSSION

We have presented a theoretically informed examination of health system factors influencing the recognition of patients with LC within SUS, identifying drivers at multiple levels of the city's public health system and the ways in which they interact to perpetuate a cycle of LC invisibilisation. In what follows, we unpack the implications for equitable access to public healthcare for LC and the broader category of IACCs in Brazil and globally, by discussing the costs of invisibilisation, our recommendations and an analytically generalisable theorisation[43] of processes of invisiblisation relevant to global equity in access to care for IACCs.

Costs of invisibilisation of LC within SUS

For people with LC, the rejection or diversion of candidacy amplifies their health and social burdens, jeopardising their access to care or limiting them to poor quality and potentially harmful care. For example, harm occurs where exercise is recommended for LC patients with unrecognised post-exertional malaise[44] or where protracted journeys navigating a fragmented healthcare system do not result in appropriate care, but exacerbate symptoms and negatively affect social and financial well-being. Further, patients who experience rejection of their candidacy may become less willing to continue to seek care[30] or exhaust the limited capital SUS users with LC possess to persevere in seeking care.

The existence of some technical notices on LC from the federal government, early investments in post-COVID-19 clinics at the municipal level and dedicated efforts of many frontline professionals indicates there is some minimal political recognition of LC and variability in the views of professionals. However, the powerful cycle of invisibilisation undermines the potential benefits and threatens the continuation of these efforts. Failing to detect demand in an over-stretched system risks a premature 'moving on' from COVID-19 and the dismantling of LC-focused responses—as experienced in other countries.[18] Dismantling multidisciplinary post-COVID-19 clinics not only reduces the availability of specialist care but also eliminates opportunities to improve *quality* of care through ongoing, multidisciplinary team-based learning.[45]

Invisibilisation risks deepening health inequalities and compounding the demands on public services. Given the disproportionate burden of COVID-19 on marginalised communities,[14 19] healthcare access inequalities risk worsening if accessing appropriate care is contingent on the socioeconomic capacity of LC patients. The disability associated with inadequate access to LC care will further strain Brazil's already limited social safety nets, potentially increasing demand for SUS services.

Recommendations: improving access to LC care

Table 2 summarises recommendations and strategies to render LC visible within SUS by improving surveillance, education and patient involvement, mitigating the risks of moral injury to staff and building on existing multidisciplinary strengths. These recommendations target failings identified in our findings and also reflect the collective expertise of our interdisciplinary, international, patient-engaged collaboration. In response to the urgent need to educate healthcare professionals about LC and the value of patient involvement, we have created and publicised awareness-raising videos (https://www.youtube.com/@harvardhpm1637).

Table 2 Recommendations for countering invisibilisation and improving access to care for LC within SUS

Recommendation	Potential strategies
Education of health professionals to improve recognition and appropriate offers of care	▶ Education on topics including: – LC pathophysiology, symptoms, disease presentations and associated diagnoses (to improve adjudication). – Appropriate management in primary care. – Available care pathways involving specialist care (including technical guidance on referral processes). ▶ All healthcare professionals to be trained, given the key role of non-physicians in triage/assessment (eg, nurses, community health agents) and in rehabilitation/management of LC (eg, physiotherapists, occupational therapists).
Support for staff given the risks of moral injury and burn-out	▶ Education and support to staff should acknowledge the particular challenges they experience with LC care by: – Recognising the risk of moral injury for staff having to make difficult diagnoses and sometimes stark choices in resource-constrained settings. – Supporting staff through the frustrations of limited treatment options and unpredictable prognosis of LC, to continue to provide care even where progress or recovery are not evident. – Countering the perception that services can 'move on' from COVID while still acknowledging the potential for burn-out from service during a pandemic.
Capitalise on existing efforts and strengths of the system regarding multidisciplinary care, and improve coordination	▶ In specialist care, build on (rather than dilute) specialist post-COVID clinics, using them to identify lessons and ways to improve. ▶ In primary care, invest in LC and IACC training and implement protocols of referral and coordination of multidisciplinary integrated ancillary health services (such as the Family Health Support Centre ('NASF')). ▶ Address failures in counter referral to enable primary care physicians to fulfil responsibilities in care coordination.
Improvements in health surveillance to detect LC demand	▶ Ensure inclusion of measures to detect LC cases as well as information relevant to understanding the healthcare needs and demands of patients. ▶ Promote consistent and appropriate use of relevant ICD codes.
Support and engage patient involvement and patient-led efforts	▶ Improve and utilise existing health system social participation mechanisms to involve patients in the ongoing improvement of post-COVID care services. ▶ Engage patients in efforts to advance patient-centred care and patient-clinician partnership.

IACC, infection-associated chronic condition; LC, long COVID.

Implementing these recommendations stands to benefit a wide range of patients and conditions, including those requiring multidisciplinary care[46 47] (given well-established care coordination challenges[48]) and those with other IACCs triggered by diseases endemic to Brazil, which are also under-counted and under-treated.[28 49] Given the relatively few SUS post-COVID clinics nationally, invisibilisation within municipalities lacking any such services may be even greater, underscoring the need to enhance the management of LC within PHC and the existing rehabilitation network.[50]

SUS is not unique in the challenges it faces; many health systems—including in well-resourced Global North settings—contend with overwhelming demand yet limited resources[51]; stubborn failures in care coordination[52–56]; or frontline clinicians struggling with the lack of medical education on IACCs and poor knowledge of appropriate LC care pathways.[26] (Arguably, these commonalities are reflected in patient testimonies of access struggles and concerns about equity of access in settings across the globe.) Thus, while these strategies are tailored to SUS, they may also be relevant to health systems facing similar challenges. Indeed, recommendations emphasising provider education, improved surveillance and care coordination align with recommendations offered by other interdisciplinary, international reviews.[57 58]

Explaining the invisibilisation of IACCs: candidacy, epistemic injustice and disease prestige

Studies in Brazil and globally have documented patients' experiences of being dismissed or 'gaslit' and their efforts to seek care for LC—and IACCs—rejected or diverted.[1 25–28] These experiences represent a form of epistemic injustice; that is, a wrong done to someone in their capacity as a knower.[59] Our theorised analysis identifies how health system factors—including the cultural construction of disease within medicine—contribute to this epistemic injustice and the struggles to establish candidacy. We suggest that these insights are analytically generalisable[43] in so far as they offer insights into the mechanisms of invisibilisation of IACCs more broadly.

While patient-led efforts may have succeeded in establishing 'collective candidacy' on some level,[1] LC appears weakly established in *professionals'* repertoire of disease categories and constructs. In contrast to negotiations over candidacy for well-understood diseases with biomarkers and well-established care pathways (eg, cardiovascular disease[60]), the experiences and symptoms driving LC patients to seek care are obscured by professionals' inability to mobilise adequate hermeneutical resources to recognise this type of disease. As such, supposedly 'new' IACCs like LC may lead to instances of epistemic (specifically, hermeneutical) injustice.[59]

Further, we suggest that characteristics of LC itself—shared by other IACCs—relegate IACCs to the status of 'low prestige' diseases within the medical culture.[61] These characteristics include diffuse (not organ-specific) bodily symptoms, lack of objective diagnostic signs (making it difficult to diagnose) and poor availability of effective therapeutic options if diagnosed.[61 62] As our participants' accounts demonstrate, amid many competing demands, often from conditions that are more acute, curable and/or objectively diagnosed (eg, tuberculosis, gunshot injuries), health professionals de-prioritise a difficult-to-diagnose condition lacking clear management guidelines. Thus, IACCs' low prestige characteristics undermine access to appropriate care.

Crucial to the *perpetuation* of epistemic injustices and the medical low prestige of IACCs is the recursive interplay we identified between judgements and perceptions at the sharp end of frontline care and managerial (in)action and (in)attention and inadequate surveillance at the blunt end of the system. When health systems rely on forms of evidence inadequate to capture certain conditions and associated disabilities, those conditions and the individuals who live with them remain socially and politically invisible,[28 50] and the gulf between clinicians' awareness of the condition's prevalence and their ability to accurately recognise and care for affected individuals is allowed to persist.

Disrupting the cycle of invisibilisation and mitigating epistemic injustices will therefore take more than narrow, condition-specific clinical education efforts. A much more significant shift in clinical approaches to IACCs is required, entailing institutionalising better training on the whole category of IACCs so that a condition like LC is not perceived as 'unexpected' and becomes better established in the canon of disease constructs. Health surveillance also needs to be better geared towards detecting and counting IACCs and the type of chronic disability these patients experience if the demands of patients with IACCs are to be heard and resourced.[28 50]

This shift also requires different approaches to offering care. In the absence of simple curative options, the organisation, training and practice of caring for patients with IACCs must emphasise holistic, relationship-based care, partnering with patients[23 63] and willingness to make a diagnosis when appropriate *even if* the clinician 'doesn't know what to do with it'.[64]

Study limitations

The recruitment of frontline staff was challenging due to heavy clinical demands; certain cadres of primary health-care staff (such as nurses in frontline roles) are under-represented. Our sampling strategy did not include specialists outside of post-COVID-19 or rehabilitation clinics. Incorporating these perspectives would likely add further valuable insights (eg, other clinical perceptions of LC or additional challenges or facilitators for inter-professional coordination). Rio de Janeiro City is a relatively well-resourced municipality; transferability of findings associated with specific health system features may be limited in regions with different resource levels or structures, and additional barriers to access may be identified through future studies in different regions.

CONCLUSIONS

Urgent action to disrupt a cycle of invisibilisation is essential to mitigate the intensification of inequalities and the enormous cost of LC to individuals, families and societies grappling with the COVID-19 syndemic. We identified multiple factors at different levels of the Brazilian health system which undermine the recognition of LC. Some of the specific factors are well-documented challenges for SUS and other health systems globally. Crucially, it is the interplay of these health system factors in ways that perpetuate a cycle of invisibilisation, which creates the most significant vulnerability in equitable access to care for LC and IACCs more broadly. Intervening to disrupt this pernicious cycle requires more than narrow clinical education efforts and portends wider benefits beyond patients with LC. While some challenges are health system-specific, some solutions for ensuring equitable, quality care for LC can and must be shared globally. For example, advancing definitions, diagnostic tools and treatments; shifting the paradigm with respect to IACCs in medical education and practice; and doing so with patients' voices at the centre. These global needs require renewed collaborative efforts towards health equity on an international as well as national scale.

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